Readiness and Capacity of Librarians in Public Libraries to Implement a Breast Cancer Outreach and Screening Campaign in Medically Underserved Communities

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Community-based partnerships are an important means of addressing cancer health disparities in medically underserved communities. Public libraries may be ideal partners in this effort. To assess the readiness and capacity of a public library system to implement cancer recruitment and outreach campaigns, 58 librarians in the Queens Borough Public Library System in New York completed self-administered questionnaires before and after a training on breast health, cancer, and screening. Results indicate that they are interested in participating in a cancer outreach campaign and feel it is a critical need in their community. Many librarians lacked the knowledge about cancer and cancer information resources needed to participate optimally. Nevertheless, librarians provide a cultural bridge to medically underserved communities. Partnering with a public library system to improve access to care has great potential, yet a number of challenges need to be overcome.

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Introduction

One of the goals of the US government's Healthy People 2010 campaign is to "eliminate health disparities," particularly with respect to illness, disability, and death caused by cancer. There is widespread consensus that partnerships between public agencies, public and private research institutions, and community-based organizations are a promising way to address these cancer disparities. Public libraries, of which there are 9,129 in the United States, could be important and effective partners in this effort.

Every state and each territory in the United States has a public library system. Research suggests that libraries possess characteristics that make them potentially ideal settings from which to conduct health outreach activities. Many public libraries are located in underserved communities and are an important resource to community residents. In fact, public libraries are often the initial point of access for community members who seek health information. Libraries provide information on community issues (eg, employment opportunities, available social services) in languages spoken in that community, they are a venue for public gatherings such as workshops and study groups, and they often provide desirable programs for adults and youth free of charge, including English as a Second Language (ESL), literacy courses, and various after-school programs. In addition, libraries provide access to computers and the Internet; it has been shown that minorities use the Internet at libraries in greater numbers than the rest of the population.

Given librarians' knowledge of community culture and history, they may be uniquely positioned to provide health information to medically underserved populations and to conduct outreach for screening and other kinds of preventive care (eg, vaccinations). Individuals who are medically underserved often experience multiple health care problems and needs. Thus, any health-related inquiry to a librarian offers an opportunity to connect underserved patients to multiple systems of care.

Our review of the literature indicated that little work has been done to examine the potential role of public libraries in providing access to cancer screening, diagnosis, and clinical trials. Public health initiatives carried out with academic, medical, and/or public libraries as partners have focused largely on improving information delivery via the Internet and on assessing the perceptions of librarians in their role as health information professionals. Additionally, a number of articles report on various ways to work with libraries to address information needs of the community. Another topic of recent interest is librarian training in health care and health information diffusion.

Wood and colleagues described a pilot project to learn more about the role of public libraries, in particular, in providing health information to the public and in helping the National Library of Medicine improve future collaboration with public libraries. The authors noted that nearly one half of the participating libraries conducted health information outreach and/or promotion. The most successful outcome programs where those that focused on a specific disease or condition.

Prior work in evaluating the use of public libraries to address health disparities, specifically, has focused on addressing the barriers to care caused by lack of health care knowledge. described the New York Online Access to Health (NOAH) initiative, which is a Web site developed to provide health information in English and Spanish (http://www.noah-health.org). This project was carried out by a partnership among libraries. The article underscored the importance of providing up-to-date health information to lay persons via the Internet in multiple languages.

Nonetheless, as Dahlen emphasizes, effective dissemination of health information to the public by libraries can be difficult, since such dissemination is affected by complex social issues, structured pricing, and information technology. Many members of minority groups are unaware of the health information services that libraries provide, and librarians have had limited success in conducting outreach in these minority groups. Only a small percentage of public libraries in the United States have the economic means and resources needed to carry out the task of providing public health information to the public.

To realize the potential of libraries as points of entry into multiple systems of health care, many challenges will have to be addressed. Public libraries serve many missions; fostering access to care would have to be coordinated with many other tasks. Librarians would require specialized training and support to provide effective health information and referral. Libraries are dense information environments, so health-related programming and activities may not stand out against the backdrop of many other offerings. Librarians would need to educate their patrons and communities about the possibility of obtaining health information and access. Public libraries would need additional resources to do this effectively. For example, the Healthy People Library Project free Web site provides a "tool kit" that helps librarians and community-based organizations promote health centers to populations in need.

