Internet Message Board Use by Patients With Cancer and Their Families

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People around the world use the Internet to access information. Estimates suggest that, in 2000, more than 175 million people logged on to the Internet to access health-related information (Appleby, 1999). Among them, 43% sought information regarding health care (Chen & Siu, 2001). Vigorous discussions about the attitudes and practices of consumers, patients (Clark & Gomez, 2001; Craigie, Loader, Burrows, & Muncer, 2002; Cumbo et al., 2002), and healthcare professionals with regard to use of the Internet are ongoing (DeLuca & Enmark, 2001; Edgar, Greenberg, & Remmer, 2002; Fingeld, 2000; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Gomella, 2000).

Patients with cancer and their families depend on the Internet as a means to obtain healthcare information, as a support resource, and as a mechanism for sharing experiences (Gruntal & Co., 1999; Han & Belcher, 2001; Hellawell, Turner, LeMonnier, & Brewster, 2000; Hertzberg, 2002; Hersheimer et al., 2000; Houston & Ehrenberger, 2001; Johnson, Ravert, & Everton, 2001; Kerwin, 2002; Klemm, Reppert, & Visich, 1998; LaCoursiere, 2001; Leaffer & Gonda, 2000; Meric et al., 2002; Mills & Davidson, 2002). Information is emerging regarding the role of the Internet as an education and communication tool, but a great deal remains to be learned about its present and potential role as a healthcare resource.

The Life After Cancer Care (LACC) Internet Web site and message board were created at a comprehensive cancer center to provide up-to-date information about different types of cancer, treatments, late effects, and research findings. The message board enables patients with cancer to exchange information on a more personal basis. During the 16-month period since the creation of the Web site, 972 people logged on to the message board and 284 people posted 619 messages. Most (64%) posted only one message. The posted messages were related most frequently to cancers of the breast, gastrointestinal system, lung, gynecologic system, head and neck, and colon. Sixty percent of the people posting messages were cancer survivors; the remaining 40% were family or friends of survivors. The most frequent query themes were concerns about treatment, support, and long-term side effects of treatment. Individuals with cancer were significantly more likely to post messages about long-term side effects of treatment than family and friends. Message boards are a useful tool for sharing information with others who have similar experiences. Message board entry data also provide valuable information that can be used to refine the boards. Message boards have not been used traditionally in healthcare research but hold considerable promise as an information resource for people affected by cancer.

**Key Words:** survivors, Internet, social support

A subsite of the University of Texas (UT) M.D. Anderson Cancer Center Web site was created as a component of Life After Cancer Care (LACC), a comprehensive cancer survivorship program. The Web site, located at www.mdanderson.org/departments/lacc, contains information about topics such as the late effects of different cancers, discussions about cancer treatments, an online health survey, brief summaries of research findings pertaining to cancer survivorship, answers to frequently asked questions about survivorship, and links to useful, related sites. In addition, a message board was created where patients with cancer and their family members can communicate with and provide support for other patients and families. The message board is accessible to anyone who visits the UT M.D. Anderson Cancer Center Web site. Some of the message board visitors have been in treatment for years, whereas others have been diagnosed recently, are still on active therapy, or may be in the process of deciding on a treatment. The characteristics of the message board visitors and the topics in which they are interested provide valuable insight about the types of information that people with a diagnosis of cancer are concerned about.
The Life After Cancer Care Web Site

Design

The LACC Web site was created and is maintained with the assistance of the UT M.D. Anderson Cancer Center Department of Information Systems (IS). The site was developed to provide healthcare professionals and the public with information about cancer survivorship. The site is updated regularly so that its educational content and research findings are current. The research content consists of published or presented findings from the LACC research team, and the educational content is scrutinized by the LACC team to ensure reliable content.

