

“Keep it simple”: older African Americans’ preferences for a health literacy intervention in HIV management

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Purpose: Health literacy is lower in minorities and older adults, and has been associated with nonadherence to medications, treatment, and care in people living with human immunodeficiency virus (HIV). Likewise, African Americans with HIV are more likely to be nonadherent to their HIV medications, less likely to keep their clinic appointments related to HIV treatment and care, and more likely to die during hospitalizations than their ethnic counterparts. The present study explored the preferences of older African Americans with HIV for a health literacy intervention to promote HIV management.

Patients and methods: In this qualitative study, 20 older adult African Americans living with HIV were recruited from an HIV/acquired immunodeficiency syndrome outpatient clinic in the southeastern region of the US. Using patient-centered participatory design methods, semi-structured individual interviews were conducted to determine patient preferences for intervention development and design. Health literacy was also measured using the Rapid Estimate of Adult Literacy in Medicine – Revised (REALM-R).

Results: Four major themes emerged related to intervention development and design: keep health information simple; use a team-based approach for health education; tailor teaching strategies to patients’ individual needs; and account for patients’ low experience, but high interest, in technology. Forty-five percent of the study population had low health literacy based on the revised Rapid Estimate of Adult Literacy in Medicine.

Conclusion: Future interventions that target minorities and older adults living with HIV should consider patients’ learning needs, sex-specific and mental health needs, and delivery approaches, in order to increase uptake and improve disease management and health outcomes.

Keywords: health disparities, health literacy, HIV/AIDS, medication adherence, older adults, racial disparities

Introduction

Advances in combination antiretroviral therapy prolong survival rates such that 70% of people living with human immunodeficiency virus (HIV) will be over the age of 50 by the year 2020.¹ Despite these advances, older people living with HIV face challenges in health literacy that can interfere with chronic disease management. Chronic disease management as it relates to HIV includes various components such as being knowledgeable about the disease process, understanding and strictly adhering to HIV medication regimens, and staying actively engaged and retained in care. Health literacy is an individual’s ability to comprehend and use health care information and related services in making informed decisions regarding their health.² Health literacy is lower in older adults and minorities than the general population,² and has been associated

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with nonadherence to medications, treatment, and care in people living with HIV.³⁻⁶

Disparities in HIV outcomes continue to persist among African Americans. African Americans with HIV are more likely to be nonadherent to their HIV medications than other races/ethnicities,^{4,7} less likely to keep their clinic appointments related to HIV treatment and care,^{8,9} and more likely to die during hospitalization than their ethnic counterparts.¹⁰ Interestingly, when health literacy was examined as a potential mediator between African American race and HIV medication nonadherence, these racial disparities were not significant.⁴ These findings indicate that health literacy is an important factor to consider in the health of African Americans with HIV, yet there is a lack of research in this area. Furthermore, because two-thirds of older adults in the US have health literacy deficits,¹¹ addressing health literacy within the context of HIV management (eg, medication adherence) is imperative in this thriving clinical population.

Previous research has shown that health education and information that is individualized and considers patient preferences, especially in low literate populations, is associated with better health outcomes.¹²⁻¹⁴ Carman et al¹⁵ developed a framework for engaging patients and other stakeholders in interventions and other areas such as in policy making and on an organizational level to improve health. Based on their framework, patients are engaged along a continuum and the range of opportunities for this engagement is determined by the topic to be addressed. In addition, engagement can occur at multiple levels and is not confined to direct patient care. Lastly, there are a number of factors, such as low health literacy, that can ultimately affect patients' ability to engage.¹⁶ The purpose of this study was to explore older African American patient preferences for a health literacy intervention to promote HIV management.

Methods

Study design and analysis

The study was based on individual interviews with patients using a qualitative description approach.¹⁷ Between March and April 2013, semi-structured individual interviews were conducted. Potential participants were identified from clinic appointment schedules and screened over the telephone to determine study eligibility with prior approval from their health care providers. The interviews were scheduled at a date and time that coincided with upcoming clinic appointments and reminder phone calls were made the day before the scheduled interviews. Informed consent was obtained and

interviews took place in private rooms immediately following clinic appointments. Interviews were audio recorded and transcribed for thoroughness and clarity. Data were analyzed based on a framework for qualitative data analysis.¹⁸ Patients received \$25 at completion of the study. The study was approved by the University of Alabama at Birmingham's Institutional Review Board.

