

UCSF

UC San Francisco Previously Published Works

Title

Understanding Health Literacy for People Living With HIV: Locations of Learning.

Permalink

<https://escholarship.org/uc/item/3t92g26v>

Journal

Journal of the Association of Nurses in AIDS Care, 29(2)

Authors

Lindgren, Teri
Reyes, Darcel
Eller, Lucille
et al.

Publication Date

2018

DOI

10.1016/j.jana.2017.10.007

Peer reviewed



HHS Public Access

Author manuscript

J Assoc Nurses AIDS Care. Author manuscript; available in PMC 2019 March 01.

Published in final edited form as:

J Assoc Nurses AIDS Care. 2018 ; 29(2): 190–203. doi:10.1016/j.jana.2017.10.007.

Understanding health literacy for People Living with HIV: Locations of learning

Teri G. Lindgren, RN, PhD, FAAN*,

Assistant Professor, Rutgers School of Nursing, Newark, New Jersey, USA

Darcel Reyes, PhD, ANP-BC,

Chief Clinical Officer and Clinical Instructor, Rutgers Community Health Center, Rutgers School of Nursing, Newark, New Jersey, USA

Lucille Eller, PhD, RN,

Professor Emerita, Rutgers School of Nursing, Newark, New Jersey, USA

Dean Wantland, PhD, RN,

Adjunct Professor, Montclair State University, Montclair, New Jersey, USA

Carmen Portillo, PhD, RN, FAAN,

Professor and Chair, University of California San Francisco School of Nursing, San Francisco, California, USA

William L. Holzemer, PhD, RN, FAAN,

Dean and Distinguished Professor, Rutgers School of Nursing, Newark, New Jersey, USA

Ellah Matshediso, PhD,

Director, HIV and AIDS Coordination Office, University of Botswana, Gaborone, Botswana

Inge Corless, PhD, RN, FNAP, FAAN,

Professor, School of Nursing, Massachusetts General Hospital Institute of Health Professions, Boston, Massachusetts, USA

Jeanne Kemppainen, PhD, RN, FAAN,

Irwin Belk Distinguished Nursing Professor, University of North Carolina Wilmington, Wilmington, North Dakota, USA

K. Dintle Mogobe, BEd Nursing, MNsc, MEd, PhD,

Head and Associate Professor, School of Nursing, and Director, World Health Organization Collaborating Centre Faculty of Health Sciences, University of Botswana, Gaborone, Botswana

Allison Webel, PhD, RN,

*Corresponding author: Teri G. Lindgren: tlindgr@sn.rutgers.edu.

Disclosures

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

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Assistant Professor, Case Western Reserve University, Bolton School of Nursing, Cleveland, Ohio, USA

Kathleen Nokes, PhD, RN, APHN-BC, FAAN,

Professor Emerita, Graduate Center, City University of New York, Stone Ridge, New York, USA

Patrice Nicholas, DNSc, DHL (Hon.), MPH, MS, RN, NP-C, FAAN,

Professor, Massachusetts General Hospital Institute of Health Professions School of Nursing, Director, Global Health and Academic Partnerships and Senior Nurse Scientist, Division of Global Health Equity, Brigham and Women's Hospital, Boston, Massachusetts, USA

Marta Rivero Mendez, RN, DNS, GCG,

Professor, School of Nursing, University of Puerto Rico Medical Sciences Campus, San Juan, Puerto Rico

Paula Reid, PhD, RNC, WHNP-BC,

Associate Professor, University of North Carolina Wilmington, Wilmington, North Carolina, USA

Solymar Solis Baez, BA,

Director of the Center for Research and Evidence-based Practice, School of Nursing, University of Puerto Rico Medical Sciences Campus, San Juan, Puerto Rico

Mallory O. Johnson, PhD,

Professor, University of California San Francisco School of Medicine, University of California, San Francisco, San Francisco, California, USA

Yvette Cuca, PhD, MPH, and

Research Specialist, University of California San Francisco School of Nursing, University of California San Francisco Women's HIV Program, San Francisco, California, USA

Carol Dawson Rose, PhD, RN, FAAN

Associate Professor, University of California San Francisco School of Nursing, Department of Community Health Systems, San Francisco, California, USA

Abstract

Health literacy, including people's abilities to access, process, and comprehend health-related information, has become an important component in the management of complex and chronic diseases such as HIV infection. Clinical measures of health literacy that focus on patients' abilities to follow plans of care ignore the multi-dimensionality of health literacy. Our thematic analysis of 28 focus groups from a qualitative, multi-site, multi-national study exploring information practices of PLWH demonstrated the importance of location as a dimension of health literacy. Clinical care and conceptual/virtual locations (media/Internet and research studies) were used by PLWH to learn about HIV and how to live successfully with HIV. Non-clinical spaces where PLWH could safely discuss issues such as disclosure and life problems were noted. Expanding clinical perspectives of health literacy to include location, assessing the what and where of learning, and trusted purveyors of knowledge could help providers improve patient engagement in care.

Keywords

health literacy; HIV; information practices; learning settings; qualitative research

Health literacy has taken on currency in health care as it has been identified as an important component in the management of complex and chronic diseases such as HIV. Health literacy has been viewed as an individual capacity and defined as the way and the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine [IOM], 2004). The U.S. Centers for Disease Control and Prevention (CDC) estimated that only 87% of people living with HIV (PLWH) in the United States know they have HIV infection, only 72% of those were engaged in health care, and only 58% had achieved viral suppression, the primary marker of controlled disease and the key factor in treatment as prevention (CDC, 2017; Hall et al., 2015). Many factors undoubtedly have contributed to this scenario, but it is likely that health literacy plays an important role that has yet to be fully understood.

