Research Article

Health Literacy: Challenges to HIV Knowledge

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Abstract

Background: Health literacy is of concern to patients and their health care providers. Failure to comprehend the information given by the health care provider can result in sub-optimal outcomes for the care-giving relationship and more particularly for the patient.

Aim: The aim of this study was to explore the concept of health literacy with patient care team members (PCTM) and investigate the challenges identified by PCTM to the provision of HIV education and the strategies they use to provide HIV education and support to people living with HIV (PLHV).

Methods: Qualitative descriptive methodology was selected for the study reported in this paper, and focus groups of PCTM were conducted in Botswana and four sites in the U.S. (Boston, MA; New York, NY; San Francisco, CA; and Wilmington, NC).

Results: The themes identified in this study were: 1) Individual challenges to HIV education, 2) Provider-associated challenges to HIV education, and 3) Systems-level challenges related to HIV education. Sub-themes for these themes were also identified.

Conclusions: PCTM used a variety of methods to address these challenges including the approaches they used for teaching and outreach to their patients. They identified approaches to system-level impediments although these approaches were often not within their power to implement. As we explicated in the discussion of these results, the cost of providing basic literacy education for all will remove some, although not all, of the basic challenges to HIV education and knowledge. Basic literacy is fundamental to improving the health literacy and health of PLHV and the nation; it is also a matter of justice as well as being the fiscally prudent approach to statecraft.

Keywords: Health literacy; literacy; PLHV; HIV; Focus Groups

Introduction

Health literacy is of concern to patients and their health care providers. Failure to comprehend the information given by the health care provider can result in sub-optimal outcomes for the care-giving relationship and more particularly for the patient [1,2]. Health literacy is defined by the Institute of Medicine (IOM) [3] as "The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (p.4). This definition places the responsibility for comprehension of health information squarely on the shoulders of the patient. Similarly, Van Servellan, and colleagues [4] defined functional health literacy as the ability to understand such patient materials as prescription bottle labels, the information on appointment slips, and other related materials for adherence to the plan of care.

Nutbeam [5] cites the IOM in noting that health literacy is comprised not only of speaking and listening skills but of reading, writing, numeracy, and cultural and conceptual knowledge. Serper and colleagues [6] add the importance of problem-solving skills to this array. Nutbeam [5] considers health literacy an asset to be developed through appropriate education.

While health literacy is often described as a competency, it can also be considered an outcome of the patient-provider inter-action. This perspective suggests that it is not just the health literacy skills of the patient but also the qualities of the inter-action with the provider where the abilities of the provider to transmit essential information are also part of the equation. Indeed, Von Wagner, and colleagues [7] emphasized provider-patient communication as key to health literacy. In this conceptualization, levels of health literacy are outcomes rather than an ability or capacity. Baker [8] argued for an assessment that includes not only the individual but also the health care system and broader society. This perspective provides a more inclusive perception of the individual and the environment. Nutbeam [5] in discussing health communications emphasized the importance of the social determinants of health. In line with this, the conceptual framework of Van Servellan and colleagues [4] includes not only individual predisposing factors to health literacy such as age, income and education, but also individual enabling factors such as psychological distress, time since diagnosis, and time on antiretroviral therapy, as well as system enabling factors such as HIV instruction/support and quality of health care provider communications. This conceptualization presents a comprehensive perspective of the factors that influence health literacy.

Why is health literacy of such concern? A lack of health literacy is a barrier to the patient's understanding of the plan of care. In addition, difficulty in distinguishing the side effects of therapy from the underlying disease may delay reporting of such side effects to the health care team. Inadequate health literacy may also be a factor in a failure to adhere to the recommended plan of care. If health literacy is also an outcome of the patient-provider interaction, it is important to consider the perspective of the provider regarding challenges to patient health literacy and the provision of HIV education to people living with HIV (PLHV).

