Health Literacy 101
Defining The Problem and
What We Can Do About It

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Department of Medicine
Issues

• Defining health literacy

• Epidemiology of literacy and its relationship to health

• Practical interventions
“As a former nurse, trauma surgeon, and public health director [I realized] there was a wall between us and the people we were trying to serve.

Health care professionals do not recognize that patients do not understand the health information we are trying to communicate.

We must close the gap between what health care professionals know and what the rest of America understands.”

Dr. Richard Carmona, U.S. Surgeon General 2002-2006
Health Literacy

“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

Healthy People 2010
National Assessment of Adult Literacy (NAAL)*

n = 19,714

- Most up to date portrait of literacy in U.S.
- Scored on 4 levels
- Levels 1 and 2 cannot:
  - Use a bus schedule or bar graph
  - Explain the difference in two types of employee benefits
  - Write a simple letter explaining an error on a bill

National Center for Educational Statistics, U.S. Department of Education
2003 National Assessment of Adult Literacy

44% Intermediate
29% Basic
14% Below Basic
13% Proficient

Basic or Below Basic
52% of H.S. Grads
61% of Adults ≥ 65

93 Million Adults have Basic or Below Basic Literacy
Not Much Improvement in 10 Years

Kutner et al. National Assessment of Adult Literacy. 2005
What about NC?

- Estimates from 1992

- Level 1 or 2 (basic or below basic literacy): 52% [National 50%]

- Because of the expansion of immigrant and retired populations since 1992, this likely underestimates the percentage reading at basic or below basic.
Percent Of Adults With Low Literacy

Map Produced by North Carolina Institute of Medicine.
Estimates not available for counties with population below 5000.
Inadequate Literacy Increases with Age

- 65-69
- 70-74
- 75-79
- 80-84
- >=85

Marginal
Inadequate

NC Program on Health Literacy

Slide by Terry Davis, PhD
Literacy and Spanish Language

• 11 million US residents do not speak English well or at all

• 8 million of these speak Spanish

Test of Functional Health Literacy in Adults at two Public Hospitals

<table>
<thead>
<tr>
<th>Language</th>
<th>Percent Low Literacy (in preferred language)</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>35%</td>
</tr>
<tr>
<td>Spanish</td>
<td>62%</td>
</tr>
</tbody>
</table>

Williams et al. JAMA 1995
Literacy and Poverty

Percentages of Adults in Poverty, by Literacy Level

**Percentage in Each Level in Poverty**

Note: Adults in poverty are those who are either poor or near poor.

<table>
<thead>
<tr>
<th>Level</th>
<th>0 to 225</th>
<th>226 to 275</th>
<th>276 to 325</th>
<th>326 to 375</th>
<th>376 to 500</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>43</td>
<td>23</td>
<td>12</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Level 2</td>
<td>41</td>
<td>20</td>
<td>12</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Level 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Seventy-eight percent of what specific group agree that their school does a good job of encouraging parental involvement in educational areas?

<table>
<thead>
<tr>
<th>% Correct</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>36%</td>
<td>All Adults</td>
</tr>
<tr>
<td>0%</td>
<td>&lt; Basic</td>
</tr>
<tr>
<td>4%</td>
<td>Basic</td>
</tr>
</tbody>
</table>

### Parents and Teachers Evaluate Parental Involvement at Their School

*Do you agree or disagree that…?*

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Elementary</th>
<th>Junior High</th>
<th>High School</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our school does a good job of encouraging parental involvement in</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sports, arts, and other nonsubject areas</td>
<td>77</td>
<td>76</td>
<td>74</td>
<td>79</td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teachers</td>
<td>77</td>
<td>73</td>
<td>77</td>
<td>85</td>
</tr>
<tr>
<td>Our school does a good job of encouraging parental involvement in</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>educational areas</td>
<td>73</td>
<td>82</td>
<td>71</td>
<td>64</td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teachers</td>
<td>80</td>
<td>84</td>
<td>78</td>
<td>70</td>
</tr>
<tr>
<td>Our school only contacts parents when there is a problem with their child</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>55</td>
<td>46</td>
<td>62</td>
<td>63</td>
</tr>
<tr>
<td>Teachers</td>
<td>23</td>
<td>18</td>
<td>22</td>
<td>33</td>
</tr>
<tr>
<td>Our school does not give parents the opportunity for any meaningful roles</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>22</td>
<td>18</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td>Teachers</td>
<td>8</td>
<td>8</td>
<td>12</td>
<td>7</td>
</tr>
</tbody>
</table>

Source: The Metropolitan Life Survey of the American Teacher, 1987
...and if this is all too confusing, we recommend logging onto our web site at www.medicare.gov questions?

