Perspectives of People Living with HIV toward Healthcare Providers: Insights into Multicultural Health Perspectives of People Living with HIV
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Objectives

1. Appraise the literature related to relationship influences on health literacy for people living with HIV

2. Evaluate study themes for application to clinical practice
   - Partnership
   - Knowledgeable health care provider
   - Understandable language
   - Respect
   - Knowing the person

3. Assess commonality of themes across cultures
Background

Health Literacy — degree to which individuals have capacity to obtain, process & understand health information & services to make appropriate decisions related to health.

Or, in plain language, health literacy is:
A person being able to understand and take the right action to make good health choices.
patients with low HEALTH LITERACY...

- Are more likely to visit an EMERGENCY ROOM
- Have more HOSPITAL STAYS
- Are less likely to follow TREATMENT PLANS
- Have higher MORTALITY RATES

www.cdc.gov/phpr
Significance

• Low health literacy
  • Associated with poor health outcomes
  • Disproportionately affects racial & ethnic minorities and those with low income levels
Purpose

• In order to further our understanding about relationship influences that impact health literacy, the purpose of study was to characterize the perspectives of a culturally diverse group of people living with HIV (PLWH)
Methods

• Sample — 17 focus groups with PLWH at 8 sites representing multicultural backgrounds in the United States, Puerto Rico & Botswana

• Procedures — Audio-recorded focus groups

• Analysis — Content analysis

• Ethical Review — Approval from each site, informed consent, pseudo-names used, incentive gift
Sample Focus Group Questions

• How did you learn about what HIV is and how it can affect your health?

• How much do you take part in your care?

• What does your health care provider say to you when she/he talks to you about something related to your health?

• Has the information you’ve been given changed the way you care for yourself?
Results — Five Themes

• Partnership
• Knowledgeable health care provider
• Understandable language
• Respect
• Knowing the person
Partnership

• Definition — Working together toward common goal

• “We are kind of insistent, almost demanding that we have a respectful partnership with our doctors because we know our bodies and we’re partnering with our doctors to get better health”

• “They should see us as equals when we discuss these health issues.”
Knowledgeable Health Care Provider

• Definition — Health care providers having information or expertise in caring for PLWH, or conversely, a lack thereof

• “But I guess the point is that HIV doctors have to be knowledgeable or need to be knowledgeable about everything there is in Medicine and in medical conditions and thank God now I have probably one of the best doctors in the state.”

• “The HIV doctor, she was a good doctor, but she had no idea about anything besides HIV and to me that’s not a good doctor, you know because if she only knows about the HIV part and she’s got four degrees sitting behind her, there’s a problem somewhere, whereas <doctor>, she knows her stuff.”
Understandable Language

• Definition — Words used in the context of health care that are understood and have meaning to PLWH

• My request is that there must be a Motswana doctor or an interpreter; so that when I am not feeling well, the nurse will be able to tell the doctor that I am not feeling well. I always go back with unresolved problems as I am unable to communicate with the doctor.

• “Help me to understand, because I don’t know and I need for you to help me to understand what is going on? Why am I going through these situations?” And that resident broke it down in simple English for me to understand . . .”
Respect

• Definition — Presence or absence of an appreciation that a person is important & should be treated as a person of worth

  • “and because she’s able to sit down and listen to you, because she sees you as a person, a human being, that’s the utmost part of the respect, instead of a doctor coming in and saying ‘Hey, look. This is what you’ve got.”

  • “When they’re talking to you like you’re somebody, like you are important, you mean something to somebody in the world...”
Knowing the Person

• Definition — Understanding the uniqueness of an individual

• “She’ll sit down, she’ll say ‘Well how have you been? What’s been going on?’ So in the conversation you’re talking to her and you’re talking about what’s going on, she’s listening and she’s gathering information from you about how you’re feeling and what you’ve been doing, what you’ve been going through, . . . . . are you depressed, this, that, whatever, and in that conversation she develops and is able to say ‘Okay, so now how are you really feeling?’”
Discussion

• Participants valued respectful partnership relationship with knowledgeable health care provider who used understandable language & regarded them as persons of worth
• Limitations
Multicultural Differences

• Problematic nature of language barriers expressed by Botswana women; need for interpreters
• Role of RN in Botswana
  • Physicians are primary prescribers of treatment, yet have limited face-to-face contact with PLWH
  • Nurses and pharmacists provide majority of care
Multicultural Similarities

• Similar expressions of desire for partnership, respect, knowledgeable health care provider, understanding of personhood
• Invisibility of nursing
Conclusions

• Relationship quality between PLWH & health care providers central to facilitating & enhancing health literacy of PLWH & likely retention in care
Finding the Right Words for Better Health