Abstract
Fatigue is a pervasive symptom in individuals with cancer that is often underrecognized and undertreated by health care providers. Contrasted with the sparse data in support of pharmacologic interventions for the management of cancer-related fatigue, the literature for nonpharmacologic interventions is vast. In particular, support groups have proven beneficial. Limited access, transportation issues, and unwillingness to share in a public forum represent just a few of the barriers to more widespread participation in face-to-face support groups. Millions of people with cancer rely on the Internet to gain information regarding their diagnosis and to validate their cancer experience. Tapping into this wealth of online information is an obvious avenue for patients with cancer-related fatigue to seek support. This article explores online- and computer-mediated support groups for fatigue. (JNCCN 2013;11:1211–1217)

Treatment for Cancer-Related Fatigue

Overview
The NCCN Cancer-Related Fatigue Panel defines the condition as “a distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.” Approximately 40% to 80% of patients with cancer experience fatigue, with the elderly, those undergoing treatment, and patients with advanced disease often reporting severe fatigue. When surveyed about the relative importance of fatigue compared with other symptoms, patients with advanced cancer ranked fatigue as the most important. Fatigue continues to challenge cancer survivors and, compared with those without cancer, is more prevalent in this population. Fatigue rarely stands alone as a symptom. When assessing a patient for fatigue, other contributing factors, especially reversible ones, must be evaluated. Examples include pain, depression, anemia, sleep disturbance, and medication side effects. General strategies for the management of cancer-related fatigue (CRF) are divided into pharmacologic and nonpharmacologic interventions. The NCCN categorizes the psychosocial interventions into behavioral therapy/cognitive behavioral therapies, psychoeducational therapies/educational therapies, and supportive expressive therapies.

Support Groups
Support groups are an example of supportive-expressive therapy. Cancer support groups can either be professionally led or self-help in nature. Regardless of the organizational structure, the therapeutic goals of these groups are the same: to provide emotional support and empowerment, and to teach coping strategies. The availability of feedback and peer support among members is a major strength of support groups.

Numerous systematic reviews and meta-analyses show the efficacy of nonpharmacologic therapies for CRF. In a meta-analysis of 30 trials by Jacobsen et al, group-based interventions had significant impact on fatigue, although the effect size was small. The included studies did not provide the eligibility criteria detailing a required level of fatigue at study entry, thus limiting the study design’s ability to detect intervention effects. Most of the studies involved women with breast cancer in whom an intervention effect was absent. In contrast, another meta-analysis restricted to patients with breast cancer reported a modest but significant summary effect size of −0.158 (95% CI, −0.233 to −0.082; P<.001) for behavioral interventions on fatigue. Differences in outcome were age-dependent, with younger
women (age <50 years) benefitting more from the psychosocial interventions. Because younger women with breast cancer at the time of diagnosis (age, 27–44 years) report worse quality of life in social domains, the differential benefit of psychosocial interventions may be attributable to their increased psychosocial burden. Whether an intervention is individual- or group-focused had no bearing on effect size according to a systematic and meta-analysis review by Kangas et al. Forty-three percent (3/7) of the randomized controlled trials categorized as supportive-expressive therapies resulted in significant improvement in fatigue. Another meta-analysis restricted to randomized controlled trials of patients receiving active treatment similarly showed efficacy of psychosocial interventions in curbing fatigue.

The Internet and Cancer

Despite concerns about the reliability of health-related information on the Internet and the challenges inherent in rating content of Web sites, the reality is that the Internet has a profound impact on contemporary public health. In 2003, an estimated 23 million persons with cancer (39%) used the Internet. These numbers roughly reflected oncologists’ estimates of their patients’ Internet use at that time (30%). The Pew Research Center’s Internet & American Life Project, a nonprofit research organization that studies the social impact of the Internet by conducting national random digit-dialing telephone surveys of both landline and cell phones, reported that currently 85% of American adults use the Internet (Figure 1). The demographic of Internet users is equally divided among men and women, yet more heavily weighted toward individuals who are younger, more educated, and in higher socioeconomic groups. Although adults with chronic illness are less likely to go online (62%), many have secondary access through their caregivers. In addition, 80% of adult caregivers have Internet access. The NCI Health Information National Trends Survey (HINTS), which tracks how patients with cancer obtain health information, reported that in 2008 nearly 60% of patients relied on the Internet as their first source of information. Interestingly, the survey revealed that patient trust in the Internet as a reliable source waned between 2002 and 2008, whereas trust in physicians increased during that same time frame. Reliance on the Internet for cancer-related information among patients with cancer is impacted by not only access issues but also computer literacy, search skills, and health literacy. Similar to the typical demographic of Internet users, patients with breast cancer who use the Internet tend to have a higher income and education level compared with nonusers.