Health literacy is derived from multiple concepts that incorporate an individual's ability to fully interpret and understand complex health information, including terminology, health care instructions, and the actions necessary to manage a chronic health condition (Cunha, Galvao, Pinheiro, & Vieira, 2017). It has been closely related to socio-economic status, levels of education, race/ethnicity, and age, and may reflect an urban/rural or developed/developing country divide (Ownby, Acevedo, Waldrop-Valverde, Jacobs, & Caballero, 2014; Zukoski, Thorburn, & Stroud, 2011). Low health literacy contributes to lack of access to care in this already marginalized and stigmatized population; in HIV research, low health literacy has been associated with less knowledge about HIV and its treatment, lower medication adherence, lower CD4+ T cell counts, and higher viral loads (Kalichman et al., 2013; Ownby, Acevedo, Goodman, Caballero, & Waldrop-Valverde, 2015).

The concept of health literacy emerged from two different perspectives, clinical care and public health, with one identifying health literacy as a clinical risk and the other as a personal asset (Nutbeam, 2008). Much of the research related to health literacy among people living with chronic diseases, such as HIV, has focused on the clinical risk of low health literacy. Measurement of health literacy has focused on known elements specifically related to individual capacities, including reading/arithmetic skills, health knowledge, information seeking, and motivation (Nutbeam, 2008; Ownby et al., 2014). Current health literacy assessment tools generally seek to quantify cognition-related elements associated with specific disease processes. The clinical conceptualization of health literacy among PLWH has focused primarily on reading and numeracy skills, specifically how to read medication bottles, warnings, and short pieces on adherence, and on calculating medication doses based on prescriptions (Cunha et al., 2017; Ownby et al., 2014). While understanding how to take medication is important, is this all there is to health literacy? What about the ways PLWH "obtain, process and understand basic health information" (IOM, 2004)?

The current narrow view of health literacy ignores the fact that to live successfully with HIV requires knowing more than how to take medications correctly and the importance of adherence. Information practices, or information-seeking practices, defined as a bundle of

organized activities that enable access to, sharing of, and evaluating information, may help us better explore the breadth of health literacy capacities and needs among PLWH (Lloyd, 2010; Lloyd, Bonner, & Dawson-Rose, 2014).

The purpose of this paper is to describe a major theme, Locations of Learning, that emerged from a multi-site, multi-national, qualitative focus group study that sought a more in-depth understanding of health literacy and information practices for PLWH (Dawson-Rose et al., 2016)(Dawson-Rose et al., 2016). Of particular interest was an exploration of how PLWH learned about the complexities of HIV and how they used this information to survive and thrive.

Methods

Data presented here were collected as part of a multi-site, multi-national, collaborative study conducted by the International Nursing Network for HIV/AIDS Research to qualitatively describe the breadth of health literacy for PLWH and to understand their information practices. A series of 28 focus groups (206 participants) were conducted across 8 Network sites in the United States, Puerto Rico, and Botswana in 2013–2014 (see Table 1). Focus groups were conducted with PLWH ($n = 135$), and separately with health care providers (HCPs), including physicians and nurse practitioners ($n = 32$) and professional care team members (PCTMs), including nurses, case managers, social workers, and pharmacists ($n = 39$). Where possible, focus groups with PLWH were conducted separately by gender.

Participants

Individuals from all three groups were recruited from clinics, hospitals, service organizations, patient registries, and HIV-related professional associations through institutional review board (IRB)-approved flyers. PLWH had to be at least 18 years of age; able to provide informed consent; speak English, Spanish, or Setswana; have a diagnosis of HIV; and available on the date of the focus group. PLWH participants were screened for cognitive impairment using the Mini Mental Status Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). Those who scored 20 or less were considered unable to actively participate in focus group discussions and were, therefore, excluded. A total of three PLWH were excluded after the MMSE screening. HCPs and PCTMs had to meet the same inclusion criteria (except for HIV diagnosis) and had to self-report working in a professional capacity with PLWH.

Participant ages across all three types of focus groups ranged from 43 to 48 years. The majority of HCPs and PCTMs were women, as were nearly 50% of PLWH (see Table 1). Forty-five percent of the HCPs were nurse practitioners and 40% of PCTM were nurses. Of the PLWH participants, 73% had at least a high school education, and most were people of color (45% were African American/Black) who had inadequate or barely adequate incomes (see Table 1).

Data Collection

Given that this was a multi-site study, to ensure consistency across sites, all focus group facilitators completed a 1.5-day focus group training, consisting of instruction and

guidelines for conducting focus groups. A semi-structured interview guide, with a list of agreed upon questions, was developed and each facilitator led a mock focus group discussion using the guide. The practice focus groups were observed by two expert qualitative researchers and debriefing feedback was provided.

At the beginning of the focus group, each participant completed the written informed consent process and then completed a brief, self-administered demographic survey. Once all focus group members (6–8/group) completed the survey, the focus group began. All focus group discussions took place in a quiet, private location, and refreshments were served. The focus groups lasted approximately 1.5 to 2 hours and included the primary discussion leader and a second trained research team member to document key points and non-verbal signals. At the conclusion of the focus groups, all participants were compensated for their time with an IRB-approved amount of money according to local standards (Table 2). All focus groups were audio recorded and the interviews were transcribed verbatim. Focus groups conducted in languages other than English were transcribed in the local language, translated to English, and verified against the initial recordings to ensure accuracy. The final, de-identified transcripts were securely sent to one of the coordinating sites at the University of California, San Francisco School of Nursing for preliminary analysis.

Ethical Approval

Each site in this study received ethical approval from IRBs associated with their universities. Additionally, the two Network coordinating centers, Rutgers University and the University of California, San Francisco, received approval for the multi-site study.

Analysis

Content analysis was used to reduce the data to identify themes that clarified health literacy and information practices of PLWH (Charmaz, 2004). An *a-priori* coding system based on Von Wagner's identified dimensions of health literacy was used for initial coding (von Wagner, Steptoe, Wolf, & Wardle, 2009). The research team at the coordinating site developed initial definitions of codes, categories, and themes; coded all of the transcripts; and returned them to site Principal Investigators (PIs). Discrepancies in coding and conceptual definitions were discussed by all PIs at face-to-face meetings until consensus was reached and themes began to emerge. PIs returned to their sites to continue theme development, which were discussed at the next Network meeting. Several major themes were derived from the wealth of data and we focus here on one of those themes. Full details on protocol and data reduction can be found in previous manuscripts (Dawson-Rose et al., 2016; Mogobe et al., 2016).

