
Information preferences and practices among people living with HIV/AIDS: results from a nationwide survey

By Timothy P. Hogan, MSLIS
thogan@uiuc.edu
Doctoral Student

Carole L. Palmer, PhD
clpalmer@uiuc.edu
Associate Professor

Graduate School of Library and Information Science
University of Illinois
501 East Daniel Street
Champaign, Illinois 61820-6212

Objectives: This study was designed to reach many segments of the diverse HIV/AIDS community and broaden understanding of how information can better assist people living with HIV/AIDS.

Methods: Data were collected through a self-administered mail survey distributed nationwide at clinics, drug treatment centers, and other AIDS service organizations.

Results: The 662 respondents preferred getting information from people—including health professionals, family, and friends—and considered people the most trustworthy, useful, understandable, and available information sources. Forty-three percent selected doctors as their most preferred source. The Internet was not rated highly overall but was preferred by those with more education or living in metropolitan areas. Seventy-two percent said they actively search for HIV/AIDS-related information, and 80% said they give advice or tell others where to get such information. However, 71% agreed that it is easy to feel overwhelmed by information, and 31% agreed that not seeking information can be beneficial.

Conclusions: Overall, information seeking is an important activity for this sample of people living with HIV/AIDS. Many sources are widely available to them but, together, can be overwhelming. They rely on health professionals far more than print or media sources and receive encouragement and support from family and friends.

INTRODUCTION

Managing information is an important part of coping with illness and includes communicative and cognitive activities like seeking, avoiding, providing, appraising, and interpreting information [1]. It is complex in that people's information behaviors and needs vary over the course of their illnesses and along with the availability and quality of information. In recent years, considerable research has been done on how people living with HIV/AIDS (PLWHA) manage information. However, understanding of the role of information in the HIV/AIDS community is still limited because of the difficulties of reaching different groups of PLWHA.

This study has been designed to reach many segments of the diverse HIV/AIDS community and broaden understanding of how information can better

assist PLWHA. The authors begin by outlining HIV/AIDS epidemiological trends in the United States and characterizing HIV/AIDS information (hereafter referred to as HIV information) and the information needs and behaviors of PLWHA as reported in the scholarly literature. After discussing our survey methods, we present results about the information preferences and practices of PLWHA and discuss the implications for information services. A more comprehensive report of the project has been written by our collaborators at Visionary Health Concepts, a health education company owned and operated by people with HIV and/or the hepatitis C virus (HCV) [2]. The results and conclusions reported here should be of particular interest to information, health, and social service professionals and are based on analysis of the survey data and parts of the aforementioned report.

BACKGROUND

HIV/AIDS epidemiological trends in the United States

The Centers for Disease Control and Prevention (CDC) recently reported that through the year 2003, the estimated cumulative number of diagnoses of AIDS in the United States was 929,985, and the estimated cumulative number of deaths of persons with AIDS was 524,060 [3]. What these statistics do not reveal, however, is the spread of the epidemic into different parts of the population since the first reported cases in 1981. In the early years, most cases occurred among whites [4]. As the decade wore on, HIV/AIDS was visible in different groups, but took a devastating toll on men who had sex with men (MSM) [5].* Although MSM remained disproportionately affected, the epidemic began to shift significantly and expand into other groups during the 1990s. These trends are still very much present.

Synthesized national surveillance data show continued HIV transmission due to high-risk sexual behaviors and injection drug use. They also show that increasing proportions of women, racial and ethnic minorities, heterosexuals, and individuals of lower socioeconomic status are living with HIV/AIDS [6]. Now accounting for more than 541,000 of the estimated cumulative number of AIDS cases in the United States [3], African Americans and Hispanics have experienced a particularly high impact from the shift in the epidemic. Obviously, race and ethnicity would not put individuals at risk for contracting HIV/AIDS. However, they do correlate with different social and economic determinants of health and other challenges associated with risk for HIV/AIDS [7–9]. For example, many of the groups now affected have traditionally had less access to health care and related resources. It can be difficult to reach them when collecting data on health issues, and they are sometimes underrepresented in studies.

