

Hopkins Teen Central: Assessment of an Internet-Based Support System for Children With Cystic Fibrosis

Kevin B. Johnson, MD*; Russell D. Ravert, MS‡; and Andrea Everton, MSW§

ABSTRACT. Support groups are an important therapeutic intervention for patients with chronic debilitating illnesses. Patients who are difficult to assemble in one physical location may benefit from participating in an electronic support group (ESG). ESGs for adolescents have not been evaluated, although studies have shown a benefit to adult ESGs. Our goals were to create a web-based support service for adolescents with cystic fibrosis (CF) and to qualitatively and quantitatively measure the effects that such a support site could have on patients' relationships with the clinic faculty and staff, access to and interaction with peers with CF, and understanding of CF.

Methods. A highly interactive ESG was developed after discussions with a team of CF specialists and patients. Eighteen of 37 teenagers with CF agreed to use this site. Each patient was asked to assess his or her perceived availability of and comfort with the clinic staff and faculty, perceived support available through peers, knowledge about CF, and perceived usefulness of the Internet as a support tool.

Results. Participants logged into the site an average of 4 times each month. Teens who owned home computers accessed the site somewhat more frequently than did teens who were provided with home Internet access for the study. Most activity occurred in those sections of the site that described the participants and that allowed them to socialize. Over one half of the participants e-mailed each other at least once a week, with 77% e-mailing peers at least every other week. There was no significant difference in the participants' scores on a quiz about CF at the beginning and the end of the study; however, there was a significant decrease in perceptions about their knowledge about CF. At the conclusion of the study, participants believed that they had more friends who they could relate to than they did at the beginning of the study. Clinic staff noticed an increase in references to peers among the group who were using the site. In addition, 4 of the teens expressed a desire to get together to meet each other as a result of their interactions on the web site. There was no significant change in perceptions about the perceived availability and comfort with the clinic staff and faculty, support available through peers, knowledge about CF, and the usefulness of the Internet as a support environment. Managing the project was

extremely easy, with virtually no technical or procedural issues arising during the study.

Conclusions. Teenagers with a chronic disease will actively participate in an ESG. The social and expressive aspects of their involvement with this support group hold much promise. *Pediatrics* 2001;107(2). URL: <http://www.pediatrics.org/cgi/content/full/107/2/e24>; self-help groups, Internet, adolescence, computer user training, cystic fibrosis, evaluation studies.

ABBREVIATIONS. CF, cystic fibrosis; ESG, electronic support group; PC, personal computer; ITVD, Internet television set-top device.

Chronic illness may have a significant impact on an adolescent's psychological well-being, body image, sexuality, and degree of socialization.¹⁻³ Parental and peer support are important to socialization and to the development of a positive self-perception during this critical time in their development.³⁻¹¹ Unfortunately, adolescents with chronic illnesses may have fewer social interactions than their well counterparts and are at risk for impaired emotional development.^{4,6,12} Factors such as frequent visits to health care providers, occasional hospitalizations, long distances between children with the same illness, and health-related exclusion from activities lead to isolation from their peer group and can be exceptionally stressful for both the patient and the family. For example, cystic fibrosis (CF) is an inherited illness affecting 1 in 3200 whites. Children with this disease suffer from chronic, often debilitating, pulmonary and gastrointestinal illnesses. Although most children with CF (85%) are in the appropriate grade level, only 69% of them participate in school physical education programs, with the majority of adolescents being less physically active than are their peers.¹³ Often, despite otherwise good health, these children are perceived as vulnerable and may be kept at home by their families.

