
The impact of consumer health information provided by libraries: the Delaware experience*†

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In the past two decades, consumer health libraries have proliferated in response to the changing health care environment and consumer demand. While this growth of consumer health resources and services has been extensively described in the literature, there is little documentation about the impact and value of providing consumer health information. This paper explores the issues of impact and value as examined in a retrospective study of consumers who received health information from the Delaware Academy of Medicine's Consumer Health Library during 1995. In this study, 270 adults were mailed a questionnaire that focused on whether the information influenced decisions, actions, anxiety levels, and patient-provider communication. The questionnaire also addressed the value of such library service in terms of likelihood of repeat use, recommendation to others, and willingness to pay. The results, based on a return rate of 86.7%, identified effects of library-supplied consumer health information that extend beyond the anticipated acquisition of knowledge to specific actions and effects on anxiety. The value of consumer health library information service was shown by the extremely high percentage of probable repeat use and recommendation to others, the willingness of 83.8% of the respondents to pay for such service, and the copious comments volunteered by the respondents.

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INTRODUCTION

The phenomenon of consumer health libraries began more than twenty years ago in conjunction with the broader consumer rights movement. In the late 1970s,

the provision of consumer health information was often a cooperative venture between public and health sciences libraries. Such ventures were fostered by Library Services and Construction Act funding and resulted in the establishment of formalized, structured consumer health information programs in cities across the United States, including the Consumer Health Information Program and Services/Salud y Bienestar (CHIPS) in Los Angeles, California; the Community Health Information Network (CHIN) in Cambridge, Massachusetts; the InfoHealth Project in Cleveland, Ohio; Health Information Service in Tulsa, Oklahoma; and the joint effort of the New York Onondaga County Public Library and Consumer Health Information Consortium (CHIC) in Syracuse, New York [1].

As early as 1979, the quality of consumer health libraries was examined. Physicians were enlisted to rate the information provided by the librarians of the Onondaga County Public Library with regard to currency, detail, and accuracy and to determine whether the librarian exceeded professional limits. The results indicated ". . . that public librarians are quite successful as providers of health-related information. They do not overstep the boundary between information-giving and providing advice; the information they provide is generally considered by physicians to be current; and they are able to respond to a wide variety of highly technical medical questions without endangering the health of anyone" [2].

The provision of consumer health information by libraries escalated as a result of changes in the health care marketplace and the increased emphasis on health prevention and promotion. In 1992, face-to-face contact with a physician during office visits averaged 17.6 minutes with two-thirds of visits involving contact of 15 minutes or less [3]. Problems in physician-patient communication related to comprehension, memory, and the reluctance of patients to ask questions [4] are likely to be compounded by such time constraints. It comes as no surprise, then, that a recent survey of 600 *Consumer Reports* readers about their involvement in their medical care found that 48% of the respondents conducted their own research about a medical condition [5].

LITERATURE REVIEW

The growth in consumer health resources, services, and programs has been well documented in the literature, but it has been noted that there is a "paucity of information available about the positive impacts of making library collections available to patients and their families" [6]. A search of library, nursing, and medical literature revealed six articles relevant to the impact of consumer health information: a user survey of a commercial health information service, two surveys of patient libraries in office settings in England,

an evaluation of clinical librarian services to patients and their families, and both a needs assessment and a case study of a Canadian consumer health information service.

Marcus and Tuchfeld report the results of a survey of 1,083 individual users of a fee-based independent health information service [7]. Based on a 64% ($n = 688$) response rate, 80% of the respondents found the information useful; 90% found it relevant; 91% found the staff helpful; and 83% indicated that they would recommend the service to others. The authors also analyzed the nature of the requests for information sought by the women (54%) and men (46%) who responded.

