PROMOTING IMPROVED ACCESS TO CONSUMER HEALTH INFORMATION



by Josephine Kaiser

"Do you have any information on lupus?"

"What are the side effects of Prozac?"

"I want to find an berbal remedy for artbritis."

Questions such as these are asked each day across the country at public library reference desks. The boom of interest in consumer health, fueled by changes in society and the medical system itself, has strained the infrastructure for dissemination of such information, including at the local public library. In response to this problem, medical libraries, led by the National Library of Medicine (NLM), have explored methods of partnering with public libraries to provide improved consumer health information for their clientele. Cooperation between medical and public libraries has proven to be quite effective.

THE CONSUMER HEALTH PHENOMENON

The explosion of interest in consumer health information has been widely reported in the professional literature. Librarians have reported that 6% to 20% of public library reference questions are health and wellness related (Wessel, Wozar & Epstein, 2003). These data indicate that not only are consumers actively seeking health information, but that public libraries are part of the "first line of defense" for patrons seeking reliable information (2003, p. 356). NLM reports that the number of MEDLINE database searches have increased from seven million to 220 million annually since the Web-based, free-of-charge PubMed search system was brought online in the late 1990s. An estimated one-third of those searches are conducted by the public, rather than professionals (Wood, Lyon, & Schell, 2000). The Internet is also heavily utilized by those seeking health information. Of the more than 60 million American adults who use the Internet on a monthly basis, 40% will look for information on health (Scherrer, 2000).

The reasons behind the growing demand for consumer health information are numerous, including the vast increase in the generation of new biomedical knowledge, and parallel improvements in communications and Internet access (Gillaspy, 2000). Other

contributing factors include increased media coverage of health-related issues and an increased emphasis on fitness, wellness, and healthy lifestyles. In addition, changing social attitudes, the financially-focused nature of managed care, and subsequent evolving attitudes of health care professionals and patients themselves have contributed to the vast demand for access to health-related information. For example, population mobility means that individuals and families are often not cared for in their homes by a single doctor over a lifetime. In addition, people without health insurance may seek health information on whether their symptoms really warrant the expense of a doctor's visit.

Over the past several decades, dramatic changes in the fundamental roles of patients and health professionals have occurred. In the past, patients did not view themselves as partners in their own healthcare. Patients took a passive role, looking to their doctors to make decisions and provide all of the answers. Currently, however, the opposite is true: a 2000 survey (Spang and Baker) showed that only 36% of adults considered their physicians to be a primary source of medical information. Patients are no longer simply 'patients' but 'consumers' of health information who are empowered to direct their own medical care.

THE CHALLENGE TO LIBRARIES

The academic health sciences, hospital, and public library communities face obstacles in providing quality consumer health information. Academic medical and hospital libraries have seen a tremendous increase in non-primary clientele requests for health information services, resources, and assistance that they are not equipped to address. At the same time, the public library is widely recognized as one of the best places to meet consumer health needs, but one must keep in mind that because the public library is called upon to meet a broad spectrum of user needs, it must not emphasize health-related services and resources disproportionably to other valued services. Other barriers to effective consumer health services include lack of funds and understaffing issues. This may translate into poor, outdated print health collections and

few or no subscriptions to consumer health databases and resources. Not owning useful health materials has been mentioned by public librarians as one of the main hindrances they face in answering patron queries (Spang and Baker, 2000). Other often cited obstacles include unfamiliarity with medical terminology, fear of providing misleading or incorrect information, a desire not to invade the patron's privacy with follow-up questions, lack of knowledge about health sources, and being too pressed for time to adequately answer indepth questions (Spang and Baker, 2000; Wessel, Wozar, and Epstein, 2003).

The health sciences library community and public libraries are increasingly exploring ways to address these issues and meet consumer health information needs. To this end, various partnership models have been formed between medical and public libraries and librarians, with the NLM and its National Network of Libraries of Medicine (NN/LM) funding dozens of grant projects whereby medical and public libraries partner with one another.

CONSUMER HEALTH INFORMATION PARTNERSHIPS

One of the most popular partnership models is the train-the-trainer model with training primarily focused on locating reliable and authoritative consumer health information, usually in electronic format. This is, of course, needed by the public librarians by their own admission; however, public librarians also need to learn how to handle the medical reference interview, to legally and appropriately deal with the ethics and privacy issues of a health-related interview. It is no wonder that public librarians may feel inadequate without training: often the public library patron's need for medical information arises from a symptom or diagnosis concerning themselves or a loved one (Allcock, 2000). A medical librarian's experience in handling such interviews on a daily basis would assist public librarians substantially.

Another popular health sciences-public library partnership model incorporates the creation of a consumer health website to serve as a local, regional, or national portal to quality information. There is such a proliferation of health sites on the web that authoritative, condition or disease-specific portals are increasingly necessary. Many partnerships have addressed this issue in combination with training-the-trainer models, effectively creating a product and then training public librarians to use that portal as well as other health information resources.

Some projects, such as HealthWeb, are actually joint projects between many academic health sciences libraries. HealthWeb, which provides organized access to evaluated non-commercial, health-related, Internet-

accessible resources, was originally designed exclusively for health professionals, but subsequently expanded to encompass consumer health topics. According to Sherrer (2000, p. 50), "Public libraries often do not have the resources to purchase expensive medical texts, but the sharing of Internet resources such as HealthWeb offers a valuable alternative."

The creation of and training on these consumer health portals is often in response to needs assessments. Public librarians have expressed a need to be trained in consumer health information and issues. When the partnership between Texas Woman's University and the Dallas Public Library began, for example, the vast majority of public librarians were inexperienced users of electronic health sources (Huber & Snyder, 2002). Correspondingly, when the Health Sciences Library System (HSLS) of the University of Pittsburgh began training public librarians in its region, only 12% of the librarians surveyed had ever used MedlinePlus, the premier consumer health information portal from the National Library of Medicine (Wessel, et al., 2003). After the training, however, 94% of librarians reported that they consulted MedlinePlus in a reference interview. In addition, 89% also used the consumer health site created by the HSLS team, and on which the librarians were also trained (2003).

CONCLUSION

Medical-public library partnerships and an increased emphasis on the production, dissemination, and evaluation of high quality consumer health information have positively impacted public librarians' abilities to serve their clientele; however, libraries are continually challenged to meet the increasingly complex and sophisticated information demands of modern health consumers. Ongoing issues such as health literacy, the medical reference interview, information-seeking and usage behaviors, and related topics need continual attention. Future projects and studies will provide valuable information and insights that will help us achieve our goals of meeting consumers' health information needs.

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