

Health Information Services Available for People Living With HIV/AIDS: Perspectives of Library and Information Professionals

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There is an urgent need for availability of life-saving health information services as well as adequate marketing, advertising, and dissemination strategies to people living with HIV/AIDS (PLWHAs), and to the broader public at large, especially in the context of a recent UNAIDS estimation that the number of people living with HIV in the United States, at the end of 2003, exceeded one million for the first time. This study explores the HIV/AIDS health information services that are available within the local community of Knoxville, Tennessee, and presents focus group perspectives of nine library and information professionals about awareness and use of these services by PLWHAs. The study forms part of a larger plan to apply a community informatics (CI) approach to examine the provision of health information services for PLWHAs in terms of how PLWHAs and other stakeholders including health care service providers, academic community at the University of Tennessee, community leaders and activists, and faith-based organizations, use and apply information and communication technologies (ICTs) to empower and enable PLWHAs to meet their information needs, goals, and aspirations. Here we report findings from the project's first phase of documenting perspectives of library and information professionals about existing HIV/AIDS information services, users of these services, barriers and challenges to effective use, and the role of health information professionals in the context of developing ideal information support services for PLWHAs.

Introduction

UNAIDS (http://www.unaids.org/en/Regions_Countries/Regions/) has estimated that the number of people living with HIV/AIDS in the United States, at the end of 2003, exceeded one million for the first time. Information from the Centers for Disease Control and Prevention (2003a) provides an estimate of 850,000 to 950,000 people who are living with HIV/AIDS in the United States, with an increasing rate of approximately 40,000 new HIV infections annually, half of which occur in individuals under the age of 25. The number of HIV/AIDS infections in women accounts for the greatest growth of new infections, from 7% in 1986 to about 25% in 2003 (Kaiser Foundation, 2004). Further, the South has "the greatest estimated numbers of people living with AIDS and AIDS cases diagnosed in 2002" (ibid). Recent research shows that people living with HIV/AIDS (PLWHA) in the southern states have special needs for health information and support services due to such factors as violation of human rights (UNAIDS, 2005a), stigma, racism and discrimination (Parker et al. 2002), and extreme psychosocial and physiological pressures (Berk and Nanda, 1997).

In addition, the number of AIDS deaths in 2003 was estimated at about 30,000, a relatively low number as compared to other countries, due to the availability of antiretroviral drugs and health information support systems and services. In order to take advantage of drug therapies, however, people need to be informed about their availability, cost, use, and other related information including insurance coverage options, side-effects, short term and long term consequences, as well as information about the existence of supporting health

information services that are available in their communities. Further, people who are well-informed are better able to understand how the infection is transmitted and measures of prevention that are available to them. In addition to the availability of life-saving health information services, an adequate marketing plan, proactive and aggressive advertising, and dissemination strategies should be available to PLWHAs, and to the broader public at large. Local health information systems and services are necessary to build plans and establish priorities that will harmonize programs and user needs of impacted populations (UNAIDS, 2005b). The HIV Prevention Community Planning Report (Centers for Disease Control and Prevention, 2003b) reveals an urgency to establish information and communication conduits between various stakeholders to increase community involvement and develop effective HIV/AIDS prevention planning strategies.

In order to identify the health information services available for PLWHAs, and to explore directions for community building efforts to make improvements for effectiveness in available services, this paper reports initial findings from an ongoing project that explores varied perspectives of different community stakeholders involved in the provision and dissemination of HIV/AIDS health information services that are available within the local community of Knoxville, Tennessee. The purpose of the project is to investigate information needs and available resources to numerous stakeholders including information providers, health care service providers, PLWHAs from the heterosexual and homosexual communities, the academic community at the University of Tennessee, community leaders and activists, and faith-based organizations. This study forms part of a larger plan to apply a community informatics (CI) approach to examine the provision of health information services for PLWHAs in terms of how PLWHAs and others use and apply information and communication technologies (ICTs) to empower and enable PLWHAs to meet their goals and aspirations (Gurstein 2000). CI principles will allow us to recognize diverse perspectives from different constituencies related to the provision of health information services for PLWHAs (Pitkin, 2001). Findings in this paper are from the project's first phase and limited to documenting perspectives of library and information professionals in the local community about existing HIV/AIDS information services, users of these services, barriers and challenges to effective use, and the role of health information and service providers in the context of developing ideal information support services for PLWHAs.

