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Internet-Based Interactive Support for Cancer Patients: Are Integrated Systems Better?

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Abstract

To compare the benefits of the Internet generally versus a focused system of services, 257 breast cancer patients were randomly assigned to a control group, access to the Internet with links to high-quality breast cancer sites, or access to an eHealth system (Comprehensive Health Enhancement Support System, CHESS) that integrated information, support, and decision and analysis tools. The intervention lasted 5 months, and self-report data on quality of life, health-care competence, and social support were collected at pretest and at 2-, 4-, and 9-month posttests. CHESS subjects logged on more overall than Internet subjects and accessed more health resources, but the latter used non health-related sites more. Subjects with access to the Internet alone experienced no better outcomes than controls at any of the 3 time points, compared to pretest levels. Subjects with CHESS experienced greater social support during the intervention period and had higher scores on all 3 outcomes at 9 months, 4 months after the intervention ended. CHESS subjects also scored higher than those with Internet access during the intervention period but not significantly after the intervention ended. Thus, CHESS (with one simple interface and integrated information, communication, and skills services) helped newly diagnosed breast cancer patients even after computers were removed. In contrast, patients received little benefit from Internet access, despite having links to a variety of high-quality sites.

Breast cancer affects one in eight women and is the second leading cause of cancer death among women (American Cancer Society, 2007). Earlier detection and improved treatment are reducing mortality from this disease, but its impact on a woman's quality of life remains substantial (Bruckner, Yost, Cashey, Webster, & Cella, 2005). Beginning with diagnosis and continuing at least through the stresses of treatment, breast cancer patients typically

experience uncertainties, anxiety, novel and difficult decisions, physical pain, impairment of everyday life functioning, feelings of social isolation, difficulties adjusting and maintaining relationships, and so on (Gustafson, Taylor, Thompson, & Chesney, 1993; Mandelblatt, Figuerido, & Cullen, 2003). Or, in summary, both the initial diagnosis of breast cancer and the subsequent treatment adversely affect a woman's quality of life.

Apart from medical treatment, a variety of resources can impact how well a woman deals with the disease. For example, mounting evidence suggests that information produces accurate disease-related expectations (Maly, Leake, & Silliman, 2004), improved health, and even increased longevity among breast cancer patients (Kiecolt-Glaser & Glaser, 1987). Patients satisfied with social support perceive their health more positively and report fewer physical symptoms (Sammarco, 2004). Thus, understanding how quality of life can be buffered against the stresses of breast cancer should allow us to develop and disseminate the needed resources. But because individuals facing a cancer diagnosis are still complex adaptive systems, providing interventions to assist them is not a matter of simply transmitting information to fill in the blanks in their knowledge. A more meaningful approach recognizes that the patient's own actions with and orientations toward potentially helpful resources are as important as the ostensible content of those resources.

A useful way to understand this individual contribution is through the prism of self-determination theory (Ryan & Deci, 2000), which makes the case that experienced quality of life is largely a matter of the degree to which three basic psychological needs for autonomy, competence, and relatedness are met. Many studies have related satisfaction of these basic needs to well-being and quality of life (Ryan & Deci, 2000). Autonomy is the sense that one's actions and experiences are volitional rather than controlled by strong external or internal forces. Competence is perceiving oneself to be efficacious. Relatedness is the need to experience connection to others. Of course, individuals may vary in the relative importance of these needs, and a stressor such as breast cancer could affect different individuals in different ways, but it seems clear that breast cancer diagnosis and treatment typically and substantially impacts all three: "My life is out of control" (autonomy), "I feel all alone" (relatedness), and "I can't do anything about it" (competence).

Although most breast cancer patients, and particularly those successfully treated for early-stage disease, will eventually regain most or all of their original quality of life, the goal of providing resources for these women is to cushion the drop in quality of life and speed its recovery. Receiving and understanding information can contribute to both autonomy and competence if it gives the patient the sense that their situation offers choices and options and that they have the knowledge and abilities to exercise such control. But when information is difficult to locate, too hard to understand, or seemingly contradictory to other information, these experiences can instead undermine competence, if not autonomy as well (Deci, Eghrari, Patrick, & Leone, 1994). And because the breast cancer diagnosis and treatment create a new and unwanted identity ("breast cancer patient") that distances the woman from her usual circle of relationships (who do not share that identity), work to rebuild these relationships or find new relationships with other patients is often an important positive response to breast cancer (Shaw, McTavish, Hawkins, Gustafson & Pingree, 2000). Both positive effects of autonomy, competence, and relatedness, and negative effects of deficits in them tend to covary or be mutually interactive. A deficit in one can undermine what might otherwise have been sufficient levels of another. For example, a lack of perceived autonomy can inhibit exercising competence or create difficulties establishing a sense of relatedness with expert sources of information such as clinicians, which in turn may inhibit use of the information they provide (Ryan & Deci, 2006).