A message board was added to the LACC site to allow cancer survivors to interact and communicate with each other. This message board was initiated because of the primary author’s previous experience with an Internet forum (Schultz, 2002) and direct input from cancer survivors requesting an avenue to discuss and share their experiences. The discussions are monitored by the LACC working group and IS staff to ensure appropriateness of content. The LACC working group receives an e-mail each time a message board entry is made, and the database coordinator reviews the messages twice a week. The database coordinator also serves as moderator of the board and as liaison between LACC and the IS staff. The home page briefly introduces the message board and includes a statement to clarify the institution’s position regarding prominent issues associated with the electronic dissemination of information, such as the absence of a doctor-patient relationship, patient confidentiality, privacy, and the institution’s right to delete messages that fail to comply with established standards.

When users log on, a menu of topics is displayed (see Figure 1): general discussion, with answers to frequently asked questions about cancer survivorship. The site is updated regularly so that its educational content and research findings are current. The research content consists of published or presented findings from the LACC research team, and the educational content is scrutinized by the LACC team to ensure reliable content.

Analysis

The LACC Web site traffic is monitored closely, and monthly reports are available to analyze Internet activity. In addition, the thematic content of the message board postings is outlined anonymously in a database (Oracle® Enterprise Edition, Version 8.1.5, Oracle Corporation, Redwood Shores, CA) that is maintained and updated on a regular basis by the institution’s IS staff and the database coordinator.

The LACC Web site can be accessed via the UT M.D. Anderson Cancer Center home page and through links from a variety of reciprocal Internet sites focusing on cancer, such as the American Cancer Society, National Cancer Institute, and a number of public-service organizations. At this time, the specific groups or individuals who visit the LACC site most often or what motivates them to search the site cannot be determined; however, the observation that LACC appears within the first 10 entries in several Internet search engines (including Yahoo!® and Google™) suggests that the site is of significant general interest.

The authors analyzed the pattern of “hits” during a seven-month period (see Table 1). Next to the LACC home page, the section with answers to frequently asked questions received the most traffic (X = 1917, SD = 458 hits per month) followed by the message board (X = 1489, SD = 133 hits per month), suggesting that individuals who are interested in cancer survivorship search for such resources. Not surprisingly, a site receives more hits than actual searches. For the message board specifically during the same seven-month period, 62 (SD = 13) people per month logged on (users) and 27 (SD = 9) people per month actually posted one or more messages (posters).

Two hundred fifty-two of the posted messages indicated whether the poster was a person with cancer: 150 posters (60%) had cancer and 102 (40%) did not. Of those who did not have cancer, 21 posters (22%) identified themselves as spouses of patients with cancer, 67 posters (69%) as other family members, and 9 posters (9%) as nonfamily members. The majority of the message posters were women (n = 205, 74%); the majority of the posters who identified themselves as people with cancer also were women (n = 108, 72%). Surprisingly, when the gender of the cancer survivor was the subject of the postings by the message posters without cancer, the survivor was more often male than female (58% versus 42%) (see Figure 2).

Messages were read and analyzed for content. The most common cancer types represented by the posted messages from cancer survivors and posters without cancer were breast, gastrointestinal, lung, gynecologic,

<table>
<thead>
<tr>
<th>AREA OF SITE</th>
<th>NUMBER OF HITS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home page</td>
<td>4485, 1810</td>
</tr>
<tr>
<td>Frequently asked questions</td>
<td>1917, 458</td>
</tr>
<tr>
<td>Message board</td>
<td>1489, 133</td>
</tr>
<tr>
<td>Resources and links</td>
<td>957, 210</td>
</tr>
<tr>
<td>Cancer complications</td>
<td>370, 41</td>
</tr>
</tbody>
</table>

Note. Hits are the number of times people logged on to the site.

During the initial 16 months since its creation, 972 individuals logged on to the message board and 284 people posted 619 messages. The majority posted only one message (64%), 59 posted two messages (21%), and the remaining posted more than two messages.

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head and neck, and colon (see Figure 3). Forty-seven messages did not indicate a specific cancer type.

Message topics were grouped into eight broad themes. The most frequent themes were questions about treatment, support, and long-term effects. Univariate analysis revealed a significantly different pattern of message themes between posters who had cancer and those who were posting a message for someone with cancer ($p = 0.0008$). For example, although the most frequent queries for all posters were about treatment (35% for posters with cancer and 57% for posters without cancer), such queries more often came from those without cancer. Posters with cancer posed questions about the long-term effects of cancer more often than those without cancer (18% versus 1%). Questions about support and diagnosis appeared to be of similar interest to both groups of posters (see Table 2).