This study is part of a larger study of health literacy in PLHV utilizing focus groups composed of male PLHV; female PLHV; health care providers (nurse practitioners and physicians); and patient care team members (PCTM) (registered nurses, social workers, and pharmacists). The research reported in this paper explores the concept of health literacy as perceived by PCTM. These team members educate PLHV about their HIV disease and their proposed or prescribed therapy. To develop a greater understanding of health literacy and the education provided by PCTM to PLHV, a qualitative, descriptive study was conducted using focus groups with PCTM at sites in Botswana and the United States (U.S.).

Aims

The aims of this study were:
1. To explore the concept of health literacy with PCTM
2. To investigate the challenges identified by PCTM to the pro-

vision of HIV education

3. To identify the strategies PCTM use to provide HIV education and support to PLHV.

Methods

Qualitative descriptive methodology was selected because it is considered the method of choice for the description of a phenomenon such as team members' responses to questions regarding health literacy [9]. To prepare for conducting the focus groups, focus group facilitators were trained at a 1.5 day meeting to ensure multi-site consistency in the conduct of the focus groups. Two investigators with expertise in qualitative methodology led the training during which site facilitators had the opportunity to lead mock focus groups. One investigator led the discussion and a colleague took notes during the discussion to provide additional data for verification and confirmation as needed. Discussion of the training experience with critique by the experienced qualitative investigators enhanced the preparation of the site researchers.

For the study reported in this paper, data were utilized from focus groups of PCTM conducted in Botswana and four sites in the U.S. (Boston, MA; New York, NY; San Francisco, CA; and Wilmington, NC). Participants for this research were recruited from HIV/AIDS clinics, AIDS service organizations and at a national AIDS meeting. Regarding the latter, the focus group for the Boston PCTM was conducted at the national meeting as that was more convenient for the PCTM. Approval to conduct the study was obtained from the requisite Institutional Review Board/ Human Subjects Committee by each site participating in the study.

After obtaining written informed consent, a team-developed sociodemographic survey and interview questions were used to obtain information about participants' personal and professional characteristics. Thereafter, focus groups were conducted using the same set of questions for the PCTM group at each site included in this study.

One of the researchers conducted the focus group assisted by a colleague who took notes as a resource for interpretation as needed for the recorded interview of the responses. Both field notes and recordings were used to document the interactions. Recordings were transcribed verbatim and the focus group interviews were imported into Atlas Ti, a software program for managing qualitative, textual data. Thematic analysis was used to determine emerging themes. Transcripts were coded and themes elicited by one coding professional. To conduct the analysis presented here, these codes were used as well as intensely reading and rereading the original textual data to identify expressions and themes [10].

Results

The themes identified in this study were: 1) Individual challenges to HIV education, 2) Provider-associated challenges to HIV education, and 3) Systems-level challenges related to HIV education. Sub themes were identified for each of these major themes. Sub-themes to the individual challenges to HIV education reported by PCTM included physical and psychological challenges, the newly diagnosed, fear of disclosure and stigma, undetected lack of basic literacy, incorrect knowledge, beliefs, behavioral issues and socio-economic factors. A number of sub-themes to provider-associated challenges were identified by the PCTM including goal congruence, provider assumptions and system demands on the provider. The sub-themes to the systems-level challenges related to HIV education included eligibility for funded care and system-level assumptions about patient literacy. The following statements by the PCTM illustrate the challenges to health literacy for each of the major themes and sub-themes.

1) Individual challenges to HIV education

Physical challenges

"Sometimes you have clients who might have a physical medical need - - -or pain management."

"And we've had patients who are deaf, who don't know sign language, and can't even read or write so it's very difficult to try to communicate anything let alone complicated information".

Psychological challenges

"- - and where they are mentally. If they are not stable, it is really hard to engage them".

"I think in the same vein that like if it's due to depression or substance abuse issues, they can learn something one day and then come back in and ask you to re-explain it again, or, you know, kind of regress and not understand a concept that they understood before".