The study reported here randomly assigned newly diagnosed breast cancer patients for 5 months to one of three conditions of access to resources that might have been expected to respond to their needs to regain autonomy, competence, and relatedness during these stressful months. A control group was given their choice of excellent book or audiotape breast cancer resources. A second group was loaned a computer, trained in Internet search strategies, and given a list of high-quality breast cancer sites.¹ The third group was also loaned a computer and trained in Internet search strategies, but they were also given password-protected access to the Comprehensive Health Enhancement Support System (CHESS), a system of breast cancer resources discussed below.

The distinctions between these conditions are much more than a matter of medium of transmission or even of differences in content between conditions. Instead, what we believe matters here is the different ways in which the resource sets of the three conditions allow and encourage recovery by satisfying the basic needs identified by self-determination theory. For example, women in the control condition were given a high-quality resource in either book or audiotape form, and of course they could also access any of the information or support resources generally available (i.e., “usual care”). A patient who was highly competent, autonomous, and with strong interpersonal support could conceivably find all the information she needed, have the self-confidence or get the help to interpret it, seek out advice on her difficult decisions, and locate other breast cancer patients to add to her support network. But this asks a lot of the patient, and frankly, those generally available resources are often less than ideal—difficult, expensive, or time consuming to access and often hard to understand. Although the stereotype of physician ineffectiveness communicating with patients is largely just that, the enormous constraints on physician time and the relative infrequency of actual contact with patients severely limit how much they can communicate disease and treatment information to patients (Dianne Publishing, 1986). Libraries require dedicated time and travel and, despite generally good intentions, are intimidating and confusing to many people (Dervin, 1981). Many communities have support groups for breast cancer patients, but attending these requires travel and their scheduled meeting times may not be frequent enough or match the times a patient needs them most. In addition, many people find in-person discussions of something as sensitive and frightening as breast cancer just too embarrassing (Shaw et al., 2000; Winzelberg et al., 2003). In short, the resources typically available to a breast cancer patient, even with our addition of a selected book or audiotape series, present enormous accessibility and usability barriers to recovering her autonomy, competence, and relatedness to deal with her breast cancer.

As a resource, the Internet offers a number of attributes that potentially respond much better than usual care to patient needs for autonomy, competence, and relatedness. The anonymity and ease of home access at any time should make it much more supportive of autonomy by removing geographic, time, and financial barriers. The wealth and variety of information and support tools (e.g., advice, treatment planning, behavior change supports) could support a wide range of competencies and put the patient far more in control of her situation (Eysenbach, 2003). Better informed patients may ask better questions, manage their disease more effectively, and even monitor and intervene to improve their care (Gustafson et al., 2001). Chat groups and e-mail may help patients cope (Hoybye, Johansen, & Tjornhorj-Thomsen, 2005) and provide social support as an alternative or addition to their usual networks that may be disrupted by the disease. These possibilities are clearly being appreciated and pursued by patients having breast cancer and other acute or chronic diseases, and the Internet attracts growing numbers seeking health information (Fox, 2005).

¹At the time of the study, the majority of women in this age group (average age of study participants was 52) were not Internet users, and even some of those who did own a home computer had one that was not adequate for reliable Internet access.

However, despite general optimism about the potential of the Internet for health information and support (Christensen & Griffiths, 2002; Spooner, 2003), there are also reasons for caution (Baur, 2000; Bernhardt, Larsen, Parrott, Silk, & Felter, 2002). Although almost any good content one can imagine can already be found somewhere on the Internet, finding those good things can be very difficult amid the near chaos of unedited information, self-promoting, and disguised commercial sites; claims unsupported by science; and uncontrolled chat rooms. On top of that, variation in interfaces and in developer expertise makes the transition from site to site difficult, and the multiplicity of sources undercuts the likelihood of achieving a sense of a sustained, continuous relationship with an information source who is an “other” who cares. Furthermore, the patient seeking detailed information about a particular disease will quickly see the same information repeatedly and could decide prematurely that she has learned all that is available.

Furthermore, much of the optimistic research about health use of the Internet presumes healthy individuals or at worst the “worried well” as its users (Rice, 2006). We argue that the potential problems with the Internet listed above should become much more serious for someone dealing with the shock of life-threatening disease diagnosis and treatment. With the pillars of quality of life already undercut, these problems and limitations of the Internet may present more substantial barriers to beneficial use. With autonomy and competence already low, the contradictions, repetitions, and variable credibility of Internet content could well limit how much a breast cancer patient persists in seeking and understanding information, and especially in how much she works to translate it to her own situation and apply it. Similarly, even if open chat rooms and forums are much easier to access than are face-to-face groups, if they contain so many users that they confuse the newcomer, or if unregistered crashers divert conversations or engage in personal attacks, patients may be unlikely to get the relatedness benefits they need.

