Providing consumer health information through institutional collaboration*

By Anne Wood Humphries, M.L.S. Assistant Director for Information Services

Julia K. Kochi, M.I.L.S. Educational Services Coordinator

Claude Moore Health Sciences Library Box 234 University of Virginia Health Sciences Center Charlottesville, Virginia 22908

In the past several years, The Claude Moore Health Sciences Library of the University of Virginia Health Sciences Center (HSC) has noted a growing demand for consumer health information. However, because the primary role of the library is to provide information services to health professionals at the HSC, questions have been raised as to the amount of time, energy, and money that should be expended to provide health care information to consumers. The library staff, because it can provide special expertise regarding the availability and utilization of consumer health materials, has felt the responsibility to participate in HSC initiatives that reach a broad audience. Library efforts in that regard include assisting with inventory and management of patient education materials, participating in a community health promotion task force, collaborating with hospital departments in planning a consumer health information center, establishing a consumer health information reference section in the library, and obtaining a grant to offer a networked health information system to local public and community college libraries. Consumers of health information benefit from the enhanced services that result from combining the expertise of health professionals and patient educators with the information management skills of library staff.

INTRODUCTION

The Claude Moore Health Sciences Library has noted a growing demand for consumer health information from patrons frequenting the library. Because the library's first priority is to provide information services to the health professionals of the University of Virginia Health Sciences Center (HSC), several questions have been raised regarding the amount of time, energy, and money the library should expend providing consumer health care information. Eakin suggested that academic, public, and hospital libraries all have expertise to confiribute, such as knowledge of resources, experience with the diversity of public needs,

and familiarity with health professionals, and that as partners these libraries can become effective information providers and in turn can gain recognition [1]. Rees suggested that the increased consumer demand for information challenges librarians to take a leadership role in opening new channels of communication between physicians and patients, and he advocated a "close and supportive relationship" between librarians and patient educators [2]. Gilpin argued that for patient education to be truly effective, an educational environment must "pervade all aspects of a patient's hospital stay" and not be limited to a single resource or opportunity [3]. In any case, current economic conditions demand that the HSC examine who has primary responsibility for patient education materials, how budget resources can be shared for this type of material, and what projects can be jointly sponsored by several departments to

^{*} An expanded version of a paper presented October 15, 1992, at the Annual Meeting of the Mid-Atlantic Chapter of the Medical Library Association, Towson, Maryland.

provide much-needed consumer health information to patients, families, and the community.

Because the library's collections are oriented toward health professionals, patients and their families often are directed to medical textbooks and general articles from the journal literature, which seldom provide the needed information in lay language. Medical Center departments are in the early stages of organizing patient education materials, but there is no consumer health information center. Both the library and the Division of Patient and Family Services are aware of the lack of this type of material and have worked together on several projects, including

- establishing a consumer health information section in the library's reference collection to improve access to selected print manuals and guides for the lay public;
- assisting the Division of Nursing in conducting an inventory and developing a system for managing patient education materials already used within the Medical Center;
- participating on the Community Health Promotion Task Force, which is looking at broader issues of HSC involvement in community health, one aspect of which is health information;
- collaborating with hospital departments in planning a consumer health information center within the hospital; and
- obtaining grant support for a networked consumer health information system at three local public and community college libraries.

CONSUMER HEALTH REFERENCE MATERIALS

The reference materials in the library have been collected primarily to serve the needs of HSC faculty, students, and staff. Materials are arranged by subject, such as dictionaries, statistics, pharmacology, education, and directories of organizations. In consulting the reference staff and reviewing lists of materials used most often to answer patients' questions, library staff discovered that these materials were scattered among other resources designed for health professionals. Motivated by other consumer health information initiatives, the library established a separate reference section devoted to consumer health materials, bringing together important sources in an area where patients and families could browse.

The library's collection development policy has not changed, in that consumer health materials remain a modest collection of authoritative sources that can be used by both health professionals and the lay public. Every effort is made to avoid duplication of services or materials already provided by the hospital patient education department or individual hospital units. Although library funding for consumer health ma-

terials has not been increased, the pending establishment of a consumer health center in the hospital is an encouraging sign that a more extensive collection of consumer health materials may soon be available.

PATIENT EDUCATION MATERIAL INVENTORY

A library staff member who was appointed as liaison to the School of Nursing was asked to participate in a task force to inventory existing patient education materials, both in the patient education department and on the various hospital floors. The goal of the task force is to create a database for patient education that could be accessed by health professionals throughout the Medical Center, who now must rely on whatever materials happen to be on hand on a particular floor. As part of the project, nurse coordinators would be assigned to each floor to provide inventories, establish lists of materials, oversee maintenance of the unit's stock supply of resources, serve as the contact person and specialist for the unit's collections, coordinate completion of standard citation and evaluation forms, and coordinate dissemination of information and training for other unit staff on use of the database.

The library was considered a valuable partner on this task force because of its experience in information management and database development. Acting as consultant, the library liaison brought up a number of concerns such as quality control, data entry, scanning technology, and choice of online systems, thereby helping to enlighten task force members as to the issues involved in establishing an online database.