The nature of HIV information

Since the earliest days of the epidemic, information has been understood as a critical resource in efforts to prevent transmission of HIV, manage the complications that accompany the disease, and prolong PLWHA's lives [10]. Information scientists have provided analyses of the distinctive qualities of the information associated with the epidemic. For example, Huber and Gillaspay [10] assert that the current knowledge of HIV/AIDS is a "diseased body of knowledge," full of the same complexities that characterize the epidemic. But perhaps the most defining characteristic of HIV information is the overlapping roles of creator, provid-

er, and seeker. In 1987, Ginn identified an increasing overlap among the information functions and responsibilities of the five sectors primarily responsible for HIV information: service organizations, health professionals, consumers, the government, and the media [11]. Huber and Gillaspay [10] later used this idea to describe a nontraditional scientific communication model of HIV/AIDS in which those typically considered information consumers (e.g., PLWHA) become information producers, and those typically considered information producers (e.g., health professionals) act as information consumers.

This convergence of information roles has had different effects. On the one hand, it has resulted in relevant information for service providers who work to combat the epidemic at what Huber and Gillaspay [10] call multiple levels—from individuals and local communities to the public at large. On the other hand, much HIV information is published and distributed outside of traditional channels, is not cataloged or indexed, and is often not part of standard clinical information resources [12]. It is gray literature, "information produced on all levels of government, academics, business and industry in electronic and print formats not controlled by commercial publishing i.e., where publishing is not the primary activity" [13]. Access to HIV/AIDS treatment fact sheets, pharmaceutical company brochures, newsletters, and other gray literature can be difficult given its limited dissemination and integration into the usual streams of health information. As a result, potentially powerful information does not always make it into the hands of individuals and organizations who could benefit from it.

Information needs and behaviors of people living with HIV/AIDS (PLWHA)

Previous studies have shown that HIV/AIDS service providers perceive the information needs of their clients as falling into two broad categories: medical information needs and social service information needs [14]. Huber and Cruz [15] pose a more comprehensive categorization of information needs that varies from drug, wellness, and financial information to information on social activities, HIV/AIDS disclosure, death and dying, and religious-spiritual topics. But the experiences of PLWHA suggest other kinds of information needs related to the clarity of information and its match to the community that are not represented in these frameworks.

Mental health professionals throughout the first decade of the epidemic saw that many PLWHA felt compelled to sort through potentially overwhelming amounts of HIV information to keep up with and stay current on issues important to their health, while others tended to avoid reading or hearing about HIV/AIDS [16]. Grim information about the course of HIV infection trapped many PLWHA "between their desire to know as much as possible about HIV and their fear of becoming immobilized by bad news" [16]. More recently, health communications researchers have shown that PLWHA use active information seeking, passive in-

* An explicit definition of the term men who have sex with men (MSM) is not offered in the CDC report referenced here. However, it is apparent from its usage in the text that it refers to both men who identify as homosexual as well as men who do not identify as homosexual and have sex with men.

formation seeking, experiential information, and information avoidance strategies to cope with and manage the uncertainty surrounding their medical, social, and personal situations [17]. While information seeking is a means to reduce or increase uncertainty, avoiding information can help PLWHA maintain a desired level of uncertainty about aspects of their condition [17].

PLWHA access and use a range of sources for information about their condition. In a study of 205 HIV-positive men and women, Huber and Cruz [15] find that AIDS newsletters, magazines, and personal physicians are the three most popular sources of information for PLWHA, followed by information from friends, pamphlets, and brochures. The Internet has also become a useful resource for some PLWHA. In a study of Internet use and coping, Reeves [18] finds that PLWHA use the Internet for locating general and specific health information, making social connections, fostering a sense of community, advocating, and escaping from the stress of living with the disease. PLWHA who use the Internet for health information seem better informed about HIV/AIDS and report more use of active coping strategies, including information seeking, and greater social support [19].