The newly diagnosed

"- - - somebody who's just finding out they are positive, their capacity to tolerate new information is really limited. They can't hear past the diagnosis. And our tendency is to try to fill discomfort with a lot of information".

"I think a barrier is when people are first diagnosed, not wanting to deal with it, denial. If I don't admit that I have HIV, then I don't need to know about medications. I don't need to take medications. I don't need to learn about this at all".

Fear of disclosure and stigma

"Fear of disclosure is a very big barrier. You would think that shouldn't exist today but it's almost as bad as when it first came out. And they will get somewhere and they hear a relative or friend or whatever make a snide remark about someone with HIV and that, right there shuts them down. I can't let anyone know what's with me. I have to hide my medications or whatever".

"- - - also the stigma, still, of having HIV. Like where I came from - - it's still a huge stigma. I had a friend who was diagnosed with a cancer and they were testing him for HIV. He said it was still a huge deal. Like 'if I'm HIV-positive I can't tell anyone'. So he was focused on that and so he didn't even want to know anything about basic HIV transmission - - -so it was like "I'm not going to deal with HIV".

"- - - We assumed that dealing with stigma is a moment in time, and what I think we learned - - is that it's a lifelong issue and it impacts some people in some ways similar over the years and in some ways differently at different moments in time".

Undetected lack of basic literacy

"There is a client from [locale] If you are talking with this person, you will have no idea that this person cannot read or write, none whatsoever, and I had been around this person for almost a year before someone told me, you know 'this' [person] can't read or write. You have to be joking; a big well of information. Gives information like crazy. And carries a conversation, can teach, can whatever. But cannot read or write. And you have no way of knowing that the person could not read or write".

"- - - we have a patient and we went over, how do you get refills, what do you ask, what do you check the pharmacy for, how do you make sure you have everything you need. He happened to be illiterate but what we didn't realize was that- it took us three or four visits to realize, you have to go to the kiosk at the pharmacist first, put in your name, print out a ticket, get the ticket, and then sit in line and wait for your number to be called - - to get your medication. And while he could talk to the pharmacist about everything, he didn't know how to use the kiosk. So for us he was saying 'Sure, sure, sure - - I know how to do this' But then we realized he wasn't picking up his medications because of the kiosk issue. - - But if we hadn't kept asking about that, and kept reassessing, we would not have known that he wasn't picking up his medications".

Incorrect knowledge

"There were two gay men who were some of the pioneering activists back in the 80's and 90's. And you know, knew everything there was to know about HIV. However 15 years ago when they met each other, they dropped out of activism. And their knowledge was extremely dated. So the initial [detox] they were extremely knowledgeable but in reality, what they knew about HIV was 15 years ago, and so meds, horrible side effects, disfiguring, difficult to tolerate, et cetera, et cetera".

 "- - -Because there's so much bad information out there, that I think can make it difficult. More and more patients that I thought would never have told me 'Oh I looked it up' are now telling me 'I've spent time on the internet looking up' whatever issue, and then they come back with very wrong information, and I think that can be a barrier".

Beliefs

 "I don't believe in taking medicines, ugh".

Behavioral issues

"Drug use is a big barrier - - -".

'- - -I think for a lot of our patients, many of them live in poverty, many of them have family issues, substance use issues - - -'.

"Their most urgent needs, which is maybe housing or substance use- - - ".

"I think the majority of the patients I work with have very few organizational and planning skills, they live day to day. There's no 'In three weeks I'm going [to] do, it's I've got to put food on the table today' or - - -'my monthly check comes today, and it's going last for a few days, and in two weeks, I don't know what I'm going do'."

"I had a client where it was, it all boiled down to time management. He would forget, he would just forget. So we had to try to figure out what are some ways- - - ".

"Some they are organized some- but for some it's difficult for them to let us know when they are not around or when they cannot come for their appointments - - -".

"- - - I have some patients that are so on the move and so on the go - - -that their organization and planning skills - - - the least important thing falls off the list and that happens to be us - - -".