As with any initiative that involves a number of different partners, a great deal of time is required to establish such a database. It is still under development, pending agreement on the responsibilities of the coordinators involved and the selection of an appropriate database management system that can be integrated into the computer workstations on the hospital floors.

COMMUNITY HEALTH PROMOTION

The library also participated in the Consumer Health Promotion Task Force assembled by the vice president and provost for health sciences. The goal was to identify the most effective ways in which the HSC could work with community organizations and individuals to improve the health of local citizens. The task force included representatives from area businesses, public schools, the community hospital, the health district, the planning commission, the housing authority, the University of Virginia (UVa), the UVa schools of nursing and medicine, and UVa hospitals. The library provided advice on information collec-

tion and dissemination, while the other members of the task force contributed their own expertise on the needs of community members for information about disease treatment and prevention.

The task force produced a major report profiling leading diseases of area residents, outlining existing health promotion activities, and identifying residents' perceptions of barriers to living healthy lives. The task force made specific recommendations for action to the vice president for improving health promotion, including information-related efforts such as supporting research initiatives and developing a central, accessible resource for health promotion information.

PATIENT EDUCATION CENTER

Eisenstein and Faust described the establishment of a consumer health information center in a hospital setting and underscored the point that, although financial support is welcome, the administration's philosophical support for the idea of public access to health information is the most critical factor determining success [4]. The HSC had both; the need for a patient education center had been recognized for a long time, and the project recently got off the ground thanks to a generous donation from the Hospital Auxiliary to purchase the materials.

A committee was established to plan for a center, which would be located strategically in the hospital between inpatient and outpatient services. The committee included representatives from patient education, a library staff member, a product development manager from the marketing department, and the director of the public library. This balanced membership helped to assure that various interests were well represented in the proposal for the center.

The librarians on the committee suggested that, to assure development of a valuable, well-organized, public-service oriented resource, a professional librarian should be hired to oversee the center. The benefits of this approach had to be balanced against the costs of hiring a professional versus relying on volunteer staff, and the public relations implications had to be assessed. Many hospitals have recognized that health education centers are not only an important public service but also valuable marketing tools that give the hospital a positive image in the community [5]. Committee members agreed that a librarian position was desirable and that the Health Sciences Library would be in the best position to hire and supervise the librarian.

Administrative issues also needed to be resolved between the library, which would be hiring and supervising the librarian, and the hospital, which would be providing funding and promoting the center. Concerns were expressed regarding the division of responsibilities between the librarian and the patient education staff. A team arrangement was developed in which the library would provide information management services to the hospital on a contract basis, and the center administrator would take on the management and development of the center's services. Job descriptions outlining the duties and qualifications for the librarian and the center administrator were developed. The librarian's responsibilities would include establishing a collection development policy; selecting a classification system; supervising technical processing of materials; establishing a training plan for the staff; and supervising research services, online searching, and development of information packets. The center administrator's duties would include planning the physical site; supervising volunteer staff; promoting services; coordinating hospital patient education activities with center activities; and managing fund-raising efforts. Collaborative duties would include developing policies and procedures, managing delivery of services, determining levels of service, and developing evaluation tools and statistical reports.

Rees' book on managing consumer health information services provided useful background on how other centers have established collections and policies [6]. A UVa consumer health information coordinator visited other centers and obtained sample policies and job descriptions from facilities such as Planetree, a model hospital unit that places special emphasis on the education and involvement of patients in the health care process [7]. The public library director provided valuable insights regarding issues that HSC librarians seldom face, such as factors to consider in dealing with the general public, library use patterns of the public, collection development specifically for the consumer, and management of a volunteer staff. Overall policies regarding hours of operation, types of services to be offered, and physical layout are being developed by the patient education coordinators and the hospital in collaboration with the library. It is expected to take approximately one year from the beginning of the project to open the center, pending official approval of the staff positions and development of the center collection.

HEALTH INFORMATION SYSTEM PILOT PROJECT

Because of the lack of appropriate tools to answer patients' questions, the library staff decided to investigate consumer health information products available on the market. The Health Reference Center (HRC) was chosen over other systems because of its ease of use, comprehensive coverage of consumer health literature, and capability to provide immediate full-text versions of many of the documents. The HRC

is a database that includes articles from health journals and newsletters, summaries written in lay language of articles in major professional journals, definitions of medical terms, and pamphlets published by national medical organizations, among other sources. In reviewing the system, Kaya and Yang pointed out that certain audiences find *Index Medicus* too technical and *Readers' Guide* not technical enough, while the HRC provides a nice balance between the professional and the lay perspectives [8].

Once the subscription to HRC was purchased, promotion and support issues needed to be addressed. Various locations were considered for the HRC. Bandy has discussed advantages and disadvantages of placing consumer health information sources in various places [9]. Outpatient and clinical areas were considered because of their accessibility to public users, but they were rejected due to the limited availability of staff to assist users and monitor the workstation. The workstation finally was placed near the reference desk in the Health Sciences Library, so patrons could request assistance easily. Promotional materials were distributed to nurses, patient representatives, social workers, the hospital information desk, and other key contacts. A press release distributed by the HSC news office was picked up by the local newspaper.