What the *%# is a web site?
Relationship Between Literacy and Health Outcomes
Outcomes Associated with Literacy

<table>
<thead>
<tr>
<th>Health Outcomes/Health Services</th>
<th>Behaviors Only</th>
<th>Knowledge Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>General health status</td>
<td>Substance abuse</td>
<td>Birth control knowledge</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>Breastfeeding</td>
<td>Cervical cancer screening</td>
</tr>
<tr>
<td>Prostate cancer stage</td>
<td>Behavioral problems</td>
<td>Emergency department instructions</td>
</tr>
<tr>
<td>Depression</td>
<td>Adherence to medication</td>
<td>Asthma knowledge</td>
</tr>
<tr>
<td>Asthma</td>
<td>Smoking</td>
<td>Hypertension knowledge</td>
</tr>
<tr>
<td>Diabetes control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mammography</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pap smear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumococcal immunization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Influenza immunization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>STD screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient Safety

Medication error: most common medical mistake

- 90 million Americans have trouble understanding & acting on health information
- Unfamiliar/complex text most difficult to read
- 3 billion Rx written a year
- Pharmacist/physician time is limited
- Elderly fill 30 Rx/year, see 8 physicians
“How would you take this medicine?”

395 primary care patients in 3 states

- 46% did not understand instructions ≥ 1 labels
- 38% with adequate literacy missed at least 1 label

Davis TC, et al. Annals Int Med 2006, slide by T Davis
“Show Me How Many Pills You Would Take in 1 Day”

John Smith        Dr. Red

Take two tablets by mouth twice daily.

Humibid LA       600MG
1 refill
Rates of Correct Understanding vs. Demonstration “Take Two Tablets by Mouth Twice Daily”

- **Low Literacy Level**
  - Understanding: 71%
  - Demonstration: 35%

- **Marginal Literacy Level**
  - Understanding: 84%
  - Demonstration: 63%

- **Adequate Literacy Level**
  - Understanding: 89%
  - Demonstration: 80%

Low Literacy Related to Worse Control of Chronic Illness

- **Diabetes**
  - Worse glycemic control
  - More long-term sequelae

- **HIV**
  - Higher viral load

- **Depression**
  - More severe disease

- **Hospitalization**
  - Consequence of several diseases

Low Literate Diabetic Patients Less Likely to Know Correct Management*

**Need to Know:**
symptoms of low blood sugar (hypoglycemia)

**Need to Do:**
correct action for hypoglycemic symptoms

*Williams et al., Archive of Internal Medicine, 1998
Literacy Level and Glycemic Control

Asthma Patients with Low Literacy have Poorer Metered Dose Inhaler (MDI) Skills

Mean MDI Score 0 - 4

Adult Hospitalization

- People with low literacy have 30-70% increased risk of hospitalization
  - RR = 1.29 (1.07-1.55) Medicare Managed Care
  - RR = 1.69 (1.13-2.53) Urban Public Hospital

*Adjusted for age, gender, socioeconomic status, health status, and regular source of care.

Literacy and Mortality

Health, Aging, and Body Composition Study

Sudore et al. JGIM 2006; 21: 806-812
What Can We Do?
Interventions to Improve Health Outcomes for Patients with Low Literacy

- Raise awareness among providers
- Develop easier to read materials
- Improve communication skills
- Practice-redesign
- Literacy training / adult education
Can Patients Comprehend Rx Drug Warning Labels?

Davis et al. JGIM 2006; 21: 847-851
Simple Familiar Wording Understood by Most Patients

84% (1st grade.)
More Complex Message Limited Comprehension

59%

(10th-12th grade.)
Unfamiliar Multi-step Instructions Rarely Understood

(12th-13th grade)

8%
Comprehension Increased with Patient Literacy Level * p<.0001, † p<.05

<table>
<thead>
<tr>
<th>Literacy Level</th>
<th>7-8</th>
<th>&gt;9</th>
</tr>
</thead>
<tbody>
<tr>
<td>79%</td>
<td>86%</td>
<td>88% †</td>
</tr>
<tr>
<td>35%</td>
<td>66%</td>
<td>78% *</td>
</tr>
<tr>
<td>8%</td>
<td>64%</td>
<td>82% *</td>
</tr>
<tr>
<td>8%</td>
<td>18%</td>
<td>23% *</td>
</tr>
<tr>
<td>0%</td>
<td>6%</td>
<td>15% *</td>
</tr>
</tbody>
</table>

In multivariate analysis only literacy and age predicted comprehension. Patients with low literacy (< 6th gd.) 3x more likely to incorrectly interpret warning labels.

What does this picture mean?

- “Someone swallowed a nickel”
- “Indigestion”
- “Bladder”
- “Looks like a ghost- Casper”
Raising Awareness

• Relatively easy, low cost intervention with excellent reach

• Low efficacy when used alone, particularly for lecture format
Example: Screening for Literacy Randomized Controlled Trial

- Physicians randomized to receive feedback on patients’ literacy levels
- 441 patients screened
- 229 scored inadequate or marginal on S-TOFHLA and were included in the trial

Seligman et al. JGIM 19(S1): 208; 2004.
Results

- Physicians more likely to use extra teaching strategies (good!)
- Physicians less satisfied with visit
- 94% of patients felt literacy screening was useful
- No improvement in A1C

Seligman et al. JGIM 19(S1): 208; 2004
Educational Materials

• Good health information is often hard to come by
• Most health information written at too high of a reading level
• Few health care systems have comprehensively integrated educational materials in their overall care plans
Use Patient-Friendly Educational Materials