In contrast, CHESS is Internet based but provides an integrated and comprehensive system of services designed to complement each other and together attempt to speak to all the needs of breast cancer patients. The 12 CHESS services share a common interface and constantly point to each other as they provide three types of content. *Information services* include (a) Questions & Answers (short answers to hundreds of breast cancer questions), (b) Instant Library (full articles on breast cancer), (c) Consumer Guide (descriptions, identifying a good provider, and being an effective consumer of key services), (d) Referral Directory (descriptions of and contacts for breast cancer organizations), and (e) Web Links (links to high-quality content in health-related and non health-related sites). *Communication services* include (a) Discussion Groups (limited-access facilitated bulletin boards for small groups of patients and families), (b) Ask an Expert (confidential expert responses to patient questions), and (c) Personal Stories (real-life text and video accounts of how others coped with breast cancer). *Decision services* include (a) Assessment (emotional status measures and tailored advice on coping), (b) Health Charts (tracks health status and links material addressing specific health concerns), (c) Decision Aid (options, values, and consequences for key decisions), and (d) Action Plan (evaluates plans for change and suggests improvements).

In contrast to the vast but unregulated body of information on the Internet, CHESS is a not-for-profit system providing focused and systematic content based on needs identified in studies of women with breast cancer, their partners, and adult children (Gustafson et al., 1993). Whereas much content on the Internet is purely informative, CHESS decision services explicitly support autonomy. CHESS does so without attempting to impose direction on the user. As an example, its Decision Aid does not reach a “you should do this” conclusion but instead helps the woman understand her options and values and lets her decide how well each option satisfies each of the values. CHESS supports competence both by providing clear and easy-to-understand information and by directing that information to

specific competence venues facing patients: how to deal with treatment information, how to prepare for clinic visits, and how to manage interactions with clinicians. Once again, the planning and decision tools (present but rare on the general Internet) specifically model and teach skills to turn knowledge into competence for dealing with the disease. Of course, the limited and protected environment of CHESS Discussion Groups should be a better environment for relatedness than their open counterparts of the Internet, and the Ask an Expert feature should be powerful in this regard. But CHESS may also foster relatedness for users with the system itself. The continuing contact with a consistent source should foster a sense of social “presence” (Lee, 2004; Walther, Pingree, Hawkins & Buller, 2005)—the sense that another is relating to and helping the patient. Other Internet resources also have the potential to create presence, but only if a user maintains a relationship with a particular source over time.

Given these considerations, we make two primary hypotheses about patient quality of life, experienced social support, and health competence. First, the great range of resources and information present in both CHESS and the Internet generally, and their shared ease of access, should make them both superior to the control condition.

H1: Breast cancer patients given access to computer-based resources (i.e., both the CHESS and the Internet groups) will have higher quality of life and social support and better competence in health information and health-care settings than controls.

But because of the problems the Internet presents to the user, the integrated system (CHESS) should be better than the Internet.

H2: The CHESS group will have higher quality of life and social support and better competence in health information and health-care settings than the Internet group.

To track whether these effects occur early or later during treatment (and the computer interventions) and whether they persist after the interventions were withdrawn, these hypotheses were tested 2, 4, and 9 months after the start of study. For a typical patient, these times roughly corresponded to the middle portions of treatment, late treatment or initial recovery, and survivorship.

An implication of our argument for H2 is that Internet subjects would use the computer less frequently for health information than would CHESS subjects, because the pieces of the integrated system pointed to each other within a single interface. In contrast, Internet users might stop seeking breast cancer information early due either to frustration or because redundancy leads them to believe that there is no more to retrieve. We also explored whether the expected outcome superiority of CHESS would be due to the Internet group’s less frequent and less health-focused computer use.

H3: The Internet group will spend less time seeking health information than will the CHESS group.

Methods

Participants

Women with recently diagnosed breast cancer were randomly assigned to one of the three 5-month interventions: (a) access to the Internet; (b) access to CHESS and through it, the Internet; or (c) receive their choice of several books on breast cancer or a set of general cancer audiotapes.

Breast cancer patients were recruited from cancer centers in Madison, WI; Cleveland, OH; Detroit, MI; and Rochester, MN. Patients were eligible if they were within 61 days of their

diagnosis, not homeless, able to give informed consent, and understand and answer sample questions from the pretest. Doctors or nurses introduced the study to patients during clinic visits. If patients permitted, a research staff member contacted the patient, saying that we were evaluating various methods of providing information and support to women with breast cancer. After the study was described, participants signed a letter of consent giving access to their medical records and allowing us to monitor their computer use (if so assigned), completed a brief pretest survey, and were randomly assigned to the Internet, CHESS, or control group. Random assignment was stratified by geographic site and ethnicity (minority or Caucasian), with each site provided two sets of randomly ordered sealed envelopes containing group assignments.

Over 83% of those invited agreed to participate (ranging from 81 to 87% at various sites). Decliners did not differ in demographic characteristics from those who agreed. A total of 257 eligible patients were recruited. Random assignment led to 83 entering each of the Internet and control conditions and 91 to CHESS. Two-month posttests were completed by 253 of the 257 subjects (98%), 246 (96%) completed the 4-month posttest, and 240 (93%) completed the 9-month posttest. The 2-, 4-, and 9-month posttest completion rates for each of the study arms were 95, 96, and 90% for Internet; 99, 93, and 88% for CHESS; and 100, 94, and 90% for controls, respectively. Participants were paid \$15 for each completed pre- and posttest.