Choosing additional test sites

Because of a reduction in the HRC subscription cost, the library had the opportunity to obtain a second workstation for the remainder of the subscription year. The staff decided to expand the pilot project to additional sites, to test the need for such a resource at various locations.

The main branch of the public library (the Jefferson-Madison Regional Library) was chosen as one location because of various referrals received from their staff. Kluge Children's Rehabilitation Center (KCRC) also was chosen as a site on the recommendation of an HSC staff member who also was a family member of a KCRC patient. KCRC provided the opportunity to place a workstation at a remote location (about two miles from the Health Sciences Library) and to evaluate usage when no staff assistance was provided.

Pilot test evaluation

During the pilot project with the HRC at the three sites, a voluntary questionnaire was distributed to users to determine the usefulness of the system and whether a collaborative arrangement might be warranted. A total of seventy-four questionnaires were returned from the three sites. Health professionals constituted the largest percentage of respondents (38%), most likely reflecting the fact that the Health

Sciences Library had the system for the longest period of time. Other groups using the system were medical and nursing students (24%), patients (7%), friends or relatives of patients (13%), and others (18%). ("Others" included HSC employees, a writer, a school counselor, an instructional technology specialist, a publications editor, a paralegal, a social worker, and a health care consultant.)

Users searched a wide variety of topics ranging from manic depression to Christian Science to pediatric AIDS. Of the seventy-four respondents, seventy-one (96%) found the system easy to use, and all seventy-four (100%) found the instructions helpful. Users at KCRC who had no staff assistance had no more difficulty using the system than did users at the other sites.

Grant proposal

As a result of the positive responses from both users and administrators at the test sites, the library applied for a state Library Services and Construction Act (LSCA) grant to establish a networked version of HRC. The proposal called for the systems to be accessible at the Health Sciences Library, Piedmont Virginia Community College, Orange County Public Library, and the Jefferson-Madison Regional Library. Funding to cover equipment, software, and communications costs was sought. The proposal was approved, and the library will be implementing a networked version of HRC within a year.

Richetelle described the establishment of Healthnet, a cooperative network for consumer health information developed in Connecticut [10]. Healthnet emphasizes the use of medical libraries' expertise to support public libraries, through training programs in medical reference techniques, advice for upgrading health reference collections in public libraries, and back-up services for more technical information needs. The HRC network established through grant funding is envisioned as a starting point for such collaborative activities in the state of Virginia to provide consumer health information.

CONCLUSION

The demand for consumer health information in an academic health sciences center raises questions concerning the amount of staff time and budget resources that should be expended for this purpose and forces an examination of the library's role in relation to other departments that also have a mission to provide this type of information. Through shared funding and collaborative projects, all parties can reap benefits. Advantages for the library include valuable contacts and networks developed through the HSC, increased knowledge of patient education and public

Humphries and Kochi

information needs, and improved visibility and recognition of professional skills in information management. Patient educators and health professionals benefit from the increased information resources that allow them to enrich patient services, improve communication, and enhance health care services. Finally, consumers benefit when the combined expertise of health professionals, patient educators, and librarians allows them to make improved health care decisions.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the assistance of Linda Watson and Jonathan Lord in the implementation of this project, and the financial support for the subscription to the HRC from Michael Halseth, executive director of the Medical Center, and Beverly Butler, director of the Division of Patient and Family Services. The authors also appreciate the collaborative efforts of Leigh Mason and Cornelia Ramsey of the Department of Consumer Health Information Services.

REFERENCES

 EAKIN D, JACKSON SL, HANNIGAN GG. Consumer health information: libraries as partners. Bull Med Libr Assoc 1980 Apr;68(2):220-9.

- 2. REES AM. Communication in the physician-patient relationship. Bull Med Libr Assoc 1993 Jan;81(1):1-10.
- 3. GILPIN L. Creating an educational environment in a hospital setting. In: Giloth B, ed. Managing hospital-based patient education. Chicago: American Hospital Association, 1993:55–75.
- 4. EISENSTEIN EF, FAUST JB. The consumer health information library in the hospital setting. Med Ref Serv Q 1986 fall;5(3):63-74.
- 5. DROSTE T. Education centers are subtle marketing tools. Hospitals 1989 Sep 20;63(18):76.
- 6. REES AM, ED. Managing consumer health information services. Phoenix, AZ: Oryx Press, 1991.
- 7. ORR R. A new design for modern healthcare: the Planetree project. World Hosp 1987 Oct;23(3/4):38-40.
- 8. KAYA KK, YANG AM. Consumer health information from Information Access Company. Database 1991 Feb;14(1):54-6.
- 9. BANDY M. Saint Joseph Hospital Health Reach Library. In: Rees AM, ed. Managing consumer health information services. Phoenix, AZ: Oryx Press, 1991:150-65.
- 10. RICHETELLE AL. Healthnet: Connecticut Consumer Health Information Network. Conn Med 1990 Nov;54(11): 632-4.

Received October 1992; accepted July 1993