Across these and other studies, important variations have been identified in the information behaviors of the groups who make up the HIV/AIDS community. For example, earlier studies show that some HIV-positive African American and Puerto Rican men feel that HIV information is vital to their health yet is not readily available in minority communities [20]. Other researchers find that informal networks of PLWHA are used as sources of information about HIV medications, particularly by HIV-positive homosexual men and injection drug users [21]. Additionally, more recent research reveals a digital divide in the HIV/AIDS community: PLWHA with twelve or fewer years of education have been found to have less experience using computers and less access to the Internet than PLWHA with more education [22]. Differences in information seeking and source use can also be traced to affiliation with activist organizations "in which skills and resources are developed, shared, and mobilized to create social and individual change" [23]. Brashers et al. [23] find that PLWHA who are members of activist organizations are able to list more HIV/AIDS treatment information sources and more likely to list information sources of a nontraditional nature (e.g., community health centers, the Internet, and pharmaceutical companies) than PLWHA who do not belong to such organizations.

We designed the following study to reach many of the different groups now affected by the epidemic, to characterize the variety of HIV information that exists, and to increase understanding of information preferences and practices in the HIV/AIDS community.

METHODS

Data were collected through a self-administered mail survey distributed nationwide. Collaboration was vital to the project. By partnering with HIV/AIDS educa-

tors and activists from Visionary Health Concepts, we were able to inform an empirical study of information seeking and use with the valuable expertise of those working on the front lines of the epidemic. All the collaborators were involved in the development of research questions, methods decisions, and mechanics of survey design. The resulting questionnaire was pre-tested with groups of PLWHA in a mid-sized Midwestern community and in New York City. The test respondents included HIV-positive men and women of various ethnic backgrounds and socioeconomic status and former injection drug users. Focus group sessions were held with participants after they had completed the survey to obtain direct feedback on the questions. The test respondents evaluated the questions in terms of clarity, readability, suitability of response options, and terminology and shared their own experiences related to the questions. This feedback was critical in assessing and revising the question categories and wording [24, 25].

Participants

The survey was distributed over an 8-week period through public and private clinics with large numbers of HIV-positive clientele, drug treatment centers, and other AIDS service organizations (ASOs), agencies involved in the prevention and treatment of HIV/AIDS, located throughout the United States. Our collaborators at Visionary Health Concepts are engaged in ongoing educational outreach activities and frequently interact with such organizations. They selected 750 organizations they were aware of, based on location and likely demographic composition of the clientele, forming a regionally balanced mix of large, medium, and small organizations serving urban, suburban, and rural areas. The major cities affected by the epidemic—New York, San Francisco, Los Angeles, Houston, Detroit, Miami, and Chicago—were covered in the sample. The overall goal was to distribute the survey widely and reach many of the diverse groups of the HIV/AIDS community: women, men, heterosexuals, homosexuals, African Americans, Hispanics, injection drug users, less educated individuals, younger adults, non-urban and urban residents, and PLWHA coinfecting with hepatitis.

Measures

The survey included thirty-five questions. The formatting included closed-ended Likert scale questions, closed-ended questions with unordered response categories, and both partially and fully open-ended questions. Participants were asked about their information needs, the information sources they used, the barriers to HIV information they encountered, the impact HIV information has had on their lives, and basic demographics. The survey also included measures to estimate the general state of health of the respondents. For example, one question was a self-report of treatment success and another asked for current and past T-cell counts (higher T-cell counts are associated with a stronger, healthier immune system).

Procedures

Survey packages—consisting of questionnaires, postage-paid reply envelopes, cover letters, and instructions for distributing the survey—were sent to the 750 organizations. Initially, we mailed 10 surveys to each organization and then followed up with telephone calls to monitor distribution rates. Some organizations were sent anywhere from 10 to 100 additional surveys during a 2nd wave of mailings. Approximately 200 surveys were hand-delivered to organizations in the New York metropolitan area after our collaborators determined this to be the most efficient way to reach people at these sites. In total, 10,500 surveys were distributed. The staff members at the organizations disseminated the survey in ways that worked best for their clientele and local situations. For example, some mailed the survey to all of their clients and others handed out the survey when clients visited the clinic.