In order to better understand the challenges of implementing a cancer public health campaign in a public library outreach site, we conducted a survey of librarians in the Public Library System in Queens, New York. Our assessment survey focused on their readiness and capacity of librarians to take on roles in providing health information, their awareness and use of different cancer information resources, and their feelings about taking on tasks and responsibilities in this area. This assessment was conducted as part of the initial phase of a public breast cancer health education and screening campaign (ASK ME) of a diverse partnership called the New York Health Literacy Task Force (The Task Force). The assessment was held on September 23, 2003, at the Queens Public Library Main Branch.
In this article, we describe the partnership, the ASK ME campaign, the impetus and procedures for the assessment, our findings, the challenges we experienced as health professionals working in this context, the implications of the findings, and our experiences for the future involvement of libraries in partnerships focused on reducing health disparities.

Methods

Context

The Task Force was formed in the summer of 2003 by public, private, academic, and community organizations to decrease public health disparities in the New York City area. Members include representatives of the New York State Department of Health, the New York City Department of Health and Mental Hygiene, The Queens Division of the American Cancer Society (ACS), the Queens Health Network, and Queens Cancer Center, Memorial Sloan-Kettering Cancer Center, New York University Center for Immigrant Health, and the Queens Borough Public Library System (QBPL). The Task Force has adopted a broad view of resources needed to promote health literacy: information must be not only “readable” but also meaningful and useful to consumers, empowering them to take action on their own behalf. By combining and leveraging resources and efforts, the Task Force aims to address disparities by improving health literacy among underserved populations, particularly immigrants, through the development of culturally sensitive health interventions.

The first project that the Task Force chose to implement was a cancer health screening campaign by the New York State Department of Health called “ASK ME” in the Borough of Queens, New York. The goals of the ASK ME campaign are to increase screening for breast and cervi-
cal cancer in minority and immigrant populations and to convey important cancer health information and build trust in this information. To achieve the ASK ME campaign goals, the 63 branch libraries of the QBPL in Queens were asked to place ASK ME posters and materials throughout the library. These posters and materials provided information about mammograms (eg, what they are and who should get them) and eligibility criteria for free mammograms. Librarians were encouraged to wear a button that prominently displayed the message “ASK ME about a Free Mammogram or Pap Test.” The buttons were designed to encourage a person-to-person interaction between librarians and patrons. The intention was that during this interaction the librarian would give the patron a card that contained referral information, specifically, phone numbers the patrons could call to obtain appointments for a mammogram and Pap test.

Campaign materials were designed in four languages: English, Spanish, Mandarin Chinese, and Korean. Phone calls were taken by the Queens Branch of the ACS, a Task Force partner. The Queens ACS had the capacity to handle phone inquiries in all four languages and was able to schedule a free mammogram with a Task Force provider partner within the Borough of Queens or other New York State counties. Screening examinations were paid with funds from the New York State Department of Health, partially supported by the Centers for Disease Control and Prevention’s Breast and Cervical Cancer Early Detection Program.

On September 23, 2003, a librarian training workshop was held prior to the launching of the first year of the ASK ME campaign. The training was conducted by Task Force partners. Librarians were provided with information about (1) breast cancer, (2) the librarians’ role in this campaign, (3) ACS screening guidelines, and (4) cancer resources available through the ACS. All 63 branches of the QBPL implemented the ASK ME program concurrently on October 1, 2003.

The Task Force identified Queens, New York, a county with 2.2 million residents, as an ideal site for this project for two reasons. First, it is one of the most polyglot counties in the country, with immigrants from over 150 countries. Many of these immigrants are medically underserved. Second, the QBPL has high penetration into these underserved communities, with 63 branch libraries and six Adult Learning Centers. The libraries already provide many programs for community residents. Librarians speak the language(s) of the communities they serve and are a trusted source of information (Figure). The system is widely used; it has circulated more books and other library materials than any other library system in the country since 1994. Thus, the QBPL had excellent potential as a sole outreach partner in the campaign. QBPL librarians were important partners in designing and implementing this campaign and also in adapting materials provided by the state. Although some librarians expressed reticence about conducting research with patrons (an issue we return to in our discussion), they were unanimously interested in knowing about librarians’ experiences with health outreach.

Participants
Librarians from 59 of the 63 Queens public libraries attended the training. Librarians invited to the training included branch library managers, assistant managers, and other librarians who could take information back to their branches and train additional staff. All of the invited branch library managers, assistant branch managers, and librarians were part of the Public Services Department of the QBPL and provided a minimum of 4 hours of direct services to library patrons (personal communication, M. O’Connor, Interim Director of Branch Services and Director of Programs and Services Department Queens Borough Public Library, June 9, 2005).