Peer support groups have been shown to be beneficial to many children with chronic illnesses.^{6-8,14-17} In addition to teaching children about their illness and treatments and providing access to peers, support groups help children to express themselves, explore situations they encounter, and learn coping strategies that help them deal with their illness. These groups take on additional value for adolescents, because of the central role of peers in their lives and the need for independent exploration and assuming responsibility for self-care. Unfortunately, convening adolescent support groups poses a chal-

From the *Division of General Pediatrics, Johns Hopkins University School of Medicine, Baltimore, Maryland; ‡Child Life Specialist, Johns Hopkins Children's Center, Baltimore, Maryland; and the §Dreamsurfer Network, Grant-A-Wish/The Children's Promise Foundation, Baltimore, Maryland. Received for publication Apr 25, 2000; accepted Sep 5, 2000.

Reprint requests to (K.B.J.) Division of General Pediatrics, Johns Hopkins University School of Medicine, CMSC 140, 600 N Wolfe St, Baltimore, MD 21287-3144. E-mail: kjohnson@jhmi.edu
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lenge. In addition to their dependence on parents for travel, geographic separation may prevent children with rare diseases from meeting frequently. Barriers are especially troublesome in children who have CF, because researchers believe that psycho-educational interventions should be encouraged, although denial might serve to create the semblance of a normal life.¹⁸ It can be difficult to motivate families experiencing denial to overcome even trivial barriers. In addition, children with CF who are infected with difficult-to-treat organisms are generally isolated from other patients with CF. Although isolation may reduce the spread of dangerous organisms,^{19–24} it also may have detrimental effects on the socialization of these children.

Studies have demonstrated that electronic support groups (ESGs) are beneficial to patients with terminal illnesses.^{25–33} ESGs offer 24-hour availability, selective participation, access to children who are homebound or otherwise unable to meet other people with their disease, and potentially faster dissemination of information to a wider audience. Anecdotal reports about one ESG, Starbright World, describe “modest support” for diminishing anxiety in a group of hospitalized children.³⁴

Despite these reports, ESGs may have some disadvantages over conventional support groups. Equipment to access an ESG is unaffordable for many families. Although 40% of households have a personal computer (PC), there is a well-recognized digital divide, with households earning \$75 000 or more being at least 20 times more likely to have access to the Internet than households at the lowest income levels, and at least 9 times more likely to have a computer at home. Internet access is also less prevalent in black and Hispanic homes, as well as in rural areas.³⁵ In addition to the costs associated with purchasing and setting up this equipment, other obstacles include training users who have varying levels of proficiency and the cost of providing 24-hour support for these users.

The ability to rapidly and efficiently disseminate information also may be a liability. For example, erroneous or misleading information quickly can spread through the Internet to many patients, who may form opinions before having a chance to discuss them with their providers.²⁶ Even appropriate information for one geographic region may be inaccurate or inappropriate for another region (ie, will insurance companies pay for summer camp for special needs children?). Perhaps one of the most significant unknowns is how well an ESG will function with children and adolescents. One study that evaluated adults and adolescents after they began using the Internet noted increases in their feelings of loneliness and declines in their perception of social support.³⁶ The authors concluded that on-line friendships are less reliable and consistent than in-person ones. Finally, the support needs of adolescents participating in an ESG are unknown. Although adolescents tend to be more facile with computer technology than many adults, this skill may be offset by their needs as adolescents who, as a group, tend to be highly im-

pressionable, risk-seeking, and, at times, overly independent.

The goal of this study was to explore issues concerning the creation and maintenance of an ESG with adolescents, with an emphasis on how such a group might impact adolescents’ perceptions of their disease, their peer support, and their assessment of the usefulness of ESGs.

METHODS

This descriptive study was conducted from August 1997 through July 1998. Institutional review board approval was obtained for this project. Children between the ages of 13 and 18 years who were followed in the Johns Hopkins CF clinic were called and sent postcards inviting them to participate. The CF clinic is a multidisciplinary clinic within an urban academic medical center. Clinic patients come from a large geographic area, with varying levels of exposure to computer technology.

