Delivering health information services and technologies to urban community health centers: the Chicago AIDS Outreach Project*

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Health professionals cannot address public health issues effectively unless they have immediate access to current biomedical information. This paper reports on one mode of access, the Chicago AIDS Outreach Project, which was supported by the National Library of Medicine through outreach awards in 1995 and 1996. The three-year project is an effort to link the programs and services of the University of Illinois at Chicago Library of the Health Sciences and the Midwest AIDS Training and Education Center with the clinic services of community-based organizations in Chicago. The project was designed to provide electronic access to AIDS-related information for AIDS patients, the affected community, and their care givers. The project also provided Internet access and training and continued access to library resources. The successful initiative suggests a working model for outreach to health professionals in an urban setting.

INTRODUCTION

Professional isolation is cited as one reason why physicians do not want to practice in a rural area. Librarians have tried to alleviate this problem among rural health practitioners by providing access to Grateful

Med and other information technologies. Many successful models for rural outreach services have been described in the literature. Isolation, however, is not unique to rural physicians. Health professionals working in community-based clinics in urban settings are subject to isolation as well. The literature contains few descriptions of successful outreach services for this population.

This paper describes one model for outreach in an urban setting, the Chicago AIDS Outreach Project. Characteristics of the model include (1) recognition of the multidisciplinary nature of community clinic workers, (2) the creation of partnerships, (3) the provision

of connectivity and equipment, (4) the provision of training, (5) respect for the ethnic and cultural diversity of the community served, (6) the provision of document delivery services, and (7) program evaluation.

BACKGROUND

The need to disseminate AIDS information is amply documented in the literature. For example, a report based on a 1993 conference that examined the role of the National Institutes of Health (NIH) in providing HIV/AIDS information recommended that NIH "support efforts to make information accessible where affected individuals are spending time" (recommendation 5.1) and "provide support and technical assistance to community-based organizations to develop and make available to patients and their families information and services relating to HIV/AIDS prevention, treatment, and disease progression" (recommendation 5.4) [1].

A study in Texas found that "information concerning consumer education, legal issues, cost of health care, and health care financing . . . is needed by AIDS service organizations. . . . Not all information needs are currently satisfied" [2]. Burrows described a project that was funded by the National Library of Medicine (NLM) and designed to meet AIDS information needs in a three-county area of Southeast Florida [3]. Turman and Self reported on AIDS outreach service models [4]. Two 1995 publications provided comprehensive reviews of the key role played by computers in meeting information needs in clinical settings [5, 6]. The importance of information to both patients and care givers has been recognized by libraries; programs and services that provide AIDS and HIV information are described by Lukenbill [7].

AIDS continues to take a disproportionate toll on some groups in this country: the homosexual population, intravenous drug users, Hispanics, and African Americans. A recent report provides sobering statistics on the toll taken by AIDS in Chicago alone. Since 1980, 10,556 cases of AIDS have been diagnosed. Of these individuals, 56% were African American and 15% were Hispanic. Of the 118 pediatric cases, 75% were African American and 30% were Hispanic. The report states that "89% of pediatric AIDS [cases] are due to transmission between an infected mother and her offspring." The need for education in all these affected groups is urgent. Of the total number of persons diagnosed with AIDS in Chicago, 6,473 (61%) have died [8].

A report released in April 1996, *A Profile of Community Area Opportunities for HIV/AIDS Prevention in Chicago*, recommends prevention activities that could be undertaken by hundreds of community-based, educational, and service agencies, which are located in every one of Chicago's neighborhoods. The report

states: "HIV/AIDS prevention efforts should be expanded. . . . there are unique HIV/AIDS prevention roles for agencies and community leaders who may not have realized that HIV/AIDS prevention must be undertaken in every single Chicago neighborhood. . . . almost every Chicago neighborhood is home to a variety of multi-service organizations which could offer HIV/AIDS prevention service" [9]. The study goes on to say: "With three million visits to the Chicago Public Library system each year, its 86 branches are well positioned to serve as neighborhood-based centers that could offer HIV/AIDS educational programs. In addition, the distribution of information on the Internet (as well as on-site distribution) by the central and branch libraries further increases their ability to offer effective educational material" [10]. There is clearly a need to link a variety of organizations to library resources to help fight the disease that has already killed thousands of Chicagoans.

