What Consumers Say...
“Help Your Patients Understand“

American Medical Association Foundation
American Medical Association
2003
Observations

• Not just “those people”
Observations

• Not just “those people”
• Shame is a major issue
Observations

• Not just “those people”
• Shame is a major issue
• Affects people from entry to exit
Observations

• Not just “those people”
• Shame is a major issue
• Affects people from entry to exit
• An issue that is often overlooked
Initial Issues, Challenges, Solutions

• Awareness
Initial Issues, Challenges, Solutions

- Awareness
- Terminology
Initial Issues, Challenges, Solutions

- Awareness
- Terminology
- Assessment
Awareness
Awareness

- Magnitude of the issue
Adult Literacy in the United States

43 per cent of the nation’s adults read at very basic levels or below.

2003 National Assessment of Adult Literacy (NAAL)
## Literacy Levels of Adults in America

<table>
<thead>
<tr>
<th>Reading Ability</th>
<th>NAAL Level</th>
<th>*Approx Grade Level</th>
<th>% of Pop.</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Below Basic</td>
<td>1</td>
<td>0-5</td>
<td>14</td>
</tr>
<tr>
<td>- Basic</td>
<td>2</td>
<td>6-8</td>
<td>29</td>
</tr>
<tr>
<td>- Intermediate</td>
<td>3</td>
<td>9-12</td>
<td>44</td>
</tr>
<tr>
<td>- Proficient</td>
<td>4</td>
<td>College</td>
<td>15</td>
</tr>
</tbody>
</table>

2003 National Assessment of Adult Literacy (NAAL)
* Estimates
## Literacy, Race and Ethnicity

<table>
<thead>
<tr>
<th>NALS Level</th>
<th>% of Pop.</th>
<th>% of White</th>
<th>% of Asian</th>
<th>% of Black</th>
<th>% of Hisp</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14</td>
<td>7</td>
<td>14</td>
<td>24</td>
<td>44</td>
</tr>
<tr>
<td>2</td>
<td>29</td>
<td>25</td>
<td>32</td>
<td>43</td>
<td>30</td>
</tr>
<tr>
<td>Totals</td>
<td>43</td>
<td>32</td>
<td>46</td>
<td>67</td>
<td>74</td>
</tr>
</tbody>
</table>

*2003 National Assessment of Adult Literacy (NAAL)*
<table>
<thead>
<tr>
<th>NALS Level</th>
<th>% of Pop.</th>
<th>% of 16-18</th>
<th>% of 19-24</th>
<th>% of 25-39</th>
<th>% of 40-49</th>
<th>% of 50-64</th>
<th>% of 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14</td>
<td>11</td>
<td>11</td>
<td>12</td>
<td>11</td>
<td>13</td>
<td>23</td>
</tr>
<tr>
<td>2</td>
<td>29</td>
<td>37</td>
<td>29</td>
<td>25</td>
<td>27</td>
<td>27</td>
<td>38</td>
</tr>
<tr>
<td>Totals</td>
<td>43</td>
<td>48</td>
<td>40</td>
<td>37</td>
<td>38</td>
<td>40</td>
<td>61</td>
</tr>
</tbody>
</table>

2003 National Assessment of Adult Literacy (NAAL)
Awareness

• Magnitude of the issue
• Complexity of the health care system
Times Have Changed

Ten or fifteen years ago, going to the doctor was a fairly simple matter...

Joseph A. Riggs, MD
President of the AMA Foundation
A Complex System

- Ever-increasing array of medicines
- Less time spent in the hospital
- More and more complicated self care regimens
- Less time spent getting information from doctor
- Continued fragmentation of care
- Increasing amount of paperwork
Awareness

• Magnitude of the issue
• Complexity of the health care system
• Level of shame involved
Shame and Literacy

I’ve had a lot of illnesses, but I preferred to stay home...

Awareness

• Magnitude of the issue
• Complexity of the health care system
• Level of shame involved
• Effect on health
The Hidden Role of Literacy

A 66 year old patient with high blood pressure, angina, diabetes and mild heart failure...

Explaining Illness
Bryan Whalet, edictor,
2000
Literacy and Health

Marginal literacy may present a problem in:
- diagnosis
- treatment
- utilization of health care
- gathering data for studies

Williams, Parker, Baker
Emory University School of Medicine
Harbor - UCLA Medical Center
Arch Fam Med, 1996
Literacy and Health

Patients with poor reading skills are more likely to:
- be hospitalized
- require treatment for preventable illnesses
- ignore notices to come for care
- die prematurely

Weiss, et al
University of Arizona College of Medicine
*J of Health Care for the Underserved, 1991*
Awareness

- Magnitude of the issue
- Complexity of the health care system
- Level of shame involved
- Effect on health
- Liability issues
Literacy, Health, and the Law

An Exploration of the Law and the Plight of Marginal Readers within the Health Care System: Advocating for Patients and Providers

