



Impact of Health Literacy Across the HIV Treatment Cascade

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Disclosure

- I have no relevant financial or non-financial relationships to disclose from today's presentation.

Objectives

- Define health literacy
- Define HIV health literacy
- Describe impact of limited health and HIV health literacy
- Describe the impact of limited health literacy related to diagnosis, retention, adherence, and viral suppression

What is health literacy?

- Health Resources & Services Administration (HRSA) – “The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”
- Office of Disease Prevention and Health Promotion National Action Plan to Improve Health Literacy principles:
 - Everyone has the right to health information that helps them make informed decisions
 - Health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life.

Health literacy indicator not rooted in educational level

- Highest level of education attainment is not an indicator of a person's ability to interpret health information. In fact, research has shown that the average person's health literacy is even lower than the level predicted from their educational attainment. ¹
- Health literacy is not completely based on an individual's ability to read, but their ability to read, listen and analyze health information in a way that enables them to apply that information in order to make complex health decisions. ²

¹ Ashley L. Philips, BA, Monisha Arya, MD, MPH, **Raising Awareness: The Overlapping Epidemics of Low Health Literacy and HIV** *JANAC*, [Volume 27, Issue 4](#), July–August 2016, Pages 372–375

² Language and Culture in Health Literacy for People Living with HIV: Perspectives of Health Care Providers and Professional Care Team Members, Keitshokile Dintle Mogobe, et al, *AIDS Research and Treatment* Volume 2016, Article ID 5015707.

Who does limited health literacy affect?

- All populations can be affected by limited health literacy
- Populations most affected by limited health literacy include:
 - Elderly
 - Low Socioeconomic Status (SES)
 - Unemployed
 - Did not finish high school
 - Members of minority groups
 - People who did not speak English during early childhood

Cost of low health literacy



- Low health literacy is a major source of economic inefficiency in the U.S. health care system.¹
- The impact on the U.S. economy is between \$106 billion to \$238 billion annually, which is enough to ensure the more than 47 million people who lack health insurance coverage.¹

¹ <http://publichealth.gwu.edu/departments/healthpolicy/CHPR/>

How does limited health literacy affect people?

- Report poorer overall health
- Have poorer ability to manage chronic diseases
- Have poorer health outcomes
- Are less likely to understand their diagnosis
- Are less likely to have screening/preventive care
- Often seek care in later stages of disease
- Less awareness of preventive health measures
- Less knowledge of their medical conditions and self-care instructions
 - 42% did not understand instructions to “take medication on an empty stomach”
 - (up to) 78% misinterpret warnings on prescription labels
 - Limited health literacy is associated with increased mortality and hospitalizations

Signs a patient maybe experiencing limited health literacy

- Does not take medications correctly
- Frequently misses his appointments
- Fails to follow through on tests or referrals
- Does not complete intake forms
- Is unable to provide a detailed history of illness or treatments
- Asks few questions
- Does not remember information read earlier



What is HIV Literacy?

"HIV/AIDS literacy is the capacity of individuals and/or communities to obtain, interpret and understand basic HIV/AIDS prevention, testing and care information, skills and services and the competence to use such information, skills and services to prevent HIV/AIDS infection and related stigma and discrimination, to know of and understand their HIV status and to enhance the physical, mental and social well-being of people living with HIV/AIDS. Education for obtaining and utilizing these capacities and competencies is trusted with HIV/AIDS educators."

National HIV/AIDS Strategy, 2020

- “...poor health literacy among people living with HIV negatively impacts their adherence to antiretroviral medications and their health outcomes.”
- Goals
 - Reduce new infections
 - Increase access to care and improve health outcomes for people living with HIV
 - Reduce HIV-related health disparities and inequities
 - Achieve a more coordinate National Response to the HIV epidemic

HIV Health Literacy

- Limited literacy skills and low literacy result in worse health outcomes and higher health care costs.
- Linked to:
 - Problems with using and accessing preventive services
 - Delay in HIV diagnosis
 - Understanding what it means to be HIV+
 - Medication adherence
 - Self-care management
 - Barriers to HIV testing and acceptance