In reading and re-reading all of the transcripts across all groups of participants, (PLWH, HCPs, and PCTMs) and all sites, discussions related to learning about HIV came to the foreground. The research team began to identify sections of texts (phrases, sentences, and quotes) that related to HIV teaching and learning. Codes associated with these text sections were identified and most fell under the category of patient information sources, providing the what and the where of information practices. The research team agreed on the relevant text sections that were compared across transcripts, using constant comparative analysis

techniques to identify conceptual similarities and differences (Charmaz, 2004). Through this iterative process, the theme of Locations of Learning, with its subthemes and categories was revealed.

Results

While exploring the various aspects of learning about HIV and its treatment, participants from all three groups (PLWH, HCPs, and PCTMs) discussed different components of information practices, particularly knowledge seeking and evaluation. As one PLWH stated, “It’s just about the knowledge, about how I get it/perceive it.” From this exploration, the theme of Location began to emerge. Location as a theme was embedded in 3 contexts: (a) location of diagnosis, (b) location of HIV in the lives of PLWH, and (c) locations of learning; but it is the latter, locations of learning that is most relevant to health literacy and information practices and is, therefore, the focus of this analysis.

All of the participants directly and indirectly addressed interactions between the where, the what, and the who of learning. What PLWH needed to know determined where they sought knowledge and from whom. Location was also clearly critical to determining what knowledge to trust and how to use it in their lives. Two overarching categories of location of learning were evident, a physical location and a more conceptual/virtual location. Each of these locations had multiple subcategories with clear delineations of who/what were trusted sources of knowledge at each location and what one learned.

Physical Locations

A number of physical locations were mentioned by participants, and these were collapsed into three categories. Physical locations included (a) institutions, (b) community-based organizations, and (c) the home/street.

Institutions—Two locations are reflected in this category, hospitals/clinics and prisons/jails. Hospitals remain a major location for learning for PLWH in areas with few professional resources, such as Botswana and Puerto Rico; in other U.S. sites, however, routine HIV care has moved into clinics. Both hospitals and clinics were seen as trusted locations for medical information. PLWH talked with HCPs about their CD4+ T cell counts and viral loads, “My numbers. My doctor is numbers. She’s all about numbers.” They also discussed antiretroviral medications, when to change medications, side effects, and potential interactions with medications for other health problems (such as hypertension). Although most participants stated that they had “no problem asking questions” of their HCP and that s/he would “break it (information) down” so they could understand, PLWH generally did not talk about non-medical things with their HCP; as one participant clearly stated: “I discuss medical things with my doctor, I don’t discuss emotional things.” It was also clear that there were things that were not brought up, such as drug use: “And if you’re on drugs they really don’t want to hear you.”

Clinics and hospitals were also sites for learning from other health professionals. It was clear from all of the focus groups that most of the teaching of clients was done by PCTMs, especially nurses, case managers, social workers, and, sometimes, pharmacists. A

Botswanan participant stated that "... doctors are for appointments only, they do not provide any education," and this sentiment was supported by both PLWH and PCTMs in the United States and Puerto Rico. PCTMs teach the basics of HIV ("HIV 101") to new and returning PLWH and they reinforce that information as often as they can. As several PCTMs noted:

It always surprises me, is even when people have been positive a really long time, I think reiterating it over and over, because there's still, even with folks that have been positive a long time, even the HIV 101, again, is helpful, because that can either have been forgotten, or whatever... I always make sure that they know what the four basic body fluids are, and I'll ask them to name them for me before I say anything, and sometimes they get it and sometimes they don't.

Jails and prisons are also important sites for learning about HIV. Although not directly queried, 38% of the U.S.-based PLWH mentioned having been incarcerated and 80% of those first learned of their HIV status while "in the system." This was also where they first received factual information about HIV, as one participant noted: "The only thing that I really got out of being incarcerated was that they had a lot of literature and information and videos on the virus." Prisons and jails conducted classes about HIV for incarcerated populations, "They have classes there. You know, while being locked up." Prisoners were captive audiences for these HIV classes, as one participant remarked, "In prison they educate you because you have nothing else to do." Despite receiving factual information about HIV and its treatment, PLWH received more limited emotional and social support after diagnosis, less information on how to disclose to family and friends, and fewer linkages to care post-release. Those who did well were linked up with community-based organizations (CBOs) before their release, "It's a good thing because if I wasn't introduced to <Named CBO> while I was in prison, I might not never had come to <CBO>, you know."

Community-based organizations—Connecting with community-based organizations (CBOs) was considered vital to surviving HIV and to expanding one's knowledge about living with HIV. CBOs not only provided resources that connected PLWH to clinics, but were also sites where PLWH could get assistance with non-medical issues, such as legal problems, housing, and transportation. They also served as trusted sites for increasing understanding of HIV disease and how to live with it. Although most PLWH stated that they felt comfortable asking their HCPs and other care team members questions about their disease, the reality was that they did not always understand what they were being told by HCPs and PCTMs. Talking with CBO staff, many of whom were peers, as well as other PLWH coming to the CBO, was an important component of understanding how to live successfully with HIV. Indeed, one of the most mentioned sites for trusted information seeking was support groups.

Support groups were used by participants as a means of exchanging knowledge and of verifying and clarifying what PLWH had heard from their HCPs, through media, or on the Internet:

Like if I come here and we're having a group, I'll bring it up in group. "Well you know I didn't understand what my doctor said about..." this or that and we would

talk about it as a group and I would get a clearer understanding of what the doctor was saying.

Groups also provided a safe place to garner much needed emotional support for such things as family issues and stigma and to learn about possible resources in the community:

Well, we attend a weekly group at the AIDS foundation, which is called the Black Brothers Esteem, and that gives us a lot of resources and information throughout the community on a weekly basis, what's going on in the community...like LGBT [lesbian, gay, bisexual, transgender] issues. There's a lot of information that's given out to us on a weekly basis.

