Brief report: A Pilot Study of a Web-based Resource for Families of Children with Cancer

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Objective To develop a Web-based resource for families of children newly diagnosed with cancer and examine the viability of this modality of providing support. **Methods** Twenty-one children (8–17 years) newly diagnosed with cancer and their families were enrolled. Quantitative data on Web site utilization and frequency of accessing specific sections and qualitative data on participant satisfaction are reported. **Results** Twenty-one families comprising 51 participants (children with cancer, parents, and siblings) had access to the Web site. Utilization was lower than anticipated, with members of only nine families accessing the site. The majority of these hits were on peer discussion groups. **Conclusion** Further research is warranted to examine whether the Internet is a viable method of delivering support to families affected by childhood cancer. The current pattern of results suggests that the timing of its introduction and the method used to train families may affect utilization.

Key words social support; cancer and oncology; parent stress.

It is estimated that >80% of children diagnosed with cancer today will become long-term survivors (American Cancer Society, 2006); as a consequence, recent attention has focused on methods of supporting the child with cancer and his/her family in order to minimize the psychosocial consequences of this stressful life experience. Lazarus and Folkman's (1984) theory of stress and coping suggests that better psychosocial adjustment is facilitated by the availability of social support. In support of this theory, evidence shows that perception of social support predicts more positive adjustment among children with cancer (Decker, 2007), their siblings (Barrera, Fleming, & Khan, 2004) and their parents (Norberg, Lindblad, & Boman, 2006; Varni, Katz, Colegrove, & Dolgin, 1995; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006), making it a possible target for intervention. To date, social support interventions have focused on face-to-face support groups that typically are associated with positive psychological outcomes for cancer patients and their families (Helgeson & Cohen, 1996;

Reele, 1994), particularly when members of the group are going through similar experiences (Thoits, 1986). However, there are many barriers that prevent families of children with cancer from participating in these support groups, including geographical dispersion and the overwhelming and time-consuming nature of pediatric cancer treatment protocols (Feldman, 1993; Thiel de Bocanegra, 1992). These barriers are a particular concern for siblings who rarely visit the medical setting and often endorse social withdrawal, feelings of abandonment/rejection by parents, and social isolation (Barrera et al., 2004).

Recent attention has focused on the possibility that the Internet may provide a more optimal vehicle for the efficient provision of information and social support to individuals with a chronic disease and to their families. For example, the Comprehensive Health Enhancement Support System (CHESS) is an Internet-based program that offers support in the form of discussion groups and education (Gustafson et al., 1993) and has been associated with increased knowledge and decreased negative

emotions among family members of women with breast cancer (Gustafson et al., 1993). Similarly, computer-mediated social and informational support has been shown to decrease social isolation among parents of children with congenital heart disease (DeMaso, Gonzalez-Heydrich, Erickson, Grimes, & Strohecker, 2000) and childhood depression (DeMaso, Marcus, Kinnamon, & Gonzalez-Heydrich, 2006) and to increase quality of life among adult bone marrow transplant recipients and their caregivers (Farnham et al., 2002). Furthermore, evidence suggests that these interventions are acceptable to patients with chronic diseases and their families, regardless of users' age, income, or prior computer experience (Balas et al., 1996; Brennan, Moore, & Smyth, 1995; Gustafson et al., 1993) and provide a means of accessing family members who do not regularly visit the medical setting.

Thus, the goals of the current pilot study were to (a) develop a Web-based resource for families of children newly diagnosed with cancer, and (b) gather initial data on the viability of this modality as a means of providing information and offering support to all family members. For this purpose, we developed a multifaceted Web-based resource that was designed to stand alone and included (a) a monitored forum for communication with members of other families, (b) a library of information on the management of emotional distress, (c) access to clinically trained research team members, and (d) information on childhood cancer-related issues. To provide initial data on the acceptability of this resource, we gathered objective data on usage of components of the site by family members and qualitative feedback regarding the perceived helpfulness of the different features.

Methods
Participants

Participants were 21 English-speaking families with a child (8–17 years) who was within 6 weeks of a new diagnosis of any cancer except central nervous system tumors and had at least one biological or adoptive parent or legal guardian who agreed to participate. Of the 64 families being treated at Children's Hospital of Pittsburgh who met these eligibility criteria between February 2006 and December 2007, 52 families (81%) agreed to be approached about participating in a larger, ongoing intervention study; 32 families (62%) agreed to participate and two-thirds of them were randomly assigned a login name and password to access the study Web site, resulting in a final sample of 21 families (24 caregivers, 21 patients, and six siblings). Informed consent was obtained in compliance with the University of Pittsburgh Institutional Review Board.