The control group received usual care plus their choice of several books or a set of audiotapes on breast cancer (to reflect ways breast cancer patients often obtain help). Patients assigned to the Internet or CHESS arms received a computer delivered to the home (a minority used an Internet-capable computer they already owned) and Internet connection paid during the 5-month intervention period (we paid for telephone line installation and local service for the small number who did not already have a telephone). All were paid by the project upon completion of surveys.

The Internet group received personal training (averaging 51 minutes) on Internet use (browsers, Web pages, hyperlinks, navigation, using search engines, etc.). We provided links to six breast cancer Web sites (an increasingly common practice in medicine), judged to be high-quality using criteria recommended by the Science Panel on Interactive Health Communication (Eng & Gustafson, 1999): expert developers, not-for-profit sponsorship, clear program aims, and user confidentiality protection. The sites were NCI, ACS, Komen, Celebrating Life Foundation (for African Americans), Y-Me, and OncoLink. All sites offered breast cancer information, five included asynchronous discussion groups, two provided experts' answers to questions, and two offered decision support. However, none offered coverage as complete as CHESS, and there were substantial redundancies between them. Of course, patients were free to search anywhere on the Internet.

The CHESS group received training (averaging 58 minutes, 10% longer than the Internet group) on basics of using a computer and the Internet but spent more time on how to use CHESS. Trainers taught subjects to use CHESS, demonstrated key services, and helped the patient write a first Discussion Group message and a question to the expert. They saw how to access a Flash training program about CHESS. Services that were not demonstrated were described.

Both CHESS and Internet groups received a manual covering their training material and follow-up training was available to both. A toll-free helpline was operated weekdays by project staff between 8 a.m. and 4 p.m. CST to help Internet and CHESS participants with computer use, modem connections, and Internet browser. At other times, users could leave a voice message. Staff checked messages 7 days a week and responded to users as soon as

possible. We received an average of four calls per week across all subjects or about one call from every three subjects across the entire study. Almost all calls were about hardware or connections problems not specific to experimental condition.

Measures

Internet and CHESS use—To track Web use, we developed a Web browser that saved the user's code name, date, time, and URL of every Web page requested on our Web server databases. Thus, our browser was always tracking navigation to and through any Web site. To assess the degree to which respondents accessed resources that might help them deal with their breast cancer, the research team coded URLs visited as either health-related or non health-related sites. Health-related URLs were subclassified as (a) health information (e.g., health information, online pharmacy), (b) health communication (health-oriented bulletin boards, chat rooms, and discussion groups), (c) alternative medicine, (d) religion and spirituality, and (e) searching by health key words. Non health-related URLs were subclassified as (a) shopping, (b) communication (e-mail, e-card, non health-related chat room, bulletin boards), (c) entertainment (games, entertainment, adult entertainment, and match making), (d) information (e.g., school, laws, recipes, jobs), and (e) searching by key words to nonhealth. We excluded from analysis URLs in which subjects spent less than 6 seconds.

Patient characteristics—Social and demographic characteristics (age, race, education, income, and living with others or alone) were assessed at baseline. Sixteen (6%) did not check a household income category. We used Census data to assign them most probable incomes using address and ZIP code. Diagnosis date, treatment schedule (surgery, radiation, and chemotherapy), and stage of disease were collected from baseline and 2-, 4-, and 9-month surveys. If discrepancies between surveys appeared, we reviewed medical records and called participants. For analyses, we classified breast cancer patients at stages 0, I, and II as early and those at stages III and IV as late because this defines a medical boundary at which treatment choices and prognosis differ considerably. Patients also self-reported degree of functional impairment due to their breast cancer at each time point using the Eastern Cancer Oncology Group (ECOG) measure.

Outcomes—This study collected nine different outcome measures to allow for eventual finer-grained analyses of specific intermediate processes. Each was transformed to a 0–100 scale for equivalence. However, for the overall comparisons reported here, we combined measures to create summative outcomes for three areas: quality of life, social support, and health and information competence. (Details on items may be obtained from the second author.) Although these were conceptually distinct groups of outcomes, we performed a second-level principal components analysis to check on the groupings. After specifying a three-factor solution (63% of the variance), varimax rotation separated the nine measures into the three specified groups with all on-factor loadings .63 or greater and only one off-factor loading greater than .30 (emotional well-being .46 on the competence dimension).

Quality of life measures—The Functional Assessment of Cancer Therapy-Breast (FACT-B) (Brady et al., 1997) was used to assess the impact of breast cancer and its treatment on dimensions of quality of life. Reliability, validity, and responsiveness to clinical change have been extensively demonstrated (Cella et al., 1993). We used FACT-B to measure Functional well-being (Cronbach's α [measuring scale internal consistency] = 0.80) and Emotional well-being (α = 0.85). The FACT-B also includes a collection of items assessing breast cancer-related concerns pertaining to different quality of life (QOL) domains. Although that scale does not have high internal consistency because concerns are partially independent issues, three of those items focusing on body image-related concerns

(feeling self-conscious about the way one dressed, feeling sexually attractive, and ability to feel like a woman) were combined into a measure of *Concerns* about body image (Cronbach's $\alpha = 0.59$). We also included a two-item scale assessing *Depression* ($\alpha = .67$). With the latter two reversed for consistency of direction, the average intercorrelation of the four scales was $r = .41$, and the average of the four was used to assess overall *quality of life*, $\alpha = .75$.