Procedures
The readiness and capacity assessment consisted of a self-administered paper and pencil 44-item pre-training questionnaire and a 16-item post-training questionnaire. Across the two questionnaires, 55 of the 60 items were closed-ended and 5 were open-ended. These instruments had face validity — extensive conversations with librarians led to their development, and they were reviewed by librarians prior to their use at the training.

Questionnaires were completed anonymously and independently by the librarians in attendance. In the questionnaires, librarians were asked to provide descriptive information about the frequency and types of health requests they receive. They were specifically asked about various forms of cancer and other chronic illnesses and about different kinds of illness prevention and health promotion. We also asked librarians to report the frequency with which different demographic groups of patrons (eg, men, women, non-English speakers, adolescents) request health information.

In addition to eliciting descriptive information, the questionnaire included items that tapped into the readiness of librarians to participate in breast health and cancer screening outreach. Specifically, librarians were asked about their comfort level with participating in these activities, the importance of library involvement in outreach to increase access to services, and the kinds of cancer needs they perceive to be in the community. They were also asked about how participation in the ASK ME program might interfere with their regular work. Finally, the questionnaires assessed the capacity of librarians and their libraries to become involved in this kind of public health effort. Librarians were asked about their knowledge of facts about breast health, cancer, and screening. They were also asked about where they refer patrons who request health information, what additional training or information they would like about breast cancer or related topics, and how they would like the partnership to assist them in meeting the health needs of their community.
Results

Of the 59 librarians who attended the ASK ME campaign training, 58 (98%) completed the pre- and post-training questionnaires. Analysis of information collected was conducted using SPSS Version 12.0 for Windows (SPSS Inc, Chicago, Ill).

Who Requests Health Information?

Findings from the pre-training questionnaire indicate that librarians receive health information requests from women more often than from men. Sixty-one percent of librarians reported that they receive requests from women for health information at least weekly, while only 33% of librarians indicated that men requested health information this frequently. Frequency of health requests was also directly related to age group. Seventy percent of librarians indicated that they receive requests from patrons aged 64 or older at least several times per month; 62% reported this frequency for patrons aged 40–64, 40% for those aged 19–39, 20% for those aged 12–18, and 16% for patrons younger than age 12. These Queens librarians also receive frequent requests for health information from patrons who speak languages other than English. Almost half (47%) of the librarians surveyed reported that they get such requests from non-English speaking patrons at least several times per month.

What Specific Information Is Requested?

Table 1 shows the types and frequency of various kinds of health information requests librarians receive. Findings indicate that libraries are seen as a source of many different kinds of health information by the communities they serve. Overall, librarians get requests most frequently for information related to illness prevention and health promotion. Specifically, patrons ask about diet and nutrition, exercise and physical fitness, and prenatal care. Requests for help in locating health providers are also common.

With respect to cancer, librarians are most often asked for information about breast cancer. Despite its prevalence in the population, librarians received the fewest requests for information about colon cancer. Among the other chronic diseases, librarians receive the most requests about health disease and diabetes and the fewest requests for information about tuberculosis. The illness prevention and health promotion area that comes to librarians’ attention least often is cancer prevention. Although librarians do receive requests for information about mental health, these requests are less frequent, occurring several times a month or less often. Few librarians report requests for mental health information weekly or daily.

Librarians’ Readiness to Be Involved in Health Outreach

Following the training, approximately two thirds of librarians surveyed (64%) reported that they felt very comfortable “discussing the ASK ME program with library patrons”; one third (31%) were somewhat comfortable, and only 5% reported feeling somewhat or very uncomfortable discussing the program with patrons. When asked about their comfort level discussing personal questions from library patrons regarding breast cancer, 41% of librarians report requests for mental health information weekly or daily.

Table 1. — Information Requests Received by Librarians From Patrons According to Frequency

