

Personal Web Home Pages of Adolescents With Cancer: Self-Presentation, Information Dissemination, and Interpersonal Connection

Lalita K. Suzuki, PhD
Ivan L. Beale, PhD

The content of personal Web home pages created by adolescents with cancer is a new source of information about this population of potential benefit to oncology nurses and psychologists. Individual Internet elements found on 21 home pages created by youths with cancer (14-22 years old) were rated for cancer-related self-presentation, information dissemination, and interpersonal connection. Examples of adolescents' online narratives were also recorded. Adolescents with cancer used various Internet elements on their home pages for cancer-related self-presentation (eg, welcome messages, essays, personal history and diary pages, news articles, and poetry), information dissemination (e.g., through personal interest pages, multimedia presentations, lists, charts, and hyperlinks), and interpersonal connection (eg, guestbook entries). Results suggest that various elements found on personal home pages are being used by a limited number of young patients with cancer for self-expression, information access, and contact with peers.

Key words: adolescent, pediatric, cancer, Internet, Web site

The experiences of young patients with cancer have been well documented in the pediatric and psychological literature. Although young survivors of cancer may typically show excellent adjustment (Fritz &

Williams, 1990), they can also encounter psychosocial problems such as social isolation, decreased social support, and lower levels of self-satisfaction (Koocher & O'Malley, 1981; Nichols, 1995; Noll et al., 1999). Teens in particular may be more at risk for depression, stress, and anxiety than children diagnosed at younger ages (Bessel, 2001; Claflin & Barbarin, 1991; Fritz, Williams, & Amylon, 1988). This study focused on adolescents in middle school through college, many of whom are not yet independent from their families.

Internet Home Pages as a Research Resource

Previous research on youth with cancer has relied mainly on questionnaires and standardized measures (Waxler-Morrison, Doll, & Hislop, 1995). Also, interviews have been used to glean "illness narratives," in which patients describe their cancer experience (Kleinman, 1988; Saillant, 1990; Skott, 2002). Such methods may unduly restrict the revelations of the respondents. However, the Internet age has now provided a different resource, the personal home page, which may afford patients greater freedom in how they describe their cancer experience and seek contact with others.

Lalita K. Suzuki, PhD, is a senior research analyst at HopeLab, Palo Alto, California. She was formerly at Children's Digital Media Center, UCLA. Ivan L. Beale is with the School of Psychology, University of New South Wales, Sydney, Australia. Address for correspondence: Lalita Suzuki, PhD, HopeLab, 101 University Avenue, Suite 220, Palo Alto, CA 94301-1638; e-mail: lsuzuki@hopelab.org.

© 2006 by Association of Pediatric Oncology Nurses
DOI: 10.1177/1043454206287301

Research on Home Pages

Most research shows that home pages are used for self-presentation and self-identity (Chan, 2000; Miller, 1995). In one of the few investigations of home pages created by the ill, content analysis identified 6 ways in which people with Down syndrome described themselves online (Seale, 2001). Another study identified differences between recovering anorexics and those endorsing anorexic lifestyles in language used in home pages (Lyons, Mehl, & Pennebaker, in press). These studies focused on self-presentation and did not present extensive analysis of differential use of individual Web site elements, although such an analysis might well provide valuable insights. A review of home page research identified a need to differentiate between home page functions and stated, "It becomes apparent that explicit self-presentation is not the only and quite often not even the most important personal home page function" (Doring, 2002, p. 19).

Cancer-Related Home Page Functions

The current study identifies whether Web site elements are being used by youth with cancer for self-presentation, cancer-related information dissemination, and interpersonal connection. There is evidence that all 3 functions are potentially beneficial.

Self-presentation. Home pages allow self-presentation through the public disclosure of illness experiences. Writing about traumatic life events, relative to writing about superficial events, has been shown to be associated with health benefits such as significant drops in physician visits and improved immunological function (e.g., Pennebaker & Beall, 1986; Pennebaker & Francis, 1996; Pennebaker, Kiecolt-Glaser, & Glaser, 1988).

Information dissemination. Home pages empower youth to share their knowledge widely, and this may be beneficial. Searching for cancer information on the Internet is reportedly a good coping strategy for adolescents with cancer (Kyngas et al., 2001). Greater access to cancer information may be associated with less anxiety, less depression, and less negative self-esteem among young patients (Last & van Veldhuizen, 1996), and greater knowledge about cancer has been found to be associated with less depression, a more positive self-image, and lower levels of anxiety about

treatments (Hockenberry-Eaton & Minick, 1994; Jamison, Lewis, & Burish, 1986; Kvist, Rajantie, Kvist, & Siimes, 1991; Last & van Veldhuizen, 1996).