Support groups were often peer-led but most of the PCTMs and PLWH in the United States indicated that their leaders received additional education and support from professionals to make sure that the information being shared was as accurate as possible. Unfortunately, the availability of support groups was dependent on community resources, reflecting somewhat of a rural/urban divide. At some urban sites, such as New York City, Boston, or San Francisco, a number of potential support groups were mentioned, but in less resourced areas in the United States and internationally, the options were limited or non-existent. What did emerge in resource-challenged areas were groups organized by fellow PLWH with limited input from professionals. Nevertheless, these groups were viewed as trusted and important sites for learning about how to survive and live with HIV.

Home or the streets—This location emerged from both PCTM and PLWH focus groups. Home was a good place for learning in two ways: as a site for learning from professionals but also as a site for learning from family members. One social worker noted:

Most of my work is done outside of the clinical setting, so if I meet someone in clinic and I know they've been given the 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. So, I think outside of the clinical setting, you tend to get, sometimes, a different picture of what their educational needs are.

Family members could also be a source of learning about HIV as one PLWH, who had lost his identical twin to HIV, noted, "My dad schools me every Sunday night after church about what's going on here like with that Truvada[®], he says that Truvada[®]'s gonna be the cure. My dad educates me every Sunday." Similarly, families were a source of support, as a Botswana PLWH noted that her siblings both encouraged her and were sources of trusted information, "I once asked my sister, who works at Centre for Youth of Hope, she is a counsellor." However, family members could also be a source of distress and stigma as one recently diagnosed participant noted, "Only my son will talk with me now."

Peers in the home setting could and did provide information they had gleaned from a variety of sources, but PLWH noted that the trustworthiness of this information was a bit more questionable: "Peers are great. There is a lot of good information that is exchanged, that is my experience. But there is also, uh, less accurate information that's also exchanged. That's when validation needs [to be done]."

The street emerged as an important place for information as well. This was where one learned from other PLWH about how to live with HIV, not how to manage the disease but how to manage one's life. If you wanted to know how to "deal" with HIV, you needed to find someone, not necessarily a peer, who was successfully living with HIV. These people were the ones you could trust to tell you how to continue your work, including sex work, when living with HIV. One participant made this abundantly clear:

A lot of information that is vital and good information... What I got was from other people that was HIV-positive. Because if you are not positive, then you really can't get me too much that I need to know to keep on living. Hallelujah! Until you either walked into and living with it and give me some knowledge about how to deal with HIV...you can't be like the way that you used to get it back in the day. You know, you learn that from other people.

Conceptual/Virtual Locations

A variety of conceptual or virtual locations emerged from the data and they varied somewhat by site. Conceptual/virtual locations included media, Internet, and, rather unexpectedly, research studies.

Media—Media was referred to often by PLWH as sources of information. For U.S. participants, media was primarily television, including documentaries on public broadcasting systems and films; for people living in Botswana, radio and drama groups were the most commonly mentioned. Print media including medical journals were also mentioned even if the language was a bit difficult to understand as one participant noted:

You may have to go with your, you know every third word you have to look up what that means and you can't get too smart 'cos I don't have the training and their experience of course, but you learn a lot about everything from persistent cough to you name it subjects to be able to actively direct and participate and take ownership of my own medical care.

POZ Magazine, a non-peer-reviewed print resource that offers daily news, treatment updates, and investigative features to address the "wide spectrum of need of people living with and affected by HIV/AIDS," (POZ.com, 2017) was specifically named as a good source of understandable and trustworthy information. At least one person in 34% of the PLWH focus groups mentioned POZ by name.

Internet or web-based information—Use of the Internet or the web demonstrated an either/or demarcation for PLWH. No one from Botswana mentioned the Internet as a source of information, but in the United States, the Internet was discussed at least minimally by all focus groups. While some HCPs and PCTMs bemoaned their clients coming in with incorrect information they gleaned from some website, only about 50% of the PLWH stated they got information from the Internet. Some PLWH self-identified as "Internet junkies" and were very much in favor of using Internet resources, "I have a computer at home and me and Google are best friends." One remarked on the wealth of information available:

I get my information at YouTube, just going typing “HIV” or “HIV new treatments.” You’d be surprised how much information. I mean they actually have medical doctors that posted things on YouTube concerning the HIV; you find tons of stuff.

However, those most active on the Internet were also very aware of the potential for misinformation and that they needed to go to reputable sites and learn to “filter.”

‘Cause anybody can put anything on there. I remember back in the day they were putting all kinds of crazy stuff on there about HIV that was totally not true. So, like I said, and that’s what kind of scared me at first back then too, so you just have to filter.

As part of filtering, Internet savvy participants identified trustable websites, such as the CDC and WebMD.

Other PLWH did not use the Internet for information stating things like, “I don’t know about computers so I can’t Internet,” or as one PLWH noted, “I don’t know about the Internet and all that, so I ask them ‘What’s this? What’s that?’ Because I don’t know the computer. I’m computer-illiterate, I ain’t scared to say.”

One might think that access to the web in communities that had technically savvy populations and free Wi-Fi, such as San Francisco or New York, would extol the value of the web more than PLWH in less technically resourced areas, but this did not seem to be the case. The 50/50 split between Internet users and non-users remained regardless of U.S.-based location.

Research studies—One area that somewhat unexpectedly emerged as a source of information was research studies, and this was evident in two ways. First, PLWH in communities that had a long history of research in HIV, such as New York, San Francisco, and Boston, remarked on the fact that they could hear about research as it was developing. They could go and listen to researchers presenting their studies, initial findings, and new treatments. In this way, they kept abreast of the changing world of HIV, both in terms of treatment and prevention. As such, these participants were quite knowledgeable about treatment as prevention and PrEP, and made decisions based on knowledge gained from listening to researchers. For example, several women with HIV in San Francisco stated that they were in discordant relationships and that they had discussed the research related to undetectable viral load and risk with their partners. Based on their understandings of the research, the couples had decided not to use condoms as the risk of infection was low, but the women made their uninfected partners get tested regularly.