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<thead>
<tr>
<th>Type of Information</th>
<th>Frequency (%)</th>
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<tr>
<td></td>
<td>Several times per day/daily</td>
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<tr>
<td>Cancer</td>
<td></td>
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<tr>
<td>Breast</td>
<td>0</td>
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<tr>
<td>Colon</td>
<td>0</td>
</tr>
<tr>
<td>Lung</td>
<td>0</td>
</tr>
<tr>
<td>Prostate</td>
<td>0</td>
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<tr>
<td>Other cancer</td>
<td>4</td>
</tr>
<tr>
<td>Other chronic disease</td>
<td></td>
</tr>
<tr>
<td>Heart disease</td>
<td>2</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>4</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>0</td>
</tr>
<tr>
<td>Other illnesses</td>
<td>15</td>
</tr>
<tr>
<td>Illness prevention and health promotion</td>
<td></td>
</tr>
<tr>
<td>Prenatal care</td>
<td>4</td>
</tr>
<tr>
<td>Exercise/fitness</td>
<td>6</td>
</tr>
<tr>
<td>Diet/nutrition</td>
<td>9</td>
</tr>
<tr>
<td>Smoking cessation</td>
<td>4</td>
</tr>
<tr>
<td>Cancer prevention</td>
<td>0</td>
</tr>
<tr>
<td>Other prevention topics</td>
<td>10</td>
</tr>
<tr>
<td>Mental health</td>
<td>4</td>
</tr>
<tr>
<td>Finding health providers</td>
<td>6</td>
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ians expressed feeling very comfortable and 43% reported feeling somewhat comfortable, while 14% were somewhat uncomfortable and 2% were very uncomfortable. Although more than half (55%) of librarians surveyed felt that the ASK ME program would not detract much from their other work, 38% expected that it would interfere “somewhat” with their other work, and 7% thought it would interfere a great deal.

When asked how important it is for their program/branch to assist people in getting access to services for early cancer detection, 31% of librarians indicated that it should be essential (the library’s highest priority), 49% reported that it should be very important (a major priority), 18% responded that it would be a good idea to do this type of campaign only if it did not interfere with current work duties, and 2% rejected conducting this type of health intervention, feeling that it was contrary to the library’s mission. Consistent with these findings, librarians reported a myriad of cancer needs in their community, including information about accessing care, information for non-English speakers, information geared toward women, seniors, students, and those of low income, and assistance with information patrons receive from their doctors.

The Capacity of Librarians to Conduct Health Outreach and Referral

Although librarians tended to answer factual “yes/no” pre-training items about breast health and breast cancer correctly, knowledge is lacking in some areas. Sixty-five percent of librarians surveyed incorrectly thought that most breast cancers occur in women with a family history of the disease. Additionally, 28% also incorrectly responded that all women with breast cancer have equal survival rates, regardless of race.

Librarians also demonstrated very mixed understanding about breast self-examination, perhaps reflecting inconsistencies in public health guidelines. Seventy percent of librarians replied that women should do breast self-examinations “once every month,” 19% responded “once every year,” and 11% responded “every week” or “every day.” Sixteen percent of librarians did not know that breast cancer can occur in men. Most librarians responded correctly to the majority of post-training questions about eligibility for free breast cancer screening through the Queens Healthy Living Partnership Program. However, a substantial percentage of respondents were ill-informed about key eligibility criteria. Specifically, 67% still did not know that the individual must live in New York State, and 46% were not aware that an individual must be over 40 years of age to quality for free screening unless there is a family history. Over a third (35%) of librarians surveyed were not aware that eligibility depended on being uninsured or unable to pay.

Many librarians wanted additional training about breast cancer or other health topics. Specifically, 51% wrote that they would like to know about useful Web sites and training on related Internet searches. Moreover, half of the librarians indicated that they would like assistance from the Queens ACS and its partnership in helping them meet the health needs of the community they serve. Ten percent of the librarians studied wanted information in languages other than English, including Creole, Russian, French, Portuguese, and Hindi, and 51% wrote that they would like the ACS and its partners provide them with on-site training.

Our results further show that health information referral resources have been underutilized by the librarians in the QBPL (Table 2). Nonetheless, consistent with the fact that public libraries are making tremendous headway in providing access to technology to their patrons,21 this

<table>
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<th>Referral Services (No. of librarian responses)</th>
<th>Frequency (%)</th>
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<tr>
<td></td>
<td>Several times per day/daily</td>
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<tr>
<td>American Cancer Society (47)</td>
<td>0</td>
</tr>
<tr>
<td>Cancer Information Services (48)</td>
<td>0</td>
</tr>
<tr>
<td>Queens Breast Health Partnership (45)</td>
<td>0</td>
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<tr>
<td>1-800-CANCER (45)</td>
<td>0</td>
</tr>
<tr>
<td>Community Information and Referral Services (46)</td>
<td>2.2</td>
</tr>
<tr>
<td>Internet Sites (43)</td>
<td>9.3</td>
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<tr>
<td>Other referral source (31)</td>
<td>3.2</td>
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study identified the Internet as the most commonly used tool among the referral services made available to patrons who request health information. Sixty-two percent of librarians indicated that they referred people to the Internet for health information at least monthly. Additionally, librarians often referred people to community information and referral services as well as the ACS. Librarians indicated that they tended to refer patrons to Cancer Information Services, the Queens Breast Health Partnership, or 1-800-Cancer several times per year or fewer.