Less than 50% of the patients have access to a PC at home. Participants without home access to a computer were provided with a WebTV (Microsoft WebTV Networks, Mountain View, CA). WebTV is a type of Internet television set-top device (ITVD)—an inexpensive, easy-to-maintain device that uses a television, phone line, and keyboard to access the Internet. Our experience with these devices has been published elsewhere.³⁷ The devices are relatively easy to set up and maintain and extremely easy to use with a minimum of training. However, we needed to modify the design of our site to support ITVD users. For example, the site had to be designed to accommodate televisions, which have lower resolution than monitors. In addition, we did not host a chat room, because WebTV did not support the software needed to run a secure Internet chat facility at the time of the study.

Before beginning the study, a team consisting of a child life specialist, a social worker, a pediatrician/medical informatician, and 2 information systems specialists designed the site that would serve as the home of the ESG. This team met approximately every 2 months to coordinate production and evaluation of the project. Development and pilot testing was performed in collaboration with teenagers. A group of health care providers from the cystic fibrosis clinic provided much of the content. Figure 1 provides some sample screens from the web site. The site was designed to be highly interactive. Buttons and banners were animated and brightly colored. Most sections of the page, as highlighted in Fig 1, allowed participants to post information. All but 2 sections of the site (the Graffiti Wall and the Diary) were moderated, and only the Diary section was truly private to each participant. In addition, any participant who was hospitalized during the study was provided with a loaner ITVD during their hospitalization.

Participants were divided into 2 cohorts. Before the site was launched, all participants completed a survey to assess their knowledge about CF, their perceptions and attitudes about the support they were provided by peers and staff, and their opinion about the potential value of the Internet as a support environment. Responses about perceptions and attitudes were based on a Likert scale, ranging from strongly disagree (1) to strongly agree (4). Cohort 1 was then given access to the site for 5 months. At the conclusion of the 5-month period, both cohorts were reassessed using the surveys described above. Recommendations for improvements in the site were implemented, after which both cohorts were given access to the site. After an additional 5 months had passed, both cohorts were asked to complete the surveys again. In addition, a focus group of teens and parents was convened to qualitatively assess the project.

Site access was measured by auditing the number of logins to a particular web page by each user. More than one login by a user on a given day was treated as 1 login. Interaction with the site was measured either by e-mails from a particular site location or by manually counting specific events (such as postings on the Message Board).

Differences between WebTV and PC users were analyzed using the Student’s *t* test for continuous variables and the Wilcoxon rank sum test for ordinal data. Nominal data were analyzed using Fisher’s exact test. The survey data were analyzed using paired *t* tests. Bivariate analytic approaches were used to assess the interaction between participants’ perceptions or site usage and other outcome variables of interest.