An analysis of books borrowed from a library in a suburban health practice found that the highest use was by women under the age of forty. Questionnaires returned from those who borrowed books indicated that 88% gained some knowledge about the subject of the chosen book, 85% found the book useful, and very few found the book upsetting. The library was found to be "used by patients of every age and educational and social background, and even by people who admit they seldom read books" [8]. Similarly, Collings et al. assessed the perceived value of information from a patients' library connected with an office practice and its effect on anxiety levels [9]. Two hundred forty-three books were borrowed in a fifteen-month period. One hundred sixty-three questionnaires included with these books were returned, for a response rate of 67%. The responses indicated that 98% found the information useful. Anxiety was reported to be reduced by 44% of the respondents and increased by only 6%. In addition to the nearly unanimous response regarding usefulness, a convenience factor was noted in that 65% of the respondents indicated that they would not have sought the information elsewhere.

Marshall has conducted several studies in the area of consumer health information services. The earliest was in conjunction with an evaluation of clinical librarians. In addition to providing services to the health care team, clinical librarians fielded requests from patients and their families. Patient information packets were reviewed by health professionals and were found to be appropriate, understandable, and accurate. Difficulties were encountered in obtaining evaluations from the patients and their families, as short hospital stays and office visits do not permit follow-up. Those evaluations that were returned indicated that the information was useful, new, and shared with others [10].

The Consumer Health Information Service (CHIS), located in Ontario, Canada, was established in 1991 with government funding as a cooperative venture undertaken by information professionals, health professionals, and a consumer organization. A survey of 143 people from the Consumer Volunteer Network assisted

in establishing the need for the service and explored the information-seeking behaviors of health care consumers. The respondents indicated that they used a variety of sources for health information: health professionals, news media, voluntary health organizations, public libraries, community information centers, and books, pamphlets, and newsletters. The information they received was used in the following ways: for self-care (87%); to increase knowledge (81%); to improve health or lifestyle (75%); to understand drugs or treatments (67%); to care for someone else (58%); to cope with a health problem (57%); to raise questions with a doctor (51%); and to assist in making decisions about treatment (43%) [11].

Subsequently, users were asked to respond to a questionnaire to evaluate the quality of the information provided by CHIS. It was found that women between the ages of thirty and forty were the most frequent users. Case studies were collected from those who indicated on the questionnaire that a decision about their health had been made by using the information provided. Evidence from more than 300 case studies suggests that consumer health information influences decisions, improves patient-provider communication, and empowers the consumer [12].

PURPOSE

The purpose of the study was to examine the use of information supplied by a consumer health library and attempt to determine whether this information had any impact on consumers' knowledge, actions, or feelings regarding personal health concerns. The study also assessed the value of the information supplied as reflected in consumers' willingness to use a consumer health library again, to recommend a consumer health library to others, or to pay for service. The study was a collaborative undertaking of librarians at the Delaware Academy of Medicine and the University of Illinois at Chicago (UIC). The decision to conduct a consumer health impact study was influenced by the limited literature found in this area and by the King and Rochester studies, which demonstrated the effects of library-supplied information on the clinical decision-making of health professionals [13, 14]. Users of the Delaware Academy of Medicine's Consumer Health Library who had received information by mail were chosen for a retrospective survey focusing on the impact and value of consumer health information. Ethical approval for the study was obtained from the University of Illinois at Chicago through the College of Medicine at Rockford.

STUDY SITE

The Delaware Academy of Medicine, located in Wilmington, Delaware, is an association of physicians and

dentists. Due to the absence of a medical school in the state of Delaware, the academy serves as a statewide resource for health professionals and consumers. The commitment to lay health education can be found in its original certificate of incorporation from 1930 and is largely realized through its library, which was established in 1933. The public has always been welcome to use the clinical and research materials of the library. Furthermore, the library has administered Delaware's TEL-MED system since 1981. This system of recorded health messages currently receives 14,000 telephone calls a month. In 1992, the academy established its Consumer Health Library, which currently serves more than 100 people a month. The addition of the Consumer Health Library supplements the clinical and research collection and TEL-MED by providing 700 consumer-oriented books, 20 consumer-oriented journals, a referral and clipping file of 300 topics, and access to Infotrac's Health Reference Center. Information from the Consumer Health Library can be requested by telephone (there is a toll-free number for the two downstate counties), mail, and telefacsimile. Referrals are made by public librarians who have received training from the academy staff on conducting medical reference interviews. The Consumer Health Library is promoted through flyers in English and Spanish, exhibits at health fairs, presentations to organizations, articles in local newspapers and magazines, a TEL-MED tape about the Consumer Health Library, and messages at the end of 330 of the 459 other TEL-MED tapes.