Background

Knoxville, Tennessee is located in Knox County in east Tennessee and has a population of nearly 175,000 in the city, and slightly over 687,000 in the metropolitan area. It is the third largest city in the state and is home to the University of Tennessee main campus, the Tennessee Valley Authority, and the nearby internationally prestigious Oak Ridge National Laboratory and tourist hot-spot Smoky Mountain National Park, both within a 30 mile radius. Knoxville's population is nearly 80% white, over 16% African American, and the remaining 4% consists of Native American, Asian, and Hispanic or Latino background. The median income per family is nearly \$38,000 or \$27,500 per household. Men report higher incomes of just over \$29,000 followed by women at \$22,500. Per capita, residents of Knoxville average \$18,171 income per year, with over 14% of families below the poverty line (2000 U.S. Census).

According to the Tennessee HIV Data (<http://www.coetenn.com/HIVdata/HIVdataCumulative.htm>), there were 691 PLWHAs in the Knox consortia region as compared to the cumulative PLWHA data of 12,329 for the state of Tennessee through March 31, 2004; there were 532 persons diagnosed with AIDS in the

Knox consortia region while the cumulative data statewide was 9,631 through the same time. Based on data provided by the Hope Center (<http://hopecenterknox.org/resources.html>) in the Fort Sanders Regional Medical Center, Knoxville, through December 2004, Tennessee had 13,362 cases of HIV and 10,182 cases of AIDS that were reported; of these, 642 were children (1-19 years of age) living with HIV/AIDS. Women accounted for 23% of the HIV/AIDS cases in Tennessee; ethnic minorities accounted for approximately 56.7% of the HIV/AIDS cases, and cumulative deaths from HIV/AIDS totaled 7,130.

A seven-part series examining the HIV/AIDS epidemic in East Tennessee that was published in the *Knoxville News Sentinel* during August 2005 titled "Living Positive: HIV/AIDS in East Tennessee" addressed issues of health information services for PLWHAs in the light of increasing numbers of HIV/AIDS cases in the region. Selected considerations related to the provision of HIV/AIDS health information services in East Tennessee that the series brought to attention include:

- Knoxville's location in the heart of the "Bible-belt" contributes to a conservative and prejudiced climate with a negative stigma and reactions towards PLWHAs who find discrimination, bureaucracy, and insensitivity in the health-care professions as painful as the disease itself;
- The HIV/AIDS virus is spreading with alarming speed in the population; swelling demographic numbers suggest that it is no longer a "big-city disease" and appropriate information support services are urgently required to respond to the changing needs of the population (Hunter, 2005);
- HIV/AIDS in East Tennessee does not have boundaries of color and the disease is rapidly spreading among ethnic minorities. During 2003 Black Americans accounted for 56.3% of PLWHAs in Tennessee (Tennessee Department of Health). The CDC reports that black women account for about 70% of new HIV infections in the United States and are 18 times more likely to be infected with HIV than white women and five times more likely than Hispanic women.
- Education and awareness are identified as key approaches to stop the spread of HIV/AIDS because health agencies like the CDC report that young American people are "at persistent risk" for HIV infection. Between the years 1999-2003, the number of people ages 13-24 with AIDS diagnoses rose 37 percent. By 2003, that age group represented 4.7 percent of all AIDS diagnoses in the country. In the south, children ages 13-19 years old account for 8% of HIV infections — four times that found in other regions of the country.
- Rural communities in East Tennessee are no longer immune to the spread of HIV/AIDS. Health officials identify higher rates of alcohol and drug abuse, inadequate and limited access to health-care resources, lack of health insurance, and higher rates of other sexually transmitted diseases (which increase risk of HIV infection) as important contributors to increasing transmission rates. The South has the country's fastest growing rates of transmission; 45% of new HIV infections in the United States occur among Southerners. Additionally, the CDC reports that two-thirds of those in rural areas are infected locally, as compared to early days of the epidemic when most people got the virus from someone outside their own community (CDC, 2003b).

- Low-income and economic deprivation, in addition to changes in coverage terms provided by TennCare, the state health insurance system, have resulted in swelling numbers of HIV/AIDS patients who are losing their benefits and will be in trouble once the new policies begin in 2006. Lori Gibbs, medical care manager in the HIV/AIDS Center of Excellence at the Knox County Health Department reports that in the beginning of 2005 there were 440 active clients, though the numbers doubled by the end of the year.