Table 1. Literacy level and characteristics of patients living with HIV/AIDS

Characteristic	Total No.	Total %
Gender		
Female	40	25.5
Male	117	74.5
Race		
Black	93	59.2
White	64	40.7
Education		
Less than high school	58	37.4
High school graduate	51	32.9
Some college	46	29.7
Literacy level		
High school or above	82	52.2
7th–8th grade	39	24.8
6th grade or below	36	23.0
Drug use		
Drug user	70	44.9
Not a drug user	86	55.1
Time since HIV diagnosis		
1 year or less	30	19.2
1–3 years	34	21.8
3–5 years	31	19.9
More than 5 years	61	39.1
Receiving free medication		
No free medication	59	49.6
Free medication at pharmacy	60	50.4

Table 2. Knowledge and medication adherence of patients living with HIV/AIDS

Characteristic	Total No.	Total %	Literacy level 9th grade and above (%)	Literacy level less than 9th grade (%)	P value
Knowledge of disease					
What is a CD4 count?					
Correct	74	47.1	68.3	24.0	<i>P</i> <0.001
Incorrect	83	52.9	31.7	76.0	
What is a viral load?					
Correct	84	53.5	79.3	25.3	<i>P</i> <0.001
Incorrect	73	46.5	20.7	74.7	
Knowledge of treatment					
Knows medications?					
Correct	108	68.8	78.1	58.7	<i>P</i> <0.010
Incorrect	49	31.2	21.9	41.3	
Knows medications instructions?					
Correct	64	42.4	50.6	33.8	<i>P</i> <0.050
Incorrect	87	57.6	49.4	66.2	
Sources of information					
Where do you learn the most information about HIV?					
Physician	82	52.2	42.7	62.7	<i>P</i> <0.050
Other	75	47.8	57.3	37.3	
If you have problems or questions, who do you ask?					
Pharmacist	50	32.1	42.0	21.3	<i>P</i> <0.010
Other source	106	67.9	58.0	78.7	
Medication adherence					
How often do you miss a dose of your medication?					
> 1 × weekly	24	16.4	14.3	18.8	<i>P</i> =0.459
1 × a week or less	122	83.6	85.7	81.2	