Social support—A six-item Social Support scale ($\alpha = 0.88$) developed for previous CHESS clinical trials assessed women's perception of emotional and instrumental support (Gustafson et al., 1999, 2001). Focus groups with previous CHESS users produced five items reporting how much the women felt a *bond* with other patients ($\alpha = 0.85$). These two scales correlated ($r = .42$), and their average was used as an overall measure of Social Support.

Health competence—We also examined impact on the patient's health-related activities using measures from previous CHESS studies (Gustafson et al., 1999, 2001). Health Self-Efficacy was a five-item scale ($\alpha = 0.83$) assessing women's perceptions of self-efficacy specific to health issues. Healthcare Participation was an eight-item scale ($\alpha = 0.85$) assessing a woman's comfort and activeness dealing with physicians and health-care situations. Can't Get Health Information ($\alpha = 0.84$) was a three-item scale assessing access to health information. With the latter reversed for directional consistency, the average intercorrelation of the three measures was $r = .44$, and their average was used as an overall measure of the woman's competence with health care and health information, $\alpha = .73$.

Data collection—Data were collected by self-administered survey. Pretest occurred before randomization. Posttests used mail delivery. Surveys were returned in preaddressed, stamped envelopes to our Madison office. To maintain comparability, we mailed surveys at the same time-from-start rather than in cohorts. Site coordinators made calls to ensure the survey arrived and to encourage prompt completion. If subjects did not respond within 1 week, we made a follow-up call and mailed a second survey. After one more week, a "last resort" attempt was made to collect the data by phone, recognizing the potential bias from altering methods. The return rate was 94%. Returned surveys were immediately entered into the database. If missing data were found, site coordinators called the patient. If data were still missing (e.g., if a patient could not decide how to answer), but more than half the scale items were answered, we used the mean of available items.

Analysis—As mentioned earlier, computer use was classified as CHESS, non-CHESS Internet health, and Internet nonhealth related. To address subjects who came to a URL and then did something else (e.g., went to lunch, leaving the computer on), we truncated time spent on a URL at 20 minutes, though very few uses exceeded 20 minutes. We then calculated number of logins, total time spent, and time spent in each category and subcategory per participant each week.

Because a few very heavy users skew measures of computer use, statistical tests employed measures transformed by natural logs (adding 1 minute to all scores to avoid attempting to take the log of zero). However, figures display the original metrics (e.g., minutes per week) for easier interpretation. For analyses comparing amount of use for all women assigned to CHESS and Internet groups (i.e., including zeros from nonusers), analyses employed a 2 (between groups) $\times$ 20 (weeks, a repeated measure for individuals) general linear model. For analyses focusing only on users, this repeated measures model was impractical because many women were nonusers during some week. Instead, we employed separate between-group *F*-tests for each week (or, when percentages were involved, separate chi-squares). Statistical significance reports two-tailed tests.

Tests of intervention effects used an intention-to-treat approach comparing original randomized groups regardless of individuals' use of CHESS or Internet. A breast cancer patient's quality of life is affected by demographic, living situation, and treatment variables. Moreover, it was important to consider the time trends of treatment effects on quality of life (increasing scores over time on most measures but lower on a few, e.g., social support). Hence, each analysis controlled for pretest level of the dependent variable. In addition, because these outcomes are often associated with other patient characteristics, the second and ninth authors jointly decided on a parsimonious set of controls for each dependent variable, based on experience and past research (Wellner, 2000). Tests with quality of life also controlled for age and race; tests with social support controlled for income; and tests with health competence controlled for age, race, and education SPSS general linear model (GLM) procedures contrasted CHESS and Internet conditions against controls and CHESS against Internet. Because comparisons of both CHESS and Internet conditions against controls stemmed from the same hypothesis (H1), each was tested with $\alpha = .025$.

Results

Internet and CHESS Use

Whether and how subjects used the Internet and CHESS is a first step in determining how they were helped by access to these technologies. Figure 1 shows that both groups used very frequently at first (around four to five logins the first week) and then used less frequently over time, declining to around one login or less per week at the end (linear contrast, $p < .001$). CHESS subjects appear in Figure 1 to have logged in more frequently than Internet subjects, but the difference is not significant ($p = .06$). The differences in average number of logins per week are paralleled by differences in the percentage logging in each week. More than 70% of the CHESS group signed on the first week (vs. just under 60% of the Internet group) and both declined across the 20 weeks, to about 30 and 15%, respectively. The CHESS group was somewhat more likely to ever use their computers (cumulative percentage 92 vs. 85 for Internet).

