Health Literacy and HIV

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Objectives

- Describe at least 3 factors associated with the impact of low health literacy on HIV outcomes
- Explain the role of culture in health literacy
- Identify at least 3 approaches for HIV care providers to improve effective communication with low health-literate clients

What is 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.”

(Institute of Medicine, 2004)
Polling Question # 1

Please evaluate the following question on a scale of 1 to 5:
   How confident are you that you can assess your clients' abilities to understand medical or health information?

1. Really not confident (1)
2. Not confident (2)
3. Unsure (3)
4. Confident (4)
5. Really confident (5)

Health care professionals routinely overestimate the ability of their clients to understand medical information.

Bass, Wilson, Griffith, & Barnett, 2002
Kelly & Haident, 2007
Low Health Literacy and Health Outcomes

- Increased hospitalizations
- Increased emergency department visits
- Decreased ability to take medications properly
- Decreased ability to interpret labels and health messages
- Worse health status and higher mortality among elderly
- Estimates of $106 - $236 billion annually in unnecessary health care costs

Berkman et al., 2011
National Action Plan to Improve Health Literacy, 2010

Low Health Literacy and HIV outcomes

- HIV testing
- HIV knowledge
- Viral loads and CD4 counts
- Hospitalization and mortality
- HIV medication adherence

Overlap of HIV and Low Health Literacy

HIV
- Minorities
- Higher in the South
- Younger adults
- Poverty
- Less education
- Hispanics/Latinos
- MSM

Low Health Literacy
- Minorities
- Higher in the South
- Older adults
- Poverty
- Less than high school education
- Non-native English speakers
- Sexual orientation can vary

Low health literacy can further exacerbate health inequities that exist among those living with HIV in the South. It can also be a more important risk factor for HIV outcomes than race!
Culture and Health Literacy

Culture is the lens through which people view and attach meaning to health communication.

(IOM, 2004)
Cultural Elements that Affect Health Care

- Language
- Family relationships and experiences
- Sex and gender
- Race and ethnicity
- Home remedies and complementary and alternative health care
- Spiritual beliefs and values
- Client views of the health care system and providers

Guidelines for Culturally Competent Care

- Conduct a Cultural and Linguistic Competency Self-Assessment (see Additional Resources)
- Do some homework
- Make your office/environment culturally comfortable
- Respect cultural differences
- Keep language simple
- Ask questions that will determine your client’s beliefs and behaviors
- Never dismiss or ridicule clients’ beliefs

Mayer & Villaire, 2007
Guidelines for Culturally Competent Care (cont’d)

- Do what you can to accommodate the client’s family
- Respect cultural beliefs that affect how bad news should be delivered
- Be aware of the first impression you make
- During all interactions with clients, listen
- Maintain a neutral stance
- Smile
- Understand that some clients may not want to make decisions about their own health care

Mayer & Villaire, 2007

Culture and Health Literacy from a Client’s Perspective (audio)

“Sometimes people of color is intimidated by people of no color. And it depends on the social element; whereas, if I hadn’t been socialized in all-White areas and went to school with predominantly White people, I would be intimidated. So, you come in here with a fear or phobia you’re dying. Your anxiety level is high. Your level of understanding is low. You come to a White clinician who’s all white coats, who’s all over you and is using words that maybe, are not big words, but they’re beyond your level of understanding. And you’re really frustrated thinking, “I didn’t understand a word he said.” And that’s really, it’s a barrier.”
Health literacy and Client-Centered Communication

Characteristics of clients with low health literacy

- Have difficulty processing detailed information
- Have insufficient language fluency to fully comprehend written materials
- Tend to interpret information literally
- Are concrete thinkers
- May make excuses why they can’t review written information with you (e.g., “I forgot my glasses.”)
Teach-Back Method

- Used to determine the effectiveness of health information communicated to clients.
- Clients are asked to verbally “teach back” the health information they’ve received in their own words to assess their understanding.
- Closed-ended questions are avoided to facilitate dialogue between the health care professional and client.

Ask Me 3

- Used to improve health communication between clients and health care professionals.
- Three questions clients should understand related to their health:
  1. What is my main problem?
  2. What do I need to do?
  3. Why is it important for me to do this?

Tips for Effective Health Communication

- Avoid medical jargon
- Slow down communication
- Focus on one idea at a time; repeat it
- Use health literacy universal precautions (i.e., treat all clients as if they had low health literacy)
- Assess and reassess for understanding
- Draw pictures or use graphics when appropriate
- Show physical representations of quantities (e.g., deck of cards showing a serving size)
- Create a shame-free environment

Polling Question # 2

Which of the following behaviors by a client may be the best indicator of low health literacy?

a. A client who fills out their registration form completely while waiting to be seen by the provider

b. A client who actively asks questions about his/her medical condition

c. A client who receives discharge instructions and states, “I forgot my glasses. I’ll read this when I get home.”

d. A client who explains to the provider why each of his/her medications are taken
Polling Question # 3

Which of the following is not an example of effective communication with a client?

a. Slowing down communication
b. Providing large amounts of information at one time
c. Showing or drawing pictures
d. Using the teach-back method

CHAT Study

The purpose of the CHAT Study (Communication on Health Attentiveness and Teaching) was to explore what older African Americans with HIV understand about their laboratory numbers (i.e., CD4 cell count and viral load).