As a means of compensating everyone involved, survey respondents had the opportunity to submit their names to a lottery for a cash prize of \$2,000. The winning respondent could then keep half of this amount and give the other half to the nonprofit service organization of their choice. To keep the survey data anonymous, we devised a “2 envelope system” to separate participant surveys from their lottery registration information. Return envelopes included no printed indication that the survey and lottery were AIDS-related. Some organizations offered additional compensation, such as transportation passes, for those clients who agreed to complete the survey. To facilitate the data collection process, we established a toll-free telephone number that either staff members or respondents could call if they had questions about the study or needed assistance in distributing or completing the survey.

Data management and analysis

All questionnaires were processed and entered into a database by experienced data entry staff. This paper is based on frequencies and first-round cross-tabulation analysis conducted to identify trends among groups in the sample.

RESULTS

Six hundred and sixty two (N = 662) usable surveys were returned from 42 states over a 5-month period. Some additional surveys were discarded either because the respondents were not HIV-positive or because they left portions of the survey blank. The base on which we calculated the following percentages fluctuates somewhat due to item nonresponse. The results that follow should be understood only in light of the shortcomings of our survey distribution procedures. First, although it is typical in survey research to calculate and report a response rate, our distribution procedures prevent us from doing so. We know that we distributed 10,500 instruments to various organizations, but it is impossible to know how many of those

surveys were actually offered to possible respondents. Based on calls to various organizations, we know that many survey packages did not reach a staff member who could recruit participants for the study, despite the fact that we mailed over 95% of them to a specific, named individual. Several organizations also later said they could not participate in the study due to time constraints and the deadline for returning completed surveys. Still other organizations requested additional surveys in quantities that later turned out to be overly optimistic given the time that their staff members had to speak with clients about the study. Our distribution technique also prevented us from forming a randomized sample. We specifically targeted organizations that served diverse clientele, and we do not know how the surveys were actually distributed at the various sites. We included instructions on how to distribute the survey, but health and social service professionals face hectic schedules and sometimes overwhelming demands. We expect that they did the best they could under these circumstances.

Finally, because our survey was distributed at health and service organizations, it only made it into the hands of PLWHA who utilize such organizations. Unfortunately, we can say nothing about the information preferences or practices of those individuals who either have no access to or choose not to use these institutional resources. Still, we believe we achieved our goal of surveying many of the diverse groups affected by the epidemic. As shown by the demographic breakdown in Table 1, we reached most of the targeted groups. However, we did not succeed in getting sufficient data from younger adults. Indeed, selection bias and underutilization of service organizations may explain why we received so few responses from this group, one in dire need of further study. Some demographic points of interest include: the range of annual incomes, from none to over \$60,000; different work situations, with 162 retired or not employed, 171 employed, and 302 on disability; and T-cell counts from 0 to 2,000.

Information source preferences

The survey explored respondents' assessments of HIV information sources along several lines. One question asked, “How do you best like to get HIV information?” and provided a series of options and space to write in “other” sources not listed. Respondents were instructed to put the numbers “1,” “2,” and “3” next to their top three choices. As shown in Figure 1, 43% of respondents selected doctors as their 1st choice, and 70% ranked doctors in their top 3 sources. HIV-positive counselors and magazines had the next highest frequencies but were more than 30% lower than doctors, and brochures and newsletters followed but had very low “first choice” frequencies.

It is important to note that while the lowest rated information sources in Figure 1 are not widely preferred, they serve some groups in the HIV/AIDS community more than others. For example, people who did not complete high school were three times more

Table 1
Demographic characteristics of sample

Composition	Number of respondents
Gender	
Men	440
Women	203
Transgendered/Other	7
Ethnicity	
White	264
African American	228
Hispanic	126
Other	14
Native American	12
Asian/Pacific Islander	5
Age	
18–29	35
30–39	214
40–49	275
50 and over	126
Education	
Some high school	93
High school graduate or GED	148
Some college or technical/trade school	265
Bachelors degree	101
Masters or doctoral degree	33
Sexual orientation	
Homosexual	299
Heterosexual	289
Bisexual/Other	55
Injection drug use (IDU)	
IDU transmission: definite or likely	102
IDU transmission: definite	85
Coinfection	
Hepatitis coinfectd	328
Location	
Major metropolitan area	185
Large city	175
Small city or large town	125
Small town or rural area	83
Suburb	54

Note: Demographic information was not fully reported across all surveys.

likely than college graduates to choose videos as a top-three choice. In general, white men who identified as homosexual preferred newsletters, the Internet, educational forums, and peers, while other groups preferred brochures, pamphlets, videos, classes, nurses, and HIV-positive counselors. There was also variation based on how long respondents had known they are HIV-positive. Doctors were still the top source by far, but for PLWHA who had lived with HIV for less than ten years, HIV-positive counselors were ranked second. For those who had lived with HIV for more than ten years, newsletters and forums were more commonly preferred sources.