Social Media

With 6 in 10 US adults accessing the Internet wirelessly, information is now widely portable. Half of American adults use social networking sites. Among Internet users, social networking use increased from 8% to 67% from 2005 to 2012. The adoption of social media in the mainstream has moved the Internet beyond a tool for obtaining health care information passively to an outlet to engage others in a very par-

Figure 1  Internet adoption, 1995–2013. Percent of American adults (≥ age 18) who use the Internet, over time. As of May 2013, 85% of adults use the Internet.
From Pew Internet & American Life Project Surveys, March 2000–May 2013, with permission.
Online Support for Fatigue

Applications of the Computer/Internet in Cancer

Symptom Reporting and Needs Assessment

Computers allow for robust data capture for patient symptom reporting and needs assessments. A Web-based pilot study aimed at assessing needs from a diverse population of cancer survivors showed feasibility of rapid and comprehensive data collection from a statewide population.26 In a systematic review of 29 randomized controlled trials of electronic symptom reporting, outcomes were categorized according to who benefitted (eg, patients, health care professionals, the health care system).27,28 Many of the individual studies showed an improvement in health-related quality of life in the intervention arms. All of the cancer studies (n=5) focused on patient-centered outcomes. Despite the demonstrated congruence between patient-reported symptoms and the symptoms addressed by the clinician, an improvement in patient satisfaction was not routinely described in the experimental arms. Continued research is necessary to determine how best to integrate electronic self-report assessments (ESRA) into routine clinical practice.

As a natural outgrowth for providing improved patient care at the individual level, ESRA may have broader implications in the public health arena for symptom surveillance. Integrating this wealth of information into a population-based clinical database could lead to the development of a “rapid-learning” health care system in which the health care system learns through analyzing captured data.29 Rapid learning health care systems are gaining considerable attention from national entities, including the Institute of Medicine and ASCO. ASCO is addressing the Institute of Medicine’s core recommendation through implementing CancerLinQ, which is in the first phase of development.

Support

Most individuals with cancer who use the Internet for health care purposes are seeking support, whether it is informational, emotional, or a combination.

Informational Support

Before the Internet, obtaining health-related information other than what was provided by the clinician was a relatively difficult pursuit. Interactive health computer systems for those with chronic illnesses have narrowed the information gap. The best known example of such a program is the Comprehensive Health Enhancement Support System (CHESS). Extensive studies of CHESS, including those specifically evaluating patients with cancer, demonstrate improvements in patient-reported quality of life.30–32

Electronic narratives allow patients to share their personal experience with illness. Retrieval of information can be a daunting task. Overberg et al33 demonstrated that user satisfaction among patients with breast cancer is improved by implementing methods to streamline the information to allow for ease in conducting tailored searches. Investigators from Oxford created a multimedia database of patients’ experiences (DIPEx), and linked these with evidence-based information about the illness, treatment, and support groups.34 DIPEx, now known as healthtalkonline.org, is an active Web site that provides the experiences of more than 2000 people with regard to more than 60 health-related conditions and illnesses.

Patients frequently rely on Internet support groups for guidance with medical decisions. The larg-
The earliest German online support group for prostate cancer was investigated to appreciate patient-to-patient communication in medical decision-making. Threads were limited to those individuals with newly diagnosed prostate cancer, with decision-making as the key topic. Although queries regarding treatment recommendations were most common, many also sought emotional support (46%). The social interactions among users were unevenly distributed, with 5% of all users contributing 70% of the postings. Hartzer and Pratt recently analyzed comparative content on Internet message boards and books to investigate how informational support provided by breast cancer survivors differs from that of clinicians. Patient expertise was defined as “experiential knowledge gained from personally managing the day-to-day experience of illness.” Patient expertise was predominantly personal in topic and offered actionable advice (eg, quick remedies for everyday issues). In contrast, clinician expertise followed a prescriptive style and focused on health care– and research-related facts. The expert advice of patients was clearly unique and offered information that clinicians frequently cannot provide.