The use of research presentations seemed to be limited to those areas in which cutting-edge HIV research was ongoing. PLWH living in regions of the United States and globally who had fewer resources did not mention research per se in their locations of learning, although some individuals did read research on-line or in journals accessed via the Internet. However, participation in research was also a critical location of learning mentioned in two sites, San Francisco and Cleveland. Participation in research, both quantitative and qualitative, was a source of income for some participants but learning took place in studies especially through

participating in “all kinds of different [research] groups.” One Cleveland PLWH noted that he got information:

Not so much the radio and TV, because I don't pay too much attention to that, but being a part in focus study groups. I have learned so much more about myself and about the things that have been outside of what my normal doctors would find because...you get a lot in research studies.

Another PLWH from San Francisco concurred with this, stating:

I found out when I was going to [specified study] I was going to the research studies here in San Francisco. And I got a lot of knowledge out of [it] and the more I went to these studies, it helped me to understand myself. It helped me to better myself.

Focus groups seemed to act like support groups for some of the participants: “I've learned through going to groups asking questions, and being in focus groups, actually a lot from here. I learned how to actually challenge my doctor.” Indeed, exchange of information occurred within the context of data collection for our study. For example, in a Newark PLWH focus group, several recently-diagnosed participants received information on how to get transportation assistance through the CBO. One participant, who revealed that her family would not talk with her after her diagnosis, was told in a group, “We are your family now.”

The fact that some PLWH who participated as research subjects saw this activity as a learning environment was not something that was mentioned by either HCPs or PCTMs. Nor did the professional focus groups discuss presented or published research as a source of learning for their PLWH clients.

Discussion

Participants from all three sets of focus groups highlighted the centrality of location or setting for teaching and learning. Gleaning, understanding, and using health information is a social activity that is embedded in the context of information seeking (Lloyd, 2012). What one needs/wants to know determines where one goes for that information. Who are trusted providers of knowledge depends on the social context of knowledge exploration. Indeed, learning tends to be relational and occurs in interaction with others but trust in the provider of knowledge is also crucial (Bonner & Lloyd, 2011). Some PLWH in our study actively sought knowledge in such places as the Internet, attending research presentations, or in peer-mediated spaces, while others more passively received information from professionals, media, family, and peers.

The importance of locations of learning reflect aspects of adult learning, specifically that of settings of learning. A traditional typology of learning settings can be conceptualized as formal, non-formal, and informal, although these settings can overlap (Merriam & Bierema, 2014). Formal settings usually encompass schools or facilities whose primary focus is education. Non-formal settings include “organized learning opportunities sponsored by institutions and community organizations” (Merriam & Bierema, 2014, p. 16) whose primary mission is not education but where education occurs in action and through

discussions with others. Informal settings are where “spontaneous, unstructured learning” (Merriam & Bierema, 2014, p. 16) is a part of everyday life and can include homes, neighborhoods (even the streets), mass media, social media, or the Internet.

All PLWH in our study agreed that the trusted location for medical information was the clinic or hospital. Although the primary role of these sites was not education, but engagement and provision of health care, from the perspective of PLWH, these were the main sites for formal education about HIV. It was in clinics and hospitals that PLWH learned about the disease process, viral loads, medication effectiveness, and the importance of adherence. The knowledge came predominantly from health professionals (providers and patient care team members), and was viewed as useful and important. This view was consistent with research conducted with adolescent males who have sex with males (Rose, Friedman, Spencer, Annang, & Lindley, 2016), but open communication and trust in provider knowledge about HIV was critical (Dawson-Rose et al., 2016; Rose et al., 2016).

HCPs were seen as those concerned most with diagnosing and managing HIV via their numbers. Adherence to the plan of care, including antiretrovirals, and response to medications were the main foci of HCP-PLWH interactions from the PLWH perspective. It was clear that PLWH in our study had absorbed messages about adherence to medication and plans of care; 92% of PLWH in our study were on antiretroviral medications and, although medication and HCP visit adherence were not directly queried, most participants mentioned that they took their medications daily and saw their providers at least twice a year. Although many PLWH stated that they felt comfortable asking their HCP questions and that the HCP would “break it down” for them so they could understand, they still tended to seek understanding from other health care professionals and/or support group members. Others felt there were things that one did not talk about with their HCPs, such as emotional issues. Of concern was the implication that there were things HCPs “really did not want to hear about,” such as drug use, which could impact patient outcomes.

Clinics and hospitals were also sites for information seeking from other HCP, such as nurses, case managers, social workers, and pharmacists. These professionals carried out most of the more formal health education. They were concerned that PLWH understood the basics of the disease process (HIV 101), as well as their plans of care. This was the focus of education efforts for newly diagnosed as well as long-time diagnosed clients. However, some HCP also discussed other issues with their clients, such as financial problems or housing difficulties, providing information on resources available to PLWH. Given that PLWH are often socially marginalized related to structural issues such as poverty, race, gender, and stigmatized behaviors such as drug use or unsafe sex (von Wagner et al., 2009), the importance of resource information should not be minimized. The extent to which PLWH felt comfortable talking about emotional problems or family difficulties with professionals was not well addressed and this could use further exploration.

Prison or jails could be viewed as both formal and non-formal learning sites. Similar to hospitals and clinics, the primary role of prisons and jails is not education, but several participants did mention attending HIV classes while incarcerated. However, they also provided more self-learning resources such as pamphlets and videos and, therefore, reflected

a non-formal setting. Despite the provision of factual information, emotional support or information about community-based resources for PLWH was not common; only a few people mentioned that a prison had connected them with CBOs or clinics for follow-up upon release.