The typical response to an off-site request is for the staff to perform manual or computer searches to identify relevant sources of information, one or two of which are then photocopied and mailed to the requester at no cost. A disclaimer reminds recipients that they have received the information from a library and should consult a health care provider for interpretation or clarification. Requesters needing more extensive searching and additional photocopies are offered these services for a nominal fee.

METHOD

The population selected for the study included people who had been mailed information from the Consumer Health Library during 1995. This group would have had sufficient time to have read and made actual use of the information. These off-site users had a clear preference for telephone contact with 86.5% ($n = 545$) making their requests by this method; 10.8% percent ($n = 68$) were referred by public libraries via fax; 2.7% ($n = 17$) sent their requests by mail. Visitors to the Consumer Health Library were excluded from the study because no addresses for visitors are kept.

As a courtesy and for screening purposes, a preliminary mailing was done. It contained a letter explaining the study, a "Willingness to Participate Form," a Consumer Health Library brochure, and a stamped, self-addressed envelope for the return of the participation form to the Delaware Academy of Medicine. The participation form clearly indicated the voluntary and confidential nature of the survey and the exclusion of minors and anyone who had used the information for reasons other than personal health concerns. The names and addresses for the individuals indicated that they were predominantly females in New Castle County, where the Delaware Academy of Medicine is located. Six percent were from outside Delaware, particularly neighboring Pennsylvania and Maryland. Thirteen envelopes from this mailing were returned as undeliverable. Two hundred seventy participation forms were returned.

A brief, narrowly focused questionnaire was designed to elicit responses regarding the impact of information on the health care consumer and the perceived value of that information. One question offered eleven possibilities of what might have occurred as a result of reading the information provided with respect to knowledge, decisions, actions, anxiety levels, and communication between patient and health care provider. Respondents were asked to check as many as applied, and space was provided for writing in other possible effects. A second question asked specifically whether the information was brought to a health care provider. Three questions addressed the perceived value of the information in terms of likelihood of repeat use, recommendation to others, and willingness to pay. Demographic information was collected to identify characteristics of the responding population (see Appendix).

In February 1996, the questionnaire, accompanied by a cover letter, was sent to the 270 adult volunteers. A stamped, self-addressed envelope was included for the return of the questionnaire to the UIC authors. A healthy return rate made a follow-up mailing unnecessary. The last questionnaires were received in April 1996.

RESULTS

Of the 270 people who agreed to participate, 239 returned the questionnaires. Of the returned questionnaires, 234 were deemed usable, resulting in an overall response rate of 86.7%. Consistent with the gender distribution of the total group and in the group willing to participate, more than three-fourths of the respondents were women (77.8%, $n = 182$). Those aged forty and over accounted for 70.9% ($n = 166$) of the responses. The breakdown by age groups was

- eighteen to twenty-four (4.7%, $n = 11$),

Table 1
Demographic characteristics of respondents ($n = 234$)

| | | | |
|----------------------|-------------------|-----|-------|
| Gender | Female | 182 | 77.8% |
| | Male | 51 | 21.8% |
| | No response | 1 | .4% |
| Age | 18-24 | 11 | 4.7% |
| | 25-39 | 56 | 23.9% |
| | 40-54 | 75 | 32.1% |
| | 55-69 | 64 | 27.4% |
| | 70 and over | 27 | 11.5% |
| | No response | 1 | .4% |
| Education | High school | 47 | 20.1% |
| | Some college | 72 | 30.8% |
| | College graduate | 110 | 47.0% |
| | Other/No response | 5 | 2.1% |
| Racial/Ethnic | African American | 14 | 6.0% |
| | Asian | 3 | 1.3% |
| | Caucasian | 206 | 88.0% |
| | Hispanic | 5 | 2.1% |
| | Other/No response | 6 | 2.6% |

- twenty-five to thirty-nine (23.9%, $n = 56$),
- forty to fifty-four (32.1%, $n = 75$),
- fifty-five to sixty-nine (27.4%, $n = 64$), and
- seventy and over (11.5%, $n = 27$).