Socio-economic factors

"- - - for me, working in a health center and in a place where - - - most of the people live 300-400% below the poverty line, to me the biggest eye-opener was - - - that right now someone might not be focused on their HIV, their focus is - - - making sure the electricity doesn't go off, or that they have food on the table".

"Sometimes if you have clients who might have physical, medi-

cal needs but the client is going back to 'I don't have anywhere to live' then - - probably that person is not going to engage the medical issues".

"Like A said, on the hierarchy of need for these patients, the medical care is so down there".

2) Provider-associated challenges to HIV education

Goal congruence

"I also find that at times, the providers have goals and things that they want to accomplish, but there is not a congruency between the goals [we] have and the goals that the client has of needs and priorities".

"When I first started, I just did my own thing. So I did a lot of power point. I thought that I should use power point here. And at first, I was kind of working it. It was novel, it was new; I was using slides and everything, so it was really cool. But I think the clients weren't really getting it - - -".

Provider assumptions

"- - - but with someone who is an EMT provider who we think perhaps would- that's just an example- know that you can't get HIV from doing mouth to mouth resuscitation without a barrier or pocket mask still doesn't know that. And so our personal assumptions that their level of education or knowledge should be at a certain place is a barrier to us being able to teach them- - -".

System demands on the provider

"For case managers, one of the biggest obstacles is the amount of paper work that's involved any time you have contact or even do a collateral contact for a client, which takes away time that you could actually be spending with the client to help them with their behavior changes or education. When I first started this work twelve years ago, our intake page was probably four pages long. It was basic information, but it allowed me to be able to have clients just drop by if they wanted to, and I could sit and spend time with them. I could do home visits, go to see two or three patients a day, and keep up with the paper work. But it's more like a business, where unless you have an appointment to see me, I really don't have time, just so I can stay on top of the paper work that's required these days".

3) System issues related to HIV education

Eligibility for funded care

"- - - challenges caused by the restrictions of funding, caused by policies and procedures of working in a hospital environment. We all talk about we want to meet the patients where they are,

but we're only allowed to do that if they qualify financially, and if they come in and do this and that".

"- - - insurance is a barrier as well, and it all has to do with access to care.

If there's a lapse in insurance or if their co-pays are so high, we're gonna see the same thing; their disconnect from care, infrequent visits, infrequent opportunities to educate them - - ".

"Yeah there's a whole group of patients who are falling through the cracks on the health safety net, the ones that earn a certain amount of money because they're partially employed, and because the health safety net is not really going to be able to cover everything, They have a huge- up to 40%-deductible rate that they just get lost, and so the medical co-pays- even if ADAP is covering their prescription co-pays, could be $8000 for a person making $20,000 a year. Nobody's ever going to be able to pay for that, and so they don't go to any appointments. I mean, that's a gap - - -".

"I have patients who have started to feel better on their ARV's and 'O.K. I want to go back to work' and then when they go back to work, then 'Oh, that's actually not cost-effective. It's better for me to be unemployed to be able to receive the care I need to take care of the things I need' and just, financially, which is crazy".

"- - - the contractors will take the clients to complete a tender in (locale). The next thing the client will be telling him I am supposed to come for a check up on such a date. He will promise that he will bring the client back, only for him to come stay in (locale) and that one will be defaulting for some months".

Systems level literacy assumptions

"I think a lot of written materials are great for people who can read, but a lot of times the literacy level of them is extremely complicated, or they're not in multiple languages - - -".

"I think language has to come back up - - - not having access to some of the materials or the interpreters that you might need, sometimes that could be huge. That would be my magic wand, having the interpreter for every language there ever was. My health center is very good in regards to having access to interpreters. But there are a few, a few languages that we cannot get and I always wonder. So we're using family members or whatever and then I'm always wondering 'What do they really understand' or 'What they really think is going on' cause you don't know".