Non-formal learning settings were also evident in the form of CBOs and some research dissemination. CBOs provided two important types of organized information-seeking opportunities: available resources and support groups. The personnel at CBOs were often not health professionals; rather, they were community activists and peers. Indeed, many were themselves PLWH who brought a wealth of experience and knowledge about living with HIV. CBOs provided classes on such things as accessing care and resources as well as one-on-one assistance. PLWH acknowledged that if you needed information about transportation subsidies, getting financial assistance, or accessing housing, the trusted source for this kind of information was a CBO. Learning also came through sharing information with others and clarifying what they had learned elsewhere, often within support groups. One community-based location of learning that was not mentioned by participants was faith-based organizations (FBOs), such as churches, or mosques, even though research has identified FBOs as potentially good community sites for teaching about health issues (Tetty, Duran, Andersen, & Boutin-Foster, 2017; Woods-Jaeger et al., 2015).

Research presentations could also be viewed as a non-formal setting, as they were organized by hospitals, clinics, pharmaceutical companies, and sometimes universities. PLWH who lived in research-rich environments were able to listen to emerging science about HIV and a number of participants in certain urban U.S. sites indicated that they took advantage of this resource to keep abreast of the changing landscape to better manage their disease. Participation in research, while not necessarily a non-formal activity, was also a good source of cutting-edge knowledge about HIV, its treatment, and prevention.

Informal learning occurred in homes, sometimes through visits from social workers or nurses, but also through family members and peers. It also occurred on the street or in neighborhoods and was very much a part of everyday life. Although health care information or even research could be part of this setting, most of the learning was relational and practical, learned through sharing with others. Although some health professionals (HCPs, nurses, social workers) might be PLWH themselves, from the perspective of PLWH in our study, if one wanted information on how to manage (or live) life with HIV, one did not ask a health professional; one sought out someone who knew the reality of HIV, someone who had walked in one's shoes and could, therefore, advise based on actual experience.

Media, including audio, visual, and print, along with the Internet were also places for informal learning. As one participant noted, "Google was a friend" to whom one could ask any question, but PLWH were aware of the need to filter out misinformation. What was interesting was the knowledge of trustable sites, such as the CDC, WebMD, and POZ, and that they read medical journals on-line, even if the language required looking up words. The Internet could be particularly useful as PLWH could ask questions and get answers, but only half of our participants used the Internet as a location of learning.

Our data also demonstrated that health literacy was not just an individual capacity; rather, all learning occurred in social contexts that reflected political, social, cultural, and economic realities (Lloyd, 2012). These contexts reflected the concept of information landscapes, defined as “communicative spaces created by shared experiences of people in interaction” (Lloyd et al., 2014) with each other and their settings. Comparison across sites demonstrated surprising similarities in locations of learning as well as differences that seemed to reflect a resource rather than a rural/urban or developed/developing divide. Internet access and television were still not common in Botswana, but PLWH there still used the hospital (instead of the clinic) as the primary source for medical information and CBOs (including support groups) and home as locations of non-formal and informal learning. Our focus groups showed that the variations of possibilities for information-seeking within these communicative spaces depended on access to resources. PLWH who lived in resource rich environments had a number of potential opportunities to engage in learning, whether through research lectures or participating in support groups in a variety of CBOs; in resource poor environments, these options were limited or nonexistent. It seems reasonable that differences in resources could lead to disparities in health outcomes for PLWH.

Use of information was evident in our data. Some participants used information to better themselves or to query and/or challenge their HCPs, but most used information gleaned through information-seeking to make decisions about how to live their lives. Deciding to adhere to their medications and stay engaged in care were positive outcomes for our participants and most stated that they followed their plans of care. However, not all of the decisions made based on information acquired through information seeking meshed with HCP recommendations, such as discordant couples choosing not to use condoms because the risk for transmission was low when the PLWH partner had an undetectable viral load.

Limitations and Strengths

While we sought to explore a more expansive understanding of health literacy, there were limitations to our study. First, we recruited from clinics/hospitals and CBOs and we incentivized participants, especially the PLWH, potentially leading to biasing our sample toward those who frequented these venues and, therefore, had a good understanding of HIV treatment and were engaged in ongoing care. However, the fact that participants from all focus groups talked about locations of learning indicated the importance of this theme. Secondly, because our questions were focused on sources of information and information seeking practices, our results could be biased toward the process of information gathering, missing other aspects of health literacy. Thirdly, we did not collect adherence data and, therefore, could not link individual responses to adherence outcomes, such as viral load; for example, were those who engaged in street learning less adherent than those who did not mention this location?

Despite limitations, we sought to increase the rigor of the research by conducting a focused, intensive training of all site investigators on using a shared protocol and interview guide for data collection. One of the strengths of our study was that we drew participants from multiple U.S. based locations, Puerto Rico, and Botswana, and sought multiple perspectives (PLWH, HCP, PCTM). We looked for themes that emerged across all sites but our sampling

method did not strive for saturation per se. However, the depth of data collected and the constant comparative analysis within and across groups and sites did provide strong support for the theme of locations of learning.

Conclusions and Implications

Understanding health literacy and its impact on behaviors of PLWH requires more than being able to read and understand basic health information needed to make appropriate health decisions (IOM, 2004). It is also more than an individual capacity or a composite of cognitive, academic, and health skills. Exploring the topic through the concept of information practices demonstrated that a broader view of health literacy is needed to know how to assist PLWH to achieve the best possible health outcomes and expand our knowledge of health literacy (Lloyd, 2010; Lloyd et al., 2014). Indeed, health literacy is embedded in information seeking and application; it is all about learning and applying knowledge to one's life (Rose et al., 2016).

To be useful, health literacy needs to expand to include information-seeking practices that lead to client learning. Measurement of health literacy also needs to encompass more than a client's numeracy skills and whether they are able to read and accurately interpret pill bottle labels and warnings. No health literacy measures currently include the concept of location as a part of assessing how people learn about their diseases. It is clear from our data that landscapes of information (Lloyd, 2012) and learning settings (Merriam & Bierema, 2014) need to be taken into account when assessing PLWH knowledge and behaviors. Indeed, where PLWH seek/access their information (locations of learning) and who they trust to supply needed information is linked to what they know and how they use the information.