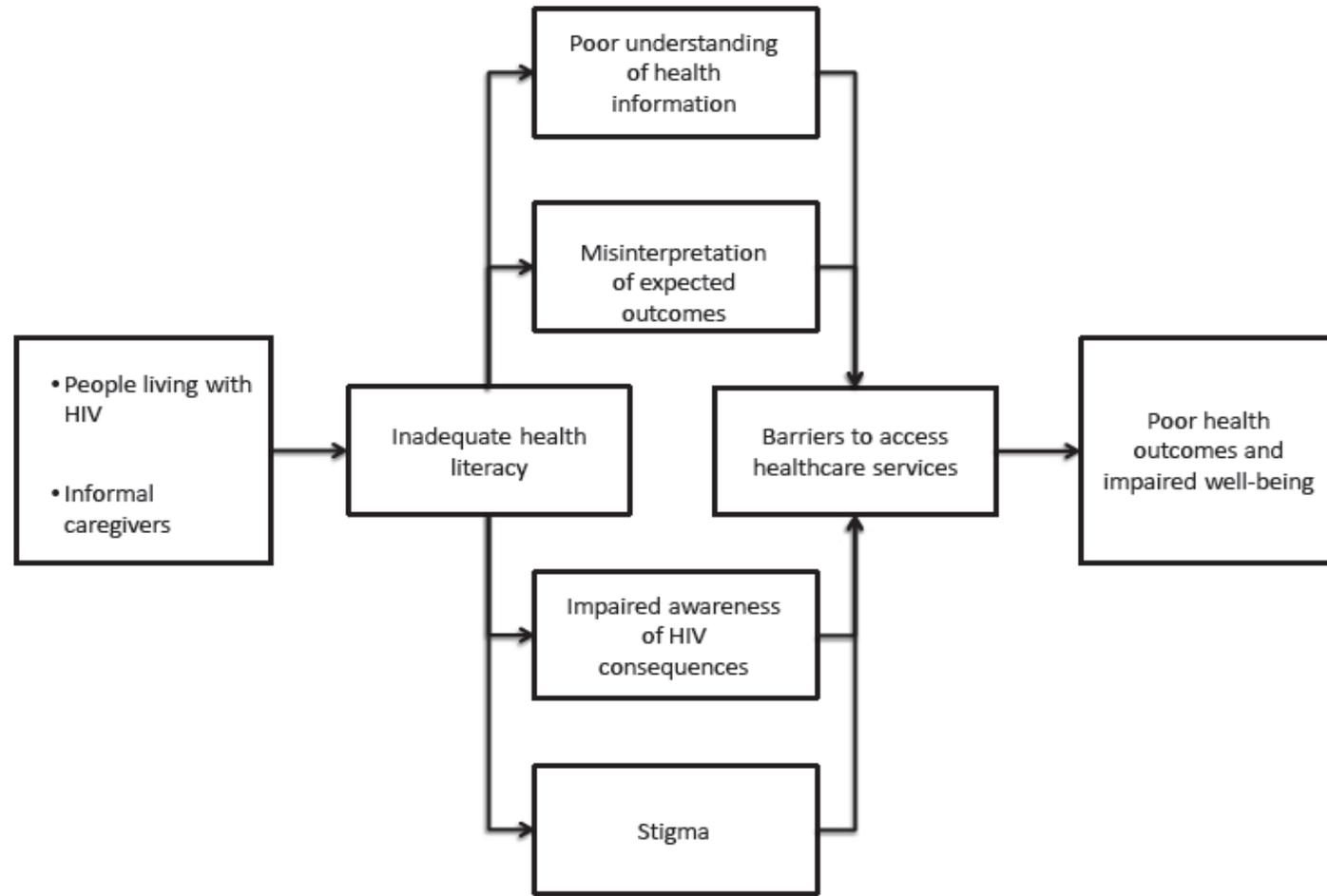
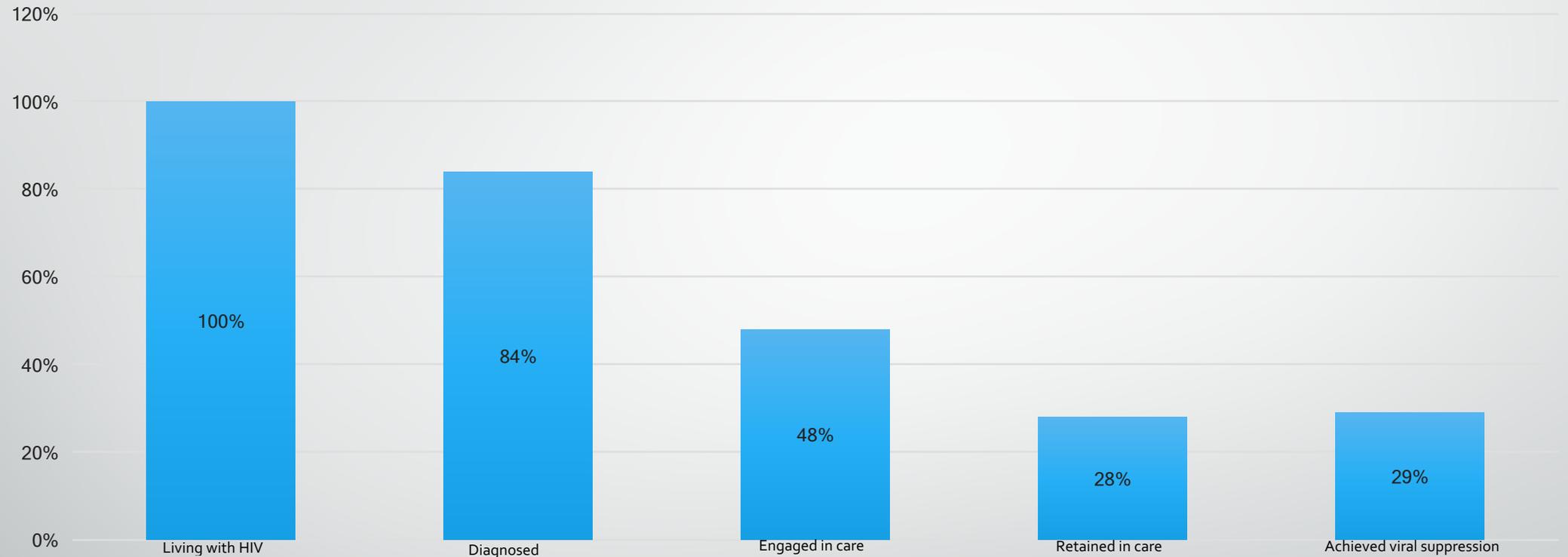


Figure 2. Inadequate Health Literacy as a Social Barrier to Access Healthcare. Source: Author's elaboration.