Interpersonal connection. There is evidence that youth with cancer want to establish contact with one another to exchange information and advice about various cancers, procedures, and treatments (Bluebond-Langner, Perkel, & Goertzel, 1991; Enskar, Carlsson, Golsater, & Hamrin, 1997) and may value this as much as support from family and friends (Dunsmore & Quine, 1995).

Methods

Home Page Identification Methods

A search was conducted in November and December 2002 to locate publicly accessible home pages authored by youth with cancer. General Web site directories (Yahoo!, Google, AskJeeves, Vivisimo) were searched, and the first 200 Web sites were sampled, using the keywords *cancer teen* and *cancer survivor personal home page*. The search also employed Yahoo!Geocities and AOL Hometown (home page directories) and www.webring.com (home pages linked by topic), using the keyword *cancer*. Links found on the above sites were also searched to see if they contained home pages that met the inclusionary criteria.

Home Page Sampling Criteria

Site inclusion criteria were as follows: (1) the home page was created by a person with cancer, (2) the home page was not created or cocreated by other parties, and (3) the home page was created by someone aged 13 to 22 (the approximate ages of youth in middle school through college). Information about school attendance was also accepted. The initial search located 3940 sites, mostly consisting of online news articles, advertisements, and Web sites for cancer organizations. Most home pages were created by older adults who wrote about their own, or their children's, cancer. Many of the teen home pages were coauthored by parents and/or organizations or were memorials for people lost to cancer. Only 21 home pages met all criteria.

Analysis Methods

Qualifying home pages were analyzed for characteristics of interest as follows:

Demographics of home page Web authors. Gender was assessed through names and/or personal photographs, if available. Age was recorded as explicitly stated or inferred from birth dates and the date on which the home page was last updated. Disease type and time since diagnosis were gleaned from personal histories and diaries.

Counts of Internet elements. Simple binary counts (used/not used) were made for each of the Internet elements of interest: home page title, welcome, personal history, diary, personal interest pages, pages about other people, personal art/poetry/essays, others' art/poetry/essays, quotes, jokes/fun stuff, news articles, multimedia presentations, photos, lists, charts, graphics, links, guestbooks, and contact information. Intercoder reliability was calculated by having 2 independent coders examine four randomly selected home pages for the existence of the elements. The intraclass correlation coefficient (ICC) for the 2 coders was in the excellent range (0.83) (Fleiss, 1981). One of the coders coded the entire data set for further analysis.

Home page elements used for cancer-related self-presentation, information dissemination, and interpersonal connection. Each element (on every home page that contained that element) was rated on a 5-point scale reflecting the extent that element was used for cancer-related self-presentation, information dissemination, and/or interpersonal connection. These constructs were defined as follows:

- *Self-presentation.* Personal cancer experiences, attitudes, and/or feelings of the Web author as indicated by what he or she chose to post on his or her home page. Items created by others were also included if they were selected by the Web author as representing the Web author's experiences, attitudes, and/or feelings about cancer.
- *Information dissemination.* Explicit information given in the form of facts, technical information, and/or practical advice about cancer, its treatment, and side effects.
- *Interpersonal connection.* Evidence that an Internet element was used by other patients with

cancer, or others affected by cancer, to communicate with the Web author.

The 5-point rating scheme used for self-presentation (scales for information dissemination and interpersonal connection were identical, with *information dissemination* and *interpersonal connection* replacing *self-presentation*) was as follows:

1. *None* of the items were used for cancer-related self-presentation.
2. More items were *not used* than used for cancer-related self-presentation.
3. *Equal numbers* of items were used for cancer-related self-presentation and for other purposes.
4. More items were *used* than not used for cancer-related self-presentation.
5. *All* of the items were used for cancer-related self-presentation.

Thus, if 6 out of 10 diary entries on a home page were about the author's experiences with cancer, it was rated "4" for self-presentation. Because coding categories were not mutually exclusive, each element on every home page received separate codes for all 3 categories. Interrater reliability was based on two independent raters scoring 4 randomly selected home pages. ICCs for ratings in all 3 categories fell within the fair-good to excellent range (self-presentation, 0.87; information dissemination, 0.65; interpersonal connection, 1.00) (Fleiss, 1981). One rater scored the entire data set for further analysis.