THE CHICAGO PROJECT

NLM responded to the report on the 1993 NIH conference by issuing purchase order awards to community-based organizations that provided services to the population affected by HIV and AIDS. Patients, their care givers, and all those needing education and information on prevention and treatment options—including health care providers—were the targets of the NLM initiatives [11].

The Chicago AIDS Outreach Project (CAOP) was initiated with funds from NLM and the University of Illinois at Chicago (UIC) Great Cities Program. The three-year project, which began on August 14, 1995, and extends through March 30, 1998, is an urban outreach effort to link the programs and services of the UIC Library of the Health Sciences (LHS) and the Midwest AIDS Training and Education Center (MATEC) with the clinic services of community-based organizations. Individuals and groups served by community-based resource centers, clinics, and libraries, as well as health practitioners, were identified as the target populations for the UIC project.

The LHS serves the six professional health sciences schools and the entire university. It is one of eight Regional Medical Libraries (known collectively as the National Network of Libraries of Medicine) in the country. LHS librarians have recently been involved in community activities within the state of Illinois through a project that brings consumer health information to the public [12].

UIC recently launched the Great Cities Program, which will implement teaching, research, and service programs designed to improve the quality of life in Chicago. In this way UIC will become a model for a land-grant university in an urban setting. As a leading public institution in a major city, UIC has a responsi-

bility and a unique opportunity to contribute to the well-being of Chicago [13]. The goal of the program is to create partnerships and strengthen relationships between UIC and community groups to improve health care, education, the arts, public policy, and other aspects of city life.

UIC has a commitment to providing HIV/AIDS education, patient care, and consumer health information. This activity is carried out primarily through the UIC Family Center for Immune Deficiency and Infectious Diseases and the Midwest AIDS Training and Education Center (MATEC). A librarian provides technical and reference expertise to the health sciences faculty and offers Internet training. These services are enhanced by the librarian's dual expertise, which is gained by working half-time in the library and half-time in MATEC.

CAOP

The CAOP has six objectives:

- to provide electronic access to AIDS information to community-based organizations in Chicago whose clients are patients who have AIDS or are HIV-positive and their care givers
- to train staff at each participating organization to access HIV/AIDS-related information
- to provide access to state-of-the-art Internet resources
- to develop and distribute Grateful Med training material in Spanish
- to provide document delivery of articles retrieved from NLM's AIDS databases
- to provide an ongoing link to the UIC-LHS resources and services

CAOP PARTNERS

UIC-LHS is the Regional Medical Library for the Greater Midwest Region (GMR) of the National Network of Libraries of Medicine (NN/LM). The UIC library and its regional sites constitute one of the largest medical libraries in the country in terms of collection size. Outreach is a major aspect of its mission.

CAOP project cofounders include MATEC and the Illinois Primary Health Care Association (IPHCA). MATEC is a consortium of professional, service, and academic organizations in six states, dedicated exclusively to HIV/AIDS education and training for primary care physicians and other health professionals. IPHCA is an association of clinics devoted to improving the health status of medically underserved populations by fostering the provision of high-quality, comprehensive health care that is accessible, coordinated, community directed, culturally sensitive, and linguistically competent.

CAOP member clinics are Federally Qualified Health Care Clinics. Half of the clinics receive Ryan White Title I, II, or III funding. These clinics are in a position to directly and immediately benefit from updated HIV information. The target population includes all individuals in Chicago who are served by the community-based organizations, clinics, and libraries participating in the CAOP. The clinics are located in areas that are designated as medically underserved. The neighborhoods are primarily African American and Hispanic. Clinic workers include not only physicians but also a range of other professionals including nurses, social workers, ministers, lawyers, business administrators, and volunteers.

Community-based clinics and organizations include the Alivio Medical Center, which provides primary health care services to a very-low-income Mexican population on Chicago's southwest side; CALOR HIV/AIDS services to Chicago's Latino community; and Circle Family Care, which provides an array of social, medical, and educational services to Chicago's west side. Circle Family Care's Early Intervention Program serves individuals at high risk for HIV infection.

Other participants are Claretian Medical Center, which provides health education and health care services to primarily minority populations with no health care providers; The Clinic at Altgeld, which provides HIV/AIDS-related services to the Altgeld Gardens/Murray Homes public housing development; Gerber Hart Gay and Lesbian Library and Archives; and the Howard Brown Health Center, which provides HIV-related services to more than 800 clients a month.