Study population

Twenty participants (50% women) were recruited from an HIV/acquired immunodeficiency syndrome outpatient clinic located in a metropolitan area in Birmingham, AL, USA. The clinic serves approximately 2,950 patients actively engaged in care, 62% of whom are African American and 39% of whom are over the age of 50 years. Inclusion criteria included the following: 1) HIV diagnosis for at least 1 year; 2) currently receiving outpatient treatment at the clinic; 3) currently taking an HIV medication regimen; 4) Black or African American; 5) age ≥ 45 years; and 6) English speaking. Exclusion criteria included: 1) cognitive impairment; 2) legal blindness; 3) severe hearing loss; 4) pregnancy; and 5) being homeless.

Data collection

Patient-centered participatory design methods were used to obtain preferences from the patients on intervention development and delivery design. Patient-centered outcomes research gives patients a voice in their health care options by assisting them in communicating and making informed decisions about their health care.¹⁹ Semi-structured qualitative interviews were conducted to explore patient preferences regarding design and delivery of an HIV management intervention. Questions were asked related to which components to include in the program and how people best learn about HIV. The following are examples of questions regarding intervention: What types of things should we include in an education program to help people learn more about how to manage HIV? What types of things would make you more interested in learning about HIV and how to take better care of yourself? Prompts with reference to different teaching modalities (eg, face-to-face) were included to facilitate dialogue between the research interviewer and the patients. The interviews lasted approximately 40 minutes to 1 hour.

Two members of the research team living with HIV who reflected the ages and race of the study population conducted the individual interviews. Both were educationally prepared at the Master's level and above and were active patients and members of the clinic's advisory boards. The research

interviewers assisted with the development and revision of the interview questions and participated in a 3-day training course in conducting in-depth interviews led by the principal investigator of the study. Included in the training were didactic lectures on interviewing techniques as well as opportunities for the trainees to practice these techniques with volunteers and role-play as both "interviewer" and "patient." Training interviews were audio recorded and the trainees were provided opportunities to listen to the interview, reflect on facilitators and barriers to effective dialogue during the interview, and gain individual feedback from the principal investigator. Once the actual interviews began, the principal investigator listened to the sessions as they were conducted and performed periodic check-ins to maintain consistency in how items were asked and how dialogue occurred. Weekly team meetings provided a mechanism for open dialogue and exchange of knowledge between the researcher and the research interviewers before, during, and after completion of the study.

In addition to the individual interviews, health literacy was also measured. The rationale for this assessment was because this population has characteristics (ie, older adults, minorities, low income) placing them at risk for low health literacy. Health literacy was measured by the Rapid Estimate of Adult Literacy in Medicine – Revised (REALM-R),²⁰ a brief examiner-administered measure that includes a written list of eight medically related words of increasing reading difficulty. The participant is asked to read each word aloud while the examiner rates whether or not each word was pronounced correctly. Scores range from zero to eight, with higher scores reflecting a greater level of health literacy.

Data analysis

A conventional approach to content analysis was used for data analysis. Conventional approaches are normally used when there is a lack of theoretical foundation or previous literature on a phenomenon.¹⁸ Transcribed interview sessions and field notes were placed into a word processing file for data coding and analysis. NVivo™ (QSR International Pty Ltd, Doncaster, Australia), the qualitative research software, was used in data coding and sorting into categories. Categories were developed through inductive content analysis procedures and data from interviews were analyzed with regard to major themes that emerged. Two researchers with qualitative research experience independently reviewed the content and coded data to explore patient preferences for design and development of an HIV management intervention. The two researchers then met

to validate the coding schema and reconcile differences in coding. Although no new themes emerged (data saturation) after the 14th patient, data collection and analysis continued in an effort to adequately represent an equal number of women and men.

Descriptive statistics were used to analyze sociodemographics of the study population and results from the health literacy measure.

Results

The study population was 50% (n=10) female with a mean age of 54.9 years (standard deviation [SD]=6.3). Seventy-five percent had incomes of less than \$20,000/year, 75% were unemployed, disabled, or retired, and 85% had completed high school or the equivalent. The mean number of years with an HIV diagnosis was 12.1 (SD=7.5) and the number of current HIV medications ranged from one to four with a mean of 2.1 (SD=1.0). Nearly half of the study population (45%; n=9) had limited health literacy based on the REALM-R (mean=5.1; SD=3.1).

Overall, patients found the concept of a health literacy intervention appealing. The most dominant themes that emerged regarding intervention preferences were categorized as follows:

1. Keep health information simple.
2. Use a team-based approach.
3. Tailor teaching strategies to patients' individual needs.
4. Account for patients' low experience, but high interest, in technology.