Examples of content. Examples of online narratives used for self-presentation, information dissemination, and interpersonal connection were selected to illustrate content. Names and other identifying information were altered to protect the Web authors' identities.

Results

Demographics

Of the sample of 21 home pages, 11 were created by females, 9 were created by males, and 1 contained no gender information. Authors' ages (given for 16 pages) ranged from 14 to 22 years (mean = 19.3, SD = 2.4). Diagnoses were Hodgkin's disease (8), leukemia (3),

non-Hodgkin's lymphoma (3), Ewing's sarcoma (2), and osteogenic sarcoma, pineal germinoma, rhabdomyosarcoma, Wilms' tumor, and an unspecified cancer of the hand (1 each). At the time that sites were accessed for analysis, 13 Web authors had completed treatment, 3 were still receiving treatment, 2 had completed chemotherapy but were awaiting further surgery, 2 gave no information about current disease status, and 1 was undergoing further treatment after relapse.

Internet Elements

Table 1 shows the distribution of use and ratings for each Internet element for self-presentation, information dissemination, and interpersonal connection.

Frequently used elements included welcome messages, home page names, personal history pages, links, photographs, guestbooks, and personal contact information. Infrequent elements included jokes, artwork, and multimedia presentations (e.g., videos).

Self-Presentation

The elements used most consistently for cancer-related self-presentation included welcomes, diary entries, personal history pages, essays, artwork, poetry, and news articles.

Welcome message. Of the 19 home pages that contained a welcome message, 17 presented information about the Web author's personal cancer experience. Most of them had straightforward presentations about their health status:

This is my page about Ewings Sarcoma . . . I had a volleyball size tumor in my pelvis with mets to skull and lungs. I am now 20 and doing great.

Diary entries and personal history pages. Nine of the home pages contained diary entries. All 9 wrote about cancer in more than half of their entries, and 3 wrote about their cancer in every entry. Personal history pages (pages in nondiary form about one's life history) were also largely devoted to cancer-related self-presentation. Of the 18 Web pages that contained personal history pages, all 18 presented discussion of their cancer at some point, and 17 discussed their cancer in more than half of their pages. Many of the self-presentations focused on the positive and even humorous aspects of having cancer. The diary and

personal history pages also provided Web authors with an outlet to air their more private hopes and fears and yielded precious information about the wants, needs, and dissatisfactions of young patients. Table 2 provides examples of such content.

Personal essays. Although only 3 sites contained personal essays, in each case these conveyed the Web author's identity as a patient with cancer. For example, a 17-year-old female posted an essay about cancer and her spirituality:

I choose to be faithful because I do not know what my future holds. . . . But I know who holds my future. I am here today free of Leukemia because God has worked through my treatment for me.

Artwork and poetry. Artwork was found on only 1 of the 21 home pages. Of the 7 home pages that contained poetry written by the Web author, all had at least 1 poem with cancer-related self-presentation, and in 5, all of the poems were about cancer. These poems covered topics such as friends lost to cancer and the support received from others during treatment. One patient wrote a poem comparing his cancer ordeal with the trials of Odysseus. Of the poems written by others, more than half were about cancer. Most were written by other young patients or by those wanting to provide solace.

News articles. Seven of the home pages contained a news article about the Web author's cancer experience (scanned newspaper articles or online articles). One article described how a Web author's class gave up money saved for their class trip to help offset the costs of his cancer treatment, and other articles highlighted the home pages created by patients. These articles allowed patients to present their cancer experience from a third-party perspective.

Information Dissemination

As seen in Table 1, in general, mean ratings for information dissemination were not as high as those for self-presentation. The elements used most consistently for cancer-related information dissemination included multimedia presentations, lists, charts, links, and personal interest pages. These elements will be discussed below.