Other partners include the Daniel Hale Williams Health Center, Lozano Public Library, Pilsen Little Village Community Mental Health Center, Erie Family Health Center, and the Test Positive Aware (TPA) Network. The TPA Network is the Midwest's largest nonprofit resource and support network for HIV-infected individuals.

CONNECTIVITY

Linking partners electronically is a key activity of the CAOP. Each participating agency, clinic, and library is provided with end-user workstations, if needed. All sites receive Grateful Med software and database training, printed classroom material, document delivery, and Internet training.

O'Brien has described the effectiveness of the World Wide Web as an information and outreach mechanism [14]. LHS and MATEC are developing a CAOP consortium Web site (http://www.uic.edu/depts/lib/services/outreach/caop/), which will be linked to the LHS, IPHCA, and MATEC Web sites. Web sites that were found to be particularly helpful as the project and information services were developed included those of the AIDS Information Outreach Projects (http:

//sis.nlm.nih.gov/aidp.htm), Detroit Community AIDS Library (http://www.libraries.wayne.edu/dcal/aids.html), and HIV/AIDS Information Outreach Project at the New York Academy of Medicine (http://www.nyam.org/library/about.html). The Mardikian guide to HIV/AIDS Internet resources was also used [15].

The LHS AIDS outreach librarian coordinators provide HyperText Markup Language (HTML) training and work with consortia members to make their unique HIV/AIDS information and provider services available on the Web site. The librarians teach members how to make available locally developed community-based clinic information specific to Chicago, and how to provide access to bibliographic information through Grateful Med. A long-term goal is to provide access to local, state, and federal government resources through the CAOP consortium Web site. Some progress has been made already. For example, three of the consortium members have their own Web pages: Howard Brown Health Center, Gerber Hart Gay and Lesbian Library and Archives, and TPA Network.

Training

Training of staff at each participating site is another vital CAOP activity. The AIDS outreach librarian coordinators make an initial site visit to assess the local networking environment. The staff at each site then receive a minimum of four training sessions: an introduction to Grateful Med, advanced Grateful Med training, an introduction to the Internet, and advanced Internet training. As part of the training, site staff are given information on how to obtain documents through Loansome Doc (a component of Grateful Med that initiates document delivery) from LHS.

Training sessions focus on how to obtain HIV/AIDS information, with an emphasis on the free AIDS databases available through Grateful Med. Training material previously used at LHS was modified as appropriate for the target group. For example, introductory DOS Grateful Med training material used at LHS was translated into Spanish. Training material is made available in Spanish at each participating community-based organization. CALOR and Lozano Public Library staff reviewed the translated material before final distribution. Internet Grateful Med training materials will be translated into Spanish during the later stages of the project.

A bilingual user manual was produced for searching AIDSLINE with DOS Grateful Med. The manual takes the user through the search process, describing how to conduct author and title searches and how to use Medical Subject Headings for subject searching. Instructions are also provided for limiting search output to Spanish-language references. The manual was produced in booklet form with English and Spanish

versions on facing pages. A brochure describing the project was also produced in English and in Spanish.

A modified "train the trainer" model is used. This model is based on the results of an NLM-funded outreach evaluation project, which documented the need for a person at each outreach site to ensure project success and continued use of Grateful Med outreach services [16]. Each participating organization designates a primary contact person to assist the LHS AIDS outreach librarian coordinators in scheduling sessions, answering questions from the rest of the staff, team teaching at the contact person's site, and coordinating remedial sessions for staff. At some sites, the contact person is responsible for administering the training program for clients who use the public access workstation. The site contact person helps resolve any questions or problems in searching or in ordering or receiving documents that arise between scheduled training sessions.

Each participating site provides space for the computer and telephone line. At the clinic sites, every attempt is made to place the computer in an area accessible to health professionals taking care of patients rather than in an administrative office. The AIDS librarian coordinators bring a portable computer for hands-on demonstrations. Some sites already have computers with modems in areas not used for patient care. These computers were used to supplement the training if more than two persons at a time attend a session. The LHS also made available a portable overhead projector system for display purposes if needed.