Development of the Web site

The Web site was developed to be a social support and informational resource for all members of the family including those who do not often visit the outpatient clinic (e.g., siblings and adult caregivers who provide more at-home care for family members). Although community-based support groups are intermittently available, they often are difficult for families to access due to the demands of the child's illness and treatment. Key features of the Web site (described below) were modeled after other Internet-based programs designed to offer social and informational support to chronic illness populations (e.g., CHESS; Gustafson et al., 2002) and were developed in consultation with Armondo Rotundi, PhD, who developed an effective Web-based support resource for caregivers of adults with traumatic brain injury (Rotondi, Sinkule, & Spring, 2005). The current Web site included the components of Rotundi et al.'s (2005) program that were identified as particularly helpful by caregivers. The site was constructed for easy use by children as young as age 8 years and by those with no previous computer or Internet experience. Prior to enrollment of the project sample, feedback on the ease of use and perceived helpfulness of the Web site was provided by two families of children with cancer including parents (two mothers, one father); two children with cancer, ages 10 and 12 years; and two siblings, ages 12 and 14 years. Feedback was uniformly positive.

Web Site Components

Key features of the Web site included: (a) Home page: an overview of the Web site; (b) Coping and relaxation: information about methods of coping along with guided relaxation exercises. This section also included the video ''No Fear, No Tears'' (Kuttner & Kuttner, 1985) on the use of mind–body techniques in pediatric cancer; (c) Discussion groups: five separate confidential discussion groups were available for (1) parents, (2) older (13–17 years) and (3) younger (8–12 years) children with cancer, (4) older, and (5) younger siblings. These bulletin boards were designed to offer support to family members from their respective peers in other families going through a similar experience and included threaded comments so that users could read and post comments at their own convenience. The discussion groups were monitored by one of the research staff and investigators; each time a message was posted by a participant, an e-mail notification was sent to the research monitor to ensure that the comment was appropriate. (d) Ask an expert: electronic mail connections to research team members who were available for

non-medical questions or discussion. Because there was a risk of family members posting urgent medical questions that might not receive timely attention, oncology team members recommended that the Web site be open to non-medical questions only. (e) Previously asked questions: a question-and-answer library including anonymous responses to questions asked in the ''Ask the expert'' section. (f) Resources and references: links to other relevant Web sites and a list of local resources around Pittsburgh, including support groups.

Web Site Training

Following consent, all family members were trained to access and use the Web site. All families were offered an in-home training session during which research staff demonstrated how to log onto the Web site and access the different components. In addition, all families were provided with a detailed instruction manual. In addition to step-by-step instructions about how to log on and access the site components, this manual included information on how to handle common computer problems, a dictionary of computer terminology, and information about how to contact research study staff. After families received training, they were encouraged to log on as frequently as desired, though no specific expectations related to use were provided. If necessary, laptop computers and Internet service were provided to families for the period of the study (6 months).

Web Site Evaluation Measures

The Web site was designed to monitor when and how often each user accessed different site components. In addition, participants completed an abbreviated version of the Website Evaluation Instrument (WEI; Rotondi, 2002). This self-report measure included nine items for adults and eight items for children. Example items include the following: ''How often did you use the Common Areas of Concern section of the website?'' and ''Please rate how easy it was to use the Web site overall.'' These questions were answered on a Likert scale from one (1) to seven (7). A post-intervention phone interview also was conducted with all adults in the study. This interview included nine questions about impressions of the site, barriers to Web site utilization, and parents' perceptions of child(ren)'s response to the site. Example questions included the following: ''What was the biggest barrier to using the Web site?'' and ''Is there anything you would like to see added to the website, or is there anything that if it were available would have increased your usage of the site?''

Results
Participant Demographics

Twenty-one families were enrolled in the pilot study; 17 families were non-Hispanic Caucasian and four families were non-Hispanic African American. Participating caregivers included 20 females and 4 males ranging in age from 31 to 73 years (mean age = 42.6 years). Two caregivers were legal guardians. Child and adolescent participants included 21 children with cancer (11 females; mean age = 13 years). Of these, 12 were adolescents (over 12 years) and 9 were children (age ≤ 12 years). Six siblings ages 10–16 years (4 females; mean age = 13 years) from six different families also enrolled. The mean length of time from diagnosis to enrollment was 17 days (range: 1–62 days). Diagnoses of the 21 children with cancer included acute lymphoblasic leukemia ($n = 6$), Hodgkin's lymphoma ($n = 5$), Burkitt's lymphoma ($n = 2$), osteosarcoma ($n = 2$), germ cell tumor ($n = 2$), acute myeloid leukemia ($n = 1$), anaplastic large cell lymphoma ($n = 1$), and lymphoma ($n = 1$).

