

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

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*Health numeracy plays a vital role in the successful management of HIV because much HIV-related health information is expressed in quantitative terms. The purpose of our study was to explore what older African Americans with HIV (N = 20) understood about their HIV laboratory numbers and to examine communication of the numbers between patients and providers during clinic visits. The following four themes emerged: (a) HIV laboratory numbers are important to understand health status; (b) the numbers can often be confusing; (c) mutual communication between patient and provider is essential to understand the numbers; and (d) when communicating numbers, use less detail. Implications for future interventions to address health numeracy deficits in this population are discussed.*

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**Key words:** African Americans, health literacy, health numeracy, HIV, older adults, patient-provider communication

Health numeracy, once thought of as a component of health literacy, was originally defined as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numeri-

cal, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions” (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005, p. 375). Since that time, improving health literacy and numeracy skills and health communication between patients and providers has become an accepted part of the nation’s public health agenda (HealthyPeople.gov, 2015; U.S. Department of Health and Human Services, 2010). In a systematic review that compared both health literacy and numeracy, numeracy skills were found

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to have stronger associations with health outcomes when compared to health literacy, although strength of the evidence was insufficient given the limited number of numeracy studies and the small number of individuals with low health literacy included in the studies (Berkman et al., 2011).

For people living with HIV (PLWH), health numeracy plays a pivotal role in understanding the use of numbers within the context of HIV management because much health information is quantitative. Laboratory numbers such as CD4+ T cell counts and viral loads remain the standard of care for monitoring HIV treatment (Lau, Gange, Kirk, & Moore, 2009) and are evaluated and communicated to patients as a gauge of health status. Effective communication of this quantitative information to patients is essential if patients are expected to respond accordingly to achieve optimal health outcomes. Thus, it is apparent that an understanding of such numbers is important to effective self-care and medical management. This is especially relevant for addressing racial disparities in health outcomes for African Americans (AAs) with HIV. This population has increased risk for morbidity and mortality, and is less likely to be engaged in HIV care than their White counterparts (Gebo, Fleishman, & Moore, 2005; Mugavero et al., 2009). Because it is estimated that within the next 5 years, 70% of PLWH will be older than 50 years of age (U.S. Senate Special Committee on Aging, 2013), it is important to examine this expanding populations' understandings about HIV numbers and their perspectives on their providers' communications about these numbers. Although there is a growing body of research in numeracy and HIV (Waldrop-Valverde et al., 2009; Waldrop-Valverde et al., 2010), little is known about health numeracy and patient–provider communications in older AAs with HIV using patient-centered approaches. Patient-centered approaches allow patients to have a voice in their health care options and better equip them to make informed health care choices (Patient-Centered Outcomes Research Institute, 2012). For the purpose of our study, we explored the following research questions:

1. What do older AAs with HIV understand about their laboratory numbers (i.e., CD4+ T cell counts and viral load)?

2. What is the process of communicating the numbers between patients and providers during clinic visits?

Health numeracy, within this context, refers to the degree of understanding of laboratory numbers in HIV management.

## Methods

For this qualitative descriptive design, we conducted individual interviews with older AA patients receiving care at an HIV outpatient clinic; data were collected between March and April 2013. Patients were recruited through convenience sampling from a clinic population with a majority (62%) of AA patients and an increasingly aging population (39% of patients were older than 50 years of age). Flyers and brochures, which included information about the study and the Principal Investigator's (PI) contact information, were placed in clinic patient rooms and in clinic office waiting areas. Those interested in the study contacted the PI's office and were prescreened to determine eligibility. Those who were younger than 45 years of age, non-AA, homeless, had a history of mental impairment, or were blind or deaf, were excluded from the study.

Interviews were semi-structured and conducted by two members of the research team, an AA man and AA woman, both Master's-prepared content experts who had been living with HIV for 30 years and 20 years, respectively, at the time of the study. Both received extensive training on patient-centered interview techniques (Gakumo, Enah, Vance, Sahinoglu, & Raper, 2015) and assisted with the development of the interview guide. The female interviewer conducted interview sessions with the female patients and the male interviewer conducted interviews with the male patients. Patients were asked questions pertaining to what they understood about their CD4+ T cells and viral loads, such as, *What does it mean if your viral load is undetectable?* and *If you have a CD4 or T-cell count of 50, what does that mean?* They were also asked questions pertaining to possible knowledge deficits such as, *What is the hardest part about understanding what your doctor or nurse practitioner tells you about your HIV?* and their health

priorities such as, *What is the most important information that you take away from your clinic visit today?* The interviews were held in private rooms in the clinic on the same day that patients attended their regularly scheduled provider visits. Prior to the interview, informed consent was obtained and patients completed a demographics instrument. Sessions lasted from 40 to 60 minutes, and each patient was compensated \$25 for participation in the study. Most recent CD4+ T cell counts and viral loads were obtained from the patients' electronic medical charts with prior written authorization. The institutional review board at the academic health center where the outpatient clinic is located approved the study.