The Internet was not rated highly overall, but whites were about twice as likely to choose it as African Americans or Hispanics. Moreover, 25% of college graduates listed it in their top 3 choices, while it was only selected by 5% of those who did not finish high school, 8% of high school graduates, and 15% of those with some college. Twenty-five percent of respondents living in major metropolitan areas listed the Internet among their top three sources. Those living in other areas listed it less

than half as frequently: large cities, 12%; suburbs and large towns, about 10%; and small towns or rural areas, 6%. Despite the subjectivity inherent in how respondents described their location, these data revealed a notable divide in Internet preference: PLWHA in major metropolitan areas favored the Internet more than those who did not live in such areas.

In two similar questions, respondents were asked (1) what people and (2) what information sources “encourage and support you to take positive actions to deal with your HIV?” For the first question, the doctor category was again rated highest, with 79% of respondents selecting it as one of their top 3 choices. Friends and family were not far behind, at 72%. Case managers were the 3rd highest, at 41%, but were more than 30% lower than friends and family. In the 2nd question, magazines and pamphlets were the highest rated information sources, at 64% and 63%, respectively, and newsletters were 3rd with 54% of respondents listing them in their top 3.

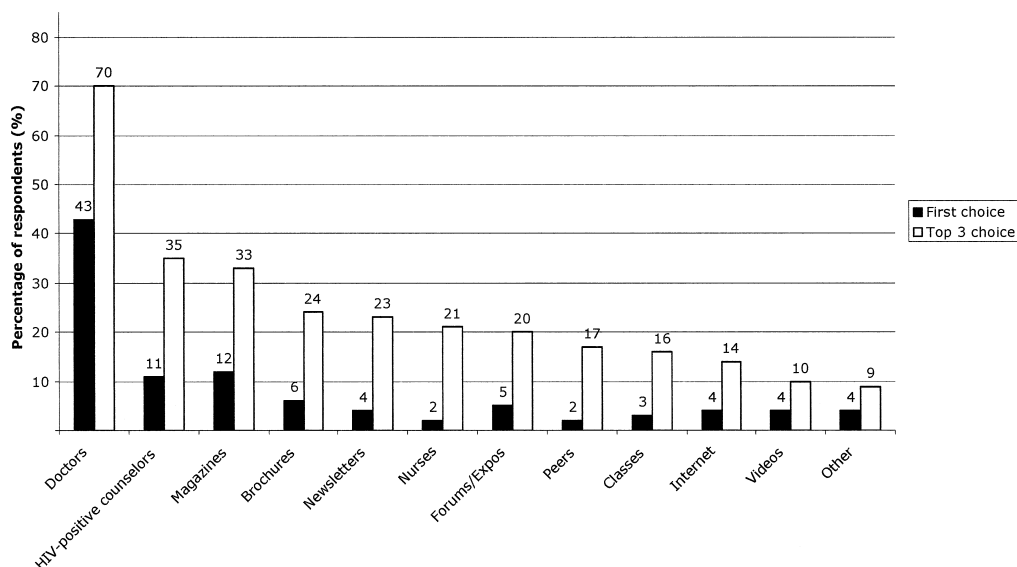
In a separate question, we asked respondents to characterize how useful, understandable, trustworthy, and available 11 different HIV information sources were to them, using a 5-point Likert scale. Together, these information attributes might be considered an assessment of reliability and quality. Table 2 presents the percentage of respondents who gave the sources the highest possible rating. People, including health professionals and individuals from the respondents’ personal lives, were rated more highly than print information and other media. Doctors, peer educators, nurses, and case managers were considered the most trustworthy sources, and they were seen as the most useful and understandable sources. Friends and peers were ranked next overall but were not particularly strong in terms of usefulness or trustworthiness. The listing in Table 2 is in rough descending order in terms of overall judgments of reliability and quality of information sources. While the sources had notable differences in terms of how useful, understandable, and trustworthy they were, their availability varied much less. Newsletters were judged the least available, with only 25% of respondents giving this source the highest availability rating. Among print sources, community-produced brochures were rated as the most understandable.