Benefits of a Community Informatics Approach

Because of the rising HIV/AIDS transmission and changing demographic patterns across the state and the country, there is a need for substantive, transformative change, integrating community stakeholders to provide long-term and meaningful solutions to the HIV/AIDS problem. It would be useful for people from different constituencies to get together around a common table, and collectively and collaboratively, share and respect diverse realities and experiences, in order to make progress and bring progressive change. The CI approach in this project (whose initial findings during the first phase are reported in the paper), attempts to motivate and mobilize, and direct efforts to understand perceptions and perspectives of various members, in order to provide possible benefits that include:

- Identification and involvement of various stakeholders;
- Documentation of experiences and realities from multiple points of view;
- Discussion surrounding barriers and challenges encountered by different constituents;
- Examination of details at the local level to answer questions of the “how tos” to build appropriate localized health information support systems and services; and
- Provision of tangible outcomes in terms of what efforts need to be made to make the system more responsive to changing needs and circumstances.

Such an agenda goes beyond isolated efforts in separate domains and tries to build community capacity and communication between different groups and individuals. It will help address issues beyond just information issues, and integrate information needs into the context of larger social and community issues in order to work more effectively with the chronically ill. Here, CI recognizes the role of culturally appropriate information and communication in order to develop empowerment of local HIV/AIDS communities to engage with one other and address the gap between the needs and services/systems that are provided. The project bases itself on the understanding of human information behavior (HIB) as a holistic socio-technical system where knowledge and information is exchanged keeping in mind the entire human condition, thus expanding information and its role in human life to its widest possible level. A CI-based HIB approach has special significance for PLWHAs since it explores answers by linking the human condition, with people, and information together (Spink, Library Trends) in relation to community dynamics and agendas.

Methodology

Three focus groups with nine library and information professionals were held during October 2005 within the local Knoxville community. Focus group participants included the following: academic reference librarian (assistant professor); medical librarian with 20 years of professional library experience; resident minority librarian intern, who recently graduated with her ALA-accredited Master's degree; academic science reference librarian (assistant professor); academic library director in a medical-related branch library; academic reference librarian in a medical-related branch library, academic technical services librarian in a medical-related branch library, and academic paraprofessional in a medical-related branch library. Semi-structured questions developed by the researchers in advance were used to guide the group discussions. Questions were designed to identify information services in the area that provided assistance to PLWHAs. Questions were designed to elicit particular information about the information services in the community. Specifically, the guiding questions that were designed to elicit feedback include:

- 1) What are the existing information services for PLWHAs in the Knoxville community?
- 2) Who do the information providers serve; who are their stakeholders?
- 3) What are the barriers and challenges that they face?
- 4) What is their idea of the ideal situation (based on their challenges)?
 - a. What would be useful for them to know?
 - b. Who could help them?
 - c. What resources are available?
- 5) How can information providers bring about change to become more effective (based on the above)?
- 6) What role can information technology play in bringing about effective change?

The focus groups were recorded on audio tape and notes were taken by both researchers during the interviews. The tapes were later transcribed and the results were categorized according to the question asked. The results from these interviews are presented in the next section. Organization of findings presented in the paper according to the asked questions allowed for simplicity and clarity in presentation, while data analysis of responses to each question involved select strategies in open, axial, and selective coding practices to identify key points representing perspectives of the participants. The process of coding interview data in this research involved: seeking multiple perspectives as a part of the research inquiry; adopting triangulation strategies that verified specific information from multiple sources; following systematic and rigorous procedures for understanding social processes and phenomena that case-participants spoke about in response to the questions; and employing techniques of induction, deduction, and verification to develop a clear understanding based on constant comparative analysis (Strauss and Corbin, 1994). Owing to reasons of brevity, it is beyond the paper's scope to detail out procedures carried out in the qualitative process of data analysis since this is not a methodology paper and the paper focus is on the findings documenting the perspectives of library and information professionals.

Results and Discussion

The results from the focus group interviews are summarized and presented below under each of the topical questions that were asked during the interview.

What are the existing HIV/AIDS information services for PLWHAs at the University of Tennessee and in the greater Knoxville community?

There was strong agreement across all focus group participants that there are very few information services available on HIV/AIDS in Knoxville and at the University. None of the participants were actively engaged in the provision of this specific information. Further, there was consensus among the participants that HIV/AIDS information could possibly be available through either the county health department or the University health center, although none of the participants were certain about whether this was accurate. There was also consensus that there are very few, if any, existing support groups for PLWHAs. One of the participants suggested that there might be support groups available through local religious communities but no one appeared to be certain about this possibility.

