# Expert searching in consumer health: an important role for librarians in the age of the Internet and the Web*

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**Objectives:** The Patient Education Resource Center at the University of Michigan Comprehensive Cancer Center conducts mediated searches for patients and families seeking information on complex medical issues, state-of-the-art treatments, and rare cancers. The current study examined user satisfaction and the impact of information provided to this user population.

**Methods:** This paper presents the results of 566 user evaluation forms collected between July 2000 and June 2006 (1,532 forms distributed; 37% response rate). Users provided both quantitative and qualitative feedback, which was analyzed and classified into recurrent themes.

**Results**: The majority of users reported they were very satisfied with the information provided (n = 472, 83%). Over half of users (n = 335, 60%) shared or planned to share the information with their health care provider, and 51% (n = 286) reported that the information made an impact on treatment or quality of life. For 96.2% of users (n = 545), some or all of the information provided had not been received through any other source.

**Discussion:** The results demonstrate that, despite the end-user driven Internet, patients and families are not able to find all the information they need on their own. Expert searching remains an important role for librarians working with consumer health information seekers.

## INTRODUCTION

Expert searching is an important role for health sciences librarians. The Medical Library Association defined this role in a policy statement that focused mainly on expert searching that addresses the needs of health care professionals [1]. Expert searching for health consumers is a service offered in a select few consumer health libraries, resource centers, hospital libraries, and public libraries. This paper presents a summary of evaluations completed by users who received expert searching services from the Patient Education Resource Center (PERC) at the University of Michigan Comprehensive Cancer Center (UMCCC).

PERC is a full-service library for patients and families receiving care at the UMCCC, the largest comprehensive cancer center in Michigan. In fiscal year 2006, the UMCCC provided 67,000 outpatient clinic visits, 37,000 infusion treatments, 3,559 courses of radiation treatment, and 4,500 adult cancer admissions.

Approximately 3,500 users per year visit the PERC. The library is managed by a master's degree–prepared librarian assisted by a team of highly trained volunteers. The PERC offers a variety of information services and tools including a reference service, a 250-title brochure collection, a circulating collection of about 800 books and 250 audiovisual materials, and 60 bibliographies on specific cancer types and supportive care topics called ''PERC Information Guides.'' PERC also provides 2 more in-depth services for UMCCC patients, including an information-packet service for remote users in the in-patient units and an expert-searching service. The information packet service is offered to hospitalized patients and their family members. In response to requests faxed by nurses on the clinical unit indicating a patient's diagnosis and related topics of interest to the requesting patient, PERC staff compiles and delivers a set of brochures and handouts that corresponds to the topics.

### Highlights

- Professional searches provided unique information that patients were not able to obtain on their own. The stress brought on by the diagnosis of cancer was reported as a barrier to information seeking.
- Overall satisfaction with the expert searching service was very high. Users reported that the information helped them to gain knowledge and better understand their condition.
- The information promotes clinician-patient communication: the majority of users reported that they shared the information with their health care providers.
- Users reported that the information improved their ability to tolerate treatment and cope emotionally.

### Implications

- Expert searching is a valuable service and should be offered in consumer, public, and hospital libraries providing medical information to lay users.
- Consumers identified relevancy, promptness, and a high level of customer service as key factors in the success of mediated searches.

* Based on a poster presentation at MLA '06, the 106th Annual Meeting of the Medical Library Association; Phoenix, AZ; May 21, 2006.

Supplemental appendixes are available with the online version of this journal.

**Table 1**
Themes summary

| | Number |
|---|---|
| Total comments (349 with 1 theme, 46 with 2 themes) | 352 |
| Total themes | 395 |
| Negative comments | |
| 1. Not enough information. Some of the user's questions were not answered | 14 |
| 2. Information was not relevant to request | 10 |
| 3. Level was not matched to request | 5 |
| Total negative comments: | 29 |
| Positive comments | |
| 1. General comments | 149 |
| 2. Information improved patient's knowledge and understanding | 46 |
| 3. Staff was helpful | 42 |
| 4. Information was provided in a timely manner | 35 |
| 5. Patient Education Resource Center (PERC) provided information user was not able to find from other sources | 27 |
| 6. Information sent was relevant to request | 15 |
| 7. Information improved communication with clinicians | 11 |
| 8. Information helped in decision making | 10 |
| 9. Information improved ability to cope emotionally | 9 |
| 10. User does not have ability to access information because of mental or physical barriers | 7 |
| 11. Information made a positive impact on quality of life | 6 |
| 12. User wished they had known about this service sooner | 6 |
| 13. Librarian helped to formulate questions | 3 |
| Total positive comments: | 366 |

The expert searching service is offered to all PERC users, including both in- and out-patients, with the purpose of providing more detailed information than that offered in basic, introductory materials such as brochures and handouts. The goals of the expert searching service are to help patients understand their illness and treatments, help them make informed treatment decisions, improve their quality of life, and facilitate a productive dialog between patients, caregivers, and clinicians. This study explored whether service goals were achieved, whether users were satisfied with the service, and how the information provided impacted the lives of users.