Mississippi HIV Continuum of Care, 2015



Among the factors that can influence outcomes at each stage of the HIV care continuum, such as poverty, homelessness, food insecurity, mental health problems, lack of health insurance, accumulated lifetime trauma, stigma related to HIV an/or other behaviors placing a person at risk, health literacy is often overlooked.

Diagnosis of HIV and Engagement in Care

- Low or limited health literacy has been shown to be a possible predictor of HIV test acceptance.
- Limited ability to read and understand a combination of written materials, including brochures, appointment information, informed consent documents, labels and instructions on medication increases likelihood of being non-adherent.
- Difficulty understanding information related to being newly diagnosed with HIV and the impact on their health, including being knowledgeable about their own health status
- Barriers to testing
 - Stigma and discrimination
 - Poor patient-physician communication

Health literacy and PLWHA

- Low health literacy has been linked to inadequate engagement in care and may serve as a contributor to poor health outcomes among people living with HIV and AIDS at three critical junctures of access to health care, interaction between patient and health care provider, and self-care. ¹
- Persons of low literacy were more likely to miss treatment doses because of confusion, depression, and desire to cleanse their body than were participants with higher health literacy.²
- Poor health literacy creates barriers to fully understanding one's health, illness, and treatments. Misperceptions of treatment in the case of HIV infection creates danger for potentially transmitting treatment-resistant strains of HIV. ²
- Awareness of disease status does not translate into knowledge of the disease

¹ Keitshokile Dintle Mogobe, et al, AIDS Research and Treatment. Language and Culture in Health Literacy for People Living with HIV: Perspectives of Health Care, Volume 2016, Article ID 5015707.
Providers and Professional Care Team Members, ² Seth C. Kalichman PhD², Bineetha Ramachandran BA², Sheryl Catz. Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy, Journal of General Internal Medicine. [Volume 14, Issue 5](#), pages 267–273, May 1999

Limited health literacy signs seen in PLWHA

- Has a consistently high or unchanged viral load
- Does not take antiretroviral therapies correctly
- Is hospitalized frequently
- Falls out of care
- Skips important preventive measures
- Cannot explain HIV or AIDS



Health literacy findings among PLWHA

- 204 patients receiving care in Shreveport, Louisiana and Chicago, Illinois.
 - One-third of patients had limited literacy skills.
 - These patients were less able to describe CD₄ count, viral load and to correctly identify medications in their regimen.
 - Limited literacy was an *independent* predictor of poor understanding of CD₄ count, correct medication identification.
 - A significant interaction was found between number of HIV medications and literacy level. Among patients taking only 1–2 HIV medications, 100% of higher literate patients were able to identify their medications, compared to **none** of the lower literate patients prescribed three or more HIV medications.

Health literacy and patient retention

- Retention in HIV care is an essential component of effective disease management. Although research on health literacy and retention in care has only recently emerged, early data suggests that patient's literacy may be important. ¹
- Adequate health literacy, defined as a patient's knowledge of their viral load and CD₄ count, more than doubled the odds of attending more than 75% of scheduled appointments for HIV care. Along with good provider relationship, HIV knowledge was also associated with higher CD₄ counts and greater odds of viral suppression. ²

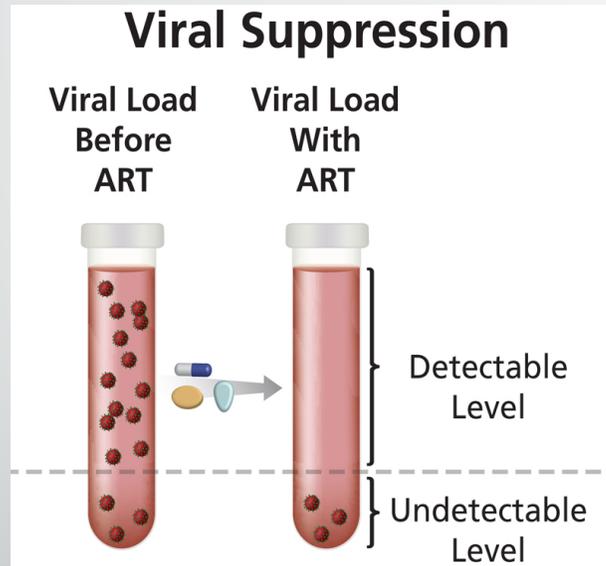
¹ Mallinson RK, Relf MV, Dekker D, et al. Maintaining normalcy: a grounded theory of engaging in HIV-oriented primary medical care, 2005