The focus group participants also seemed consistent in their perception that usually libraries (public, academic, medical, and other) are not receiving questions about HIV/AIDS owing to various factors that include: lack of patron's need; hesitancy and fear to ask such questions; availability of such information elsewhere (thought research participants were not sure where these sources were); inappropriate venue for asking such questions; amongst other reasons. When asked about specific information services that might be available to PLWHAs locally, participants mentioned MEDLINE Plus training; outreach to HIV/AIDS groups; the local health department; a local Hospital library where one of the participants worked; Hospice; Google; Lambda (a gay student organization at the University of Tennessee); advertisements in a local weekly newspaper called *Metropulse*; support groups that might exist, including those at churches; and the University Health Clinic, which offers voluntary counseling and testing (VCT). There was thus, an inconsistency across the focus groups between participants' responses to when they were asked the question in a broad, general sense, and when the question was asked in terms of providing specific feedback.

Who uses these services?

The participants repeated that they did not have much professional experience in providing HIV/AIDS information so they could only speculate about who would use these services. They agreed that anyone could use these services, although they speculated that it would be a small percentage of the population. One of the participants from the University library stated that she wasn't certain that the ones who would come to the University library would necessarily be students.

Have you encountered anyone asking questions about HIV/AIDS?

Most of the participants reported that they didn't remember having had questions about HIV/AIDS. One participant estimated that she had probably had one question about HIV/AIDS in ten years of practice. Another participant estimated about four or five people who had asked questions on HIV/AIDS in her experience, although these inquiries were over the telephone so that customers could not be identified with their question. The participant suggested that she thought that there were more likely to be greater number of telephone requests for this type of information if patrons knew that their confidentiality would be protected. Another participant reported that one person in her memory shared personal information about HIV/AIDS.

What are the barriers and challenges that library and information professionals face in providing these services?

There were a number of barriers and challenges identified by the participants regarding the provision of HIV/AIDS information services. Nearly all participants reported that administratively, this was not a politically popular topic. This was attributed to an air of “conservatism in the local community” and on the University campus. One participant suggested that the provision of HIV/AIDS information “could be seen as promoting sexual behavior or endorsing a certain life style.”

Another barrier facing library and information professionals in providing HIV/AIDS information that was reported included personal bias and stigma. Several participants explained their concern that there is a stigma associated with HIV/AIDS that makes the provision of HIV/AIDS information very difficult. It is also compounded by the controversy that exists on campus and within the local community between church and political groups.

When asked how this barrier could be overcome, several participants reported that they were not sure how it should be done, that they were not sure what else is being done to know what needs to be done. Further, they reported that they were not sure how to integrate these services with their constituencies. One participant reported that the community does not view the role of the library as a support group, reflecting a more traditional perspective on library service. Negative letters to the editor was reported as an example of this perspective. Concern was expressed by several of the participants regarding the possible vandalism of AIDS displays that the library might provide, again reflecting the stigma within the community.

Restrictions to web access were also seen as a challenge for library and information professionals in providing HIV/AIDS information. One participant suggested that socioeconomic issues could prevent access to HIV/AIDS information, such as limited access to computers and lower literacy levels. Getting materials for minority populations when they have limited web access was mentioned as a challenge for library and information professionals.

Another participant suggested that people don't see library and information professions as a source for this kind of information, which leads to a kind of inertia by libraries. She suggested that libraries could offer conference programs on HIV/AIDS. It was also suggested that churches could set up an information center and offer training on how to find information. In addition, the community center could offer information in a variety of languages, targeting those whose native language is not English. The location of the center, however, was considered problematic; should it be placed near the gay community? Should it be near or affiliated with a specific church? For example, a social service group could meet once a month at a church. In addition, the community center could provide a referral service. This would be an effort to reach out to those with limited income.

Finally, one of the participants noted the divide between university (academic) and community practitioners as a challenge for library and information professionals in the provision of HIV/AIDS information.

What would be an ideal HIV/AIDS information service (based on challenges identified by the focus group participants)?

- a. What would be useful for the library and information professionals to know?
- b. Who could help them?
- c. What resources are available?

The focus group participants were asked to identify what an ideal HIV/AIDS information service would look like, given the limitations they had just identified. The result was a “shopping list,” presented in Table 1.

Table 1. Components of an “Ideal” HIV/AIDS Information Service

HIV/AIDS Information Services	
Referral services	Outreach efforts and activities
Programs, activities, and events	Special collections
Speakers to address topics of concern	Coordination with other organizations
Christian radio programming	Distribution of flyers
Displays on bulletin and discussion boards	Web links
Let people know there is no judgment	Ask ALICE
Databases of information resources	Public library
Boys Club	Schools and local colleges
Information should be out in the open	Information on counseling/testing
Support groups	Mental health facilities
Counselors should be trained to know what they’re legally allowed to ask	Evaluate/update collections (e.g., Books, DVDs)
Pathfinders (library guides)	Signage and proactive advertising

One of the participants identified educational institutions (schools, colleges, and universities) as being an important component in the provision of an ideal HIV/AIDS information service. For example, the University of Tennessee has a program called “Life of the Mind,” where every entering freshman class is required to read and reflect upon a book that has been chosen for that particular class. The participant suggested that the selected book could be a story about HIV/AIDS, which would be a particularly effective way of providing information without encountering the obstacles identified in the previous question.