In addition to Grateful Med training, CAOP participants receive training in use of the Internet. The CAOP awards funds for up to one year of commercial Internet access for sites lacking other means of access. Training documentation is based on materials developed by NN/LM GMR librarians. In addition, site contact persons are asked whether they are aware of any Internet resources that should be emphasized or demonstrated in the training sessions. During the first year of funding, thirty-five persons were trained to use Grateful Med to search the NLM databases and thirteen were given basic Internet training. Projections are that fifty persons will be trained during the second phase of the project.

Document delivery

Document delivery enhances the link between the community-based organizations and LHS information resources. Photocopies of articles retrieved from NLM's AIDS databases are provided free of charge when requested through Loansome Doc. The delivery of documents from the LHS collection will begin to create an ongoing relationship between consortium member organizations and library resources and services.

The NLM outreach awards provide the means to form partnerships among a variety of community groups in order to increase their effectiveness in providing vitally needed direct access to HIV/AIDS information sources. The organizations participating in the CAOP are working to provide AIDS patients with critically needed services and educational programs. Document delivery is a very practical, tangible demonstration of the benefits of linking consortium members to improve access to needed information.

Evaluation

Plans for evaluation of the project include a variety of assessments to be conducted throughout the three-year period. Evaluation of each training session is conducted with a written form. Several Grateful Med evaluation forms are placed next to each computer workstation, and users are asked to complete a form. Follow-up meetings with project participants are held to discuss advanced training needs and progress. The CAOP is modified according to their comments.

Grateful Med use logs from each site are monitored by the AIDS librarian coordinators on a regular basis. The use of databases and workstations continues to be monitored and evaluated. Data are collected from use logs, user evaluations, Loansome Doc document delivery requests, and personal contacts with site representatives. These data are used in developing objectives for advanced Internet training, revising appropriate documentation, and determining the best ways to pursue project goals.

The CAOP Web site is monitored to note the number of links made to locally developed home pages and resource lists. Success will be determined by the number of sites that continue to subscribe to Internet access services once NLM funding ends. A follow-up questionnaire to be administered at the end of the three-year period is being designed by the project coordinator with assistance from faculty in the UIC School of Public Health and students in the UIC School of Biomedical and Health Information Sciences.

Preliminary results indicate that participants are being trained. Yet use of the system is low. A needs assessment and an evaluation to investigate the reasons for the low level of use are planned for the last half of the project.

CONCLUSIONS

The CAOP has experienced problems that are often related to start-up ventures. The bidding and purchase approval process takes time. Often training sessions are scheduled and then need to be rescheduled because of last-minute time conflicts within the community-based group. Sometimes more or fewer than the expected number of staff members show up for training and the trainer has to adjust to the new circumstances. Training sessions seem to last only forty-five minutes during the lunch break, and staff tend to drift in and out of sessions because of clinic demands.

Modem connections often do not work on the first try. Equipment may not work if connected through a local area network. The AIDS outreach librarian must be prepared with back-up materials in case equipment or connections fail to work. In addition, some commercial Internet providers cannot handle billing for accounts with organizations that do not have credit cards. In some cases, individuals at the clinics contract with the Internet service provider and then are reimbursed by the clinics. In other cases, another Internet provider that can handle nonstandard billing is chosen.

The experience has demonstrated that the process of changing the information-seeking skills and habits of staff at community-based organizations is facilitated by repeated contact. Such contact includes telephone calls and drop-in visits in addition to the scheduled training sessions. Hands-on training and the identification of site contact persons who can call on the AIDS librarian for help are essential. It has also been helpful for one of the AIDS librarians to be a member of the target community. Community partnerships, including multilingual groups, are essential to the effective dissemination of AIDS-related information.

The need to establish an e-mail discussion group for CAOP sites as a way of interconnecting sites and improving communications is being assessed. Once all participants are comfortable with their capability of supplying the defined services, there will be a mailing to establish contact with other health care agencies and outreach centers and publicize the availability of AIDS databases. A press release for community and Spanish-language newspapers is being written.

This paper describes a model for delivering outreach services in an urban setting. The ultimate success of the CAOP will be revealed by the ability of the community-based partners to maintain connectivity, continue to make Grateful Med available, and absorb the cost of the Internet accounts once grant funds run out; and the ability of LHS to continue to provide the link to health information services for these groups.

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