In a separate question on barriers to using HIV information, availability was rated the lowest. As illustrated in Figure 2, only 8% of respondents indicated that HIV information was “hard to find” as a top 3 barrier, while 35% listed that “too much” information was available. The 2 options most selected as top 3 barriers were “hard to understand,” at 40%, and “not sure whether to trust,” at 38%. The most frequently selected 1st choice related to applicability, with 15% listing “not enough information applies to me” as the biggest barrier. Variability across demographic groups was limited on this question.

Information practices

Questions about information seeking and sharing were distributed across the survey, and each elicited similar

Figure 1
Sources of HIV information



Percentages were calculated using the number of actual responses to the question. Some respondents selected fewer than three sources.

responses, as shown in Table 3. A majority of respondents agreed or strongly agreed that they actively searched for information, were confident in their abilities to find information, and regularly read to learn more about HIV. They also agreed that new information helped keep them healthy and helped them feel good about themselves.

Demographic breakdowns show 56% of Hispanics and 58% of African Americans strongly agreed that they actively searched for new HIV information, compared to 39% of whites. Confidence in finding information was also higher for African Americans (57%) and Hispanics (53%) than for whites (40%). Women appeared to be more active readers than men: 62% strongly agreed that they regularly read to learn about HIV, compared to 47% of men. Respondents with self-reported high treatment success also tended to be active information seekers, 75%, compared to 55% for those

reporting low treatment success. Responses to the 6th entry shown in Table 3 indicated that information sharing was a common practice. Eighty percent of respondents agreed or strongly agreed that they gave advice or told others where to get information. Among those who reported sharing information, a segment of respondents (105 in total) demonstrated faulty knowledge about the implications of T-cell count measures (they did not know at what number of T-cells a person risks getting opportunistic infections). These respondents were about as likely to share information as those who had correct understanding of the implications of T-cell counts for their health, raising important questions about the quality of information being transferred informally among PLWHA.

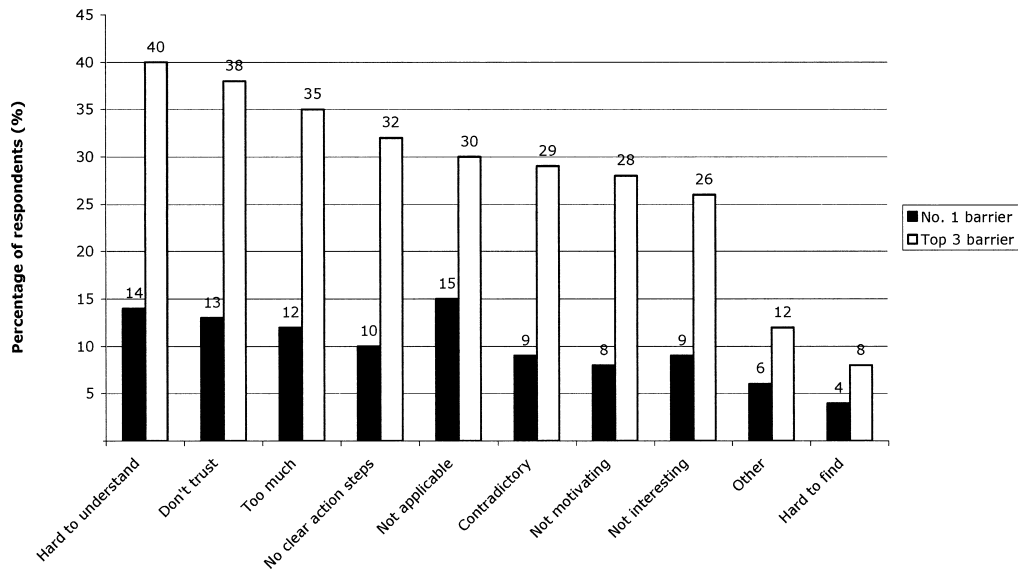
While most respondents actively sought information, their interactions with it were not always positive. The responses shown in the 7th entry in Table 3