² Jones D, Cook R, Rodriguez A, Waldrop-Valverde D. Personal HIV knowledge, appointment adherence and HIV outcomes

Retention in care

- Limited health literacy may interfere with medical management of HIV infection. ¹
- Successful retention in medical care – 2 clinic visits during a calendar year spaced at least 2-6 months apart.
 - Improves survival
 - Improves viral load control
 - Decreases race or ethnicity related healthcare disparities
 - Newly diagnosed – HIV care every 3-4 months until immunologically stable and virally suppressed
 - ART initiated in first year of care are more likely to be retained ²

Impact of not being retained in care



- Viral suppression takes longer to achieve
- Increased risk for treatment failure and drug resistance
- Increased risk for risk for opportunistic infections

Importance of adherence

- Medication adherence for PLWHA means sticking to an HIV regimen.
- Non-adherence to medication regimens among PLWHA has been associated with poor health literacy.
 - A person with low health literacy is twice as likely to misinterpret medication labels and understand instructions:
 - Take on an empty stomach
 - Take 1 pill every 12 hours by mouth with a meal
 - Swallow whole, do not chew or crush
 - Take with food
 - Avoid prolonged exposure to direct sunlight while taking this medication
 - Medication should be taken with 8 ounces of water
- Non-adherent patients risk damaging their immune system



Improving chances for adherence and achieving viral suppression

- Treatment plan must be tailored to the patient's specific needs in order to increase medication adherence and understanding of their disease.
- Tied to patient-provider communication about the importance of ART adherence and its benefits for patient's health.
- Psychosocial factors may influence decision making in taking medications as prescribed.
- Discounting language and cultural barriers may impact medication adherence.
- Level of health literacy required may change as a result of disease progression
- Constant stream of new science and information can sometimes be complex.
- Explanations are given using complicated medical terms.
- Stigma associated with HIV/AIDS.



Fostering a care partnership to create a health literate environment

1. Provide HIV information to client in a way that can be understood

2. Listen to client and answer his/her questions

3. Treat client with respect, honesty, and compassion

4. Respect client's privacy and privacy of his medical information

5. Communicate openly about benefits and risks associated with any of client's treatments

6. Provide client with information to help client make informed decisions about his care and treatment options

7. Include client as a member of the care team

8. Work with client, and any other partners who treat or support him, in coordination of his/her care

9. Commit to the highest quality and safety standards

10. Help client to set goals for his health care and treatment plans

Strategies to improve patient perceptions of health professionals



- Be self-aware
- Acknowledge personal limitations
- Sit down with patient
- Slow down your speech
- Portray approachable body language
- Make patient feel valued
- Understand patient-provider communication may vary depending on level of health literacy
- Ask patient's preferred method of learning
- Know your patient. Inquire and gain understanding about gender, ethnicity, beliefs, behaviors, culture, literacy skills, personal goals, and current knowledge.

Creating a health literate workplace

- Include information on health literacy in staff orientation
- Provide a presentation on health literacy at a staff meeting
- Distribute relevant research and reports on health literacy to colleagues
- Propose starting a workgroup to explore some simple changes that can be made to promote health literacy



Final points

- Link to HIV treatment outcomes and could be related to disparities seen in HIV outcomes
- Patient-provider trust is an important component of long-term engagement in HIV care
- The meaning of health literacy for patient and provider is multidimensional and dynamic
- Patients' health literacy is associated with health knowledge, health status, and use of health services
- Health literacy plays an important role in disease prevention through the understanding of risk and the identification of necessary behavioral changes
- More research is needed to evaluate the link between patients' health literacy and HIV knowledge among uninfected at-risk patients
- Assurance of understanding the meaning, importance, and difference between CD₄ count and viral by the patient is critical to ensuring medication adherence, retention and engagement in care, and reducing HIV transmission rates

Thank you!

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