## DESCRIPTION OF THE EXPERT SEARCHING SERVICE

The expert searching service is offered to users who present questions that cannot be fully addressed utilizing the most readily available cancer consumer health materials. Brochures, books, and the major cancer Websites are not always sufficient for users seeking in-depth information about complex medical issues, state-of-the-art therapies, and rare cancer types and subtypes. It has been the experience of the PERC librarian that in order to respond appropriately to advanced information needs, a professional-level search, either on the Internet or in subscription-based databases, is required. To this end, the librarian established an expert-searching service.

The search process starts when PERC staff identifies a question or questions that cannot be fully answered utilizing the reference and brochure collection. At this point, the reference staff asks the patron to complete a search-request form (Appendix A).

PERC volunteers receive extensive training on evaluating health information on the Internet and utilizing electronic resources such as MedlinePlus, Health Reference Center, and authoritative cancer sites. The training is delivered through an educational orientation, annual professional development days, and on-going feedback from the librarian. Volunteers begin the search process by gathering materials and drafting a cover letter. The PERC librarian reviews each search, discards redundant or inappropriate materials, and adds additional materials. The librarian makes certain that all materials are current; obtained from authoritative, unbiased sources; and are at the appropriate educational level. The librarian's review guarantees that every search adheres to the same quality standards, regardless of the experience or knowledge of the volunteer, and that every user benefits from the knowledge and experience of a professional librarian with expertise in cancer-related consumer health information and access to subscription-based databases. Search results are sent to users within five business days via ground mail, along with an evaluation form (Appendix B) and a self-addressed stamped envelope.

## DATA COLLECTION

The evaluation form (Appendix B) includes multiple-choice questions and a space to write comments. To understand the trends and concepts expressed in the comments, each comment was entered into an Access database and analyzed by the PERC librarian (Volk) for recurrent themes. The analysis identified sixteen separate themes: three expressing negative feedback and thirteen expressing positive feedback (Table 1). Some of the comments touched on two concepts; therefore, each comment was assigned up to two separate themes.

## RESULTS

The data presented in this paper cover the period from July 2000 to June 2006. During this period, a total of

**Table 2**
Search evaluations summary (n = 566)

| Question | Responses | No. | Percent |
|---|---|---|---|
| 2. Did you receive the information as soon as you needed it? | Yes | 487 | 86.0% |
| | No | 55 | 9.7% |
| | N/A | 24 | 4.2% |
| 3. To what extent was the information relevant to your request? | Exactly what I needed | 404 | 71.3% |
| | Relevant information, but not enough | 114 | 20.1% |
| | Too broad, too much information | 10 | 1.7% |
| | Completely irrelevant | 5 | 0.8% |
| | Only part was relevant | 22 | 3.9% |
| | N/A | 12 | 2.1% |
| 4. Have you received the information from a different source? | Yes | 19 | 3.3% |
| | Yes, part of it | 179 | 31.6% |
| | No | 366 | 64.6% |
| | N/A | 2 | 0.3% |
| If yes, where did you get the information from? | Personal search on the Internet | 152 | 26.8% |
| | Family or friends | 34 | 6.0% |
| | Health care provider | 42 | 7.4% |
| | Library | 35 | 6.1% |
| | National organization | 17 | 3.0% |
| | Other | 15 | 2.6% |
| 5. Have you shared or do you plan to share the information with your health care provider? | Yes | 336 | 59.7% |
| | No | 128 | 22.6% |
| | N/A | 102 | 18.0% |
| 6. Has the information you received made an impact on the treatment or quality of life? | Yes | 286 | 50.5% |
| | No | 104 | 18.4% |
| | N/A | 176 | 31.1% |
| 7. Overall, how would you rate the service? | Excellent | 472 | 83.4% |
| | Good | 72 | 12.7% |
| | Fair | 8 | 1.4% |
| | Poor | 3 | 0.5% |
| | N/A | 11 | 1.9% |

1,523 searches were conducted and 566 user evaluations returned (37.2% return rate); 352 of these evaluations (62.2%) included free-text user comments.