• Simple wording, short sentences
  – 4\textsuperscript{th}-6\textsuperscript{th} grade level
• Picture based
• Focus only on key points
• Emphasize patient concerns
  – What the patient may experience
  – What the patient should do
• Minimize information about disease statistics, anatomy, and physiology
• Be sensitive to cultural preferences
Information Recommended by Guidelines

- General topics
- Explanation of heart failure
- Expected symptoms vs symptoms of worsening heart failure
- Psychological responses
- Self-monitoring with daily weights
- Action plan in case of increased symptoms
- Prognosis
- Advanced directives
- Dietary recommendations
- Sodium restriction
- Fluid restriction
- Alcohol restriction
- Compliance strategies
- Activity and exercise
- Work and leisure activities
- Exercise program
- Sexual activity
- Compliance strategies
- Medications
- Nature of each drug and dosing and side effects
- Coping with a complicated regimen
- Compliance strategies
- Cost issues

Patient Education Materials
Example: Heart Failure
Development of Educational Materials

- Distilled to essential information
- Collaborated with medical illustrator
- Focus group feedback
- Cognitive interviews
- Revised materials
Information We Included

• Explanation of heart failure
• Expected symptoms vs symptoms of worsening heart failure
• Self-monitoring with daily weights
• Action plan in case of increased symptoms
• Sodium restriction

• Compliance strategies

Congestive Heart Failure

With congestive heart failure, the heart cannot pump the blood well. As a result, blood doesn’t flow well.

Fluid leaks out of your blood vessels and backs up in the lungs and the legs.

Salt makes it harder for your body to get rid of fluid. You should avoid salt.

Fluid in lungs
Fluid in legs
How Bad Is Your Congestive Heart Failure?

You can tell how well your heart is doing by how you feel and what you can do.

**SWELLING**
- Good – No Swelling
- OK – Swelling in Ankle or Shin
- Bad – Swelling in Knee Area

Call the UNC Clinic / 919-843-6480

**WALKING**
- Good – You can walk easily with no shortness of breath
- OK – Shortness of breath when walking fast
- Bad – Short of breath at rest

Call the UNC Clinic / 919-843-6480

**SLEEPING**
- Good – Sleeping flat, no shortness of breath
- OK – Needing 2 pillows or more to avoid shortness of breath
- Bad – Have to sleep upright to avoid shortness of breath

Call the UNC Clinic / 919-843-6480
Living with Heart Failure Program

• Focus on self-management training
  – 1-hour individualized education session
  – Education booklet < 6th grade level
  – Scheduled follow-up phone calls

• Digital bathroom scale provided
• Easy access to care team (1-800 number)
• Help with barriers to care
• No efforts to adjust/change medication
Additional Program Elements

• Scheduled phone calls
• Reinforce teaching
• Motivate patients
• Address transportation barriers
• Help patients enroll in pharmacy assistance program
Organized Self-care Education Improves Health Outcomes

• Trial of intensive educational program vs. generic HF brochure

• Intervention reduced incidence of hospitalization or death: IRR 0.56 [0.32, 0.95]

• Low literacy patients seemed to benefit more: adjusted IRR 0.38 [0.16, 0.88]

DeWalt DA et al. BMC Health Serv Res. 2006; 6:30
Improved Communication: “Teach-back”

- Ensuring agreement and understanding about the care plan is essential to achieving adherence

- “We don’t always do a great job of explaining our care plan. Can you tell me in your words how you understand the plan?”

- Some evidence that use of “teach-back” is associated with better diabetes control
Teach-back

Explain → Assess → Clarify → Understanding

NC Program on Health Literacy
Practice Re-design Example: Diabetes Care
Diabetes Disease Management

- Tracking registry
- Patient education
- Care coordination
- Phone follow-up
- Use of treatment and monitoring algorithms
- Address barriers of insurance, transportation, and communication
Educational Strategies

- Patient centered learning
- Therapeutic alliance
- Teach-back method
- Repetition/reinforcement
- Survival skills
Care Coordination

• Call patient at least once a month

• Review self-care skills

• Help to navigate health care system
Improvement in HbA1c

Diabetes Control:
Results for Patients with Literacy Above 6th Grade Level

Difference = 0.55  (p=0.20)

Diabetes Control: Results for Patients with Literacy at or Below 6th Grade Level

![Graph showing A1C levels over time for low-literacy control and intervention groups. The graph illustrates a difference of 1.4 with p=0.052.]

Literacy Training

• Improving patients’ reading ability helps address underlying problem

• Resource-intensive: requires significant time and effort for students and teachers

• Goal: one year of adult education can produce one additional grade level in reading skill

• Small improvements may have big effects on patient health outcomes and well-being
Literacy Training Example: Montana Program

• Randomized trial of 70 patients with depression

• Allocated to standard depression treatment alone vs. standard treatment + literacy education (mean of 18 hours)

• Intervention patients had greater improvement in depression scores

Weiss JGIM 2006; 21:823-8
Summary

• Low literacy is common and is associated with adverse health outcomes

• Interventions to mitigate the impact of literacy on health have not been well-studied

• Some evidence suggests that practice system changes and perhaps adult education can improve outcomes
The End

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