Internet Technology-based Patient Education: The CHESS Program

by James A. Stewart, M.D., Robert P. Hawkins, Ph.D., and David H. Gustafson, Ph.D.

Cancer management is complex, costly, technology dependent, and long-term, extending from prevention to end-of-life care.[1] Since patient-specific options and risk-benefit scenarios are numerous, the need for guided education of patients with cancer is greater than ever. Explaining treatment, either within or outside of a clinical trial, may require numerous discussions with several doctors, nurses, and clinical research associates. In light of these complexities—and with the increasing acceptance of electronic communication—thoughtful decision making requires that we adopt new strategies in patient education.

Today's new approaches involve using the resources of the Internet and e-mail. Comfort with Internet technology is increasing, and for those with access the convenience factor is a strong incentive for its use. Before and even after making initial treatment decisions, patients often "study" their disease intensely, frequently through the resources of the Internet. In a recent survey of patients in the University of Wisconsin (UW) Medical Foundation health care system, the top four reasons to access a health care Internet site were to: 1) obtain general health information, 2) schedule appointments, 3) access lab test results, and 4) communicate via e-mail with a doctor or other health care provider.[2]

Communication via e-mail directly between the physician and patient offers opportunity but also presents problems if such communication occurs without thoughtful planning.[3] Issues of security and confidentiality, medical/legal liability, loss of the physician/patient bond, and inequitable access to technology must be addressed. Nevertheless, many physicians do respond to patient inquiries via e-mail. These may range from simple requests for rescheduling, appointments, or tests to detailed discussions about prognosis and treatment options.

A recent poll of physicians by Harris Interactive[4] reported that 14 percent of physicians use e-mail to send patient-specific information. More physicians (39 percent of respondents) would do so if the security and privacy of e-mail were guaranteed; but even with such measures, 40 percent said they would not send clinical information by e-mail. As privacy becomes legally mandated by HIPAA regulations, the survey predicts that physicians will probably adapt. Most will welcome the end of "phone tag" and clinic interruption when they can use e-mail for clinical discussion.

While some physicians may be reluctant to share as much information in an e-mail as they would in person, some patients may be more candid on e-mail than in a clinic setting. The faceless e-mail interaction may make it easier to ask the doctor hard questions.

PATIENT EDUCATION

At most cancer centers, multiple electronic tools are being developed to meet the needs of patients with cancer. At the UW Comprehensive Cancer Center, the need for general cancer materials and information about clinical trials is met, in part, by a phone/e-mail service known as Cancer Connect. In the year 2000, this public link to the cancer center responded to approximately 9,000 inquiries regarding clinical trials (53 percent), appointments (14 percent), general information (12 percent), and treatment (11 percent). Interestingly, 46 percent of these inquiries were from a relative or friend of the patient, and only 29 percent from a person diagnosed with cancer that had been seen by a physician.

A patient who is well educated about his or her disease, prognosis, and treatment choices is likely to work better with the medical system and have greater overall satisfaction with care than a patient without disease-specific knowledge. An educated patient finds fewer surprises during treatment and follow-up, understands the role of multidisciplinary treatment, and is usually more comfortable participating in cancer clinical trials.

Whether treatment is within or outside a clinical trial, decision making can be among the most challenging aspects of cancer care. Information must be accessible, credible, and available in a format that the patient can receive and understand at his or her own pace. The patient needs time to digest the information, ask questions, and address concerns with family members. Ideally, patients should be able to access such a system at their convenience. Those with Internet access are able to tap into a vast but unfocused repository of cancer

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information of varying quality. Reliable and focused information is important for patients, especially for those in the midst of making decisions about cancer treatment.

CHESS: INTERNET BASED

A consumer health informatics system known as CHESS (the Comprehensive Health Enhancement Support System) was first developed in 1989 at the University of Wisconsin to address patient education and decision making for common but challenging health problems.[5] Following earlier computer-facilitated technologies, CHESS is now Internet based and being tested as a research tool in clinics and hospitals throughout the country. CHESS programs are based on needs assessment surveys that typically involve several hundred patients and their families. User groups test content developed by clinical experts for relevance and readability. The development of CHESS has been a productive collaboration among experts in industrial engineering, mass communication, medicine, psychology, and family studies, as well as patients—all of whom were necessary to create relevant research questions and methods.

CHESS is a non-commercial system owned by the University of Wisconsin. CHESS Research Consortium members include the Allina Medical Group, the Dana-Farber Cancer Institute, Fletcher Allen Health Care (Vermont), Hartford Hospital (Connecticut), Harvard Pilgrim Health Care, the Mayo Clinic, the Merck Outcomes Research Department, St. Paul's Hospital (Vancouver), and the University of Wisconsin. The consortium contributes to CHESS's design, content, and testing.

Patients receive access to CHESS through their health care provider, and the system is continually tested in controlled trials, such as randomized studies comparing CHESS use to unguided Internet use.