Table 2
Characterizing HIV information sources

Information sources	How useful is the source?	How understandable is the source?	How trustworthy is the source?	How available is the source?
Doctors	51%	48%	55%	53%
HIV-positive peer educators	35%	39%	36%	34%
Nurses	31%	35%	32%	36%
Case managers	33%	37%	33%	36%
Friends and peers	21%	31%	22%	35%
Newsletters	18%	22%	16%	25%
Community-produced brochures	19%	30%	20%	29%
Magazine articles	15%	21%	12%	31%
The Internet	15%	20%	12%	36%
Drug company-produced brochures	15%	18%	16%	31%
Advertisements	9%	18%	8%	29%

Percent who responded "a lot" on a 5-point scale ranging from 1 = "a little" to 5 = "a lot." Note: Percentages were calculated using the number of actual responses to the question.

Figure 2
Barriers to using HIV information



Percentages were calculated using the number of actual responses to the question. Some respondents selected fewer than three barriers.

show that 71% agreed or strongly agreed that it was easy to feel overwhelmed by HIV information. The frequencies for this question were similar across all groups of respondents, including those who had been living with HIV/AIDS the longest. Interestingly, while a large majority of respondents were overwhelmed with information, a substantial segment (43%) strongly *disagreed* that at times it was better not to seek information. On the other hand, 31% either agreed or strongly agreed that not seeking information could be beneficial.

It also appeared that PLWHA's ability to make treatment choices and follow their medication schedules could benefit from better information support. Thirty-eight percent of respondents agreed or strongly agreed that they did not know enough to make good treatment choices. Also, education level was an important factor in understanding treatment choices. Few college graduates (6%) felt that they did not know enough to choose wisely, but 34% of those without a

high school degree felt this way. Adherence to treatment is a critical issue in self-care and disease management. The World Health Organization recently defined adherence as "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a healthcare provider" [26]. Among PLWHA, not adhering to combination antiretroviral (ARV) regimens might result in drug resistance and treatment failure. Unfortunately, 35% of respondents strongly or somewhat agreed that they were not getting much useful information on how to stay consistent with taking their medications. The rates were higher for unemployed respondents (45%) and non-high school graduates (44%). Moreover, those with less adherence-related information might be managing their medications in a more haphazard manner. Among the 35% not encountering adherence-related information, 40% did not systematically keep track of when they missed taking their medications.

Table 3
Information seeking and sharing

Survey questions	Strongly disagree	Somewhat disagree	Neither agree or disagree	Somewhat agree	Strongly agree
I actively search for new HIV information.	6%	7%	15%	24%	48%
I am confident that I can find the HIV information I want and need.	3%	6%	11%	31%	49%
I regularly read things that help me learn more about HIV.	3%	4%	11%	31%	51%
Learning new HIV information helps to keep me healthy.	5%	2%	13%	25%	55%
I feel good about myself when I seek out new HIV information.	3%	2%	17%	25%	53%
I try to give friends advice about HIV or tell them where to go to get more HIV information.	6%	4%	10%	24%	56%
It is easy to feel overwhelmed by AIDS/HIV information.	10%	8%	11%	36%	35%
At times it is better not to seek more AIDS/HIV information.	43%	11%	15%	16%	15%

Note: Percentages were calculated using the number of actual responses to the question.