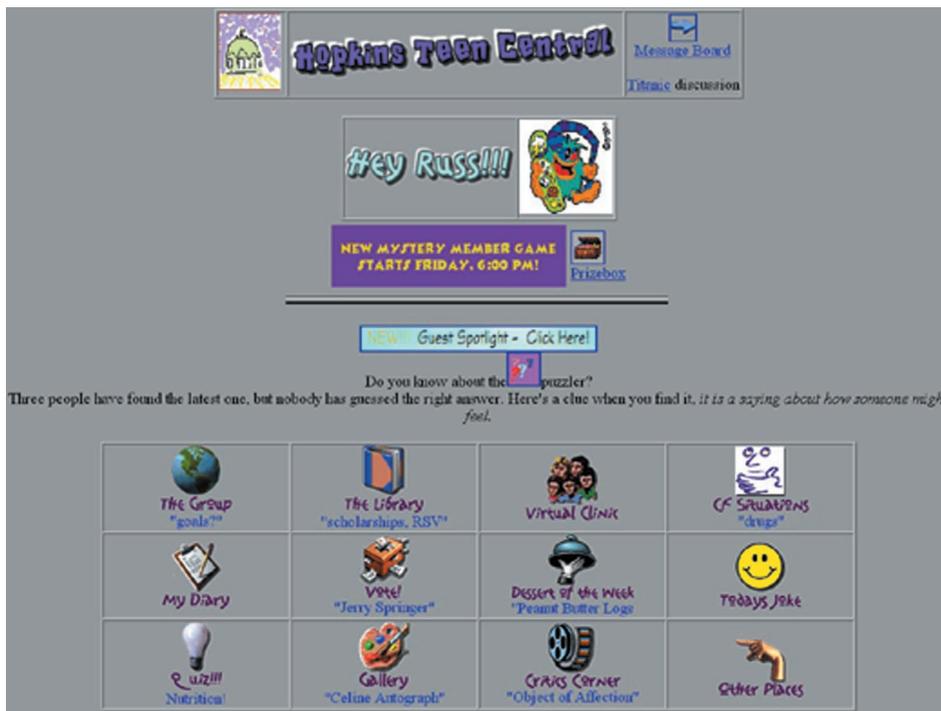


Fig 1. CF teen web site home page.

RESULTS

A total of 37 patients were eligible to be included in the study. All of the eligible participants received mail and a telephone call about the project. Eighteen patients agreed to participate in the study. These patients had a median age of 13 years. Seven patients had access to a home computer. The other 11 patients were given ITVDs. These users received 1.5 hours of training, concentrating on an introduction to the Internet/e-mail and instruction in setting up their ITVD. Participants also attended a training session, consisting of education about the use of the Internet, including the purpose and functions of the site, and policies on confidentiality and acceptable language. One child who was planning to use an ITVD purchased a computer after we discovered that we could

not provide local phone call access to WebTV from her area. A typical home ITVD setup is shown in Fig 2.

Site Access

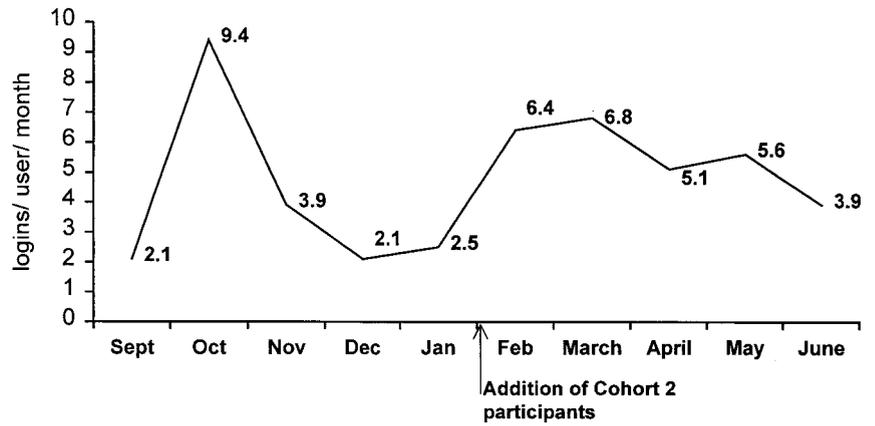
Figure 3 shows how site access changed over time. Users logged in to the site an average of 4 times per month over the study. Cohort 1 use of the site peaked at 9.4 logins/user/month, and reached a steady state of ~3 logins/user/month after 12 weeks of use. In January, when cohort 2 teens were added to the site, usage peaked at 6.8 logins/user/month, with a slower decline and no clear steady state by the end of the study. Hospitalized participants also accessed the site by using the inpatient ITVD.

Periodically, special events were hosted on the

Fig 2. WebTV access to CF teen web site.



Fig 3. Site use.



web site to improve participation, as might be done with any in-person support group. These events are described in detail in Table 1. Each of these events was associated with increased logins. There was a trend for ITVD users to access the site less frequently than PC users (24 logins vs 64 logins; $P = .06$). Site use was most frequent in the evenings and on weekends, as shown in Fig 4.

Figure 5 shows the frequency with which different components of the web site were accessed. Throughout the study, teens most commonly used sections that contained information about their peers. The personal sections (User Profile and Diary) were the most frequently accessed sections. However, both the social (Message Board, CF Situations, Critics Corner, etc) and knowledge (Dessert of the Week, Library) sections had over 600 accesses during the study.