Personal interest pages. Personal interest pages are pages devoted to the Web author's chosen subjects. Of

Table 1. Distribution of Web Site Elements and Ratings of Elements for the Separate Functions of Self-Presentation, Information Dissemination, and Interpersonal Connection

Element Type	# (of 21)	Self-Presentation Ratings					Information Dissemination Ratings					Interpersonal Connection Ratings							
		1	2	3	4	5	Mean	1	2	3	4	5	Mean	1	2	3	4	5	Mean
Welcome	19	2	0	0	0	17	4.58	15	0	0	0	4	1.84	19	0	0	0	0	1.00
Site name	18	7	0	0	0	11	3.44	18	0	0	0	0	1.00	18	0	0	0	0	1.00
Personal history	18	0	1	0	1	16	4.78	3	7	0	2	6	3.06	18	0	0	0	0	1.00
Links	18	2	3	2	4	7	3.61	2	3	2	4	7	3.61	18	0	0	0	0	1.00
Photographs	15	3	3	1	6	2	3.07	5	7	1	2	0	2.00	15	0	0	0	0	1.00
Guestbook	15	14	1	0	0	0	1.07	11	4	0	0	0	1.27	1	9	0	4	1	2.67
Personal contact information	15	15	0	0	0	0	1.00	15	0	0	0	0	1.00	15	0	0	0	0	1.00
Personal interest pages	13	3	2	1	4	3	3.15	3	1	1	3	5	3.46	13	0	0	0	0	1.00
Lists	11	2	2	1	2	4	3.36	0	1	1	3	6	4.27	11	0	0	0	0	1.00
Diary	9	0	0	0	6	3	4.33	1	8	0	0	0	1.89	9	0	0	0	0	1.00
Graphics	9	8	0	0	0	1	1.44	8	0	0	0	1	1.44	9	0	0	0	0	1.00
Personal poetry	7	0	2	0	0	5	4.14	6	0	1	0	0	1.29	7	0	0	0	0	1.00
News article	7	0	0	0	0	7	5.00	3	0	0	0	3	3.00	7	0	0	0	0	1.00
Page about others	6	2	0	0	0	4	3.67	6	0	0	0	0	1.00	6	0	0	0	0	1.00
Others' poetry	6	0	0	0	1	5	4.83	6	0	0	0	0	1.00	6	0	0	0	0	1.00
Other fun stuff	6	4	0	0	0	2	2.33	4	0	1	1	0	1.83	5	1	0	0	0	1.17
Others' essays	4	1	0	0	0	3	4.00	2	0	0	0	2	3.00	4	0	0	0	0	1.00
Quotes	4	2	2	0	0	0	1.50	4	0	0	0	0	1.00	4	0	0	0	0	1.00
Charts	4	3	0	0	0	1	2.00	1	0	0	0	3	4.00	4	0	0	0	0	1.00
Personal essay	3	0	0	0	0	3	5.00	1	0	1	0	1	3.00	3	0	0	0	0	1.00
Multimedia presentation	2	1	0	0	0	1	3.00	0	0	0	0	2	5.00	2	0	0	0	0	1.00
Personal art	1	0	0	0	0	1	5.00	1	0	0	0	0	1.00	1	0	0	0	0	1.00
Others' art	1	0	0	0	0	1	5.00	1	0	0	0	0	1.00	1	0	0	0	0	1.00
Jokes	0	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—

Table 2. Examples of Self-Presentation in Diary and Personal History Page Content

Theme	Examples
Finding meaning	“The support and courage I had in battling this disease made me reevaluate my life, and also made it better. An ultimately terrible event in my life, brought out the best in me, and the people around me.”
Humor	[On going to a fertility appointment] “There were all these couples . . . and me . . . and my dad. I was wondering if anybody thought that my dad and I were another freaky couple but I decided against it. I said ‘Yes, DAD,’ ‘No DAD’ a few times though anyway—just to be sure!”
Anger and fear	“I’ve had a lot of people compliment me on the way that I’ve been handling this. . . . Well, I’m a good actor. This is the truth. I am scared, angry, and sad. All this positive (<i>sic</i>) stuff is mainly for my family and friends. . . . What kind of messed up thing did I have to do to have God slap me in the face like this.”
Treatments	“Today was the worst out of all of them, my bone marrow biopsy. It feels like getting a tooth drilled without any pain meds except in your hip instead of your mouth. And afterward it feels like you fell down the stairs and landed on your ass really hard.”
Doctors	“If you’re a doctor reading this . . . never ask parents if they have other children. . . . I wanted to scream, I’m not disposable, you can’t replace me, four children instead of five isn’t good enough. I seriously freaked out.”
Body image	“This really sucks . . . how am I going to get my nice six pack for the beach if I can’t even work out like I normally would. And on top of that the steroid I’m taking is supposed to make me gain weight, and if I can’t work out as hard as normal then I don’t know how I’m going to keep myself in shape.”
Death	“I understood very strongly that in order to die, you must first melt away physically. I had seen it happen to many other children. Kids who ate did not die. Therefore I ate; no matter how much my throat hurt or my gums bled. I would eat and throw it up, and then I would eat again.”
Home pages	“After putting down what I was feeling in this journal things didn’t seem so bad, and making things seem not bad to a guy with cancer is a wonderful thing.”