A Qualitative Study on Health Numeracy and Patient–Provider Communication of Laboratory Numbers in Older African Americans with HIV

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Gakumo et al., 2016
Methods

- Qualitative, descriptive design
- Patient-centered, semi-structured interview guide
- Health literacy measured using the Revised Rapid Estimate of Adult Literacy in Medicine (REALM-R; Bass et al., 2003)
- Participants recruited from the UAB 1917 HIV Clinic (N=20)
  - Inclusion criteria
    - HIV infected for at least 1 full year
    - African American aged 45 or above
    - Currently on HIV medication regimen
  - Those with cognitive impairments excluded
- Data coded using NVivo™ Qualitative software
- Research interviewers both living with HIV

Selected Interview Questions

- “What is the hardest part about understanding what your doctor or nurse practitioner tells you about your HIV?”
- “What is the most important information that you take away from your clinic visit today?”
- Patients also asked questions pertaining to what they understood about their CD4 counts and viral loads.
Sample Demographics ($N = 20$)

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<th>Variable</th>
<th>Number (%)</th>
<th>$M$ ($SD$)</th>
<th>Range</th>
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<tr>
<td>Gender</td>
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<tr>
<td>Men</td>
<td>10 (50%)</td>
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<tr>
<td>Women</td>
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<td>Annual Income</td>
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<tr>
<td>$&lt;$ $10,000</td>
<td>7 (35%)</td>
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<td>$10,000 - $19,999</td>
<td>8 (40%)</td>
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<tr>
<td>$20,000 and over</td>
<td>5 (25%)</td>
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<td>Employment Status</td>
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<tr>
<td>Unemployed/Disabled/Ret.</td>
<td>15 (75%)</td>
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<tr>
<td>Employed full or part time</td>
<td>5 (25%)</td>
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<tr>
<td>Education Completed</td>
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<tr>
<td>$&lt;$ 12 years</td>
<td>3 (15%)</td>
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<tr>
<td>12 years/GEQ</td>
<td>5 (25%)</td>
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<tr>
<td>College/Vocational</td>
<td>12 (60%)</td>
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<tr>
<td>Age (years)</td>
<td>54.9 (6.3)</td>
<td>45.0 – 66.0</td>
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<td>Health Literacy (REALM-R)</td>
<td>5.1 (3.1)</td>
<td>0.0 – 8.0</td>
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<td>Years Living with HIV</td>
<td>12.1 (7.5)</td>
<td>1.0 – 25.0</td>
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<tr>
<td>Number of Current HIV Medications</td>
<td>2.1 (1.0)</td>
<td>1.0 – 4.0</td>
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Results

Key Themes:
1. HIV laboratory numbers are important for survival
2. The numbers can often times be confusing
3. Mutual communication between patient and provider is essential to understanding the numbers
4. When communication the numbers, less is more
Theme 1: HIV laboratory numbers are important for survival

Interviewer: Why is your blood work important to you?
“The blood work is important because it helps me to understand a CD4 count, where it is in conjunction with my viral load, and to make sure that gap is getting wider and wider, you know…”

Interviewer: What does your viral load mean to you?
“The viral load means as long as the numbers are going down, it means I’m in pretty good health, you know, as having my HIV under control and it means right now I’m undetectable. So, it means that right now I’m doing the things that I guess I should do.”

Theme 2: The numbers can often times be confusing

Interviewer: What is the hardest part about understanding what your doctor or nurse practitioner tells you about your HIV?
“Most of the time, for me, it be either the T-cell count and the viral load ‘cause either one of ‘em be up and the other one be down; and up is good on one of ‘em. I don’t know which one is good of ‘em and which one is bad of ‘em.”
Theme 3: Mutual communication is essential to understanding the numbers

Interviewer: How comfortable are you with talking to your doctor about HIV?

“I can talk to him about anything. I mean, we just got that kind of relationship, so, it’s not hard to talk to them at all, about anything! They’ve gone through a lot with me—a whole lot! And, uh, so I feel very, very comfortable… He’s more like a friend, he, he – than a doctor. I feel that he genuinely cares.”

Source: Google images

Theme 4: When communicating the numbers, less is more

“I understand my viral load. That I understand; but when they say like, “Your CD4 count…” I say like, “…Okay.” And they’ll say “You can call and get the results” but I, uh…as long as they tell me, “Everything looks good,” I’m good with it.”

Source: Google images
Implications for Practice

- Patient awareness and understanding of numbers within the context of health have the potential to improve engagement in care and treatment adherence
- Patient preferences on how to receive medical information, especially among older adults and minorities, should be considered to foster more effective communication
- Future interventions developed to address health disparities in vulnerable populations should focus on keeping health information concise, nurturing continued communication, and considering patients’ life experiences.

In which step of the HIV care continuum do you think health literacy initiatives can have the greatest impact?

- Diagnosing with HIV
- Linking to Care
- Engaging / Retaining in Care
- Prescribing Antiretroviral Therapy
- Achieving Viral Suppression
QUESTIONS/COMMENTS?

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Additional Resources

- Cultural and Linguistic Competency Self-Assessment Checklist
- National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care
- Teach Back
  - http://www.ethics.va.gov/docs/infocus/InFocus_20060401_Teach_Back.pdf
- Ask Me 3
  - http://www.npsf.org/?page=askme3
- National Action Plan to Improve Health Literacy
References