Overall satisfaction with the expert searching service reported by users was very high. Table 2 shows that 83.4% percent (n = 472) indicated that they would rate the service as excellent and 12.7% (n = 72) rated it as good. The high level of satisfaction is also supported by 71.3% (n = 404) of users who indicated they received exactly the information that they wanted. Several users noted potential for improvement: 114 users (20.1%) selected the option ''Relevant information, but not enough''; 22 users (3.9%) said that only part of the information was relevant; ten users (1.8%) reported ''Too broad, too much information''; and only 4 (< 1%) said the information they received was completely irrelevant.

Table 2 shows that 64.6% of users (n = 366) did not receive the information sent by PERC from any other source; 31.6% (n = 179) indicated that they found part of the same information, but not all of it, in other sources such as the Internet, a health care provider, family or friends, a library, or a national organization. Only 3.3% of users (n = 19) indicated they found the same information on their own. Altogether, PERC provided unique information to 96.2% of users. The majority of users (77.8%, n = 152) who received information from a different source obtained it from the Internet (Table 2). This number represents 26.8% of total respondents.

With regard to impact, this study found that the majority of users (59.7%, n = 336) reported that they shared or planned to share the information with their health care providers. It should be noted that some of the search topics concern practical and psychosocial issues that patients do not typically discuss with their doctors, indicating that the service may be supporting increased patient-doctor communication. A little more than half of the users (50.5%, N = 286) indicated that the information made a difference in their treatment or quality of life.

## USER COMMENTS

Table 3 provides a selection of user comments examined in the theme analysis. Twenty-seven users commented that PERC provided them with information they were not able to find from other sources. Seven users described specific mental or physical barriers that prevented them from doing research on their own, such as not having an Internet connection at home, not feeling well enough to do their own research, or just lacking the time. These comments suggest that the extra stress brought on by a diagnosis such as cancer may be a barrier to information seeking.

Users' comments supported the high level of satisfaction shown by the quantitative evaluation data. Only 29 negative comments were expressed, as opposed to 366 positive comments. Six users commented that they wished they had known about the service sooner. The biggest benefit and most frequently recurring theme (n = 46) was gaining knowledge and increased understanding of the topic of interest. Promptness emerged as an important factor in satisfaction:

**Table 3**
Sample comments

| Theme | Comments |
|---|---|
| PERC provided information user was not able to find from other sources | • I had searched high and low for information—from the doctor to the Web—and found nothing. Thanks so much!<br>• Thank you. I could not find in-depth info on HLA typing, and appreciate your finding what I needed. |
| User does not have ability to access information because of mental or physical barriers | • I find your service extremely helpful because running around taking care of an ill child plus still taking care of a family and working full time you don't always have the time to do the research you want to do so you were a great help.<br>• This is a great service especially for patients like me who do not feel well enough to sit and search the Web for information.<br>• Very helpful for those who cannot get out of the house.<br>• It is very helpful to have assistance like this—my daughter had a difficult course and we don't have the Internet. |
| Information improved communication with clinicians | • I have a greater understanding of my cancer. I can ask more intelligent questions.<br>• This answered some of my questions and now I have some for the doctors. |
| Information made a positive impact on quality of life | • Thank you. The info made huge difference in my ability to understand and tolerate the effects of my first round of chemo. It has also provided me the info I need to follow up with my physician. |
| Information helped in decision making | • Thank you for your excellent service. The material is most helpful in helping me to decide the very difficult decision: tamoxifen alone or chemo + tamoxifen.<br>• Unfortunately, as your info helpfully explained, the cancer involved is too high risk for a cool cup. But thank you.* |
| Information improved ability to cope emotionally | • This knowledge has relieved a lot of fears. This can now be controlled—I am happy with it.<br>• I appreciate the detailed search. The information you provided will help to relieve some of the stresses that I am faced with<br>• Knowledge is power and I'm fully charged!!! Thank you so much. |

* Author's note: Cool cap is a treatment to prevent chemotherapy related hair loss, utilized mostly in the United Kingdom and Europe.

86% (n = 487) of users indicated receiving the information when they needed it, and 35 comments included timeliness as a specific reason for satisfaction. Good customer service was mentioned by 42 users who particularly appreciated the staff's empathy, willingness to help, and ability to help them formulate questions and articulate information needs.

## DISCUSSION

The most unexpected and important finding of this study was that, for almost all users (96.2%), professional searches offered unique information they were not able to obtain on their own. This finding was very surprising in light of data about the large volume of health-related searches on the Internet. A Pew Internet & American Life Project study published in 2006 estimated that 80% of the online population, which translated to approximately 113 million American adults, searched the Internet for information about health [2]. A 2006 study investigating Internet use among cancer patients found that, upon diagnosis, cancer patients increased their usage of the Internet [3]. The current study provides some data indicating that, despite the widespread penetration of Internet technology, users are still not always able to access relevant and helpful health information on their own.