the 13 home pages that contained such pages, 10 had at least 1 page that provided explicit cancer information, and 8 had cancer information on more than half of the personal interest pages. The information on these pages spanned topics such as chemotherapy drugs and their side effects, alternative therapies, and even the history of cancer and its treatment. Information was presented in a style varying from highly technical to simple. A common format was the presentation of tips and advice to other young patients with cancer. Typically, this was practical advice given in an informal tone not normally found in medical pamphlets. Table 3 provides examples of the types of information provided on these personal interest pages.

Lists and charts. All 11 home pages with lists had some type of explicit cancer information on at least 1 of their lists, and 6 had all of their lists providing cancer facts, advice, and other information. Many were

lists of cancer-related tips, and others were lists of facts, covering issues such as the steps that take place during radiation treatment and questions to ask one’s doctor.

Although only 4 home pages contained charts, 3 had all of their charts containing cancer information. One chart listed and described elements contained in blood (e.g., platelets, red blood cells). Another chart showed which of 7 chemo medications the author took during each of her 12 weeks of chemotherapy.

Multimedia presentations. Only 2 of the home pages contained multimedia presentations, both providing explicit cancer information. One was a 27-page presentation that covered such topics as the role of physical therapy for patients with osteosarcoma and limb-salvaging techniques. The other contained a short video of the author’s stem cell transplant.

Table 3. Examples of Information Dissemination in Personal Interest Page Content

Theme	Examples
Definitions (technical)	“Osteogenic Sarcoma (osteosarcoma) is a bone forming cancer. It is the most frequent type of bone tumor and is most common between the ages of 15 and 25. Over 90% of tumors are located in the metaphysis (the growing ends of the bone).”
Definitions (teen oriented)	“The CT Scanner is like a big wide metal hula hoop. You lie on the table and it moves you through the hoop as it scans you. It isn’t one of the claustrophobic tests, the only thing you have to do is lie very still.” “When a normal testicle is examined it is round, soft and smooth . . . I know you probably don’t want to talk about this or do the exam, but remember, having cancer sucks, the treatment really sucks.”
Tips	“Travel sickness wristbands are a miracle. Wear them religiously.” “Don’t eat anything you really like right after your first treatment of anything. You will NEVER be able to think of it again without feeling sick.” “I strongly recommended getting [a port]. Otherwise they [need] to insert an IV every time you get chemo. . . . It’s a tube that is surgically inserted through a small operation into a major vein.”

Links. Among the 18 home pages with links, 16 had at least 1 link that provided cancer-related information, and 7 had all of their links providing cancer information. Many links were to national cancer organizations (e.g., www.candlelighters.org; www.cancer.org) and disease-specific sites (e.g., www.leukemia.org). Links were often organized by topic, such as coping with hair loss (e.g., www.lookgoodfeelbetter.org; www.2bme.org), support organizations (e.g., www.cancerhopenetwork.org; www.chemoangels.com), and cancer discussion forums (e.g., www.acor.org). Many sites were specifically for youth, with topics such as scholarships for young people with cancer (e.g., www.andriveroflife.org/award.html; www.ulmanfund.org), fertility (e.g., www.ivf.com), and links to the personal home pages of other teens with cancer.

Interpersonal Connection

Guestbooks. Most Web elements (e.g., diary entries, links) cannot support interpersonal connection, and in fact, guestbooks (contained in 15 of the Web sites) were the only Internet element consistently and clearly used for that purpose (average score for interpersonal connection = 2.67). (Note, however, that this score is lower than many of the scores for self-presentation and information dissemination.) Guestbooks are electronic “bulletin boards” where site visitors can post public messages to the Web author. Of the 15 home pages with guestbooks, 14 contained at least 1 entry, and in 5, more than half of their entries ostensibly were written by someone affected by cancer. It is possible that some guests

affected by cancer did not indicate this. Table 4 provides examples of content found in guestbooks.