Web Site Training

Overall, four families were provided hands-on Web site training using a computer. Among these families, all had at least one member who logged on to the Web site at least once and one family had two members (one caregiver and one adolescent patient) that each logged on multiple times. Eighteen families (46 participants) declined a home visit and were trained by means of a verbal description of the Web site along with the manual; this training occurred either during an inpatient stay or a clinic visit. Among these families, five had at least one member who logged onto the Web site at least once and two families had at least one member who logged on more than once. Although the sample size is too small to permit meaningful analyses, hands-on training using a computer may be a more effective means of orienting families to the Web site, leading to increased utilization.

Web Site Access

Of the 21 families participating in the study, 6 families did not have access to computers at home and were loaned laptop computers and given Internet access for the 6-month study period. Two of these six families received hands-on training. The remaining 15 families had computers and Internet access when they enrolled.

Nine out of the 21 families had at least one member who logged onto the Web site at least once, with a total of 11 participants accessing the site. Five caregivers from five families logged on to the Web site. Of the caregivers who

Table I. Website Usage by Families and Family Members

	Given access to website	Logged onto website
Total families	21	9 (43%)
Caregiver	24	5 (21%)
Male	4	1 (25%)
Female	20	4 (20%)
Patient	21	4 (19%)
Child (8–12years)	9	1 (11%)
Adolescent (13–17 years)	12	3 (25%)
Male	10	2 (20%)
Female	11	2 (18%)
Sibling	6	2 (33%)
Child (8–12 years)	2	0 (0%)
Adolescent (13–17 years)	4	2 (50%)
Male	1	0
Female	3	2 (50%)
Total Participants	51	11 (22%)

Table II. Total Hits by Section of Website (Child 8–12 years; Adolescent 13–17 years)

Section of website	Website component	Total hits
Discussion groups	Confidential bulletin boards	257
Caregivers		88
Adolescent siblings		73
Adolescent patient		44
Child patients		7
Child siblings		5
Resources	Articles on topics relating to childhood cancer	78
Home page	Overview of *Connections to Coping* program	72
Previously asked questions	Library of answers from the "Ask an Expert" section	66
Connect to coping	Information on coping techniques	67
Connect to other sites	Links to other relevant websites	49
Ask an expert	Questions for clinical research team	17

logged on, four were females. Four patients logged on to the Web site. Half of the patients who logged on were female ($n = 2$), and 75% were over the age of 12 years ($n = 3$). Two siblings logged on to the site, both of whom were female adolescents. Across all groups (caregivers, patients, and siblings), 8 of the 11 participants logging on were female, and 10 were adolescents or adult caregivers. Table I summarizes these data.

Table II shows the number of times the various components of the site were accessed. The discussion groups had the most hits ($n = 257$), with 88 parent, 73 teen sibling, 44 teen patient, 7 child patient, and 5 child sibling discussion group hits. Other more frequently accessed sections of the Web site included "Common areas of concern" ($n = 78$ hits), "Previously asked questions" ($n = 66$ hits), and "Connect to Coping" ($n = 60$ hits). Overall, the Web site was utilized frequently by a few participants; however, the majority of participants did not access the site. Although a total of 21 families were enrolled in the study, no more than six families had access to the Web site at any one time due to the timing and duration of each family's enrollment in the study.

Qualitative Web Site Evaluation

Between 2 and 4 weeks after they completed the study, caregivers were asked about barriers to Web site use. The primary reasons for not accessing the site were dislike or unfamiliarity with computers (24%) and being too busy (21%). Unstructured responses included spending a significant amount of time in the hospital where there was no Internet access; having sufficient information from the

research and medical staffs; and preferring face-to-face interactions over online discussion groups. Among the five caregivers who accessed the Web site, the "Ask an Expert" and "Previously Asked Questions" components were reported to be most helpful. Caregivers also reported on possible reasons that their children did not use the Web site more often. Twenty-eight percent of caregivers thought their ill child did not want to spend more time focusing on the illness. In their qualitative responses, caregivers noted that patients just wanted to feel "normal" when home; had sufficient social support from family and friends; were too sick; and only used the computer for games and talking to friends. For the siblings, 43% of caregivers endorsed that their children were too busy to access the site.