On a positive note, PLWH generally trust health professionals' medical knowledge and that adherence messages are clearly being received. Additionally, despite concerns of providers, especially related to Internet information seeking, PLWH in our study demonstrated the ability to critically appraise the information they obtained from peers, support groups, and the Internet. They also used health professionals, especially providers and nurses, to validate or explicate information gleaned from other sources. Therefore, it is incumbent on nurses and providers to continue to be a bastion of accurate health information and to correct misinformation that patients may have heard or seen elsewhere.

Conversely, health professionals were not perceived as relevant providers of information on how to live successfully with HIV. Although HCPs and PCTMs believed that they talked to patients about all aspects of their lives, PLWH in our study still mentioned areas where they either felt they would not be heard (such as drug use) or where professional knowledge was not deemed useful. From the perspective of the PLWH in our study, unless someone had lived with HIV, s/he did not know how it felt or what accommodations needed to be made to continue to enjoy life or generate income within the changed reality of being a PLWH. This type of information was sought outside the health professional/patient encounter. Health professionals who were themselves infected with HIV could provide this needed perspective but would have to disclose their status to patients. Additionally, more work may be needed to create a non-judgmental, safe environment where continuing risky behaviors can be talked

about with HCP. Nevertheless, to fully assist clients, health professionals must be aware of where PLWH are getting information, what kind of information they are seeking and from whom, how they understand that information, and how they apply it. Further research on the ways PLWH use the information they have gleaned from various locations and its impact on adherence to medications and engagement in care is warranted.

Acknowledgments

This study was supported in part by HIV/AIDS Nursing Care and Prevention (NIH T32 NR007081, Principal Investigator: C. Portillo); Irwin Belk Distinguished Professorship, University of North Carolina Wilmington; AIDS Funding Collaborative of Cleveland; and Human Resource Development Council Botswana.

References

- Bonner A, Lloyd A. What information counts at the moment of practice? Information practices of renal nurses. *Journal of Advanced Nursing*. 2011; 67(6):1213–1221. DOI: 10.1111/j.1365-2648.2011.05613.x [PubMed: 21382078]
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2015. 2017. Retrieved from <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>
- Charmaz K. Premises, principles, and practices in qualitative research: Revisiting the foundations. *Qualitative Health Research*. 2004; 14(7):976–993. DOI: 10.1177/1049732304266795 [PubMed: 15296667]
- Cunha GH, Galvao MT, Pinheiro PN, Vieira NF. Health literacy for people living with HIV/Aids: an integrative review. *Revista Brasileira de Enfermagem*. 2017; 70(1):180–188. DOI: 10.1590/0034-7167-2015-0052 [PubMed: 28226058]
- Dawson-Rose C, Cuca YP, Webel AR, Solis Baez SS, Holzemer WL, Rivero-Mendez M, ... Lindgren T. Building Trust and Relationships Between Patients and Providers: An Essential Complement to Health Literacy in HIV Care. *Journal of Association of Nurses in AIDS Care*. 2016; 27(5):574–584. DOI: 10.1016/j.jana.2016.03.001
- Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975; 12(3):189–198. [PubMed: 1202204]
- Hall HI, An Q, Tang T, Song R, Chen M, Green T. ... Prevention. Prevalence of Diagnosed and Undiagnosed HIV Infection—United States, 2008–2012. *MMWR Morbidity and Mortality Weekly Report*. 2015; 64(24):657–662.
- IOM. Health Literacy: A prescription to end confusion. 2004. Retrieved from Washington, DC: <http://www.nationalacademies.org/hmd/Reports/2004/Health-Literacy-A-Prescription-to-End-Confusion.aspx>
- Kalichman SC, Cherry C, Kalichman MO, Amaral C, White D, Grebler T, ... Schinazi RF. Randomized clinical trial of HIV treatment adherence counseling interventions for people living with HIV and limited health literacy. *Journal of Acquired Immune Deficiency Syndrome*. 2013; 63(1):42–50. DOI: 10.1097/QAI.0b013e318286ce49
- Lloyd A. Framing information literacy as information practice: site ontology and practice theory. *Journal of Documentation*. 2010; 66(2):245–258. DOI: 10.1108/00220411011023643
- Lloyd A. Information literacy as a socially enacted practice Sensitising themes for an emerging perspective of people-in-practice. *Journal of Documentation*. 2012; 68(6):772–783. DOI: 10.1108/00220411211277037
- Lloyd A, Bonner A, Dawson-Rose C. The health information practices of people living with chronic health conditions: Implications for health literacy. *Journal of Librarianship and Information Science*. 2014; 46(3):207–216. DOI: 10.1177/0961000613486825
- Merriam, SB., Bierema, LL. *Adult learning: linking theory and practice*. 1. Vol. 2014. San Francisco: Jossey-Bass; 2014.