Discussion

Librarians provide a cultural and linguistic bridge to underserved populations. In this study, we assessed the readiness and capacity of public libraries in Queens, New York, to engage in a breast cancer outreach and screening campaign, with the support of a city-wide health task force. Our findings support the idea that public libraries are potentially excellent partners in health outreach, although there are a number of challenges to engaging them in such efforts.

Results indicate that the Queens librarians are already seen as a significant resource in their communities for information about a variety of health and disease prevention topics. Health outreach to medically underserved residents has not been a primary mission of these libraries, yet many librarians surveyed saw great need in their communities. The vast majority felt that assisting residents in getting access to services for early cancer detection should be a major priority for the library. Moreover, librarians seemed motivated and willing to actively participate in health outreach, and they reported feeling comfortable working with patrons in this way. They also felt that this type of health intervention would not take too much time from their current work duties.

Although librarians appeared to be committed to fulfilling this need in their communities, many did not yet have the capacity to be effective partners in a health outreach effort. A substantial number of librarians surveyed were uninformed about breast health and breast cancer issues. For example, 28% incorrectly responded that all women with breast cancer have equal survival rates, regardless of race. Furthermore, a large proportion of librarians were unaware of the eligibility criteria for free breast cancer screening through the Queens Healthy Living Partnership Program (even after a training session that covered this topic). Librarians also did not make full use of the referral sources available to them. For this reason, a multi-institutional health promotion partnership must constantly be aware of challenges that partners face in implementing health outreach campaigns. While the Internet, which was a frequent referral source used by librarians, can be an excellent tool to overcome lack of resources to provide health information, there are limitations to using the Internet for health referral purposes. Birru and colleagues22 found that Web health information requires a reading level that greatly limits optimal access by low-literacy adults.

Many of the librarians clearly recognized their need to be better informed, and a number of those surveyed indicated that they wanted additional training about breast cancer or other health topics; quite a few indicated that they would like more assistance meeting the needs of the communities they serve. Studies involving primary care physicians and community members have also demonstrated gaps in knowledge regarding breast cancer risk factors and cancer screening guidelines, which suggest a greater need for consensus for cancer screening guidelines and education.25-27 Through involvement in such a multi-institutional partnership, such as the Task Force, libraries can receive up-to-date, accurate health and disease information, as well as information on public health programs specifically designed for at risk or medically underserved populations that the library serves and information about how to use referral resources effectively. A partnership can further fulfill librarians' requests and needs for more seminars and community workshops conducted by health professionals who are trained in cultural and ethnical issues of the particular community. A diverse health partnership can also provide public libraries with the resources, skills, and support they need to conduct important health outreach efforts, including referral to breast and cervical cancer screening, vaccinations, and clinical trials. This is consistent with the guidelines of the American Library Association, which indicate that libraries should meet the need for information services by the community.28

Despite the tremendous potential of working with libraries as a way to address cancer and other health disparities, this partnership work is not without its challenges. We found that some high-level library management initially viewed research institutions with considerable wariness. In particular, they were concerned that academic research in the libraries, even in the context of health outreach, might breach librarians' strong code of ethics, which dictates that librarians must ensure patrons' right to privacy and confidentiality with respect to information requested or provided.29 Overcoming this resistance due to concerns of intellectual freedoms, as well as the bureaucratic mechanisms in place that prevent access to the branch libraries, was not easy. Identification of key people with decision-making authority and clear communication about the benefits and risks of engaging in a health outreach partnership helped to overcome these initial barriers. Additionally, giving librarians timely feedback about the results of the libraries' readiness and capacity to implement a public breast cancer educational and recruitment campaign served to build trust and demonstrated the value of libraries' involvement in this effort. Key to working with the library branches was identifying “cheerleaders” or personnel within each library branch who would
be knowledgeable about the campaign, responsible for campaign materials needs, and tailor the intervention as needed for the local community. Adapting the campaign for the multitude of diverse communities in Queens was essential for its success.30

Conclusions

We learned a significant amount through this experience, yet there is much more work to be done. Future research in libraries could benefit from data collection techniques that do not depend on librarian recall (eg, asking librarians to maintain logs of patron requests as they occur). Moreover, we must investigate further what is needed to build capacity in libraries outside of Queens, New York, to partner in health outreach campaigns and create new initiatives to improve access to care and reduce health disparities in underserved populations. We also need to learn more about what is necessary to build and sustain effective partnerships with library systems.

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