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04. Health literacy and health communication in community engaged research

Russell Rothman
Vanderbilt University

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Health Literacy and Health Communication in Community Engaged Research

Russell Rothman MD MPP
September 26, 2011

Associate Professor, Internal Medicine & Pediatrics
Director, Center for Health Services Research
Chief, Internal Medicine & Pediatrics
Co-Director, Community Engaged Research
Outline of Talk

• What is health literacy and numeracy?
• Scope of problem
  – Examples in research, nutrition, diabetes, pediatrics
• How to identify low literacy
• What can you do to address literacy?
• Interventions for low literacy and numeracy
• Conclusions
Concern about Literacy and Numeracy Skills
What is Literacy/ Health Literacy?

• Literacy: “ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop ones knowledge and potential”

• Health literacy: “the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”
Components of Literacy

- Cultural and Conceptual Knowledge
- Listening
- Speaking
- Writing
- Reading
- Numeracy
  - Oral Literacy
  - Print Literacy

IOM, Health Literacy, 2004
Numeracy

• A component of overall literacy
• “The ability to understand and use numbers and math skills in daily life”
• Calculations, deduction/logic, interpretation of graphs/labels, time, probability, etc.

Rothman et al, J Health Comm, 2009
Numeracy vs Literacy

• Highly correlated with literacy, but not perfect
Who has poor literacy?

- NALS (1992) and NAAL (2003)
  - 40-44 million Americas are functionally illiterate
  - 50 million have marginal literacy skills
- Average American reads at 8\textsuperscript{th}-9\textsuperscript{th} grade level
- Low literacy more common among:
  - Immigrants
  - AA, Hispanic, Asian (up to 50%)
  - Elderly (up to 66%)
Who has poor numeracy?

• NALS (1992) and NAAL (2003)
  – 25% could not perform rudimentary skills
  – 32% had only marginal numeracy skills
    • could perform simple one-step arithmetic problems if the numbers were explicitly stated to them
    • could not perform multi-step arithmetic, or determine what math skills were needed when reading a problem.
    • Could not interpret a bus schedule
Why is literacy important in health care and research?

• Patients with low literacy have:
  – Trouble reading prescriptions, following medical instructions
  – Trouble understanding educational materials
  – Trouble interpreting and applying numbers to health situations
  – Trouble consenting to research or procedures
  – Difficulty answering survey items or other measures
  – Difficulty following research protocols
Why is numeracy important in health care?

• Patients with low numeracy may have trouble:
  – Understanding dosages of medications
  – Understanding the timing of when to take medications or have them refilled
  – Interpreting nutritional information
  – Understanding volume status
  – Interpreting blood sugars, adjusting insulin
  – Understanding risks and probability
Impact of Literacy in Health Care and Research

• Less likely to obtain tests or follow-up
• Lower knowledge of their disease
• Lower quality of life and satisfaction measures
• Increased risk for hospitalization
• Poorer clinical outcomes
• Poorer understanding of consent process
• Difficulties with measures and protocol adherence
What is it really like for patients?
Health Literacy and Patient Consent Forms

• Reviewed 114 US Medical Schools’ IRB text for consent forms

• Average Readability was 10.6\textsuperscript{th} grade level

• Of 61 sites that set targets (5\textsuperscript{th} to 10\textsuperscript{th} grade), 57 exceeded target:

• Paasche-Orlow, NEJM, 2003
## Examples of Consent Text

<table>
<thead>
<tr>
<th>Readability Level</th>
<th>Voluntary Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>4th Grade†</td>
<td>“You don’t have to be in this research study. You can agree to be in the study now and change your mind later. Your decision will not affect your regular care. Your doctor’s attitude toward you will not change.”</td>
</tr>
<tr>
<td>6th Grade†</td>
<td>“Taking part in this study is your choice. If you decide not to take part, this will not harm your relations with your doctors or with the University.”</td>
</tr>
<tr>
<td>8th Grade†</td>
<td>“Participation in this study is entirely voluntary. You have the right to leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.”</td>
</tr>
<tr>
<td>10th Grade†</td>
<td>“Your participation in this study is voluntary and you are free to withdraw at any time. Participation or withdrawal will not affect any rights to which you are entitled.”</td>
</tr>
<tr>
<td>12th Grade¶</td>
<td>“Your participation in this study is strictly voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without prejudice to your future health care or other services to which you are otherwise entitled.”</td>
</tr>
<tr>
<td>College¶</td>
<td>“You voluntarily consent to participate in this research investigation. You may refuse to participate in this investigation or withdraw your consent and discontinue participation in this study without penalty and without affecting your future care or your ability to receive alternative medical treatment at the University.”</td>
</tr>
</tbody>
</table>
Health Communication and Consent Process