Teen Interaction With Site

Table 2 describes the extent to which participants submitted content to interactive sections of the site. Posting messages to the Message Board was the most common interaction with the site (588 postings), followed by responding to requests for information about themselves as a part of the User Profile (page 113). In addition, they participated to varying degrees in other components of the site. Even with voluntary participation, most teens took most of the on-line quizzes that were created during the study.

E-mail Use

Because teens were able to send e-mail from outside of the site, we were unable to quantify the exact

number of e-mail interactions among them. However, 37 messages were sent from the site by 4 of the teens. In addition, the study coordinator received 33 e-mail messages ranging from general information ("I got my license!") to messages about the web site and other group-related issues ("We need a new vote [about a movie]!"). However, when teens were surveyed at the conclusion of study, 10 (59%) reported sending mail at least every week to another group member, while 77% reported sending mail to another teen at least every other week. When asked whether the mail was about CF, only 2 teens stated that e-mail was often about CF issues, compared with 9 who stated that e-mail was not often or never about CF.

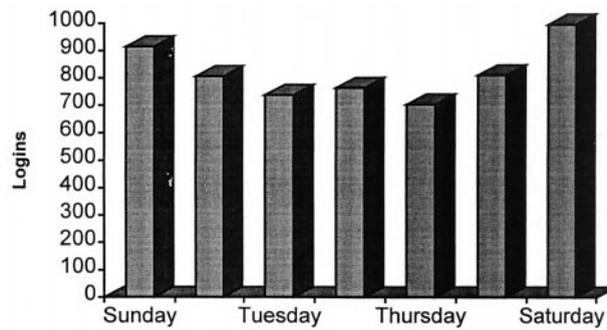
Focus group participants consisted of 9 children and 7 parents. During the focus group with the participants, the benefit of e-mail access to other teens with CF was one of the most consistent themes of the conversation. One teen said, "I liked meeting the people. The other stuff was nice, but the people were really nice like to know and stuff." Another teen expressed how e-mail improved her communication with other teens with CF, "All I know is we've been in clinic together since I was 5 months old, and [e-mailing you on the web site was] the first time I've talked to you." The teens expressed a strong interest in adding a chat room, as well as a group e-mail address, for announcements about parties, events, or sad news.

Knowledge and Attitudes

Before beginning the project, most participants disagreed or strongly disagreed with the statement that they "had friends with CF that I can relate to",