However, potential benefits of computer use for breast cancer patients are likely a function of both frequency of logins and time spent during them. One might expect that a longer login offers more opportunity to learn, greater depth of thought, or other benefits. Simply examining group differences in total time logged on, the CHESS group as a whole spent more time online ($p < 0.001$). However, it could simply be that this results from the CHESS group's greater likelihood of logging on at all, rather than spending more time when they do. To get an independent test of this, we compared time using the computer only for those who did at some time log on, and then there was no significant difference in the amount of time spent online between CHESS and Internet groups.

However, even frequency and length of use may not necessarily capture effective use. One should not assume that breast cancer patients only seek information and support about their disease and its treatment when online. Users could be shopping, playing games, reading news, searching aimlessly, or using e-mail. Our tracking system allowed us to see which URLs were visited and to categorize them into health-related and non health-related URLs. Considering only breast cancer patients who actually used their computer in a given week, the Internet group used non health-related sites much more than the women in the CHESS group ($p < .05$ for each of the 20 weeks). Conversely, the CHESS group spent much more time on health content ($p < .01$ during each of the 20 weeks).²

²These two significance tests are not redundant because it includes only those who used each type of content in a given week.

Because all CHES contents were classified as health, a final analysis excluded CHES use and compared amount of use of non-CHES Internet health information, to which both groups had equal access. Those among the Internet group who did use their computers (always a smaller percentage than the CHES group) spent more time on non-CHES health-related URLs than the CHES group (significant at $p < .05$ for 13 of the 20 weeks). However, after the first 2 weeks the differences are quite small. This suggests that the Internet group quickly used up locatable health resources and moved on to other non health-related issues. Put another way, in addition to the much larger time CHES users spent on health information within CHES itself, they also spent almost as much time on health information outside CHES as did the Internet group who had no alternative.

Outcomes

Tables 1–3 report regression analyses comparing Internet, CHES, and control groups at 2, 4, and 9 months after intervention began (on average, intervention occurred 31 days after diagnosis), controlling for pretest level of the dependent variable. Each table summarizes results at one of these times and displays three pair-wise comparisons between experimental groups.

At 2 months (Table 1), neither the group that received CHES nor the Internet group showed significantly greater positive change in these three measures than controls (recall that $p < .025$ is required for comparisons with controls, as the CHES and Internet groups share alpha here). But it is noteworthy that in all three comparisons, the Internet group improved *less* than controls, who were thus intermediate between the two computer intervention groups, rather than trailing both as expected. For testing the second hypothesis, the CHES group was significantly better off than the group receiving the Internet on all three measures: quality of life, social support, and health competence.

At 4 months, when initial treatments and recovery have typically been accomplished (Table 2), the CHES group scored higher than controls for social support, but again the Internet group did not differ from controls on any measure. Here, the CHES group scored higher than the Internet group on both quality of life and social support.

By 9 months (Table 3), several months after the interventions had ended and computers were returned, the CHES group scored significantly higher than controls on quality of life and social support (and the difference for health and information competence was at $p = .028$). Although again no comparisons were significant between the Internet and control groups, it may be noteworthy that the negative signs of earlier tables were here reversed, leaving the Internet group in the intermediate position of the three groups. At this point, the CHES group no longer scored significantly higher than the Internet group on any of the three outcomes.

Discussion

This research assigned recently diagnosed breast cancer patients to receive either (a) unlimited, home-based access to the Internet, including guidance to high-quality breast cancer sites, (b) added to that access to CHES, an integrated computer-based health support system previously shown to have positive impact on quality of life, or (c) cancer information from traditional, universally available media: books or audio-tapes. Treating this latter group as a usual-care control, we hypothesized that access to computer-based resources (i.e., the Internet and CHES groups), and even more so CHES, would help breast cancer patients achieve better quality of life, social support, and competence dealing with health information and the health-care system.

The sample included most types of women with breast cancer (variation in age, stage, treatment, education, income, and insurance), except patients who could not read because of illiteracy or vision problems. Subjects were 25% minorities, nearly all African American. The four midwestern U.S. cancer center recruitment sites drew patients from urban, small city, and rural areas (40% of Caucasians were from rural areas) and included public and private hospitals. Results should thus be fairly generalizable, except for non-African American minorities or patients treated at small general surgery clinics. We spent similar time training Internet and CHESS subjects. However, CHESS training focused on the content and operation of that single system, whereas training for Internet subjects focused on Internet navigation and searching.

The hypothesis that computer-based access to information and support (i.e., both the CHESS and the Internet groups), with its greater ease of access, much greater range and potential depth of content, and greater potential to be up-to-date, would provide an advantage over usual-care controls for quality of life, social support, and health competence received only limited support overall. After dividing alpha between the two group comparisons, none of six comparisons were significant at 2 months, at 4 months only one of six, and at 9 months two of six. In contrast, the hypothesis that CHESS would provide added benefits beyond those of the Internet was supported, especially early on: for all three outcomes at 2 months and two of three at 5 months, but none at 9 months.