Provider approaches

Approaches used by the PCTM to confront these challenges are varied but included the following: appraising readiness to

learn, meeting the client where they're at, the use of non-verbal cues, your plan of care, teach-back, provider-outreach, research nurse time, learning from other professionals.

Appraising readiness to learn

"I think that what I find is that HIV is not their biggest problem. And they're dealing with so many other problems that this is just one more thing that they'll deal with later".

"- - - they leave and come back later is important because sometimes people aren't ready. And we will see it will take ten admissions before they are ready to talk about anything. Or sometimes I remember there'll be a patient who - - -hated me, and we just didn't get along and then he would come back later and he recognized me but he couldn't remember if he hated me or loved me - - and I just - - pretended we had been friends, so then we got along great. Now he's housed and doing well. So I think that's how you do it. You just have to go on their time and not rush things".

Meeting them where they're at

"On a very individual basis, I work to identify how best they like to learn, I think that's always part of the conversation".

 "I use their terminology, which sometimes is not what I'd prefer to use, but I've got to go where [they're at] so that they are comfortable speaking with me. My main job when they're first coming in is to get them comfortable so they will tell me anything".

"You have to meet them where they are at, maybe don't talk about multiple issues, talk about their greatest concern, battle that, focus on that, little by little approach other illnesses or conditions".

"Just meeting them where they're at. And encouraging them in any way you can - - -".

 "Educational levels would be a barrier especially for some patients who don't read or write. So that affects how you do an assessment, that affects the amount of information that they are able to retain, what kind of information they retain".

The use of nonverbal clues

"I think there, there are patients that are just going [to] come out and they're going [to] tell you what they think. But the challenge is those who don't. So, ummm, so, the body language is important. I think the behavior is important, too. So somebody who misses their appointments, or tells you over and over again that they are taking their medications but yet they have a viral load that won't come down. - - - And there's some discrepancy between what the patient's saying and they're go-

ing [to] do, or want [to] do and the reality of it".

Your plan of care

"I think if you present it as a tailored plan of care, like I'm here to work with you to make your plan of care and I'm not telling you what it is, but I'm here to like, help you learn some things that are important, but what's important to you for your plan of care".

Teach-back

 "I think you were saying like teach-back".

Outreach

"- - - so if I meet someone in clinic and I know they've been given HIV 101, then I'll be with them in a home visit and there will be lots of questions or concerns that they'll raise that they didn't feel comfortable raising in the clinic but will want a little more clarification in the home. Like, the doctor said this, but I didn't really understand it, but I didn't want to ask".

"Or go find them on the street. They may not even have a phone, and you know where they sleep, or hang out, and so you can go and bring them their medications or whatever; in your free time".

"I know that in our clinic, we work with a lot of homeless people, and we actually have a peer that can go out into the field. - - -the peer will meet them at the homeless shelter and accompany them to their appointment, which has worked pretty well in most cases".

Research nurse time

 "I have a bit of a luxury in that I do HIV research, so we have, I think, a lot more time to spend with folks, a lot more time to break down challenges that they might experience in the immediacy of finding out their diagnosis or approaching health care - - -".

Learning from other professionals

"a long-time HIV pharmacist, I think, I learned from her, the most important question that is going to predict adherence is if you ask the patient 'what do you think these medications are going [to] do for you?' And if what comes out is a list of side effects, terrible things, remind me of every day I have HIV, make me nauseated, make me disfigured, make me whatever, the chance of successful adherence is going to be a lot less than if the patient's going [to] say 'it's going [to] save my life, it's going [to] bring my viral load down, it's going [to] give me the chance to go back to school, to have a child, to maybe be in a relationship- to not transmit HIV', all of those things. And I think our

field doesn't do that great a job of training us about what are those questions that really work."

Discussion

As can be observed from the comments recorded from the focus groups, when the PCTM think about health literacy they think about HIV education. They note the multiple challenges to educating their patients about HIV and PLHV becoming knowledgeable about HIV and achieving health literacy. The challenges identified in this study were individual, provider-related, and systems issues and are inter-related. And while the subthemes for the major themes identified in this study are not unknown, it is their combination that amplifies the challenges in providing HIV education. PCTM also identified the approaches they used to confronting these challenges as well as the challenges that were beyond their scope to address.