From these postings, it is clear that the home pages were being used by people affected by cancer to contact the Web author and to gain information and support from each other. Some guestbook visitors were “repeat posters,” sending frequent updates and information to the Web author over a period of time, indicating that an interactive relationship had been established.

Discussion

These results provide an introduction to the use of home pages in revealing the cancer experiences of young patients. Cancer-related self-presentations on home pages were not limited to prose but also included poetry and news articles. Although some narratives were traumatic, many also talked about the positive consequences of surviving cancer and its treatment. Such comments support existing research that patients with cancer often find new meaning and positive changes following their illness experience (e.g., Novakovic et al., 1996; Thornton, 2002). Research has also shown that people with illnesses can use humor and spirituality as a means of coping (Jenkins & Pargament, 1995; Kyngas et al., 2001; Tebbi, Mallon, Richards, & Bigler, 1987), and examples of both were also found on the home pages.

Childhood cancer survivors report an increased capacity for empathy and a desire to help others (Karian, Jankowski, & Beal, 1998). This desire was evident in the Web authors’ attempts to share cancer

Table 4. Examples of Interpersonal Connection in Guestbook Entries

Theme	Examples
Gratitude	<p>“Recently I have lost my ‘support group’ of friends who all understood what I was going through . . . they have all died and it seems like they left me all alone at the worst point in my life. I was diagnosed with AML when I was 9, and in February we found out that it was back. Thank you for this site, it has been an encouragement to me .”</p> <p>“I ran into your site somehow and I used to read it religiously to know what was coming up for me . . . I’m very glad to see that you’re still there, as I am going to keep looking at your site to see what’s in store for me!”</p>
Sharing experiences	<p>“I was told 5 months ago that I had the same type of cancer you got. The doctors told me that I had until dec of this year (2000) to live. The cancer has spread (<i>sic</i>) throughout my body and all the chemos that I’ve had done already have not help much. This is the hardest things that has happened in my life.”</p>
Finding peers	<p>“I’ve never got a chance to talk with anybody under the age of 40 that has had cancer. So any teens that read this pleaseeee e-mail i would luv to talk.”</p>
Offering help and encouragement	<p>“I’m not a teen, but I did want to let you know that I also had Wilms’ on the right kidney, 44 years ago. . . I was able to have children and lead a pretty normal life for a long time. You hang in there and take care and know that the Lord loves you. God Bless!”</p> <p>“Call me. I had Osteo over 4 years ago and was 22 when I was diagnosed. I first had a cadaver’s bone put in but it broke two years ago and now have the same device you are going to have. I have a good deal of experience with it and may be able to help you out on what to expect. I can be reached at the below numbers.”</p>
Exchanging information and support	<p>“My son found out he had cancer when he was 17 he past (<i>sic</i>) away 4 months ago at the age of 19 my heart is broke i just cant get over it.”</p> <p>A fellow mother replied: “I know how you feel . . . I lost my beautiful 26 yr old daughter to osteosarcoma 2 years ago. . . If you feel up to writing me, I would feel honored to hear about your son.”</p>

information. Many home pages had pages of statistics, definitions, and advice about cancer, including links to external Web sites prescreened as personally relevant. Although some information was technical, other information was based on personal experience and had particular relevance to adolescent issues, such as advice about coping with teasing and the importance of preserving fertility. The use of informal wording on many sites may assist to make cancer information more accessible to teens than content found on more formal Web sites, and the frequent use of slang may facilitate sharing of a group identity (Cooper & Anderson-Inman, 1988). Finally, guestbooks revealed that Web users with cancer were accessing the Web sites’ cancer information, and the sites were being used to connect Web authors and respondents in a cyberspace cancer community, providing potentially valuable patient-to-patient support. It is notable that many of the Web sites served the functions found in other research to be characteristic of the use of the Internet by youth using self-disclosure: to attract

social support, to model coping through self-expression, and to share companionship (Tichon & Yellowlees, 2003; Tichon & Shapiro, 2003).

It is important to note, however, that many other aspects of the youths’ lives depicted on the pages were not addressed in the current study. For example, many Web authors discussed other interests (e.g., choral music, linguistics, raising dogs). Furthermore, some Internet elements were mainly used for non-cancer-related purposes. For example, although photographs depicted Web authors as patients with cancer, more often they portrayed the patients without evidence of disease, posing with family, interacting with friends, and going on trips.