- Often confirmation of patient understanding of consent is not adequately performed.
- Consent process more challenging in patients with limited English proficiency.
- Subjects often sign consent quickly without complete understanding of risks.
- Study of online consent form for genetic study demonstrated that:
  - median time to consent was 53 seconds.
  - 23% of participants consented within 10 seconds,
  - 93% of participants consented in less than the minimum predicted reading time.

Outcomes Associated with Literacy

Health Outcomes/Health Services
- General health status
- Hospitalization
- Emergency department use
- Prostate cancer stage
- Depression
- Diabetes control
- HIV control
- Mammography
- Pap smear
- Pneumococcal immunization
- Influenza immunization
- STD screening
- Cost

Behaviors Only
- Substance abuse
- Breastfeeding
- Behavioral problems
- Adherence to medication
- Smoking

Knowledge Only
- Birth control knowledge
- Cervical cancer screening
- Emergency department instructions
- Asthma knowledge
- Hypertension knowledge

DeWalt, JGIM 2004
Literacy and Diabetes Outcomes

Schillinger, JAMA, 2002
Numeracy and Food Labels

<table>
<thead>
<tr>
<th>Nutrition Facts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Serving Size</strong> ½ cup (114g)</td>
</tr>
<tr>
<td><strong>Servings Per Container</strong> 4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Amount Per Serving</th>
<th>% Daily Value*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Calories</strong> 90</td>
<td><strong>Calories from Fat</strong> 30</td>
</tr>
<tr>
<td>Total Fat 3g</td>
<td>5%</td>
</tr>
<tr>
<td>Saturated Fat 0g</td>
<td>0%</td>
</tr>
<tr>
<td>Cholesterol 0mg</td>
<td>0%</td>
</tr>
<tr>
<td>Sodium 300mg</td>
<td>13%</td>
</tr>
<tr>
<td>Total Carbohydrate 13g</td>
<td>4%</td>
</tr>
<tr>
<td>Dietary Fiber 3g</td>
<td>12%</td>
</tr>
<tr>
<td>Sugars 3g</td>
<td></td>
</tr>
<tr>
<td>Protein 3g</td>
<td></td>
</tr>
</tbody>
</table>

| Vitamin A 80% | Vitamin C 60% |
| Calcium 4% | Iron 4% |

* Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs:

<table>
<thead>
<tr>
<th>Calories:</th>
<th>2,000</th>
<th>2,500</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Fat</td>
<td>Less than 65g</td>
<td>Less than 80g</td>
</tr>
<tr>
<td>Sat Fat</td>
<td>Less than 20g</td>
<td>Less than 25g</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>Less than 300mg</td>
<td>Less than 300mg</td>
</tr>
<tr>
<td>Sodium</td>
<td>Less than 2,400mg</td>
<td>Less than 2,400mg</td>
</tr>
<tr>
<td>Total Carbohydrate</td>
<td>300g</td>
<td>375g</td>
</tr>
<tr>
<td>Dietary Fiber</td>
<td>25g</td>
<td>30g</td>
</tr>
</tbody>
</table>

| Calories per gram: | Fat 9 • Carbohydrate 4 • Protein 4 |
# Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Avg (SD) or Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>43 (15)</td>
</tr>
<tr>
<td>Female</td>
<td>72%</td>
</tr>
<tr>
<td>African American</td>
<td>25%</td>
</tr>
<tr>
<td>Family Income &lt; $20,000</td>
<td>25%</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>75%</td>
</tr>
<tr>
<td>HS education or less</td>
<td>33%</td>
</tr>
<tr>
<td>Chronic Illness requiring dietary restriction</td>
<td>41%</td>
</tr>
<tr>
<td>BMI (n=151)</td>
<td>30 (7)</td>
</tr>
<tr>
<td>Reads Food Labels</td>
<td>89%</td>
</tr>
</tbody>
</table>
# Literacy, Numeracy, Food Labels