The authors also analyzed whether the type of cancer identified in the messages affected the theme of the message. The authors limited the analysis to the five most common message themes and the seven most frequently represented cancers (see Table 3). Indeed, the message themes were not similar for posters interested in different specific cancers. For example, posters dealing with breast cancer were more likely to post messages about treatment (24.7% of messages about treatment) than posters dealing with head and neck cancer (6.2% of messages about treatment). On the other hand, posters dealing with lung cancer were more likely to post messages about support (27.3% of messages about support) than posters dealing with colon cancer (4.6% of messages about support). In general, treatment was the most predominant message theme.

### Discussion

The authors’ review of the traffic to the UT M.D. Anderson Cancer Center survivorship Web site and message board indicated that patients with cancer and their families use this resource to obtain information about a number of topics, including treatment options, late effects of disease, and sources of social support. The kinds of questions vary depending on the poster (person with or without cancer) and the type of cancer about which queries are made. The authors’ findings provide additional support for the notion that the Internet is an increasingly important information resource (Chen & Siu, 2001; Craigie et al., 2002; Hellawell et al., 2000; Monnier, Laken, & Carter, 2002).

Message board entries reflect yet another aspect of cancer survivors’ experience. Cancer survivors are interested in obtaining educational information (Fingeld, 2000; Han & Belcher, 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000), sharing their experiences about cancer treatment with others (Pereira, Bruera, & Quan, 2001), and providing social support (Schultz, 2002; Shortliffe, 2000). The Internet provides consumers with a variety of places to engage in discussion forums in the quest for healthcare information and support in dealing with healthcare problems, including cancer. At HealthBoards .com (www.healthboards.com) for example, individuals have a choice of communicating through more than 100 message boards all concerned with healthcare issues.

The importance of the Internet in the healthcare arena is being increasingly appreciated and discussed (Appleby, 1999; Cumbo et al., 2002; Fogel et al., 2002; LaCoursiere, 2001; Sieving, 1999). Consumer and patient interest in oncology is becoming more prominent, and professional and lay organizations are developing Web sites through which in-
formation can be disseminated to consumers and patients can communicate. In general, literature pertaining to health care and the Internet highlights the significance of this resource and the level of interest in both topics. Less data are available about the types of information on which Internet users tend to concentrate. Such information would allow healthcare providers and educators to develop materials better suited to respond to the needs of consumers and patients.

Patients with a cancer diagnosis go through several disease phases and, thus, their need for information and support changes. Initially, most of their questions relate to treatment options, control of side effects, and need for emotional support. They seek to share their experiences with other individuals with the same diagnosis. Over time, questions about treatment-related late effects, social re-entry, recurrence, and secondary cancers become prominent topics. The questions of interest may vary depending on patients’ age and gender, the type of cancer, and the type of treatment they received. By reviewing the questions posted on the LACC message board, the authors were able to detect that message posters were most interested in support issues if they were dealing with lung cancer and least interested if they were dealing with head and neck cancer. In addition, message posters were most interested in support issues if they were dealing with lung cancer and least interested in support issues if they were dealing with colon cancer.

The concept of using the Internet and message boards for data collection and research has not yet received a great deal of attention in the healthcare arena. The authors suggest that continued, systematic analysis of Web site traffic, message content, and patterns of use may prove promising in clarifying the interests and information needs of patients and their families.

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References

Meric, F., Bernstam, E.V., Mirza, N.Q., Hunt,
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Rapid Recap

Throughout the world, people access the Internet for healthcare information. People with cancer and their families often use the Internet as a tool to obtain healthcare information, as a support resource, and as a mechanism for sharing experiences. Internet message boards can be created to allow people with cancer and their families to communicate with cancer survivors and their families. Data about Web site and message board use can be used to refine the content and format of Internet healthcare information sites, as well as provide data about who is using the Internet to access health-related information and how they are choosing to access it.