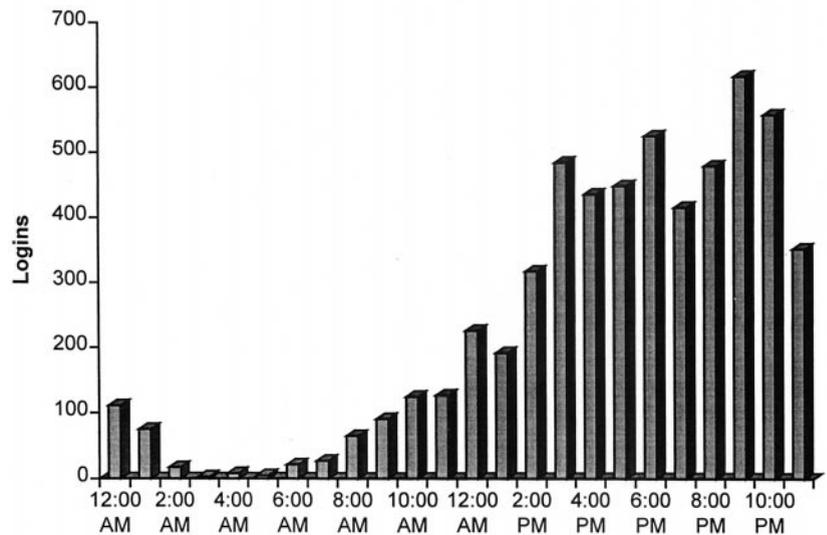
TABLE 1. Special Events

Event	Description
Scavenger hunt	(Once) 10 clues constructed from 10 items on the web site, such as, "Which member of the clinic staff has a Fox Terrier?" First 2 to answer all questions win.
Who's who game	(Once) One fact from each teen sent via regular mail. First 2 to match all facts correctly with a member of the site win.
BINGO	(Once) Game card mailed to home. Twice a day for a week, a new word appears on the home page. First 2 to BINGO! win.
Mystery member game	(~4 times) 10 facts collected about one teen. These facts displayed on homepage 4 times a day for 5 consecutive days. First 2 to identify correct teen win.
Puzzler	(~5 times) Create a logic puzzle at a page, and put a pink question mark throughout the site. First to figure out puzzler emails answer and wins a prize.
Guest spotlight	(Once) Young adult with CF, status/post 2 lung transplants, now in advertising, dropped puck at opening of MCI Center in Washington, DC.



Logins by day of week

Fig 4. CF teen log-in data.



Logins by hour of day

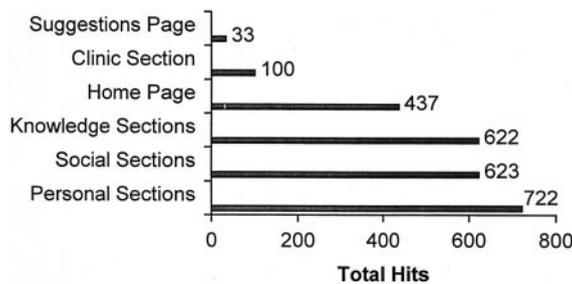


Fig 5. Site section use ("hits").

TABLE 2. Teen Interaction With Site

Type of Interaction	# Interactions
Suggesting a topic for the vote section	2
Submitting recipes	3
Requesting topics for library books	10
Email for help with technical problems	11
Submitting jokes	14
Submitting movies to review	17
Suggesting a profile question	25
General questions to site coordinator	25
Submitting response to CF situation	34
Starting quizzes about CF	79
Submitting User Profile information	113
Message Board postings	588

although 80% said that "it can help for a teen to relate to another teen with CF." They also generally believed that they knew what they needed to about CF. However, at the conclusion of the project, a follow-up survey showed a significant increase in their perceptions of their support from peers with CF (1.9 vs 9.6; $P = .02$), as well as a decrease in their perceptions about their knowledge of CF (2.4 vs 4.1; $P < .01$), as shown in Table 3. One teen stated that participating in the site made him realize how little he knew about CF. There was no significant change in their assessment of the Internet as a "good place to get support from other teenagers with CF." There was no correlation between the activity of the participants and their reported need for peer support.

When given a general quiz testing their CF knowledge, there was no difference between scores at the beginning and end of the study (72% vs 73%; $P = .70$).

Barriers to Use

Although the participants used the site consistently during the study, they did identify some barriers that limited their access to the ESG. Three of the 9 children who used an ITVD responded that they never had problems. The other ITVD users cited a series of problems, as shown in Table 4. Of note,

TABLE 3. Survey Results

Question	Pre	Post	P Value
1. Support from other teens is important to me.	3.0	3.2	.38
2. It can help for a teen to have friends with another teen with CF.	2.9	3.0	.54
3. I have support from other teens when I need it.	3.3	3.4	.75
4. I have friends with CF that I can relate to.	1.9	2.6	.02
5. The Internet can be a good place to get support from other teenagers.	3.0	3.1	.72
6. An Internet group could be a good place to get support from other teenagers with CF.	3.0	3.2	.38
7. It is important to understand my CF.	3.3	3.5	.19
8. It is important to know where to go with questions about CF.	3.2	3.4	.54
9. I know everything I need to about CF.	2.4	2.1	.009
10. I can easily get my questions about CF answered.	3.3	3.2	.43
11. The Internet could be a good place to get questions about CF answered.	2.9	3.1	.22
12. An Internet group could be a good place to get information about CF.	3.2	3.3	.75
13. It is important to feel comfortable with your doctors and clinic staff.	3.4	3.5	.67
14. It helps to know that your doctor and clinic staff are available when you need them.	3.4	3.3	.77
15. I feel comfortable with my doctors and clinic staff.	3.1	3.3	.50
16. The CF doctors and clinic staff are available when I need them.	3.2	3.1	.72
17. An Internet group could help teens become more comfortable with their doctors and clinic staff.	2.9	3.0	.46
18. It could help teens to have their clinic staff available on the Internet.	3.4	3.4	.72