Conventional approaches were used to analyze the data. This was considered the best approach to use because of the lack of previous literature in this area, which warranted the use of conventional approaches (Hsieh & Shannon, 2005). Data were audio-recorded and transcribed verbatim, then entered into NVivo™ (QSR International Pty Ltd, Doncaster, Australia), a qualitative research software used for data storing, coding, and analysis. Inductive content analysis procedures were used to categorize the data to reveal emerging themes. The authors reviewed the transcripts independently and then met to develop a coding scheme. Data were categorized and the group met to discuss areas of consensus and disagreement on interpretation of the data. To help ensure confidentiality, no patient identifiers were included on transcribed interviews and study information was kept in a locked file cabinet in the PI's office. Moreover, data were entered into a password-protected file stored on the university server.

## Results

Data saturation was reached after the 14<sup>th</sup> patient, although a total of 20 patients were included in the study for an equal representation of male and female patients. The mean age was 54.9 years ( $SD = 6.3$ ), 50% were female, and all were AA. Although 85% of the sample completed high school or obtained an equivalent diploma, only 25% had incomes of more than \$20,000 per year. In addition, 75% were unemployed, retired, or on disability. Participants had been

diagnosed with HIV for a mean of 12.1 years ( $SD = 7.5$ ), and the mean CD4+ T cell count was 566.2 ( $SD = 296.1$ ). Viral loads ranged from nondetectable ( $<50$  copies/mL) to 123,000 copies/mL (see Table 1).

Four major themes were revealed in relation to health numeracy and patient-provider communication: (a) HIV laboratory numbers (i.e., CD4+ T cell counts and viral loads) are important to understand health status; (b) the numbers can often be confusing; (c) mutual communication between patient and provider is essential to understand the numbers; and (d) when communicating numbers, use less detail. No major differences in themes were noted between men and women with regard to numerical understanding and communication preferences.

## HIV Laboratory Numbers Are Important

When asked about the importance of their laboratory work, many participants stressed the importance of what their CD4+ T cell counts and viral loads told them in terms of understanding their HIV progression/suppression and health. A 66-year-old female

**Table 1.** Sample Demographics ( $N = 20$ )

Variable	Number (%)	$M$ ( $SD$ )	Range
Gender			
Men	10 (50%)		
Women	10 (50%)		
Annual income			
< \$10,000	7 (35%)		
\$10,000-\$19,999	8 (40%)		
\$20,000 and over	5 (25%)		
Employment status			
Unemployed/ disabled/retired	15 (75%)		
Employed full or part time	5 (25%)		
Education completed			
< 12 years education	3 (15%)		
12 years/GED	5 (25%)		
College/vocational	12 (60%)		
Age (years)		54.9 (6.3)	45.0-66.0
Years living with HIV		12.1 (7.5)	1.0-25.0
Number of current HIV medications		2.1 (1.0)	1.0-4.0

GED = General Education Diploma.

patient stated the following about her HIV laboratory work: “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 ...” When asked about the meaning of her viral load, she stated,

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.

In like manner, a 58-year-old female patient had this to say about why her laboratory numbers were important to her: “Because that’s the only way that I’ll know what my, uh, how my medicines are helping my, the HIV ... virus.”

### Numbers Can Be Confusing

Although patients were familiar with the concepts of the CD4+ T-cell count and viral load, several were confused about the differences between the two laboratory numbers and in which direction they ought to go (i.e., up or down). For example, a 55-year-old male patient had this to say about the difference between his CD4+ T cell count and viral load:

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.

Similarly, a 58-year-old male patient had this to say in response to a question about understanding his viral load:

You know what? I’m slowly but surely learning the difference between that [viral load] and the other [CD4+ T cell count]. That, the viral load, that’s the one that’s what? Making sure I understand; but I’m trying, I’m finally understanding ‘em.

When asked to elaborate further on his understanding, he stated:

That the, that the, okay, well one is 5, is 773, whatever it is. If it goes, let me see, I wanna

get it right. It goes, if it stays at that certain level then it’s lookin’ good; but if it go over, wait a minute—go under; I ain’t explaining that right. But I do understand; I’m gonna leave that there. [Laughs]

A 57-year-old female patient had this to say when asked about the meaning of a high CD4+ T cell count, “[It means] that the virus is attacking you still in your system, you know. It’s very heavy, you know.” When asked her interpretation of a low CD4+ T-cell count, she stated that it means the following to her: “That you’re in good health?”