<table>
<thead>
<tr>
<th>Variable (n=200)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy (REALM) &lt;= 8th Grade</td>
<td>23%</td>
</tr>
<tr>
<td>Numeracy (WRAT) &lt;= 8th Grade</td>
<td>63%</td>
</tr>
<tr>
<td>Food Label Score (Range 30% - 100%)</td>
<td>69% (19%)</td>
</tr>
<tr>
<td>Internal Reliability (KR 20)</td>
<td>0.87</td>
</tr>
</tbody>
</table>
Sample Questions and Results

• You drink this whole bottle of soda. How many grams of total carbohydrates does this contain?

• Correct Response: 67.5 grams

• Only 32% answered correctly.
• How many grams of dietary fiber are in 5 candies?

• Correct Response: 1 gram

• Percent Correct 66 %
## Nutrition Score by Characteristics

<table>
<thead>
<tr>
<th>Variable (n=200)</th>
<th>Mean Nutrition Score (SD)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 65</td>
<td>70 (21)</td>
<td>0.04</td>
</tr>
<tr>
<td>≥ 65 yrs</td>
<td>59 (19)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>67 (21)</td>
<td>0.04</td>
</tr>
<tr>
<td>Male</td>
<td>74 (20)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>White</td>
<td>74 (19)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>57 (18)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>77 (18)</td>
<td></td>
</tr>
<tr>
<td>Private Insurance</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Yes</td>
<td>73 (20)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>59 (19)</td>
<td></td>
</tr>
<tr>
<td>Chronic Illness*</td>
<td></td>
<td>0.04</td>
</tr>
<tr>
<td>Yes</td>
<td>65 (20)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>72 (20)</td>
<td></td>
</tr>
<tr>
<td>BMI</td>
<td></td>
<td>0.04</td>
</tr>
<tr>
<td>&lt; 30</td>
<td>73 (21)</td>
<td></td>
</tr>
<tr>
<td>≥ 30</td>
<td>66 (20)</td>
<td></td>
</tr>
</tbody>
</table>
Nutrition Score Correlations

• Higher performance on the food label survey was significantly correlated with:
  – Higher education (r=0.44)
  – Higher income (r=0.56)
  – Higher literacy (r=0.52)
  – Higher numeracy (r=0.67)
Conclusions

• Patient comprehension of food labels was fair.
• Comprehension was worse when patient needed to apply serving sizes, or perform multi-step math.
• Comprehension was worse for patients who were obese or had chronic illness
• Comprehension was highly correlated with math and literacy skills
Numeracy and Diabetes
Diabetes and Numeracy Study

• Cross sectional survey of 398 patients
• Mean score on Diabetes Numeracy Test was 61% (SD 25%)
• Trouble Spots
  – Interpreting serving sizes
  – Fractions or decimals
  – Applying multi-step regimens (ex. sliding scale and carb-ratios)
  – Applying titration instructions

• Huizinga et al, BMC Health Services Res, 2008
• Cavanaugh et al, Annals of Internal Medicine, 2008
Serving Size

• If you ate the entire bag of chips, how many total grams of carbohydrate would you eat?

Correct Response: 63 gms
Correct: 44%
Monitoring

• Your target blood sugar is between 60 and 120. Please circle the values below that are in the target range (circle all that apply):
  55
  145
  118

Correct Response: Circle 118 only
Percent Correct: 74%
Insulin Correction Scale (I)

- You are told to follow the sliding scale shown here. The sliding scale indicates the amount of insulin you take based upon your blood sugar levels:

<table>
<thead>
<tr>
<th>If Blood sugar is:</th>
<th>Units of Insulin</th>
</tr>
</thead>
<tbody>
<tr>
<td>130-180</td>
<td>0</td>
</tr>
<tr>
<td>181-230</td>
<td>1</td>
</tr>
<tr>
<td>231-280</td>
<td>2</td>
</tr>
<tr>
<td>281-330</td>
<td>3</td>
</tr>
<tr>
<td>331-380</td>
<td>4</td>
</tr>
</tbody>
</table>

- Percent Correct: 85%
Insulin Correction Scale (II)

After seeing the Doctor, you are given the following instruction to lower a high blood sugar level before a meal:

“Starting with a blood sugar of 120, take 1 unit of Humalog insulin for each 50 points of blood sugar.”