Keep health information simple

When patients were asked how they understand health information, many expressed the need to limit the amount of medical jargon that may not be easily understandable. A 55-year-old female patient reported the following about pamphlets and brochures related to HIV:

"Uhm...I mean...I'm interested in 'em. [If] there's not a whole bunch of long, long drawn out stuff that lose, you know, that loses you. It's uh, just keep it simple and, and, and learnable, you know, that you can learn something from 'em. Even the personal stories of the people that has the HIV; just keep 'em simple without them going into too much medical stuff that you're not gonna understand anyway, you know? Just, uh, "doctor's talk" and stuff like that, that's not meaning anything. You know, you're interested in the research and all of that but when it goes into, like, medical educatin'...it loses me there...But if they keep

the stories simple and on layman's terms where you can understand it and then, I like for 'em to be like that."

Similarly, a 57-year-old female patient reported:

"Well, just put it in English that a person, you know, a person that's not a doctor can understand. The words that, you know, common, you know, that people can understand."

Use a team-based approach for health education

When asked about whom they would like to facilitate educational programs related to HIV management, the vast majority of the patients noted the importance of including both their peers who are currently living with HIV as well as health care professionals who have expertise in the field. The study population emphasized the relevance of their peers taking on a more active role in educational programs because of their experience in living with HIV. One 45-year-old male patient stated the following:

"To me, it would be better if you have people in it [the intervention program] that are living with the disease that have been through the, uhm, been through the medications, that have had the symptoms, that knows the steps of this disease. They can better inform you that, as far as, versus a health professional that does not have the disease; they know how to treat the disease, but living with it is, is, you know, a different story."

When asked about the inclusion of both HIV-positive peers and health care professionals in the program, a 66-year-old female stated the following:

"Because one thing...that person that hears you talking when you tell that individual that I'm positive, they'll listen to you sometimes quicker than they will with somebody that's not experiencing it...I think it's going to take teamwork...this is going to have to incorporate everybody...whether you're positive or negative."

Tailor teaching strategies to patients' individual needs

The patients also commented on the need to individualize the intervention based on the diverse needs of patients such as sex-specific, mental health, or health literacy/learning needs. One 66-year-old female patient stated:

"...women are built different than men. So, it's something that I have been actually advocating about for

a long time...they seem to see HIV as just the virus itself, but we have other issues we deal with along with the HIV as being a female...Our body itself is built different[ly], you know, where we have certain times of the month...some of us are going through menopause; there are some of us that's grandmothers that are even caregivers."

A 46-year-old male patient stated:

"...I think HIV, a person with HIV, that's the core of their medical issues; but, you know, a lot of times people have other things that's going on in their life, you know, other than HIV, and I just think it's always important for people to be able to address all the issues that's going on, as far as medical, you know, spiritually – whatever it is – to be able to address whatever is going on in their life – depression – just address things, man."

One 57-year-old male patient stated:

"...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 the CD4 value, what does that mean?" Or, "what is [it] about your viral load that is so critical?" Those are the kind of things people want to know."

When asked if she would be interested in an HIV management program, one 60-year-old female patient stated:

"Yeah, I would be interested. I might learn something. But, I don't know, it's just like when you've been living with this disease for 20 years, it's like every time you go somewhere [HIV education program], they're saying the same thing over and over and you just get so fed up. You know, it's like, to me, they should have newly-diagnosed programs and they should have old-timer's programs, you know?...You know, when they have something [HIV education program], they stick you all together and then they tell you the same thing, and I guess that's why I got burnt out 'cause it's like, I've been living with this disease 20 years, I don't want to keep HIV 101. I need more."

Account for patients' low experience, but high interest, in technology

Most of the patients discussed their lack of experience with technology or mentioned that they had only recently learned to become more proficient, and were generally in favor of the

use of technology (eg, apps) in interventions. A 45-year-old female stated:

"...I never knew that you can go on the internet and learn about HIV. I thought it was, you know, everything private, you just go to the doctor and, like, we're setting here and, you know, learn more about it, like that; but I never knew that you can go on the internet and learn anything about, uh, HIV."

A 53-year-old female stated the following:

"Someone just recently showed me how to download an app... [laughter]... in the last 2 months so I become really good. I could care less about electronics but I know there's a need to make things more efficient – they can make your life more efficient."

A 60-year-old female stated the following when asked about the use of the internet in programs to learn more about HIV: "I'm computer illiterate. I don't know anything about trying...So, I really need to take some computer classes and learn."

Additional findings

Minor themes of the interviews included addressing stigma, including information on medication education and adherence, having face-to-face interaction with HIV-positive peers and health care professionals, and favoring the use of educational DVDs in locations that are both convenient and private.