Discussion

The primary goal of this Web site resource was to enable all members of the family to have confidential access to social support from parallel members of other families going through a similar pediatric cancer experience. In addition, the Web site provided access to a library of information on the management of emotional distress, access to electronic communication with the research team, and information on issues related to childhood cancer. Although findings from studies that examine families confronting other chronic diseases suggest that computer-based interventions may provide a viable means of supporting families (Balas et al., 1996; Brennan et al., 1995; Gustafson et al., 1993), data from our pilot project are equivocal and utilization was less than what others have reported among a similar population (DeMaso et al., 2000;

Farnham et al., 2002). In fact, only 9 of the 21 participating families had at least one member access the Web site at least one time; this represented 11 individuals.

Because utilization of the site was considerably less than anticipated, it is important to consider what might enhance utilization in subsequent trials. Based on our findings, we suggest the following possibilities. First, utilization may have been affected by the timing of the provision of this type of support. In the current study, families were recruited within 6 weeks of the diagnosis of cancer (mean = 17 days) and had access to the Web site for the following 6 months. This is a time of extremely high stress for most families, when caregivers confront the multiple implications of having a child diagnosed with a life threatening disease and of handling the complex treatment regimen. Our recruitment of families at this difficult time was intentional, as our greater goal was to provide families with different ways of accessing support as they navigate this difficult period. However, the current findings suggest that this may not be the best time for families to access Web-based support. Indeed, qualitative feedback about barriers to accessing the Web site included a lack of interest in ''more input of any kind,'' and observations that they were ''too tired'' and ''too overwhelmed'' when at home to focus on anything beyond pressing home responsibilities. It is possible that there would have been greater interest in and use of Web-based support if it were offered after the acute phase of treatment, as families turn their attention to the chronic nature of childhood cancer and its treatment and the prolonged nature of the associated family disruption.

Second, the current results suggest that the method by which families are introduced to the Web site may influence their future use of the site. All families that received hands-on training went on to access the site, whereas only five families (24%) that received verbal instruction accessed the site. These findings are consistent with unpublished findings (Armando Rotondi, personal communication, January 10, 2008). In addition, qualitative feedback from parents in the current study revealed that 24% disliked or were unfamiliar with computers; thus, it is possible that providing hands-on training may decrease avoidance related to a perceived lack of confidence or competence. The percentage of participants reporting less comfort with computers in this small study also is higher than that reported in other Web site studies, which may also contribute to lower utilization among this sample.

Third, of the multiple components of the Web site, the discussion groups were accessed most frequently, suggesting that family members have an interest in connecting with others going through similar experiences. Unfortunately, the availability of others to join a discussion and post comments was limited to the approximately six families who had access to the site at any single point in time. Comments that were posted most often related to a desire to share the experience with someone going through a similar event. However, most participants' attempts to access others were unsuccessful because there simply were not enough participants at any point in time. Interestingly, this did not deter a number of individuals from entering the discussion groups multiple times. For example, the two adolescent siblings logged on to the discussion group 73 times. Indeed, 13- to 17-years-olds were more likely to access the Web site than 8- to12-year-olds. These observations suggest that if more families had access to the site, there may have been greater use, particularly by caregivers and adolescents.

Finally, studies of support offered by means of the Internet (DeMaso et al., 2000, 2006; Farnham et al., 2002) have focused on adult caregivers or those over the age of 18 years. Although several Web sites provide Internet support for parents of children with health problems (Nolan, Camfield, & Camfield, 2008), we were unable to identify any studies employing a Web site to address support needs of the ill child and his/her family members. Thus, it may be that the scope of such an inclusive Web site (i.e., children, adolescents, and caregiving adults) was a deterrent and in an effort to reach all, we actually decreased the desirability. Future research may include targeting specific groups within families (e.g., siblings) and customizing the Web site based on their unique developmental and experiential needs.

In summary, further investigation of the viability of a Web-based resource to enhance social support and coping among families facing childhood cancer is warranted. In order to maximize the effectiveness of this emerging modality and to provide targeted information and support, it will be important in future work to carefully consider the timing of Web-based social support opportunities, to employ hands-on training with potential users, and to assure an adequate number of users to enable conversation and support. We hope that our work stimulates further research in this area.

Funding

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