However, the pattern of mean pre-post differences was so different between the CHESS and the Internet groups that the assumptions behind the first hypothesis may themselves have been flawed. Clearly, access to the Internet and to CHESS did not produce anything like comparable advantages over usual-care controls. Despite the lack of significance, it is striking that the Internet group trailed controls on five of six measures at 2 and 4 months, whereas the CHESS group led controls on all six. Given this apparent lack of comparability, it is worth noting that the CHESS group's social support score would have been significantly higher than controls at 2 months as well ($p = .039$) if alpha had not been divided due to the two groups sharing this hypothesis. Similarly, although the CHESS group had significantly better quality of life and social support than controls at 9 months, the difference was also near significance ($p = .028$) for health and information competence.

It is somewhat surprising, but nonetheless encouraging for long-term effectiveness, that these differences remained and were largest after the intervention was removed. It may be that CHESS leaves a lasting impression that there are others who care and empathize and that the confidence developed in dealing with clinicians continued to grow.

Thus, rather than computer access generally helping breast cancer patients more than usual care (Hypothesis 1), the apparent differences between these groups and their shifts over time suggest that the two computer-based conditions had quite different effects. It would seem that simple access to Internet services provided patients little or no benefit over usual care. In fact, the negative signs of these relationships at 2 and 4 months, although not significant, instead suggest the Internet might even have had an initial detrimental effect. In other words, access to the Internet provided no benefits and might even have been initially less helpful than books or audiotapes, despite the wealth of potential services available, a highly motivated group of users, and our training in search strategies. Access to an integrated system of services, on the other hand, apparently helped patients more than usual care, initially only with social support but by 9 months with quality of life and health competence as well. That differences between the CHESS and Internet groups were large initially and nonsignificant (though still positive) after 9 months might thus represent the initial combination of small CHESS benefit and small Internet decrement versus controls, and later, a growing and significant CHESS benefit over controls, whereas the Internet finally

began to be of some use to patients (and the Internet group may have found ways to continue their Internet use even after the intervention ended and the loaned computer was returned).

So how can these two interventions have had such different impacts? The data on patients' computer use may provide some explanation. Note first that both groups made far more use of the Internet than controls, 65% of whom reported using the Internet once or less during the first 2 months of study. Then, even though the patients in the Internet group were directed to good Web sites, fewer in the Internet arm than in the CHESS group ever used their computers and fewer used the computer in any given week. Hence, any benefits over controls realized by some in the Internet group may have been diluted by those who did not take advantage of the resource. Next, recall that women in the two groups who did use their computers spent comparable time online. But except for the first weeks, the Internet group spent most of their time on non health-related content such as e-mail, whereas the CHESS group focused overwhelmingly on health content. In addition to substantial CHESS use, the CHESS group spent almost as much time as the Internet group at health Web sites outside of CHESS. Thus, despite having access to a wide range of resources that could have addressed their breast cancer concerns, women in the Internet group made relatively little use of what should have been most useful to them. Coupled with the outcome differences between the groups, we must wonder whether the Internet subjects were getting enough help dealing with the disease.

CHESS and Internet subjects were asked open-ended questions about what they liked most and least about their system. By far, the Internet group most liked the multiple sources of information, followed by the convenience of access to information. The CHESS group also most liked the convenience and many sources of information but also the ability to get and give support through the discussion group. Four negative characteristics stood out among the Internet group that may explain the lack of use: long time required to find information, difficulty of navigating different sites, inability to find information they needed, and slowness of the computer. Thus, although the Internet group began with a number of high-quality breast cancer URLs bookmarked, it may have been more difficult to navigate within and between sites with different interfaces than for the CHESS group, who could seek their disease and treatment information within a single, integrated site. The CHESS group *least liked* the slowness of the computer and the discussion groups ($n = 14$). Interestingly, the discussion group was also the most liked aspect of CHESS (for 39 respondents).

Zuboff and Maxmin (2002) argue that what consumers want is trustworthy assistance with life's intricate problems and not deception, arrogant expertise, or on-again/off-again service. Help that is provided in one-shot approaches is not real help. Consumers might get exactly what they need in that single transaction, but it is not likely. Life's major problems are rarely simple enough to be solved with one dose of not necessarily credible or deep help. The experiences breast cancer patients had with the Internet in this study may have been examples of single transaction-level conditions, in Zuboff and Maxmin's terms. It is entirely possible to find some part of an answer to questions and gain significant help on the Web, but it is a lot of work and not very satisfying. Also, this difficult search process needs to be repeated at each use episode.

In contrast, CHESS is an example of a system that provides deep, there-for-the-duration support. It is engineered to provide ongoing support in its interactive systems, deep content, and relationship-focused discussion groups. It is not surprising that the most noticeable effects can be found in the relationship-oriented variable of social support and that the most used service is discussion group.

Given these results, we suggest the following for eHealth systems.

We deeply respect the need for innovation to improve Internet capabilities and usability, and successful innovations spread and breed further innovation. However, the Internet may be too chaotic, confusing, and untrustworthy for many people facing the stresses of a life-changing illness. As one Internet subject noted: “(The Internet) hindered a lot. Much of what I read seemed so scary (BAD news and bad stats) and worse case scenarios. I preferred not to surf for information, but to rely on my own provider.”