How much insulin should you take for a blood sugar of 375?

43. ANSWER ___________ units

Percent Correct: 37% (accept 5-6 units)
DNT and other measures

• Higher DNT scores are sig. correlated with higher:
  – education ($r=0.51$)
  – literacy ($r=0.50$)
  – math skills ($r=0.64$)
  – diabetes knowledge ($r=0.78$)
  – Frequency of glucose monitoring ($r=0.21$)

and lower:
  – A1C ($r=-0.08$, $p=0.11$)
  – In multivariate analysis, each 10 point increase in DNT score was correlated with a 0.1 point decrease in A1C ($p<0.05$).
Conclusions

• Performance on DNT was fair/poor
• Disconnect between what is taught and what patients can do.
• Performance on DNT was correlated with literacy and math skills.
• Performance on DNT was also correlated with A1C, when adjusted for other covariates.
Portion Size Study

- Enrolled 164 pts
- Asked to serve “single serving” of 4 items, and then told to serve actual amount (in oz or grams)
- 2/3 had inaccurate estimation of portion sizes
- Poor estimation linked with literacy and numeracy

20 Years Ago

- 500 calories
- 333 calories
- 85 Calories

Today

- 1,025 calories
- 590 calories
- 250 Calories

Parental Health Literacy Activities Test (PHLAT)
Identifying Patients with Low Literacy
Assessing Literacy Status

• Not Reliable
  – Asking directly
  – Asking educational status

• Quick Techniques
  – Pill bottle
  – Signing name
  – Red Flags (Missed Appts, noncompliance, etc)

• Validated Techniques
  – REALM
  – TOFHLA
  – The Newest Vital Sign
  – WRAT, SORT, PIAT
Communicating: What can you do?

- Use low literacy and picture based materials
- Individualized education
- Teach concepts in a simplified manner
- Use teach back technique
- Shared goal setting
- Address cultural issues
Low literacy Information

• Most patient information is written at or above the 10\textsuperscript{th} grade levels
• Low literacy materials can improve patient knowledge and outcomes.
• When making materials:
  – Avoid pathophysiology and jargon and focus on key concepts/actions.
  – Use figures to simplify text
  – Increase white space
  – Try to write for the 4\textsuperscript{th}-6\textsuperscript{th} grade level
  – Use SMOG, FRY, Flesh-Kincaid Methods to assess your materials
Resources for Low Literacy Material

• Writing your own:
  – http://www.pfizerhealthliteracy.com/
  – http://www.chcs.org/resource/hi.html
  – http://www.usability.gov/

• Available Materials:
    (click on easy to read)
  – www.niddk.nih.gov/health/eztoread.htm#dia
Sample Materials
Readability

- Over 40 formulas (ex. SMOG, Fry, Flesh-Kincaid)
- Focus on word difficulty (syllables) and sentence length
- Can test running text (prose), but not tables, graphs, word lists, etc.
- Can be done by hand (ex Fry) or with computers (ex. Word or www.readability.info)
- Readability formulas are available for other languages (ex. Spanish Chinese, Vietnamese)
- Goal: 4\textsuperscript{th} to 6\textsuperscript{th} grade if possible!

- Teaching Patients with Low Literacy Skills, Doak, Doak, & Root, 1996
# Suitability Assessment of Materials (SAM)

## 1. CONTENT

<table>
<thead>
<tr>
<th>(a) Purpose is evident</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) Content about behaviors</td>
<td></td>
</tr>
<tr>
<td>(c) Scope is limited</td>
<td></td>
</tr>
<tr>
<td>(d) Summary or review included</td>
<td></td>
</tr>
</tbody>
</table>

## 2. LITERACY DEMAND

<table>
<thead>
<tr>
<th>(a) Reading grade level</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) Writing style, active voice</td>
<td></td>
</tr>
<tr>
<td>(c) Vocabulary uses common words</td>
<td></td>
</tr>
<tr>
<td>(d) Context is given first</td>
<td></td>
</tr>
<tr>
<td>(e) Learning aids via “road signs”</td>
<td></td>
</tr>
</tbody>
</table>