### Mutual Communication

The majority of participants commented that their providers communicated effectively with them and they actively asked questions when they had difficulty understanding the provider. This 55-year-old female patient had the following statement about her relationship with her provider:

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.

A 46-year-old male patient had the following statement about communication with his provider if his viral load was too high:

High viral load would mean that things are kind of getting out of whack and either maybe I need to talk with the doctor, we need to either see why, you know, if it has to do with maybe something I’m doing personally or maybe we may have to discuss changing the medication.

### Use Less Detail

Several patients discussed the need to limit the amount of information given about their numbers or that they preferred for their providers to just let them know that they were on the right track. For example, a 60-year-old female patient stated this in response to the interviewer’s question about what a

viral load means to her: “Nothing. [Laughing] I’m sorry, I don’t mean to be like that, but it don’t mean, see, ’cause I don’t even get my viral load.” The interviewer went on to ask if the participant knew what her last viral load was. Her response was as follows:

I don’t know what it’s been for 20 years! I knew the first year, but after then I didn’t care to know anymore, so they just ... I mean, they tell me it’s undetectable. It’s been undetectable for years ... So, I just assume that it’s still undetectable because they haven’t said anything, but they don’t tell me, because they know I don’t want to know.

Similarly, a 58-year-old female responded to a question about communicating with her provider:

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.

A 57-year-old male patient stated the following:

... for people who don’t really understand, you don’t want to give them too much information at one time. You want to cover certain areas like, “What is a CD4 value, what does that mean?” Or, “What is [it] about your viral load that is so critical?” Those are the kind of things that people want to know.

## Discussion

The purpose of our study was to explore older AAs’ understandings about HIV laboratory results and their perspectives about communication of these numbers by their HIV providers. Four key themes were identified: (a) HIV laboratory numbers are important to understand health status; (b) the numbers can often be confusing; (c) mutual communication between provider and patient is essential to understand the numbers; and (d) when communicating numbers, use less detail. These findings highlight the importance of health numeracy within a

medical context for vulnerable populations and ongoing relationships and communications between patients and providers to address health disparities in HIV outcomes. Moreover, patient-centered approaches were used in the development of the interview guide as well as in data collection strategies to determine knowledge gaps that existed in health numeracy. As people continue to age successfully with HIV, there are growing concerns for minority populations about how to effectively manage comorbidities such as hypertension, dyslipidemia, and diabetes, conditions that also require increasing health numeracy skills (Monroe, Rowe, Moore, & Chandler, 2013).

A major theme that emerged from the interview sessions was that HIV laboratory numbers were important to understand health status. Patients noted the importance of having the numbers regularly monitored as an indicator of health. In a study of 210 patients living with HIV, Jones, Cook, Rodriguez, and Waldrop-Valverde (2013) examined patients’ knowledge of their CD4+ T cell counts and viral loads. They found that those who could accurately recall these numbers were more adherent to their clinic appointments and, when examined in conjunction with a good relationship with a provider, were more likely to have higher CD4+ T cell counts and undetectable viral loads (Jones et al., 2013). In the patient–provider relationship dyad, communications regarding HIV laboratory numbers can often move beyond an awareness of the importance of the numbers for an increased understanding of how the numbers play a role in HIV management; however, this needs to be tailored to the individual’s knowledge level and readiness.

In our sample, confusion about CD4+ T cell counts and viral loads was also a recurrent theme. These findings were not surprising, as nearly half of the sample ( $N = 9$ ) had low health literacy based on a validated health literacy measure (Bass, Wilson, & Griffith, 2003). In a sample of 204 patients with HIV, Wolf and colleagues (2005) found correlations between low health literacy and patients’ abilities to describe their CD4+ T cell counts and viral loads ( $p < .001$ ). However, Griffey and colleagues (2014) found that in a sample of emergency department patients ( $N = 446$ ), even patients who had adequate health literacy



scored significantly lower on numeracy measures ( $p < .0001$ ). Although numeracy was not measured quantitatively in our study, findings demonstrated that much could be learned from addressing understanding of and differentiation between these two values.

Mutual communication between providers and patients being essential to understanding the numbers was also a theme. Dickens, Utley-Smith, Stott, and Relf (2013) evaluated the outcomes of a workshop to enhance HIV provider communication skills with patients with low health literacy. Findings indicated that, on evaluating the effectiveness of the workshop, providers reported that a number of techniques were used with their low literacy patients, including speaking at a slower pace, presenting a few concepts and assessing for understanding, using teach-back methods, using simple language, handing out printed material, writing instructions, and following up with an adherence nurse. Future studies should assess which particular techniques older minorities would find most useful when presenting numerical information and if those methods would differ based on what numerical information was presented (e.g., laboratory numbers or complex medication regimens).