TABLE 4. Barriers to Site Use by WebTV Users

Problem	# Responses
Busy phone line	5
Busy television	1
Other user	1
Forgot to use it	1
Wasn't programmed right	1
No problems	3

access to the phone or TV were the most often cited reasons, accounting for more than one half of the reasons offered by the teenagers. Each teenager was asked, "If you could change one thing about the way the WebTV was set up in your house, what would it be?" Three of the teenagers would have added a phone line, while another group of 3 would have obtained a second WebTV, because another family member was using theirs. The other 3 teenagers said that they would get a bigger or smaller TV² or move the WebTV to another site in the house.¹

During the focus group, the parents of the participants did not identify any problems with ITVD use in the home. However, parents of 2 teens reported that they limited their child's use of the television (and phone) so that they would complete their homework and so that their children would have time to engage in other activities. Parents, in general, were unaware of how their children were using the Internet and limited their activity on the computer in an effort to maintain balance between this and other activities. One parent noted that her child was generally healthy and that she would probably be more liberal with respect to her child's use of the Internet if her child became homebound.

Site Management

One of the authors (R.D.R.) monitored messages sent to most of the ESG pages. During the study, 5 messages were edited before inclusion on the site. These messages contained inappropriate language. No teen sent misleading or erroneous information to

the site. Participants used very little profane language in their communications. There were very rare technical questions from any of the participants. Two siblings in the study became infrequent users of the site ~6 months into the study. Through the follow-up survey, it became clear that their use was affected by trouble they had connecting their ITVD and video player to the same television.

DISCUSSION

This study of a group of teenagers using an ESG provides many insights into the potential of similar groups. Although we were unable to demonstrate any improvement in knowledge about CF despite widespread use of the sections of the site devoted to improving knowledge, we were able to demonstrate a significant change in the perception that participants had about their access to other teenagers with CF.

There were many intriguing comments made by participants during the focus group. The most significant event that this project catalyzed was an opportunity for the participants to bond and to discuss both typical adolescent issues and those specific to CF. Learning about each other through interactive parts of the site was an essential component of their bonding. However, there is tremendous potential for the knowledge sections of the site to be improved, and there is ample evidence that the teens will voluntarily engage in activities that contribute to their learning and that test their knowledge. For example, information gathering from the site might be enhanced by allowing user-specific views of information, providing a search capability, and allowing users to annotate the contents to provide a peer review mechanism, as has been done with other web sites. We also were reassured that most of the teens continued to visit the site even after obtaining the e-mail addresses of its members. This participation suggests that there is an opportunity to provide more support to these teens than was provided during this pilot.

We were encouraged by the success that we had

with most ITVD users. These devices are inexpensive—an ITVD with a wireless keyboard costs less than \$300.00; the addition of a separate phone line for 2 years and separate television raises the cost to \$1280.00, which is roughly equivalent to a computer without the separate phone line. Moreover, we found that ITVD users had virtually no technical problems and were able to access the features of this site without difficulty. There was a trend toward less use of the site by ITVD users. We suspect that a combination of factors led to this trend. For example, ITVD users did not have a private location to participate with the ESG. A few of the ITVD group stated a desire for an additional phone line or television; competition for those resources may have limited their time on the Internet. A more thorough discussion of this technology has been published elsewhere.³⁷ However, given the ease with which this technology is maintained, we would recommend using this technology to help conquer the digital divide in similar projects.