## 3. GRAPHICS

<table>
<thead>
<tr>
<th>(a) Cover graphic shows purpose</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) Type of graphics</td>
<td></td>
</tr>
<tr>
<td>(c) Relevance of illustrations</td>
<td></td>
</tr>
<tr>
<td>(d) List, tables, etc. explained</td>
<td></td>
</tr>
<tr>
<td>(e) Captions used for graphics</td>
<td></td>
</tr>
</tbody>
</table>

## 4. LAYOUT AND TYPOGRAPHY

<table>
<thead>
<tr>
<th>(a) Layout factors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) Typography</td>
<td></td>
</tr>
<tr>
<td>(c) Subheads (“chunking”) used</td>
<td></td>
</tr>
</tbody>
</table>

## 5. LEARNING STIMULATION, MOTIVATION

<table>
<thead>
<tr>
<th>(a) Interaction used</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(b) Behaviors are modeled and specific</td>
<td></td>
</tr>
<tr>
<td>(c) Motivation—self-efficacy</td>
<td></td>
</tr>
</tbody>
</table>

## 6. CULTURAL APPROPRIATENESS

| (a) Match in logic, language, experience |   |
| (b) Cultural image and examples |   |

---

2 points for superior rating  
1 point for adequate rating  
0 points for not suitable rating  
N/A if the factor does not apply to this material  

---

- Teaching Patients with Low Literacy Skills, Doak, Doak, & Root, 1996
Teaching Concepts

- Limit advice to key concepts. Focus on behaviors and actions
- Simplify concepts
- Focus on one concept at a time; partition information
- Use concrete terms and examples
- Make info culturally relevant and personal
- Avoid Jargon!
**Avoid Jargon!**

“Do you know what the number one cause for people in this country being on dialysis is? Diabetes”

<table>
<thead>
<tr>
<th>Would you please tell me in your own words what <strong>dialysis</strong> means?</th>
<th>In your own words, what do you think the doctor was trying to tell the patient?</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Check something every day.”</td>
<td>“Sugar is too high.”</td>
</tr>
<tr>
<td>“What? Is that about you toes?”</td>
<td>“I can't say it.”</td>
</tr>
<tr>
<td>“It means that your diabetes is going worse that you have to exercise to make diabetes.”</td>
<td>“Means that more people are getting diabetes.”</td>
</tr>
<tr>
<td>“You got to get on machine to pump.. redo blood to come up to par.”</td>
<td>“That the sugar was not...hmm.”</td>
</tr>
<tr>
<td>“...regarding kidney.”</td>
<td>“Diabetes is one cause of kidney problems.”</td>
</tr>
<tr>
<td>“That is a warning...about the kidney...my doctor told me about those side effects of the diabetes.”</td>
<td>“About dialysis, because they are warning us, they are telling me about the complications...that if I'm having problems in my kidney, I'm going to have dialysis.”</td>
</tr>
<tr>
<td>“It’s a way to clean blood get off toxins out the blood.”</td>
<td>“That you need to be on dialysis to cleanse blood or gonna die.”</td>
</tr>
</tbody>
</table>
Teachback technique

Clinician Explains New Concept
Patient Recalls and Comprehends

Clinician Clarifies and Tailors Explanation

Clinician Assesses Patient recall and Comprehension

Clinician Reassesses Patient Recall and Comprehension

New Concept: Health Information, Advice, or Change in Management

Adherence

Schillinger, Arch Int Med, 2003
The role of feedback

Physician Variables, Stratified by Glycemic Control and Odds of Good Glycemic Control:

