Internet Message Board Use by Patients With Cancer and Their Families

Pamela N. Schultz, PhD, RN, Charles Stava, Martha L. Beck, FNP-C, and Rena Vassilopoulou-Sellin, MD

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 healthcare (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, Lemmonier, & Brewster, 2000; Hertzberg, 2002; Hersheimer et al., 2000; Houston & Ehrenberger, 2001; Johnson, Ravert, & Everton, 2001; Kerwin, 2002; Klemm, Reppert, & Visich, 1998; La-Coursiere, 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 only 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.

Submitted April 2003. Accepted for publication May 20, 2003.

(Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Clinical Journal of Oncology Nursing or the Oncology Nursing Society.)

Digital Object Identifier: 10.1188/03.CJON.663-667