When users log on to CHESS, they see a main menu that allows them to select a keyword, topic, or service, such as information, communication, and analysis. Selecting a topic such as breast cancer, for example, brings users to a page filled with timely article choices. (See page 12.)

- *Information services* include a lengthy list of frequently asked questions, an "Instant Library" with links to full-length articles, "Weblinks" to high-quality web sites, and a "Consumer Guide" that provides examples of clinical needs and responses from the medical system.

- *Communication services* offer information and emotional support. "Discussion Groups" provide a forum for sharing information and support among patients and families. There are separate groups for patients, partners, or any other CHESS user. Professional facilitators enhance the discussions. Specific questions can be sent to "Ask an Expert," staffed by specialists at the National Cancer Institute-supported regional Cancer Information Service. "Journaling" provides a private place where users put their thoughts and feelings about their disease into text. "Personal Stories" are professionally written accounts of the experiences of real patients with cancer-related problems and individual coping strategies.

- *Analysis services* guide users to think through key issues in their medical decision making. "Assessments" focus on specific issues of importance to patients such as depression. In "Health Tracking" users enter data on their health status every two weeks and see graphs of how their health is changing. "Decisions-Decisions" help patients and families evaluate important treatment choices. Patients can see video clips of others talking about how they made treatment choices. More structured examples of decision analysis show options, value clarification, and consequences of specific decisions. "Action Plan" uses a decision-theory model to help patients plan behavior changes by identifying goals, resources, and ways to overcome obstacles.

> An educated patient finds fewer surprises during treatment and follow-up…

Patients who have used CHESS provide the strongest impetus for its continued development. One woman remarked: "Nothing has changed my life like the day you brought that computer into my home. It didn't change my diagnosis of breast cancer; it changed how I responded to the diagnosis. CHESS gave me hope, gave me information, and gave me support from those who understand."

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OUTCOMES OF CHESS EVALUATION

Although measuring the use and impact of consumer health information systems is a complex process, techniques have been developed to quantify CHESS use. Web site hits on individual CHESS pages are counted and user sessions are timed. These early years of CHESS evaluation have yielded important lessons for continued development. Much CHESS research has been directed toward medically underserved populations, often those on the wrong side of the "digital divide."

For general populations, the acceptance and use of CHESS is typically about 75 percent. There was concern that underserved populations such as the elderly and minorities would not use a computer-based system at all for health education. In fact, typical CHESS use is *not* affected by race, gender, education, age, or computer experience, although different populations use the system in different ways. Elderly women with breast cancer, for example, use CHESS differently from young Caucasian women.[6] Elderly women are more likely to use "Ask an Expert," while young white women are more likely to participate in discussion groups. In general, underserved populations tended to use the communication and discussion services

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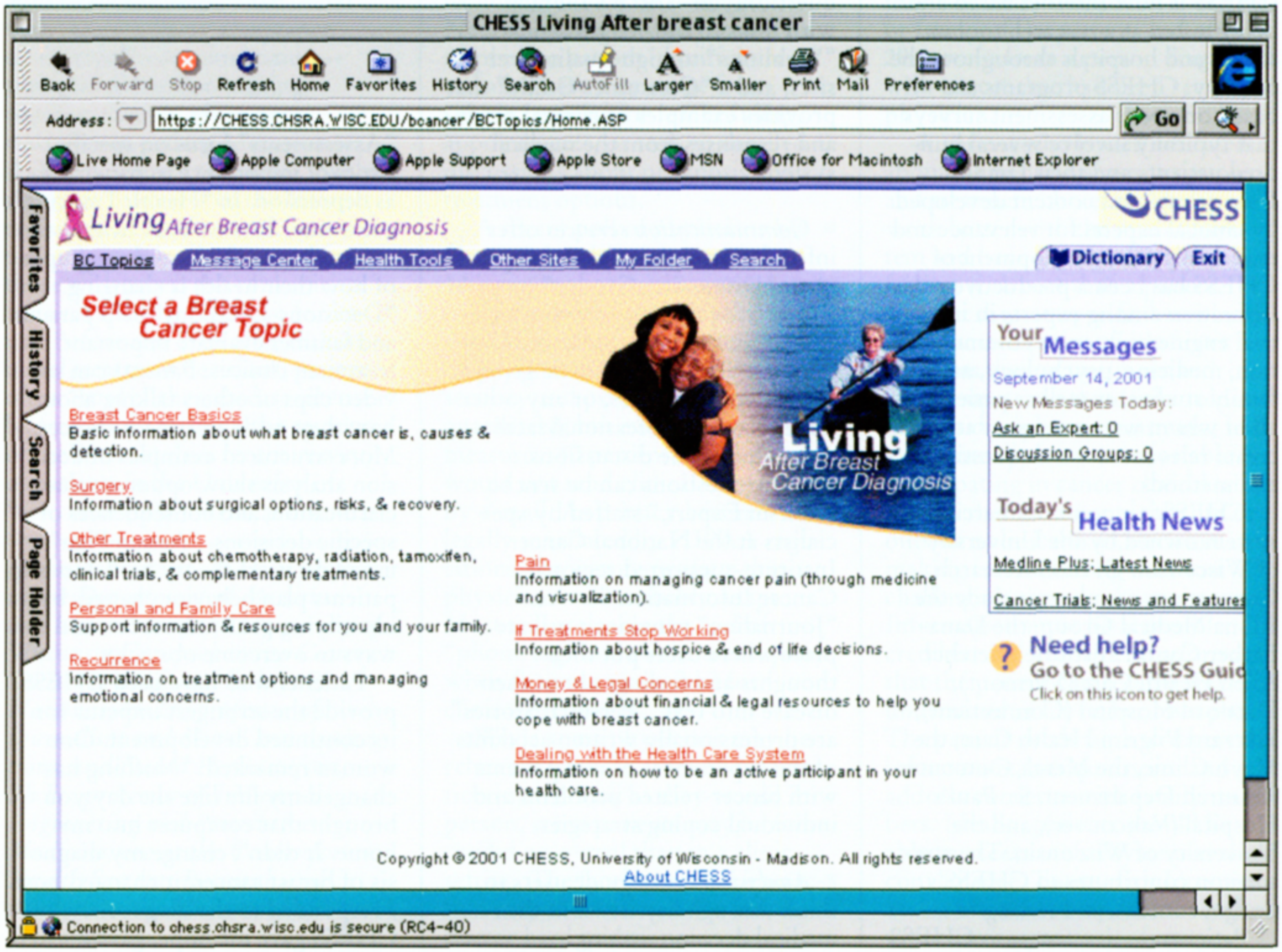