The data also suggest that the provided information may have facilitated dialog and promoted clinician-patient communication. Almost 60% of users reported that they shared the information with their health care providers, and 11 users commented that the information improved communication with clinicians and enabled them to ask questions. A little over 50% of users indicated that the information had an impact on their lives: 6 users indicated that the information had a positive impact on quality of life; 10 users reported that the information helped in decision making; and 9 users reported that the information improved their emotional well-being and ability to cope with their cancer.

This study echoes the results of other studies that reported high satisfaction with consumer health information [4]. Previous studies reported that information increased users' knowledge about an illness or a health concern, stimulated the creation of new questions for clinicians, and improved understanding of information received from a health care provider. Health information also reduced anxiety levels about a user's disease or a health concern and influenced treatment decisions [2, 5, 6].

The impact-related conclusions of this study are somewhat limited by the structure of the evaluation form: the impact question was double-barreled and prevented the distinction between impact on quality of life or on treatment decisions. The original intention was to keep the survey as short and easy to complete as possible. Future surveys will split this question into two options, one regarding impact on quality of life and the other regarding impact on decisions. The self-reported nature of the data may also limit the generalizability of the current results. Future research would be strengthened through survey of clinicians to confirm that users have indeed shared the information as reported.

## CONCLUSIONS

This study confirms the initial assumption that professional level searches are a valuable service that makes a positive impact on the lives of cancer patients and families. The fact that professional searches provided 96.2% of users with information they were not able to find on their own underscores the important role of expert searching in the realm of consumer

health. It seems that, despite the penetration of the Internet in society, other barriers may prevent patients and families from accessing relevant information when they need it. One of these barriers is the physical and mental stress brought on by a serious medical condition. Another barrier may be low information literacy skills. The data suggest that the librarian's specialized skill set and knowledge of the principles of information organization and retrieval are essential to locating information on the vast Internet.

Users' inability to access information that had such a strong positive impact on their cancer experience suggests that the end-user-driven Internet creates an illusion: information providers, information seekers, and patient educators may have the impression that all health information needs can be met by utilizing the Internet, but this, in fact, is not true. The Medical Library Association policy statement on the role of expert searching in health sciences libraries notes the continued importance of the health sciences librarian in identifying relevant and high-quality information, despite the ubiquitous electronic availability of information [1]. The policy statement discusses this concept as it applies to professional end users, but this study suggests that it also applies to health consumers. Expert searching skills are needed both for evidence-based practice and for self-care and education.

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## APPENDIX A

### PERC search request form

### Part one

To be filled out by the requester:
Name _____
Address _____
City, State, Zip _____
Phone (work) _____ Phone (home) _____
Email _____
For office use:
Date _____ Search number: _____
Search topic: _____

### Part two

Section one: to be filled out by the requester:
Cancer type _____ Stage (if applicable) _____
Is the patient a child? _____ An adult? _____
Medical name of cancer type _____
Your question: (Please include as much information as possible including medical terms and stage of disease if applicable. Use other side if needed.)

_____
_____
_____
_____

Please check level of materials requested:
☐ Basic level ☐ Advanced lay-person level
☐ Professional level

Section two: to be filled out by staff:
For office use:
Date: _____ Search number: _____
Volunteer name _____
Client request: (Please include additional details such as stage of disease, age, type, etc.)

_____
_____
_____

Materials given _____

Follow up:
Cover letter and envelope prepared on: _____
Please place search request materials in the librarian's drawer
Request completed and sent on _____
(to be filled out by librarian)

## APPENDIX B

### Professional search evaluation

Please help us to evaluate the professional search we did for you, so that we can improve our service.
Search topic _____
Did you get your search as quickly as you needed it?
☐ Yes ☐ No
To what extent was the information relevant to your request?
☐ Exactly what I needed
☐ Relevant information, but not enough
☐ Too broad, too much information
☐ Only part was relevant
☐ Completely irrelevant
Have you received the same information from a different source?
☐ Yes ☐ Yes, part of it ☐ No
If yes, where did you get the information from?
☐ Personal search on the Internet
☐ Family or friends
☐ Health care provider
☐ Library
☐ National Organization
☐ Other: _____
Have you shared or do you plan to share the information provided with your health care provider?
☐ Yes ☐ No ☐ N/A
Has the information you received made an impact on treatment or quality of life?
☐ Yes ☐ No ☐ N/A
Overall, how would you rate the service?
☐ Excellent ☐ Good ☐ Fair ☐ Poor
Please send additional comments in the space below:

_____
_____
_____
_____