Discussion

Patients' perspectives and preferences are important factors to consider in the development and design of educational health interventions. In this qualitative study, older African Americans with HIV identified the following preferences for an HIV management intervention: keep health information simple, use a team-based approach for health education, tailor teaching strategies to patients' individual needs, and account for patients' low experience, but high interest, in technology. In addition, other important elements include addressing stigma, medication education and adherence, face-to-face interaction, and convenient and private educational DVDs. These findings underlie the relevance of multiple approaches as opposed to a "one size fits all" approach to intervention design. In a systematic review of interventions specifically designed to address low health literacy,²¹ it was found that intensive, mixed-strategy designs focused on disease

management were effective at reducing emergency department visits, hospitalizations, and disease severity. Such approaches are essential to the development of interventions that are predictably effective in improving HIV management and clinical outcomes.

In addition to keeping health information simple (ie, addressing low health literacy), using a team-based educational approach was a common theme noted in the findings. Although peer educators have commonly been included in intervention programs focusing on people living with HIV,²²⁻²⁴ patients also understood the expertise of health care professionals in the field. Findings indicated preferences for increasing the role of peers in health education mainly because of their ability to relate to others who deal with managing HIV on a day-to-day basis.

Tailoring teaching strategies to patients' individual needs was also a frequent theme in the interviews. Specific tailoring was related to sex-specific needs, mental health needs, the amount of health information presented at one time, and modifying for those who have been diagnosed for a number of years as opposed to those newly diagnosed. A number of studies have focused on the diverse needs of women in the management of HIV such as biological and contextual factors,²⁵⁻²⁷ and the mental health needs of patients with HIV who live with depression and are further stigmatized.²⁸⁻³⁰ In addition, other qualitative studies have noted difficulties that older adults face in engaging in their care when health care professionals overwhelm them with too much information.³¹

Educational interventions focused on chronic management for those diagnosed with HIV for many years are highly relevant because although older adults are typically more likely to adhere to their HIV medications, declines in neurocognitive functioning can affect adherence levels.³² Approximately 50% of people living with HIV have HIV-associated neurocognitive disorder,³³ which can interfere with retaining and processing health information for which they may not have a frame of reference. Difficulty understanding such HIV health information may be compounded for older people living with HIV who also have to manage information regarding age-related comorbidities such as renal disease, liver disease, heart disease, hypercholesterolemia, hypertension, and diabetes, which occur more frequently in this population.³⁴

Finally, patients were generally in favor of using technology for health education although they acknowledged lacking experience with the technology. Nearly all of the patients

affirmed that if given the sufficient education in this area, they would support the use of technology in HIV education. Many advances in HIV interventions, for example, involve the use of mobile applications and electronic medication reminders.^{35,36} However, these interventions have not been tested in this population. This study is among the first to elicit preferences for the use of technology in interventions among older adults with HIV.

This study has its limitations. The study was limited to older African Americans and does not necessarily reflect other populations living with HIV. It also did not include the views of health care professionals who are involved in the patients' care. However, because this was a qualitative descriptive study, the main purpose was to gain information from a particular demographic for use in intervention development. In addition, the views obtained were from patients who were active in care and did not reflect the perspectives of those not engaged in the health care system. Finally, social desirability could have been an issue, although several patients stated during the interview that they felt very open discussing their preferences with the interviewers, who were older African Americans that openly disclosed their HIV status to the patients.

Conclusion

The results from this study can greatly inform the development of future interventions to improve HIV management in minorities and older adults living with HIV. For example, HIV education materials tailored toward this population should be written in plain language and at lower reading levels. In addition, the amount of information presented in programs should be curtailed or divided into multiple sessions to allow for adequate processing. The study findings can also further complement existing interventions that have demonstrated efficacy in producing optimal health outcomes. The use of both peers and health care professionals in education delivery, for example, with more emphasis on the role of peers should be considered in established programs that focus solely on either health care professionals or trained peers as the main source of health information. Knowledge and support gained from both the medical expert and the "lived experience" expert can increase patient engagement and further improve overall outcomes. Tailored health education that incorporates multiple approaches (ie, support from peers and use of technology) for culturally diverse and aging populations is vital for successful programs with long-term sustainability. Such education should also be modified to address other individual aspects such as sex-specific issues,

mental health needs, and health literacy deficits. Furthermore, health literacy interventions and programs can be greatly improved if patients are considered equal partners in intervention development and design.

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Disclosure

The authors report no conflicts of interest in this work.

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