Address: https://CHESS.CHSRA.WISC.EDU/bcancer/BCTopics/Home.ASP

Select a Breast Cancer Topic

Breast Cancer Basics
Basic information about what breast cancer is, causes & detection.

Surgery
Information about surgical options, risks, & recovery.

Other Treatments
Information about chemotherapy, radiation, tamoxifen, clinical trials, & complementary treatments.

Personal and Family Care
Support information & resources for you and your family.

Recurrence
Information on treatment options and managing emotional concerns.

Pain
Information on managing cancer pain (through medicine and visualization).

If Treatments Stop Working
Information about hospice & end of life decisions.

Money & Legal Concerns
Information about financial & legal resources to help you cope with breast cancer.

Dealing with the Health Care System
Information on how to be an active participant in your health care.

Your Messages
September 14, 2001
New Messages Today:
Ask an Expert: 0
Discussion Groups: 0

Today's Health News
Medline Plus: Latest News
Cancer Trials: News and Feature

Need help?
Go to the CHESS Guid
Click on this icon to get help.

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About CHESS

Connection to chess.chsra.wisc.edu is secure (RC4-40)

Unguided use of the Internet is not the answer for efficient health education.

less and the information gathering and analysis services more than the served population.[7]

Breast cancer CHESS users say the system has met their information needs, given them more confidence that they can cope with and manage information, and encouraged them to participate more in their own health care.[8] People with HIV and AIDS say they have improved their quality of life and reduced their use of medical services by using the HIV CHESS system.[9]

Underserved clients seemed to reap more benefits from using CHESS than clients in better-served groups. After using CHESS, breast cancer patients in underserved populations report understanding more information, feeling more empowered, and improving their quality of life more than those in better-served populations.[8,10] Underserved minority patients with breast cancer had similar scores to middle class white women using CHESS in emotional well-being, resolution of breast cancer concerns, and information gathering skills.

The Internet will certainly grow as a source of information for people with cancer. Unfortunately, the thousands of health-related sites, many of which exist only to sell a product, can be overwhelming to the average patient. Unguided use of the Internet is not the answer for efficient health education. We found that patients who used the Internet guided by CHESS spent more than twice the time (77 percent vs. 31 percent of nearly equal total time) on health-related sites than those merely given Internet access without CHESS guidance.

How patients use CHESS determines how much they benefit from visiting the web site. A qualitative analysis of a small sample of patients with HIV who used CHESS revealed that quality-of-life improvements were greatest in those who used the "Information Services" tools.[11] Although the total time spent using CHESS was similar in those who improved and those who did not, improvers exhibited focused, thoughtful use. They followed topics across services and used analysis services. This may explain the greater benefits for underserved breast cancer patients noted above.[8]

Although CHESS can reduce the burden of cancer by educating patients and their families, guiding decision making, and helping people develop coping strategies, more work is needed to understand differences among cancer populations and how to enhance their interaction with CHESS. There is good evidence that CHESS can benefit a broad range of populations, but access—getting CHESS to the underserved—remains a major barrier. Programmatic development must be based on careful needs assessments and a multidisciplinary approach.

Continuing research will examine why CHESS works. Are its benefits derived primarily from information or from more complex communication and support elements? The technical interface with the Internet is also being improved. We will be looking for ways to tailor CHESS to its users, make it a source of data for informed consent in clinical trials, and take it to underserved populations.

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