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>HbA$_1c$ Level, %</th>
<th>Unadjusted</th>
<th>Adjusted†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>≤8.6 (n = 38)</td>
<td>&gt;8.6 (n = 23)</td>
<td>OR (95%CI)</td>
</tr>
<tr>
<td><strong>Physician Variables</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>19</td>
<td>15</td>
<td>0.53 (0.18-1.55)</td>
</tr>
<tr>
<td>Male</td>
<td>19</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Level of Training</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending physician</td>
<td>13</td>
<td>9</td>
<td>1.24 (0.42-3.61)</td>
</tr>
<tr>
<td>Resident</td>
<td>25</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal medicine</td>
<td>32</td>
<td>17</td>
<td>1.88 (0.43-8.20)</td>
</tr>
<tr>
<td>Family medicine</td>
<td>6</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>New concepts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;1</td>
<td>25</td>
<td>14</td>
<td>1.24 (0.42-3.61)</td>
</tr>
<tr>
<td>1</td>
<td>13</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Recall and comprehension assessed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11</td>
<td>1</td>
<td>8.96 (1.07-74.90)</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>22</td>
<td></td>
</tr>
</tbody>
</table>

Schillinger, Arch Int Med, 2003
Cultural Challenges

• Language
  – Limited English proficiency

• Family Structure
  – Multiple caregivers

• Health Beliefs
  – Dissonance from the “biomedical model”

• Campinha-Bacote, 2003
Addressing Language Barriers

• Improve your language proficiency

• Use language-appropriate handouts

• Use a language interpreter ...
  – If you are not “natively fluent”
  – If you cannot “tell a joke” in that language
Working with an Interpreter

• Use only professionals
  – Not family members
  – Not other health-care providers

• Address the parent
  – Direct words and eyes toward the family

• Respond to verbal and non-verbal cues
Improving the Consent and Measurement Process

• AHRQ Informed Consent Toolkit
• Use of Plain Language
  – Avoid jargons
  – Readability at 4th- 6th grade
  – Use of pictures to improve understanding
• Use of teach back to confirm understanding
• Proper translation of forms, and use of a translator
Literacy Interventions
Diabetes Intervention

• To examine whether literacy influences the effectiveness of a comprehensive diabetes disease management program to improve glycemic control.

Rothman, JAMA, 2004
Rothman AM J Med, 2005
Methods

• **Design:** Examined literacy within a randomized controlled trial of intensive diabetes disease management program

• **Duration:** One year

• **Setting:** UNC general medicine clinic

• **Population:** Type 2 diabetes with poor glucose control (A1C ≥ 8.0%)
Methods: Enrollment Process

Poor Control (HbA1c \geq 8.0\%) → Initial Pharmacist Session

Baseline: Control - 6 Month Follow-Up: Control - 1 Year Follow-Up: Control

Interv.: 6 Month Follow-Up: Interv. - 1 Year Follow-Up: Interv.
Intervention

• Diabetes Education
• Evidence-based medication algorithms
• Database to track and manage patient outcomes
• Diabetes Care Coordinator

• Addressed literacy by using:
  – Individualized verbal education
  – Low literacy material
  – Teaching concepts in a simplified manner
  – “Teach back” techniques to confirm learning
Results: Study Flow

- **217 Patients**
- **Initial Pharmacist Session**
- **Baseline**:
  - 105 Control
  - 112 Interv.
- **6 Month Follow-Up**:
  - 99 Control
  - 105 Interv.
- **1 Year Follow-Up**:
  - 95 Control
  - 98 Interv.
## Similar Patient Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control (n=105)</th>
<th>Interv. (n=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>56%</td>
<td>56%</td>
</tr>
<tr>
<td>Age</td>
<td>57 yrs</td>
<td>54 yrs</td>
</tr>
<tr>
<td>African American</td>
<td>60%</td>
<td>69%</td>
</tr>
<tr>
<td>Household Income ≤ $20,000</td>
<td>75%</td>
<td>70%</td>
</tr>
<tr>
<td>Less than a High School Education</td>
<td>44%</td>
<td>36%</td>
</tr>
</tbody>
</table>
Similar Diabetes Measures

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control (n=105)</th>
<th>Interv. (n=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline A1C (%)</td>
<td>10.7</td>
<td>10.9</td>
</tr>
<tr>
<td>Duration of Diabetes</td>
<td>8.6 yrs</td>
<td>8.1 yrs</td>
</tr>
<tr>
<td>Use of Insulin at Enrollment</td>
<td>38%</td>
<td>40%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>82%</td>
<td>83%</td>
</tr>
<tr>
<td>Hypercholesterolemia</td>
<td>63%</td>
<td>60%</td>
</tr>
</tbody>
</table>
## Similar Literacy