Health Literacy Project and Consulting Attorneys

Health Promotion Council of Southeastern Pennsylvania, Inc.
Legal Implications

Attorneys estimate: Clinician‘s communication style and attitude are major factors in 75% of malpractice lawsuits

Patient Dissatisfaction

Communication problems involved in lawsuits
• Explanation of diagnosis is inadequate
• Explanation of treatment is inadequate
• Patient feels ignored
• Clinician fails to understand perspective of patient or relatives
• Clinician discounts or devalues views of patients or relatives
• Patient feels rushed

Vincent C, Young M, et al
Lancet 1994

Hickson GB, Clayton EW, et al
JAMA 1992
JAMA 1994
Slow Down – Here’s Why

Data from several state indicate:

- PCPs who have been the target of malpractice liability claims spend an average of 15 minutes with each patient.
- PCPs who have never had a malpractice claim against them spend an average of 18 minutes with each patient.
Awareness

- Magnitude of the issue
- Complexity of the health care system
- Level of shame involved
- Effect on health
- Liability issues
- Health care costs
New Report Estimates Low Health Literacy Between $106 Billion and $236 Billion Annually

Low Health Literacy: Implications for National Health Policy

John Vernon, PhD
Department of Finance
University of Connecticut
October 2007
Issues, Challenges, Solutions

• Awareness...

• Terminology
Clarify Terminology:
3 Sources of Confusion

A. Literacy vs. Health Literacy

B. “Literate” vs. Easy-to Read, Reader/Patient-Friendly

C. Health Literacy vs. Clear Health Communication
Clarify Terminology – Issue A

A. Literacy vs. Health Literacy
A. “Literacy” Meaning #1

1. Ability

“The quality or state of being literate, esp. the ability to read and write”

Random House Webster’s Unabridged Dictionary
Terminology – Issue A

A. “Literacy” Meaning #2

1. Ability
   “The quality or state of being literate, esp. the ability to read and write”

2. Knowledge
   “A person’s knowledge of a particular subject or field” (e.g., health, health care, financial, computer)

Random House Webster’s Unabridged Dictionary
1. **Literacy**
   Issues having to do with people’s basic *ability* to read and write

2. **Health Literacy**
   Issues having to do with person’s *knowledge of* health and healthcare issues.
Health Literacy:

*Health* literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions…
Clarify Terminology – Issue B

A. Literacy vs. Health Literacy

B. “Health Literate” vs. Easy-to Read, Reader/Patient-Friendly
Can a piece of print material be “literate”?
Can a piece of print material be “literate”?

Can it be “health literate”? 
Material can be…
• Easy-to-read
• Reader-friendly
• Patient/Consumer-friendly
• Written in plain language
It is *people* who can be…

- “Literate”
People can be…
• Literate
• Health Literate
• Illiterate (offensive)
People can be…
  • Strong readers
  • Marginal readers
Or, people can have…
• Adequate literacy skills
• Marginal literacy skills
• Inadequate literacy skills
Clarify Terminology – Issue C

A. Literacy vs. Health Literacy

B. Literate vs. Easy-to Read, Reader/Patient-Friendly

C. Health Literacy vs. Clear Health Communication
Clarify Terminology – Issue C

Health Literacy vs. Clear Health Communication?

- Consider which will be the easiest to understand
- Consider which will keep us focused on the action goal
Initial Issues, Challenges, Solutions

- Awareness
- Terminology
- Assessment
Common Myths
AMA: “You Can’t Tell by Looking”

People with marginal reading skills:
- are slow learners
- have poor appearance
- use broken English
- have fewer years of schooling
- don’t care
- will admit reading problems

Doak, Doak and Root
Teaching Patients with Low Literacy Skills
1996
How to Tell???

Clues

**Patient may:**
- Carry many papers around.
- **Fail to take medicine as prescribed.**
- Fail to know the name of a familiar medicine.
- **Fail to ask questions after “reading” materials.**
- Write with difficulty
- Misspell words on forms that they fill
How to Tell???

Clues

Patient may say:
- I forgot my glasses.
- Could you fill this out for me?
- I’ll take this home for my husband to look at.
How to Tell???

Literacy and Health Literacy Testing

- REALM (Rapid Estimate of Adult Literacy in Medicine)
- TOFHLA (Test of Functional Health Literacy in Adults)
- The New Vital Sign
### Rapid Estimate of Adult Literacy in Medicine (REALM)™