One respondent failed to indicate gender and age. Most of the respondents either were college graduates (47.0%, $n = 110$) or had some college education (30.8%, $n = 72$). Eighty-eight percent of the respondents were Caucasian ($n = 206$) and 6% were African American ($n = 14$).

Respondents were asked to indicate in what ways they used the information after reading it by checking as many of the options as were appropriate and by writing in options not anticipated. Almost all indicated that the information had increased their knowledge about an illness or health concern (94.0%, $n = 220$) and nearly half (46.6%, $n = 109$) better understood information received from a health care provider. As a result of reading the information, 52.1% ($n = 122$) indicated that their anxiety about an illness or health concern was reduced, 51.3% ($n = 120$) had asked questions of a health care provider, and for 35.5% ($n = 83$) a decision about treatment options was influenced. Responses in other categories were: 20.1% ($n = 47$) made a lifestyle change, 17.5% ($n = 41$) followed instructions given by a health provider, 17.5% ($n = 41$) sought a second opinion, 12.0% ($n = 28$) made an appointment with a health care provider, and 9.8% ($n = 23$) indicated that their anxiety was increased. Ten respondents wrote in other consequences of reading the information. Of these, six may be characterized as sharing the information with others, and two indicated that it led to further research. Only three respondents (1.3%) indicated that the information had no effect at all. A separate question asked whether the information was brought to a health care provider and 41.4% ($n = 97$) responded yes.

Table 2
Effect of information

| | | | |
|------------------|--|-----|-------|
| Knowledge | Learned more | 220 | 94.0% |
| | Better understood information from health provider | 109 | 46.6% |
| Actions | Questions were asked | 120 | 51.3% |
| | Brought information to health provider | 97 | 41.4% |
| | Decision about treatment | 83 | 35.5% |
| | Change in lifestyle | 47 | 20.1% |
| | Compliance with instructions | 41 | 17.5% |
| | Second opinion sought | 41 | 17.5% |
| Feelings | An appointment was made | 28 | 12.0% |
| | Anxiety reduced | 122 | 52.1% |
| | Anxiety increased | 23 | 9.8% |

Satisfaction with the service may be assumed in that all but one respondent indicated a willingness to use it again and to recommend the service to others. An attempt to assign a monetary value to the service was made by asking participants how much they would be willing to pay for such information, and 83.8% ($n = 196$) were willing to pay something. The most frequent response for this question was one to five dollars (53.0%, $n = 124$); 19.2% ($n = 45$) selected the five-to-ten-dollar range; 8.1% ($n = 19$) chose ten to twenty dollars; and for 3.4% ($n = 8$) more than twenty dollars was acceptable.

Comments, many of considerable length, were supplied by 54.3% ($n = 127$) of the respondents.

DISCUSSION

This study of users seeking information about a specific health concern from one consumer health library identifies the nature of the impact of that information. Although the findings are not from a representative sample and the effects of the information were self-reported, the study suggests that the impact goes far beyond an increase in knowledge. It leads to consumer contact with a health care provider for appointments or second opinions. It assists the consumers in choosing treatment options. It promotes communication between patients and health care providers by suggesting questions to ask and by reinforcing information received from a provider. It encourages compliance with instructions from a health care provider and contributes to changes in lifestyle. Quite often the information is literally brought to the health care provider. This should counter reservations about patients obtaining information on their own and without the guidance of medical personnel that emerged in the results of an exploratory survey of a small number of rural physicians [15].