How the Internet affects the doctor-patient relationship is not well-known. Interviews from 28 current Internet users and 5 never-users all with prostate cancer, revealed 3 central themes. The Internet enhanced the patient’s sense of control, provided anonymity to allow for openness to discuss sensitive subjects, and improved the decision-making process. The patient’s sense of empowerment was ultimately determined, however, by the clinician’s receptiveness to the individual’s use of the Internet. The study did not show that the Internet necessarily resulted in a better doctor-patient relationship.

### Emotional Support

The original virtual or electronic support groups (ESGs) focused on psychiatric support for those with depression or anxiety. An estimated 79 million Americans have joined online support groups since their inception, and 23% of Internet users with chronic health conditions have sought others with similar health concerns online. In a systematic review of the efficacy of virtual communities, Eysenbach et al were unable to show a beneficial intervention effect with consumer-led peer-to-peer communities, yet the “pure” peer-to-peer interventions were limited to 6 studies. Most of the studies analyzed were complex and had multiple components within the interventions, making it impossible to draw conclusions about the generalizability of the results.

The earliest online cancer support groups began in the 1990s. The Cancer Support Community initiated an online support group more than a decade ago that continues today. It is professionally facilitated and convenes weekly for 90 minutes. Currently, most ESGs are not professionally facilitated but instead follow a peer-leader model. According to the HINTS survey, prevalence estimates of Internet-based support groups among cancer survivors were 8.1% (95% CI, 4.6, 11.5) in 2008. These estimates are similar to data from Lavoie Smith et al, who reported that 8.2% (45/547) of patients with cancer were currently engaged in Internet support groups. Another 23% of those surveyed thought they might possibly use Internet support groups in the future. The Health eCommunities Project sought to evaluate what kinds of support ESGs offer for cancer survivors and caregivers through systematically sampling e-mail messages from cancer mailing lists hosted by the Association of Cancer Online Resources (ACOR). The most common topics were informational in nature, with a specific focus on treatment and how to communicate with health care providers. The study unexpectedly found that members were more likely to offer support than to solicit it. Additional research showed that the high-frequency correspondents on Internet cancer support groups tend to offer rather than receive support, in contrast to the low-frequency correspondents who more frequently seek support. A similar thematic analysis of the types of support sought by adolescents with cancer posting on a message board, Teens Living with Cancer (www.teenslivingwithcancer.org), demonstrated frequent instances of both emotional and informational support. Adolescents frequently requested social support, suggesting a need for moderators of sites geared toward this population to tailor their services accordingly.

Cultural and gender differences play a role not only in online cancer support group participation but also in how the participants engage. In a subset analysis of discussion group use in the CHESS study of patients with breast cancer, Caucasian women spent more time on the discussion group and wrote more messages compared with “women of color” as defined by the CHESS group (African American, Native American, and Asian). Caucasian women were significantly more likely to write messages dealing with daily life and to offer support to others, whereas...
women of color were more likely to focus their discussions on treatment. Interestingly, women of color randomized to participate in CHESS reported greater confidence in their health care team and in making health care decisions, and described improved social support compared with Caucasian women. Men are less likely to participate in online cancer support groups. A sampling of 4 online, professionally led, mixed cancer diagnosis support groups to evaluate gender differences suggested that men are less likely to express negative emotions and more likely to emote fear and sadness compared with women.

**Internet-Based Interventions for CRF**

Much can be learned in the arena of self-help Internet-based interventions through exploring the available psychiatric literature, with a particular focus on interventions for depression and anxiety. Some of the first described Internet-based randomized controlled trials were developed for the management of depression and anxiety. Although the success of these interventions has not been uniformly demonstrated, the literature lends support to the necessary emphasis placed on clinical trial design. Specifically, using validated outcomes measures and establishing meaningful effect sizes a priori are key for interpreting study results. Additionally, a well-planned control group, such as the commonly used wait-list group, should be embedded in trial designs when feasible.