**Terry Davis, PhD • Michael Crouch, MD • Sandy Long, PhD**

<table>
<thead>
<tr>
<th>List 1</th>
<th>List 2</th>
<th>List 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>fat</td>
<td>fatigue</td>
<td>allergic</td>
</tr>
<tr>
<td>flu</td>
<td>pelvic</td>
<td>menstrual</td>
</tr>
<tr>
<td>pill</td>
<td>jaundice</td>
<td>testicle</td>
</tr>
<tr>
<td>dose</td>
<td>infection</td>
<td>colitis</td>
</tr>
<tr>
<td>eye</td>
<td>exercise</td>
<td>emergency</td>
</tr>
<tr>
<td>stress</td>
<td>behavior</td>
<td>medication</td>
</tr>
<tr>
<td>smear</td>
<td>prescription</td>
<td>occupation</td>
</tr>
<tr>
<td>nerves</td>
<td>notify</td>
<td>sexually</td>
</tr>
<tr>
<td>germs</td>
<td>gallbladder</td>
<td>alcoholism</td>
</tr>
<tr>
<td>meals</td>
<td>calories</td>
<td>irritation</td>
</tr>
<tr>
<td>disease</td>
<td>depression</td>
<td>constipation</td>
</tr>
<tr>
<td>cancer</td>
<td>miscarriage</td>
<td>gonorrhea</td>
</tr>
<tr>
<td>caffeine</td>
<td>pregnancy</td>
<td>inflammatory</td>
</tr>
<tr>
<td>attack</td>
<td>arthritis</td>
<td>diabetes</td>
</tr>
<tr>
<td>kidney</td>
<td>nutrition</td>
<td>hepatitis</td>
</tr>
<tr>
<td>hormones</td>
<td>menopause</td>
<td>antibiotics</td>
</tr>
<tr>
<td>herpes</td>
<td>appendix</td>
<td>diagnosis</td>
</tr>
<tr>
<td>seizure</td>
<td>abnormal</td>
<td>potassium</td>
</tr>
<tr>
<td>bowel</td>
<td>syphilis</td>
<td>anemia</td>
</tr>
<tr>
<td>asthma</td>
<td>hemorrhoids</td>
<td>obesity</td>
</tr>
<tr>
<td>rectal</td>
<td>nausea</td>
<td>osteoporosis</td>
</tr>
<tr>
<td>incest</td>
<td>directed</td>
<td>impetigo</td>
</tr>
</tbody>
</table>
### Nutrition Facts

<table>
<thead>
<tr>
<th>Amount per serving</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Calories</td>
<td>250</td>
<td></td>
</tr>
<tr>
<td>Total Fat</td>
<td>13g</td>
<td>20%</td>
</tr>
<tr>
<td>Sat Fat</td>
<td>9g</td>
<td>40%</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>28mg</td>
<td>12%</td>
</tr>
<tr>
<td>Sodium</td>
<td>55mg</td>
<td>2%</td>
</tr>
<tr>
<td>Total Carbohydrate</td>
<td>30g</td>
<td>12%</td>
</tr>
<tr>
<td>Dietary Fiber</td>
<td>2g</td>
<td></td>
</tr>
<tr>
<td>Sugars</td>
<td>23g</td>
<td></td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
<td>8%</td>
</tr>
</tbody>
</table>

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

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.
Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?
   **Answer:** 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
   **Answer:** Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container. Note: If patient answers “two servings,” ask “How much ice cream would that be if you were to measure it into a bowl.”

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
   **Answer:** 33 is the only correct answer

4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
   **Answer:** 10% is the only correct answer

READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
   **Answer:** No

6. (Ask only if the patient responds “no” to question 5): Why not?
   **Answer:** Because it has peanut oil.

**Interpretation**

<table>
<thead>
<tr>
<th>Number of correct answers:</th>
</tr>
</thead>
</table>

Score of 0-1 suggests high likelihood (50% or more) of limited literacy
Score of 2-3 indicates the possibility of limited literacy.
Score of 4-6 almost always indicates adequate literacy.
Assessing Literacy Skills

**Literacy- Ability**
- Inadequate Literacy Skills
- Marginal Literacy Skills
- Adequate Literacy Skills

**Health Literacy**
- Low Health Literacy
Literacy Testing
Considerations and Limitations

- Should respond appropriately to the results
- Raises concerns re privacy and security
- Raises concerns re embarrassment
- May predict ability but not willingness
- Takes time that may not be available
- May have decreasing accuracy if patient takes same test on several occasions
How to Tell???

AMA Foundation – Help Your Patients Understand

• Design and use a short easy-to-read intake form
  - 7 to 8 questions – some easy to read (5th grade) – some more difficult
  - Notice problems and offer help
  - Make it part of the routine (waiting room to provider’s office)

• Take a detailed social history
  - Cultural background
  - What kind of work do you do?
  - How far did you go in school?
  - How happy are you with how you read?

• Conduct a brown bag medication review
  - Show me how you’re supposed to take these medicines
  - How did you get from your doctor’s writing the prescription to knowing what comes out of the bottle? (Colors? Shapes?)
Assessing Readability of Materials

• Fry
• SMOG

• Flesch-Kincaid
• Micro Power and Light
• Fryinator
• Health Literacy Innovations
Assessing Readability of Materials

Advantages

• Quick and easy to use
• Provide some tangible measure
• Screen materials for general difficulty
• Remind writers to choose words carefully
• Can supplement, but don’t replace the need to field test
Assessing Readability of Materials

Limitations

They do not measure:

• The influence of layout, design or illustrations
• The influence of length or concept density
• Clarity of the intended messages
• Sensitivity to culture and diverse perspectives
• Credibility or believability