The Consumer Health Library of the Delaware Academy of Medicine received a ringing endorsement from the respondents. This is reflected in the nearly unanimous willingness of respondents to use the ser-

vice again and to recommend it to others. In fact, most indicated they would be willing to pay for such a service and many comments disclosed the personal value of the information to them. In addition, seventy-five of the comments praised or expressed gratitude for the relevance and currency of the information provided, the professional and courteous manner of the staff, and the timeliness in responding to requests. The comments also illustrate the significance of the information in ways that the pointed questions cannot. The nature of the comments may be roughly categorized as appreciation for the service, acknowledgment of the general or personal importance of consumer health information, and concerns and suggestions regarding costs of and publicity for the service. While most respondents were willing to pay something for the service, the comments serve as reminders that some seeking consumer health information are on fixed incomes or burdened with medical bills and would find fees to be a barrier to access. The suggestions and comments about publicity confirmed that the visibility of the Consumer Health Library could be improved.

This study lends support to some findings of the previously mentioned studies in the area of consumer health information provision. Consumer health information seekers are most likely to be women. The provision of consumer health information does not increase anxiety for the vast majority. Consumers often share information with family members, friends, clients, or health care providers, thereby extending its impact even further.

This study was not, by design, based on a systematic random sample, therefore, one would expect anomalies in comparison with 1990 U.S. census characteristics for the state of Delaware. Indeed, respondents were overrepresented in the following categories: female (77.8% in the study compared with 51.5% in the census), Caucasian (88.0% compared with 80.3%), and college graduates (47.0% compared with 21.4%). Adjusting for the age restrictions imposed in the study, there appears to be overrepresentation in the fifty-five-and-over age group (38.9% compared with 28%). Although not a concern of this study, these anomalies broach the subject of underserved user groups.

The high response rate of this study and the copious comments volunteered indicate that consumers are as willing to participate in evaluation studies as they are in their health care. After analyzing the responses to the questionnaire, only one modification is suggested for others wishing to employ it. An additional impact choice should be listed in the first question about sharing the information with someone else. Other approaches to exploring impact and value should also be considered. Randomly selected consumers could be asked to request information on a topic, as was suggested by Marshall [16]. The use of anxiety scales in a comparative study of patients and consumers using

information with and without support of a health care provider was recommended by Bolton and Brittain [17]. This study focused on consumer health information selected by library staff. It will be critical to establish the unique role the librarian plays in the provision of consumer health information. Comparisons with other sources and providers of health information—human, electronic, institutional, or print—are in order.

There is no doubt that consumers will continue to seek health information, and it is likely that they will do so in greater numbers. As one respondent to the questionnaire commented, "The library is a very valuable service. It is essential to have a means to learn more about medical problems and conditions. . . ." This sentiment is echoed by the former surgeon general of the United States, C. Everett Koop, M.D., in his promotion of a new series of videos for patient education: "Even though nothing can be a substitute for the expertise of your own doctor, no prescription is more valuable than knowledge." As consumer health libraries move into their third decade, they and their users would profit from increased efforts to assess the role libraries play in the acquisition of such knowledge.

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APPENDIX

Consumer Health Questionnaire

1. Which of the following occurred as a result of reading the information provided? (Check all that apply)
 - learned more about an illness or a health concern
 - an appointment with a doctor or other health care provider was made
 - questions were asked of a doctor or other health care provider
 - information received from a doctor or other health care provider was better understood
 - instructions given by a doctor or other health care provider were followed
 - a second opinion was sought
 - a decision about treatment options was influenced
 - a change in lifestyle was made
 - my anxiety about an illness or health concern was increased
 - my anxiety about an illness or health concern was reduced
 - the information had no effect at all
 - other _____
2. Did you bring the information to a doctor or other health care provider?
 - yes
 - no
3. Would you use this service again?
 - yes
 - no
4. Would you recommend this service to others?
 - yes
 - no
5. If there had been a fee for this service, how much would you have been willing to pay?
 - \$0
 - \$1-5
 - \$5-10
 - \$10-\$20
 - more than \$20

For statistical purposes, please complete the following:

Gender:

female male

Age:

18-24 55-69
 25-39 70 and over
 40-54

Education:

high school or other _____
 equivalent
 some college
 college graduate

Racial/ethnic background:

African American other _____
 Asian
 Caucasian
 Hispanic

Comments: