Low Literacy, Non-Adherence, or Internet Interference: Can You Tell the Difference

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Disclosure
The following person has no relevant financial, professional or personal relationships to disclose:

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There are no commercial supporters of this activity.
Learning Objectives

• Recognize the signs of low literacy in a client with HIV

• Use screening tools effectively to assess for low health literacy

• Implement interventions that will assist the client with self-management of HIV disease

Literacy in the Future:

“The illiterate of the future will not be the person who cannot read. **It will be the person who does not know how to learn.**”

Alvin Toffler
Future Shock
Health Literacy Greetings From New York

- http://www.youtube.com/watch?v=iFCbIxW4db0.

What is Literacy?

- Literacy
  - Cultural and Conceptual Knowledge
  - Listening
  - Speaking
  - Writing
  - Reading
  - Numeracy
    - Oral Literacy
    - Print Literacy
What is Health Literacy?

Health literacy is “the degree to which individuals can obtain, process, understand, and communicate about basic health information and services needed to make informed health decisions.”

The National Survey Of Health Literacy found:

- Proficient: 12%
- Intermediate: 53%
- Basic: 22%
- Below Basic: 13%

77 million American adults have basic or below basic literacy skills.
Who is most likely to have low literacy?

By Race

What increases the risk of low health literacy?

Age greater than 65

Enrollment in Medicaid, other public insurance or public assistance

African American race
Hispanic/Latino ethnicity

Race and Ethnicity as a risk factor decreases as income and education increases!

Fluent in a language other than English
Many Public Hospital Patients* Do Not Understand Basic Health Care Information

- 26% when next appointment is scheduled
- 65% to take medication on an empty stomach
- 75% how to determine if eligible for financial aid

*% of 679 low-income patients

Lack of Disclosure of Reading Difficulty by Patients* Who Admit Low Literacy

- 67% spouse
- 52% children
- 58% relatives
- 85% co-workers
- 62% friends
- 15% told no one

*58 low-literate patients
Source: Patikh, et al., 1996.
Let's Compare Health Literacy!

Albany county
- 8% of the residents of Albany county have low literacy

Westchester County
- 13% of the residents of Westchester county have low literacy

The Bronx
- 41% of the residents in the Bronx have low literacy

Why is there such a difference between Albany, Westchester, and the Bronx?
What’s happening in your clinics?

Here is how to find out:

The Research

PEOPLE LIVING WITH HIV AND LOW HEALTH LITERACY

Health Literacy and HIV medication Knowledge

Table V. Staging of correct medication identification based on the GEE model.

<table>
<thead>
<tr>
<th>Stage</th>
<th>HIV medications</th>
<th>Literacy level</th>
<th>Patients, no. (%)</th>
<th>Correct medication identification (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1–2 medications</td>
<td>&gt;8th grade</td>
<td>30 (18.0)</td>
<td>100.0</td>
</tr>
<tr>
<td>2</td>
<td>1–2 medications</td>
<td>≤8th grade</td>
<td>20 (12.0)</td>
<td>65.0</td>
</tr>
<tr>
<td>3</td>
<td>≥3 medications</td>
<td>&gt;8th grade</td>
<td>85 (50.8)</td>
<td>35.3</td>
</tr>
<tr>
<td>4</td>
<td>≥3 medications</td>
<td>≤8th grade</td>
<td>32 (19.2)</td>
<td>0.0</td>
</tr>
</tbody>
</table>
PLWHA and low health literacy are **more** likely to:

- have negative perceptions of their health care experiences
- perceive their care as poor
- have lower CD4 counts and higher VL
- Have more frequent hospitalizations
- *Visit healthcare providers on a monthly basis*
- Have misconceptions about how HIV is transmitted.

PLWHA and low health literacy are **less** likely to:

- View providers as involving them in decision making
- **understand provider explanations of treatment plans and disease processes**
- know the meaning of the terms “CD4” and “Viral Load”
The AIDS Treatment for Life International Survey of 2,035 PLWHA in 2010 found that:

35% of PLWHA in North America identified HIV drug resistance as a good thing.

*What about PLWHA in the of the world?*

Africa: 24%
Latin America: 16%
Europe: 15%
Asia: 14%


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**PLWHA do not perceive that they are getting adherence messages**

![Graph showing adherence rates by region](image-url)
WHAT'S IT LIKE TO BE A PATIENT?

- Do people understand the instructions we give them?
- How do instructions look to people with low literacy?
- How easy is it to follow instructions?

Do people understand the instructions we give them?

- https://www.youtube.com/watch?v=zG2DVoRP86g.
How do instructions look to someone with low literacy?

Your naicisyhp has dednemmcocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovnignitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.

The previous slide said:

Your physician has recommended that you have a colonoscopy. A colonoscopy is a test for colon cancer. It involves inserting a flexible viewing scope into your rectum. You must drink a special liquid the night before the examination to clean out your colon.
10th grade
The average reading level of health communications material

5th grade
The reading level of 30 million Americans

Can you follow directions?
1. Fold a square piece of paper in half on the vertical axis. Crease and unfold
2. Fold about ¾ of an inch up from the bottom edge.
3. Fold both sides into the center
4. Flip paper over
5. Fold both sides inward
6. Make 4 folds on the diagonal
7. Fold down the tips
8. Flip over and your heart is complete.

• So Easy! Wasn’t it?
CASE STUDIES:

Wise teaches me a lesson.
Brian swears he’s taking his once a day regimen
Herman’s HIV is under control, what’s up with his BP?
Serena brings her medications in.

Wise

- He brings these medications to the visit:
  - Fluticasone/salmeterol (Advair)
  - Tiotropium bromide (Spiriva)
  - Lopressor
  - Metoprolol
  - Toprol XL
  - NO HIV medications (selling for narcotic pain)
Is it drug use or low literacy?

• Here are some hints:
  - The counter on the Advair is still on 60
  - Wise **swallows** the Spiriva **instead of** inserting the capsule in the dispenser
  - He is taking the Lopressor, Metoprolol and Toprol XL together

The Wise Solution
Health Literacy **RED FLAGS**

- Difficulty explaining symptoms
- Use excuses to avoid reading, e.g., “I forgot my glasses.”
- Lots of papers folded up together in purse or pocket—important, unimportant, and expired
- Missed appointments
- Difficulty explaining how to take medications
- Take overly long or refuses to fill out forms.

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This is one simple tool to assess for health literacy

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Local Pharmacy
123 MAIN STREET
ANYTOWN, USA 11111
(800) 555-5555
DR C. JONES

NO 0060023-08291 DATE 06-23-09

JANE SMITH
456 MAIN STREET ANYTOWN, US 11111

TAKE ONE CAPSULE BY MOUTH THREE TIMES DAILY FOR 10 DAYS UNTIL ALL TAKEN

AMOXICILLIN 500MG CAPSULE

QTY MRG
NO REFILLS - DR. AUTHORIZATION REQUIRED

USE BEFORE 06/23/12
SLF/SLF
```
Assess health literacy with four simple questions

Do you like to read?

or

How happy are you with the way you read?

What is the best way for you to learn new things?
How confident are you to fill out medical forms by yourself?

How often do you have problems learning about your medical condition because of difficulty understanding written information?
Brian and Emily

- Brian cannot read or write, but he has his own business in home remodeling (numeracy)

- Brian never misses a visit, always repeats instructions back to you and calls the pharmacist on his cell phone at each visit

- Brian was on a once a day regimen and insists he missed no doses.

- New labs show a viral load of >1000

- The genotype showed resistance in all classes

Brian’s past has caught up with him

- These are old mutations

- Because Brian cannot read or write, he has no record of his previous regimens

- Now Brian needs a new regimen consisting of four pills
  - Some pills Brian will take twice a day
  - Some pills Brian will take once a day
  - Emily wants to help Brian. She can read and has a high school diploma.
The Newest Vital Sign

Brian has “visual literacy.” He can identify his medications easily, and you know he has “numeracy” skills. You can use these two skills to help Brain take his new regimen by using the “teach back” strategy.

Herman’s Blood Pressure

- Herman’s HIV is under control: his CD4 count is in the 400s,
- and his viral load is undetectable
- His blood pressure is consistently high
- Herman insists he is taking his medications.
Herman shows you his medicine

- **Loratadine 10 mg**
  - once a day
- **Lisinopril 10 mg**
  - once a day

We labeled the medications with pictograms

- **Loratadine**
  - For lung/respiratory problems
  - © 1997 USPC
- **Lisinopril**
  - For hypertension (high blood pressure)
  - © 1997 USPC

www.usp.org/audiences/consumers/pictograms/form.html
Serena’s Cholesterol

• Serena is adherent to her once a day HIV medication

• Her cholesterol is out of control

• Her diabetes is poorly controlled

• You have changed medications, added medications and sent Serena for nutritional counseling many times

• You decide to do a medication review

Serena brings in her meds

But that wasn’t all......
Serena brought this bag in too!

What’s going on here?

How different do these pill bottles look to you?
HIV medications look like this

HIV medications are easy to pick out in a bag full of brown bottles

Ways to help Serena identify her medications include:

- New medication/medication reconciliation forms: [www.healthliteracynow.org](http://www.healthliteracynow.org)
- Pictograms also help: [www.usp.org/audiences/consumers/pictograms/form.htm](http://www.usp.org/audiences/consumers/pictograms/form.htm)
Clear communication is a health care skill!

How much information can people retain?

The experts say people only remember 5-7 bits of information!

Most healthcare visits result in INFORMATION OVERLOAD

Doaks, Doaks, & Root, 1996
### What is a simpler word?

<table>
<thead>
<tr>
<th>Term</th>
<th>Simplified Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cellulitis</td>
<td>Skin infection</td>
</tr>
<tr>
<td>Lipids</td>
<td>Fats in blood</td>
</tr>
<tr>
<td>Monitor</td>
<td>Keep track of, keep an eye on it</td>
</tr>
<tr>
<td>Mutation</td>
<td>The virus changes</td>
</tr>
<tr>
<td>Resistance</td>
<td>The virus fights the HIV medicine</td>
</tr>
<tr>
<td>Inflammation</td>
<td>Irritation, swelling, infection</td>
</tr>
<tr>
<td>“the results are negative”</td>
<td>Normal test</td>
</tr>
</tbody>
</table>

### What are our goals for today?

Teach your patient to ask:

- What is my main problem?
- What do I need to do about the problem?
- Why is it important for me to do it?
End your visit with this statement:

I bet a lot of questions have been on your mind as we’ve talked.  
*Tell me 1 or 2 questions you’ve been thinking about.*
What’s the problem with most health information websites?

- The reading level of most are 11th grade
- Use scientific language or medical jargon
- Lots of words!
- People can't tell the difference between commercial websites, government websites, or research institutions or...
- The difference between advertisements and real information

How many HIV websites are out there?

**GOOGLE:** 203,000,000

**YAHOO:** 134,000,000

**BING:** 137,000,000

“More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google.”
Why is this important?

84% of people start with a search engine
13% start at a health website
2% start at Wikipedia
1% start at a social network

How reliable are HIV websites?

• A survey of 137 HIV health information websites found:
  • 35% did not have a current date within 1 year of the survey
  • Only 7% had information reviewed by an expert
  • Only 4% had information that was journal referenced
  • One website promoted avoidance of HIV medications and provided anecdotal stories of cures without HIV medications

Horvath, Harwood, Courtnay-Quirk, McFarlane, Fisher…Rosser, 2011
Literacy Doesn’t Matter on the Web!

- People with both HIGH and LOW health literacy believed the claims of fraudulent websites.

- People with HIGH health literacy believed websites that claimed herbal cures for HIV as evidence-based websites equally.

- Believed that HIV did not cause AIDS.

- Believed that scientist were still debating the cause of AIDS.

- Experienced more HIV symptoms, had less adherence to treatment regimens, and were less likely to be undetectable.
Results of a focus group study indicated that PLWH:

- Prefer information from their providers rather than internet information
- Rely on family and friends to help them find internet health information
- Believed that a celebrity contacted them personally through his website
- Thought anti-virus programs prevented navigation to unreliable websites
- Reported being “tricked” by websites into spending money for health products
- Did not use mobile internet technology – why?

Reyes & Nokes, 2013, unpublished

What makes a website reliable?
Evaluating Internet Health Information


Some Tips:

• **KISS**
  • Keep It Short and Simple

• Pictures speak louder than words

• Personalize, don’t Generalize!

• See it, hear it, and do it and repeat it!

• Safest internet sources: .gov, .edu, and .org, and sites with a HON designation

• Literacy is the latest vital sign!
Remember the wisdom of POOH:

It is more fun to walk with someone who doesn’t use long, difficult words but rather short, easy words, like “What about lunch”

Health Literacy Resources

• http://www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf
• http://nchealthliteracy.org/communication.html
• http://www.healthyroadsmedia.org/index.htm
• http://www.cms.gov/WrittenMaterialsToolkit/

If you can only download or print one, I suggest this last resource, The Health Literacy and Plain Language Resource. It is the most comprehensive:
Thank You!

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