CONCLUSIONS

This study contributes to understanding the information preferences and practices of PLWHA and represents many of the diverse groups now affected by the epidemic. Our results are of particular interest in relation to studies based on more homogenous samples. Huber and Cruz [15]—whose sample is 59% white and 90% male, of which 83% identify as homosexual—find that newsletters and magazines are more highly rated sources of information than personal physicians and friends. Our results show that newsletters are still important for this group, but, for our sample at large, health professionals are the central source of information. The value of newsletters should not be discounted, however. They have the lowest availability of all the sources represented on our survey and may not be making it into the hands of many respondents. Nonetheless, the role of people as information sources needs to be recognized and utilized, and future researchers may find it beneficial to explore the different forms of information provided by different people (e.g., doctors may talk with clients but also give them pamphlets to read). Likewise, friends and family are key providers of encouragement and support for the PLWHA who completed our survey. This suggests that other people in the lives of PLWHA need quality information resources of their own from which to build a solid base of knowledge about HIV/AIDS.

Based on our data, more information is not the answer for improving information services for PLWHA. Availability of information was not reported as a problem by many respondents. Almost all the sources represented on our survey seem widely available to them and, together, constitute an overwhelming mass of information. The more pressing need might be understanding individuals and specific groups, getting the right information out to them, tailoring it so it is applicable, and improving it in terms of readability, provision of actions steps, and consistency. This requires not only creativity on the part of information producers and distributors, but also attention to what Resnicow et al. [27] term the surface and deep structure dimensions of cultural sensitivity. Whereas surface structure sensitivity involves matching health information to observable characteristics of a group, deep structure sensitivity involves understanding the cultural, social, historical, environmental, and psychological forces that influence the health-related behaviors of a group [27]. The trust factor is a related matter, and doctors and other health professionals, the central information source for respondents in this study, can do much to help PLWHA learn which sources are most trustworthy.

This study provides basic insights into the use of the Internet by PLWHA. However, the Internet is a compilation of many types of information, not one centralized resource. Among the masses of available Web-based information, some material is highly authoritative and some has strong community appeal, but much is also of questionable quality. It is beyond the scope

of our project to differentiate Internet materials, and considerable research still needs to be done in this area to fill out the picture of the Internet's contribution and potential. However, our results as well as those of Huber and Cruz [15] suggest that service providers must not depend on the Internet as the primary means of information dissemination for PLWHA. Huber and Cruz [15] find that 67% of respondents never use the Internet for HIV information, and our results also show low usage. We believe that Web resources will continue to increase in importance, but, at present, they could be missed by many PLWHA. Information and support provided through other highly accessible channels—health professionals, friends, peers, and selected print media for different groups—would likely have a greater chance of being trusted and used.

Information seeking is clearly an important activity in the lives of the PLWHA who participated in our study. They see HIV information as a resource that helps to keep them healthy, and seeking that information helps them feel better about themselves. Because the survey responses are decontextualized, self-reported perceptions, they do not necessarily tell us how well respondents are really locating information, what quality of information they find, how the information is actually used, or what its effects on health are. Yet the association of information seeking with positive attitudes about health is an important phenomenon that relates to people with all kinds of health conditions. At the same time, however, information dissemination needs to be managed to reduce overload, and information avoidance needs to be recognized and respected as a coping strategy. The high level of information sharing reported by respondents also needs attention. Service providers could build on this pattern of behavior by making PLWHA aware of their role as information providers, the high value of passing on quality information, and the problems with misinformation that filters through personal networks.

Adherence to treatment regimens is a recognized area of concern in treating HIV/AIDS, and responses to our survey indicate gaps in the provision of adherence-related information. This is not surprising as Reynolds points to several researchers who find that PLWHA believe they are not provided with enough information about their ARV medications and related side effects [28]. We see adherence as an information-intensive activity and agree with Reynolds who states that it may be possible to promote adherence through explicit information about the experience of treatment.

Information is an essential resource for people with serious medical conditions like HIV/AIDS. Elsewhere, we have stated that looking at the sources of information PLWHA use in terms of demographics can help researchers and health professionals understand how best to get information to particular groups [29]. However, other important research questions also need to be more thoroughly explored. These include how PLWHA experience information, how they assimilate and manage the information they gather, what role information plays in taking medications, and how infor-

mation can be used to improve adherence practices. We intend to use this broad base of survey results to inform additional qualitative studies in these areas. Results from this and future research can facilitate the development of better information services and education-based health interventions for the diverse groups now affected by the AIDS epidemic.

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