Limitations

The small cohort of children who were self-selected to participate limited this study. We chose to follow a model that is typically recommended for conventional support groups. Therefore, we did not include children with CF who were followed in other settings, and we did not include adults or children under the age of 13 years. The effect of enrolling a larger cohort of patients, some of whom might not have an interest in accessing an ESG, is not known. This study suggests that certain aspects of the project, including the Message Board feature, e-mail communication, and user profiles, might be enhanced through the creation of a larger group. However, the bonding of a group of teens who share similar developmental issues and who have the same chronic illness might be hampered by making the group diverse in either age or disease type.

Although no substantive changes were made to the site after the study began, minor additions in content, as well as an irregular approach to site management, might have affected use to varying degrees during the study. For example, regularly scheduling group activities might result in improved attendance and might result in higher satisfaction with the site, more frequent group interaction, and higher interactivity site use. An alternative hypothesis is that the natural history of such a site begins with initial interest, followed by a decline in participation once they have made contact with other teens. Additional longitudinal studies should address this issue.

Surveys were administered using pen and paper and were mailed to those teens who could not attend group sessions. A possible limitation might be that surveys results, therefore, did not accurately represent the knowledge or attitudes of the participants. We elected not to use a web-based tool to administer the surveys, in the event that problems with the tool or with the study environment would confound the results.

Implications

As health care in the home becomes more widespread and larger catchment areas for referral centers develop conventional support groups sponsored by health care providers are likely to become more challenging to organize. This study provides evidence that ESGs can be constructed using inexpensive technology and can help meet the psychosocial needs of many adolescent patients. These results support the use of ESGs to help augment patients' knowledge about their disease.

Future research should evaluate the role of newer technologies to help teens find information and demonstrate coping skills that have been shown to be effective in traditional support programs.^{38,39} For example, web sites could use computer-tailoring techniques to customize information based on a teens needs or create interactive games to demonstrate coping skills. We are encouraged by our results and believe that providing these kinds of knowledge can be done electronically with peer group and health provider collaboration. Future projects also should consider how group size affects participation and should determine how including children with a variety of diagnoses in the group affects the group dynamics.

The digital divide represents one of the most significant obstacles to the success of an ESG. We have shown that one brand of ITVD (WebTV) can be set up and maintained by adolescent patients with a minimum of training and support. We also have shown that ITVDs do not significantly influence the ability to participate in web-based discussions, although they do constrain the technical capabilities of the ESG. Therefore, we believe that providing ITVDs to patients is effective at eliminating the technical barrier that would otherwise restrict access to an ESG. In addition, ITVDs represent an inexpensive, portable tool for hospital-based access to the web and to e-mail.

Although we were surprised by the limited need for supervision of this ESG, we are confident that additional group activities would have improved participation, and will likely change our approach to providing such supervision in the future. It was clear that without daily attention to the site, either by changing banners or by initiating conversations, the teen's interest in the site could wane. It was also clear that a technically sophisticated team would be necessary to build and maintain such a site over time. Support groups of any kind require participation, management, and supervision by qualified staff. As was heard from parents, ESGs might benefit from providing the parents with education and the support group agenda, so that family-imposed restrictions to Internet access can be relaxed as appropriate. There are likely to be other operational considerations, including notifying the group when events occur among the members, and occasionally dispelling any rumors that may start. For example, we did not encounter any deaths among the study participants. The death of a participant could spark a sensitive discussion that might require intensive sup-

port from our moderating team, or it could precipitate a drop-off in visits to the site, as participants try to avoid the issue of death.

CONCLUSION

A carefully designed ESG provides enormous potential benefits and few risks. The study supports the undertaking of these groups on a broad scale and describes some potential outcomes that can be assessed after these groups have been implemented.

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