Mental health services were also identified as a component for ideal HIV/AIDS information services so that people are “not just left with an answer that is a surprise to them.” Pathfinders were listed to enable people to go directly to the stacks without having to ask for information. Signage would also assist people in locating the information they need without having to go through a human intermediary.

In sum, the focus group participants agreed that finding out what communities need is the first step towards building an “ideal” HIV/AIDS information service. This includes identifying what resources exist in the community and who could help library and information professionals build a better service. This includes locating any existing support groups as well as identifying those who are in need of service.

How can information providers achieve the ideal service to become more effective based on the answers to the previous questions/discussion?

There were several suggestions for how information providers can achieve the ideal service to become more effective. One participant recommended that library and information

professionals should pay more attention to neglected topics (e.g., GLBT issues) that are often overlooked. The Library Bill of Rights can serve as a guideline in this regard.

Other suggestions were aimed at facilitating and protecting the confidentiality of patrons. By letting individuals check out their own books and publicizing the confidentiality of circulation records, information professionals can reassure patrons that they can seek HIV/AIDS information in private and without judgment.

Another participant emphasized the importance of the demeanor of the information professional. She suggested that library and information professionals should never judge and should maintain a neutral tone of voice. It was also suggested that library and information professionals should demonstrate cultural awareness and sensitivity. Further, information providers should keep their own perspective to themselves, regardless of their own personal beliefs.

It was also suggested that library and information professionals should be trained by health workers in order to be knowledgeable about necessary HIV/AIDS information. One of the participants suggested that a literature review should be conducted to identify successful research models for community outreach. The literature should be scanned in order to identify where and how others have conducted community outreach and best practices and case studies. It was also suggested that a health awareness day, called something like "Healthfair," could be held each year in order to make private spaces for people to talk. Drug companies could be approached to sponsor the fair, along with advertising and door prizes. Test kits could be made available to take home and send back in.

What role can information technology play in bringing about these changes?

When asked what role information technology could play in bringing about these changes, there were several responses. First, the Internet was identified as a key source, particularly as it pertains to allowing the County health service to post its information on a web site. Library catalogs were also identified as an information technology that would facilitate the changes that were identified to address the problems of HIV/AIDS. The same was true for making databases available (e.g., MEDLINE Plus) to the public. It was agreed by most participants that websites with information would be useful. Online support groups were also mentioned, particularly with their capability of providing anonymity. It also allows outreach to others who cannot be there geographically.

Conclusion

This paper presents initial findings from a community informatics study that involved one group of stakeholders in the provision of health information support services to PLWHAs. The group (namely, library and information professionals) shared their perspectives about the existence of local information services for PLWHAs, the clientele for these resources, barriers and challenges to their effective access, vision of an ideal resource, their own role in bringing change for effective use, and the role of information technology in the process. Feedback provided by study participants calls for greater efforts to develop more information support services for PLWHAs as well as the need for library and information professionals to create greater awareness about what is available. Participants also mentioned the need for proactive engagement on the part of local library and information professionals to collaborate with other community agencies towards meeting missing needs for this disenfranchised population. Efforts to provide signals of a supportive and bias-free

environment where patrons feel free to address their HIV/AIDS related questions was another direction for improving existing services being provided.

One limitation in this exploratory study was that participants focused on male concerns and there was not adequate representation and discussion on issues related to women and their needs (e.g., very little information was provided on how women can stay safe). Additionally, the limitation of having participants from only library environments will be addressed in future work that will be conducted across various settings and with other constituents that include health care service providers, PLWHAs from the heterosexual and homosexual communities, community leaders and activists, school representatives, as well as those from faith-based organizations, amongst others. The goal is to gather adequate feedback from various impacted and involved communities in order to direct equity of representation towards effectiveness in service design and delivery mechanisms. A CI approach helps identify strategies to achieve that goal by building partnerships and collaborations within and across the academy and with various groups within local communities to promote social equity and justice for individual, social, and community-wide empowerment of the underserved. A CI approach will also promote efforts to sustain a bottom-up approach by identifying localized efforts from the micro-level of individual settings within the community. Such efforts will synergize the top-down policy and service initiatives with bottom-up approaches where voices of those who are underrepresented to be involved in the decision-making processes associated with the provision of HIV/AIDS health information services.

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