- Mogobe KD, Shaibu S, Matshediso E, Sabone M, Ntsayagae E, Nicholas PK, ... Wantland D. Language and Culture in Health Literacy for People Living with HIV: Perspectives of Health Care Providers and Professional Care Team Members. *AIDS Research and Treatment*. 2016; 2016:5015707.doi: 10.1155/2016/5015707 [PubMed: 27340564]
- Nutbeam D. The evolving concept of health literacy. *Social Science and Medicine*. 2008; 67(12):2072–2078. DOI: 10.1016/j.socscimed.2008.09.050 [PubMed: 18952344]
- Ownby RL, Acevedo A, Goodman K, Caballero J, Waldrop-Valverde D. Health literacy predicts participant understanding of orally-presented informed consent information. *Clinical Research Trials*. 2015; 1(1):15–19. DOI: 10.15761/CRT.1000105 [PubMed: 26767117]
- Ownby RL, Acevedo A, Waldrop-Valverde D, Jacobs RJ, Caballero J. Abilities, skills and knowledge in measures of health literacy. *Patient Education Counseling*. 2014; 95(2):211–217. DOI: 10.1016/j.pec.2014.02.002 [PubMed: 24637163]
- POZ.com. POZ Magazine. 2017. Retrieved from <https://www.poz.com/>
- Rose ID, Friedman DB, Spencer SM, Annang L, Lindley LL. Health Information-Seeking Practices of African American Young Men Who Have Sex with Men: A Qualitative Study. *Youth & Society*. 2016; 48(3):344–365.
- Tettey NS, Duran PA, Andersen HS, Boutin-Foster C. Evaluation of HeartSmarts, a Faith-Based Cardiovascular Health Education Program. *Journal of Religion and Health*. 2017; 56(1):320–328. DOI: 10.1007/s10943-016-0309-5 [PubMed: 27709319]
- von Wagner C, Steptoe A, Wolf MS, Wardle J. Health literacy and health actions: a review and a framework from health psychology. *Health Education & Behavior: The Official Publication Of The Society For Public Health Education*. 2009; 36(5):860–877. DOI: 10.1177/1090198108322819 [PubMed: 18728119]
- Woods-Jaeger BA, Carlson M, Taggart T, Riggins L, Lightfoot AF, Jackson MR. Engaging African American Faith-Based Organizations in Adolescent HIV Prevention. *Journal of Religion and Health*. 2015; 54(4):1358–1374. DOI: 10.1007/s10943-014-9932-1 [PubMed: 25169052]
- Zukoski AP, Thorburn S, Stroud J. Seeking information about HIV/AIDS: a qualitative study of health literacy among people living with HIV/AIDS in a low prevalence context. *AIDS Care*. 2011; 23(11):1505–1508. DOI: 10.1080/09540121.2011.582077 [PubMed: 22022854]

Key Considerations

- Health literacy is a multi-dimensional concept that reflects where PLWH seek information, from whom, and how this information is used to manage HIV and one's life.
- Locations for learning are varied and depend on what PLWH need to know, but health care professionals continue to be the trusted source of accurate health information and misinformation correctors.
- Access to a variety of health information resources contribute to health literacy and may be related to health disparities.
- From the perspective of PLWH, health care professionals know about managing the disease but not how to successfully live with HIV; linkages with community-based organizations remain critical in meeting all the information needs of PLWH.

Table 1

Demographics of Focus Groups

	PLWH (<i>n</i> = 135)	HCP (<i>n</i> = 32)	PCTM (<i>n</i> = 39)
Demographic Characteristics			
Age (<i>Mean</i> ± <i>SD</i>)	48.00 ± 9.18	45.41 ± 10.16	42.72 ± 11.14
Gender			
Male	65 (48.2%)	6 (35.3%)	6 (27.3%)
Female	68 (50.4%)	11 (64.7%)	16 (72.7%)
Other	2 (1.5%)	0	0
Race/Ethnicity			
African American/Black	60 (45.1%)	3 (9.4%)	6 (15.4%)
Hispanic/Latino	30 (25.6%)	8 (25.0%)	3 (7.7%)
Non-Hispanic White	23 (17.3%)	11 (34.4%)	20 (51.3%)
Asian/Pacific Islander	0	2 (6.3%)	4 (10.3%)
Native American Indian	0	1 (3.1%)	0
Other	20 (15.04%)	7 (21.9%)	6 (15.4%)
Education level			
11 th grade or less	35 (26.5%)		
High school or GED	49 (37.1%)		
2 years of college (AA)	28 (21.2%)		
College (BA or BS)	12 (9.1%)		
Master's Degree	2 (1.5%)		
Doctoral Degree	1 (0.8%)		
Work for pay (<i>yes</i>)	47 (35.07%)		
Adequacy of income			
Totally inadequate	15 (13.6%)		
Barely adequate	66 (60.0%)		
Enough	29 (26.4%)		
Have health insurance (<i>yes</i>)	104 (77.6%)		
Years living with HIV <i>Mean (SD)</i>	15.1 (8.4)		
Ever had an AIDS diagnosis (<i>yes</i>)	54 (40.3%)		
Taking HIV meds	124 (91.8%)		
Health Care Providers (prescribers)			
Nurse practitioner/APN		14 (45.2%)	
Physician		11 (35.5%)	
Registered Nurse*		3 (9.4%)	

	PLWH (<i>n</i> = 135)	HCP (<i>n</i> = 32)	PCTM (<i>n</i> = 39)
Other (medical assistant) *		3 (9.4%)	
Professional Care Team Members (non-prescribers)			
Registered Nurse			15 (39.5%)
Licensed Clinical Social Worker			3 (7.9%)
Case Manager			4 (10.5%)
Other (e.g., licensed vocational nurse, pharmacy technician)			16 (42.1%)

Note. PLWH = people living with HIV; HCP = health care provider; PCTM = professional care team member; GED = general equivalency degree; AA = Associate of Arts; BA = Bachelor of Arts; BS = Bachelor of Science; APN = advanced practice nurse.

* Specially trained registered nurses and medical assistants in Botswana prescribe antiretroviral medications and are, therefore, considered prescribers.

Table 2

Sites for Data Collection and Incentives Provided to Participants

Locations	Incentives*
Boston, Massachusetts, USA	PLWH-10 USD for screening, 25 USD for focus group PCTM and HCP-no incentive
San Francisco, California, USA	PLWH 10 USD for screening; 30 USD for focus group PCTM and HCP 50 USD for focus group
Cleveland, Ohio, USA	PLWH, PCTM and HCP 25 USD for focus group
New York, New York, USA	PLWH 10 USD for screening, 20 USD for focus group PCTM and HCP 20 USD for focus group
Wilmington, North Carolina, USA	PLWH 10 USD for screening; 20 USD for focus group PCTM and HCP 50 USD for focus group
Newark, New Jersey, USA	PLWH 10 USD for screening, 20 USD for focus group No PCTM or HCP recruited
San Juan, Puerto Rico (U.S. territory)	PLWH, PCTM, HCP 40 USD for focus group
Gaborone, Botswana	PLWH-10 Pula for screening, 30 Pula for focus group (3.92 USD) PCTM and HCP no incentive

Note. PLWH = people living with HIV; HCP = health care provider; PCTM = professional care team member; USD = US dollar.

* Incentives at each site were based on local institutional review board requirements. All sites provided some food for participants (snacks, lunch, or dinner).