Numerous studies evaluating Internet-based interventions for patients with cancer are actively recruiting patients. These are mostly focused on weight loss, depression, anxiety, insomnia, and smoking cessation. The ClinicalTrials.gov Web site highlights only one Web-based study that solely focuses on CRF (identifier: NCT01228773; Principal Investigator: Youngho Yun, PhD).

With the field of Internet-based interventions for cancer-related symptoms still in its infancy, the available literature specifically for CRF is limited. The American Cancer Society piloted an online cancer fatigue class as a logical extension of their I Can Cope educational program. The study incorporated the Health Belief Model, because health behavior theory suggests that perceived beliefs can impact behavior. The 2-hour focus groups consisted of a pre-class survey, online class, and post-class survey, followed by a facilitated group discussion. The surveys assessed fatigue knowledge and beliefs using measures specifically created for the study. The online class had a 2-tiered content that allowed users to determine the level of detail presented. The first tier provided an educational overview of CRF and the second tier provided several links to more in-depth information. Among the 33 participants (26 survivors and 7 caregivers) who completed the class, significant improvements were gained in both fatigue knowledge (P<.001) and belief (P<.001) scores. During the facilitated group discussions, participants perceived the class positively. Additional research is needed to determine whether enhanced knowledge and beliefs will ultimately result in behavioral changes.

In the single published randomized controlled trial of a Web-based education program for cancer survivors with CRF, Yun et al demonstrated the efficacy of this novel approach. Cancer survivors, restricted to individuals who completed treatment within the past 24 months and with ongoing moderate to severe fatigue, were randomized to either participate in a 12-week Internet-based, individually tailored CRF education program or receive routine care. The routine care arm was a waitlist control. Primary outcomes of fatigue were measured by the Brief Fatigue Inventory (BFI) and Fatigue Severity Scale (FSS), and secondary outcomes included anxiety/depression and quality-of-life scores. Patients with fatigue that could be explained by other conditions were appropriately excluded. The intervention program, named Health Navigation, was based on the 2008 NCCN CRF Guidelines, and incorporated the transtheoretical model of behavioral change and education sections based on cognitive behavioral therapies. Small, moderate, and large effect sizes were defined as 0.2, 0.5, and 0.8, accordingly. A clinically meaningful change was defined as an effect size greater than 0.5 relative to baseline at 12 weeks. Of 273 randomly assigned participants, 83% (n=113) of the intervention group and 95% (n=130) of the control group completed the 12-week study. The Internet-based self-management group improved fatigue and health-related quality of life more than routine care in all of the scores, although the effect sizes measuring the difference between the 2 arms were less than 0.5 for all of the various scales tested. The effect sizes for global BFI and FSS were 0.29 and 0.27, respectively (P=.001 for both measurements). The largest effect size was seen in the reduction of
anxiety (0.33; P=.004). Clinically meaningful improvements in worst fatigue were most apparent in individuals with baseline BFI scores of 4 or greater (adjusted odds ratio, 2.24; 95% CI, 1.22–4.14). Although additional studies will be required to validate these findings, the results of this well-designed study are certainly promising.

Conclusions
The Internet allows for people to engage with each other in ways that were unimaginable 20 years ago. The Internet may be able to successfully overcome some of the barriers encountered by patients in obtaining relief from cancer-related symptoms. Its widespread use and the demonstrated benefit of Internet-based cancer support groups indicates the importance of continued development of Web-based cancer-related symptom interventions. As of yet, a robust body of literature is lacking for computer-based CRF interventions, although when extrapolating from other behavioral interventions, a potential benefit is suggested. The framework for CRF-based interventions already exists, although the best constructs for establishing the most effective Web-based interventions must be ascertained. Additional well-designed randomized controlled trials are needed. Although CRF is a subjective symptom, validated patient-reported outcomes tools must be relied on to ascertain an effect size of an intervention. Sustainability for these programs will require participation from “emotional providers.” The most appropriate roles for moderators and their training backgrounds must be considered. Recognizing the significant scope that CRF has on quality of life, national cancer organizations should assume a leadership role in the oversight of well-constructed and validated Internet-based behavioral interventions.

References
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