Health-care providers should direct people facing serious illness or injury to a single high-quality Web site that is comprehensive and regularly updated by objective and unbiased experts. Proprietary Web sites face enormous incentives to bias presentations to promote products they sell. Moreover, the Internet’s growing capability to influence behavior and evidence that people are attracted to glitz, not quality (Bader & Strickman-Stein, 2003; Eysenbach & Kohler, 2002), makes it essential to direct users to sites driven by quality-promoting incentives. Hence, we believe that the federal government or a respected not-for-profit advocacy group should develop and maintain such sites just as they operate telephone information services.

Web sites for serious illness and injury should contain (a) an extensive collection of current, high-quality information written for those with low literacy, (b) communication (anonymous discussion groups limiting access to people known to be facing the illness and ability to ask experts questions), (c) tools (e.g., decision analysis, action planning tools, skills training tailored to the condition), and (d) monitoring (tracking user needs and then guiding users to appropriate resources in and outside the Web site). Their contents should be based on a thorough assessment of user needs, one that identifies changes in needs over the illness trajectory. We believe that effective use of such Web sites requires attractive, informative online training so users know what to expect and how to navigate and get the most out of the program. Few sites contain such training.

Finally, this study needs confirmation to determine whether the results hold for similar populations, whether they hold only for certain diseases, and whether disease severity influences the utility of the Internet. It is possible, as more people become familiar with the Internet, that the initial problems reported here will diminish. However, such optimism must be qualified by the concern that diagnosis with a life-threatening illness may be so different from previous experience that a whole new set of Internet skills must be developed to effectively apply open access to the Internet to such situations. If so, the relative benefits of integrated systems may well persist.

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Figure 1.
Average number of logins per participant.

Table 1

Mean Differences Between Conditions at 2 Months

Variables	CHES (n = 90)			Internet (n = 79)			CHES (n = 90)		
	Minus Control (n = 83)			Minus Control (n = 83)			Minus Internet (n = 79)		
	M (SD)	Effect Size	p Value	M (SD)	Effect Size	p Value	M (SD)	Effect Size	p Value
Quality of life	0.02 (0.54)	0.29	.058	-0.02 (0.56)	-0.03	.84	0.18 (0.53)	0.34	.029*
Social support	0.16 (0.49)	0.32	.039	-0.08 (0.56)	-0.14	.39	0.23 (0.49)	0.47	.003**
Health and information competence	0.12 (0.47)	0.25	.126	-0.03 (0.48)	-0.06	.69	0.17 (0.39)	0.44	.007**

Note: Means are covariate adjusted for control variables described in text. Pre-post difference score analog results from also covarying pretest level of dependent variable.
CHES = Comprehensive Health Enhancement Support System.

* p < .05.
** p < .01. CHES versus control and Internet versus control comparisons share alpha, thus p < .025 for significance.

Table 2

Mean Differences Between Conditions at 2 Months

Variables	CHESS (<i>n</i> = 85)			Internet (<i>n</i> = 80)			CHESS (<i>n</i> = 85)		
	Minus Control (<i>n</i> = 78)			Minus Control (<i>n</i> = 78)			Minus Internet (<i>n</i> = 80)		
	<i>M</i> (<i>SD</i>)	Effect Size	<i>p</i> Value	<i>M</i> (<i>SD</i>)	Effect Size	<i>p</i> Value	<i>M</i> (<i>SD</i>)	Effect Size	<i>p</i> Value
Quality of life	0.10 (0.53)	0.18	.24	-0.07 (0.59)	-0.12	.44	0.18 (0.58)	0.31	.047*
Social support	0.25 (0.53)	0.46	.004**	0.03 (0.60)	0.05	.77	0.20 (0.56)	0.35	.027*
Health and information competence	0.07 (0.40)	0.17	.32	-0.05 (0.45)	-0.10	.53	0.19 (0.40)	0.23	.15

Note: Means are covariate adjusted for control variables described in text. Pre-post difference score analog results from also covarying pretest level of dependent variable.

* $p < .05$.

** $p < .01$. CHESS versus control and Internet versus control comparisons share alpha, thus $p < .025$ for significance.

Table 3

Mean Differences Between Conditions at 3 Months

Variables	CHES (n = 80)			Internet (n = 75)			CHES (n = 80)		
	Minus Control (n = 75)			Minus Control (n = 75)			Minus Internet (n = 75)		
	M (SD)	Effect Size	p Value	M (SD)	Effect Size	p Value	M (SD)	Effect Size	p Value
Quality of life	0.18 (0.54)	0.39	.018*	0.07 (0.45)	0.16	.33	0.11 (0.45)	0.24	.14
Social support	0.21 (0.55)	0.38	.021*	0.06 (0.58)	0.10	.57	0.13 (0.54)	0.24	.14
Health and information competence	0.18 (0.48)	0.38	.028	0.06 (0.49)	0.12	.48	0.12 (0.37)	0.24	.16

Note: Means are covariate adjusted for control variables described in text. Pre-post difference score analog results from also covarying pretest level of dependent variable.

* $p < .05$. CHES versus control and Internet versus control comparisons share alpha, thus $p < .025$ for significance.