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control (n=105)</th>
<th>Interv. (n=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Realm Score (0-66)</td>
<td>46</td>
<td>45</td>
</tr>
<tr>
<td>Low Literacy (≤ 6th Grade)</td>
<td>32%</td>
<td>44%</td>
</tr>
</tbody>
</table>
Significant Clinical Improvements at 12 mos

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control (n=95)</th>
<th>Intervention (n=98)</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1C (%)</td>
<td>-1.2%</td>
<td>-2.1%</td>
<td>0.9% (0.8,1.0)</td>
</tr>
<tr>
<td>SBP (mmHg)</td>
<td>+2.3</td>
<td>-6.9</td>
<td>9.2 (2.3,16.1)</td>
</tr>
<tr>
<td>DBP (mmHg)</td>
<td>+1.2</td>
<td>-3.6</td>
<td>4.8 (1.1,8.6)</td>
</tr>
<tr>
<td>ASA (mmHg)</td>
<td>+6%</td>
<td>+47%</td>
<td>41% (25-55)</td>
</tr>
<tr>
<td>T. Chol. (mg/dL)</td>
<td>-12</td>
<td>-27</td>
<td>15 (-4, 35)</td>
</tr>
</tbody>
</table>
Impact on Literacy

Influence of Patient Literacy on the Effectiveness of a Primary Care–Based Diabetes Disease Management Program

High Literacy Patients

- Control High
- Intervention High

Low Literacy Patients

- Control Low
- Intervention Low

* Difference (Adjusted)
-0.6, 95% CI (-1.2, 0.1)

-1.2, 95% CI (-1.9, -0.6)
Diabetes and Numeracy RCT
DLNET Study Results

<table>
<thead>
<tr>
<th></th>
<th>3-months</th>
<th>Adjusted p-value [Intervention vs. Control]*</th>
<th>6-months</th>
<th>Adjusted p-value [Intervention vs. Control]*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>-1.63 [ -2.03 , -1.23]</td>
<td>0.03</td>
<td>-1.11 [ -1.54,-0.65]</td>
<td>0.437</td>
</tr>
<tr>
<td>Control</td>
<td>-0.97 [ -1.37 , -0.53 ]</td>
<td>0.03</td>
<td>-1.17 [-1.61,-0.71]</td>
<td></td>
</tr>
</tbody>
</table>

Mean [95% bootstrap Confidence Interval]
*Adjusting for age, gender, race, type of diabetes, income level, site of intervention and baseline DNT score and Hba1c levels

• In adjusted analyses, there were no significant improvements in Self-Efficacy or Self-Management behaviors

Cavanaugh KL et al. Diabetes Care 2009
CHF Randomized Trial

http://www.shareddecisionmaking.org

NIH (NIDDK) R18 Study

• To address health communication issues to improve diabetes care in middle TN
• 5 year cluster randomized study involving 10 Health Dept Clinics
• Collaboration between TN Department of Health, Vanderbilt, and Meharry
National Initiative (GreenLight)

- Project supported by NIH (NICHD). Collaboration between Vanderbilt, UNC, NYU, and UMiami
- Will enroll 1,000 English and Spanish speaking families with children age 2 months and follow for 22 months. Intervention sites will focus on obesity prevention, while control sites will focus on injury prevention.
- Will train intervention Pediatric providers in improved health communication skills and give them a literacy sensitive toolkit to use with families to promote healthy lifestyles for their children.
Native American Research Center for Health (NARCH)

- IHS/NIH. PIs Hayes (USET), Bernard (VU). Project PIs: Schlundt and Rothman
- First NARCH serving NA in Eastern US
- CBPR project using health information technology (HIT) to improve diabetes care
  - People with diabetes
  - Health care providers: Reduce complexity of using computer technology
  - Tribal leaders: Better access to information about tribal health & improved ways to communicate with tribal members about health issues
- Opportunity to develop additional projects and training component
Overall Conclusions

• Low literacy/numeracy and poor health communication are common barriers to quality health care and participation in research

• Even patients with high literacy skills can struggle to navigate our complex system and perform self-care

• Interventions that improve communication and address literacy issues can improve quality of care and participation in research
Questions
• If you have a question,
  • raise your hand and
  • wait for the microphone
  • or
  • write your question and pass it to a conference assistant.

• THANK YOU