All of these issues need to be addressed if the challenges to health literacy are to be reduced. One approach is to develop well-rounded programs to confront the issues related to language and culture, as well as health literacy [11]. Language and cultural challenges concern not only attributes of the individual but also those of the system including how health literacy is assessed.

Zanchetta and Poureslami [12] provide the example of the university educated German immigrant who as a result of not speaking English or French would score low on a health literacy scale. Thus, individuals identified as lacking functional health literacy may have been improperly assessed. Further, the lack of ability to read and write is not equivalent to a lack of knowledge as was evident in the PCTM statements concerning the undetected lack of literacy. In an interesting and important conclusion regarding health literacy, Ohi and colleagues [13] note that patient reporting of educational attainment was more accurate in identifying low health literacy than the observations of providers or the results of a screening instrument.

Educational attainment may be a proxy measure of low health literacy, or at least of literacy, but additional facilitators and inputs such as education by health care providers are required for specific health or illness conditions. And given the data from this investigation, there are numerous challenges to the provision of HIV education by the PCTM and to the attainment of health knowledge and thus health literacy by the patient. While some of these challenges are related to PLHV individual issues other challenges emanate from provider associated and system issues including the patient-provider relationship. Challenges that are potentially most remediable are those of the patient-provider relationship.

In a study examining health literacy in the nurse-diabetic patient relationship, the authors cite the use of medical jargon as a barrier to health education [14]. Further, they discuss closing the communication loop through the use of repetition, clarification, asking for understanding and seeking the patient's perspective as necessary components to the process of effective education.

Clearly basic literacy is an important foundation for health literacy. Yet even if the educational challenges, as well as provider-patient and some systems challenges to health literacy were eliminated through education, the individual socioeconomic, personal health and behavioral challenges would still be present. The difference would be the improved literacy skills of the individual to confront these issues.

Watson [15] noted the economic impact and estimated the cost of low health literacy to be between $106-$236 billion dollars per year. It was also found that people with poor health literacy were more likely to use an array of health services. Justice requires that governments assist their citizens in becoming literate. And fiscal probity supports this approach. The costs of providing education will ultimately be surpassed by the savings, both in human and financial terms, of having a literate population, a prelude to having a health literate populace as well as improving health outcomes.

Limitations and future research

A number of challenges have been identified by PCTM to imparting HIV information. The limitations of this study are the multiple challenges identified and the need to pinpoint the challenges of greatest salience to the attainment of HIV knowledge both those creating the greatest impediments to such attainment and the challenges most readily resolved. This is also where future research will play an important role.

Conclusions

Although the overall purpose of the focus groups was to expand our understanding of the concept of health literacy, the results of this study indicate that the PCTM focus groups were concerned about the numerous factors that constitute challenges to HIV knowledge and to health literacy. Three themes and a number of sub-themes were identified in this study. Individual challenges to HIV education included physical and psychological challenges, the newly diagnosed, fear of disclosure and stigma, undetected lack of basic literacy, incorrect knowledge, beliefs, behavioral issues and socio-economic factors. The sub-themes to the second theme, provider-associated challenges to HIV education, included goal congruence, provider assumptions and system demands of the provider. The third theme, systems-level challenges related to HIV education, included eligibility for funded care and system-level assumptions about patient literacy.

PCTM used a variety of methods to address these challenges including the approaches they used for teaching and outreach to their patients. They identified approaches to system-level impediments although these approaches were often not within their power to implement. As we explicated in the discussion of these results, the cost of providing basic literacy education for all will remove some, although not all, of the basic challenges to HIV education and knowledge. Basic literacy is fundamental to improving the health literacy and health of PLHV and the nation, it is also a matter of justice as well as being the fiscally prudent approach to statecraft.

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