Mutual communication also required effort on the part of the patient or consumer of health care. When asked, nearly all of the patients in our sample stated that they asked questions of their providers when they did not fully understand instructions or health information. While these findings were encouraging, Kalichman, Pellowski, and Chen (2013) found that in low health-literate patients living with HIV ( $N = 474$ ), those who requested assistance with reading and understanding health information showed poorer treatment adherence and viral load suppression than those who did not ask for assistance. HIV care providers have been shown to overestimate their patients' literacy/numeracy levels (Ohl et al., 2010). Thus, when patients ask questions regarding health information, providers should give sufficient teaching and monitor understanding on a continuous basis, especially in aging patients with HIV, who show higher rates of cognitive decline than their uninfected aging counterparts (Hardy & Vance, 2009; Vance, Fazeli, & Gakumo, 2013).

The need to be less detailed when communicating numbers was also a common theme. This can be especially germane as it pertains to reducing the amount of health information presented, which has been found to help older adults' comprehension and understanding (Efraimsson, Sandman, & Rasmussen, 2006). Furthermore, low health literacy may place limitations on patients' abilities to engage with their providers (Maurer, Dardess, Carman, Frazier, & Smeeding, 2012).

It is important to note that two of the themes from our study—Theme 2 (numbers can often be confusing) and Theme 4 (when communicating numbers, use less detail)—are supported by theory. Fuzzy Trace Theory is a dual-process theory that explains how people prefer to receive and interpret information and make decisions. The two main constructs of the theory, gist representations and verbatim representations, each occupy a side of the cognitive continuum. Gist representations are largely qualitative and nebulous; they are based on emotion, education, culture, life experience, worldview, and developmental level. Verbatim representations, in contrast, are exact, quantitative, and taken at face value; they incorporate spoken information, graphs, numerical data, and images. Fuzzy Trace Theory asserts that people prefer to interpret and make decisions on the simplest form of gist representations as opposed to verbatim representations (Reyna, 2008). Take, for example, a patient who is newly diagnosed with HIV. A provider may attempt to explain how HIV affects the body using formal information including numbers and graphs (verbatim representation). What the patient gleans from the knowledge of a new diagnosis, however, is more dependent on his emotion discovering he has HIV infection, his life experiences, and current knowledge about HIV, whether or not it is accurate (gist representation), as well as his ability to interpret and understand the provider's words and explanations.

Findings from the two aforementioned themes indicated that many patients in our sample tended to interpret and make judgements based on the crudest gist representation (e.g., general statements by their providers instead of detailed numerical information). For example, statements reflecting confusion in knowing whether the CD4+ T cell count or

viral load should be low or high or even difficulty recalling these numbers only minutes after the clinic visit ended were common. Several patient statements demonstrated that they mainly desired a good report from their providers or to know that they were on the right track based on a provider's interpretation of the CD4+ T cell count and viral load. As a collective group, the patients included in the sample were generally healthy, the mean CD4+ T cell count was 566.2 cells/mm<sup>3</sup> and the majority had undetectable viral loads. However, patients may take continuous good reports from their providers as a justification to become less adherent to antiretroviral therapy or clinic appointments. It is important for providers to spend an appropriate amount of time assessing patients' understandings of information presented and tailor messaging accordingly.

Our study was not without limitations. Convenience sampling was used and the sample also was not representative of PLWH not actively engaged in care, whose views may differ. In addition, social desirability bias could have been present because the study took place at the clinic where the patients received HIV care.

## Conclusions

Our study findings fill a gap in the literature by using patient-centered approaches to elicit information about numbers within the context of HIV management from the patient perspective. For PLWH, the concept of health numeracy is particularly meaningful. Numeric skills require patients to have an increasing awareness and understanding of numerical health information. Moreover, these skills may provide vital indications about a patient's ability to be actively engaged in care and adherent to treatment and therapy. Future interventions developed to address health disparities in vulnerable populations, such as older AAs with HIV, should focus on (a) keeping health information concise so as not to disengage patients, (b) nurturing continued communication in the patient-provider relationship, and (c) considering patients' life experiences as the frame of reference for receiving information and making health care decisions.

## Key Considerations

- Health numeracy consists of quantitative knowledge and skills to make effective health decisions and is as important as health literacy on patient outcomes.
- Health numeracy plays a pivotal role in successful HIV management because much HIV-related health information is numeric.
- Patient awareness and understanding of numbers within the health context have important implications for improved engagement in care and treatment adherence.
- Patient preferences on how to receive numeric information, especially for older adults and minorities, should be considered in order to foster effective communication between patients, nurses, and other health care providers.

## Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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