Caution should also be taken not to generalize any inferences made about Web page authors to all youth with cancer. Those who created Web pages may be healthier than most youth with cancer, more economically advantaged, or better educated. Ability to use effective coping strategies offline may also influence the likelihood that youth will use the Internet as

a coping vehicle (Seepersad, 2004). Furthermore, although the incidence of cancer among youth 15 to 19 years old is estimated to be about 4000 per year (Ries et al., 2002; Smith, Gurney, & Ries, 1999), an extensive search located only 21 Web sites that met all of our criteria. Either most teens with cancer have not created personal home pages or have created pages that were difficult to access. It may also be the case that cancer patients prefer not to divulge information about their illness experience on home pages. However, although the number of existing Web sites that we found was small, there is evidence that many people are accessing these sites. One site had more than 10,000 hits or visitors, whereas another had more than 53,000 hits since its creation in 1998.

We conclude that home pages are being used by young patients with cancer in a way that may provide informational and psychosocial support, but this use seems to be confined at present to a small proportion of this population. Nevertheless, home pages clearly are an additional Internet resource for young cancer patients that can be added to the psychosocial and informational Internet supports already flagged in other research reports (Carlson, Reilly, & Hitchens, 2005; Decker, Phillips, & Haase, 2004; Kelly & Porock, 2005; Suzuki & Kato, 2003). The home pages are potentially a useful resource not just for the young patients who might create or access them but also for oncology professionals such as psychologists and nurses, both as source of information about patients' illness perceptions and an alternative resource to which patients and families can be directed. Finally, home pages are a valuable resource for research investigating patients' perceptions of their illness and their responses to it. Future studies should address the associations between use of the Internet, including other platforms such as blogs, bulletin boards, and chat rooms, and improvements in patient coping and health outcomes.

Acknowledgments

This research was supported by HopeLab, Palo Alto, California, and a grant from the National Science Foundation (NSF) to establish the Children's Digital Media Center. The authors would like to extend thanks to Pamela Kato, Patricia Greenfield, and James Pennebaker for helpful comments on earlier versions of this article and to Stephanie Morgan, who carried out the reliability coding.

References

- Bessel, A. G. (2001). Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences. *Exceptional Children, 67*(3), 345-359.
- Bluebond-Langner, M., Perkel, D., & Goertzel, T. (1991). Pediatric cancer patients' peer relationships: The impact of an oncology camp experience. *Journal of Psychosocial Oncology, 9*(2), 67-80.
- Carlson, C., Reilly, M., & Hitchens, A. (2005). An innovative approach to the care of patients on Phase I and Phase II clinical trials: The role of the experimental therapeutics nurse. *Journal of Pediatric Oncology Nursing, 22*, 353-364.
- Chan, S. Y. M. (2000). Wired selves: From artifact to performance. *Cyberpsychology & Behavior, 3*(2), 271-284.
- Clafflin, C. J., & Barbarin, O. A. (1991). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology, 16*(2), 169-191.
- Cooper, D. C., & Anderson-Inman, L. (1988). Language and socialization. In M. A. Nippold (Ed.), *Later language development: Ages nine through nineteen* (pp. 225-245). Austin, TX: Pro-Ed.
- Decker, C., Phillips, C. R., & Haase, J. E. (2004). Information needs of adolescents with cancer. *Journal of Pediatric Oncology Nursing, 21*, 327-334.
- Doring, N. (2002). *Personal home pages on the Web: A review of research* [online document]. Retrieved November 2002 from <http://www.ascusc.org/jcmc/vol7/issue3/doering.html>
- Dunsmore, J., & Quine, S. (1995). Information, support, and decision-making needs and preferences of adolescents with cancer: Implications for health professionals. *Journal of Psychosocial Oncology, 13*(4), 39-56.
- Enskar, K., Carlsson, M., Golsater, M., & Hamrin, E. (1997). Symptom distress and life situation in adolescents with cancer. *Cancer Nursing, 20*(1), 23-33.
- Fleiss, J. L. (1981). *Statistical methods for rates and proportions* (2nd ed.). New York: John Wiley.
- Fritz, G. K., & Williams, J. R. (1990). Issues of adolescent development for survivors of childhood cancer. In M. E. Hertzog (Ed.), *Annual progress of child psychiatry and child development* (pp. 208-218). Philadelphia: Brunner/Mazel.
- Fritz, G. K., Williams, J. R., & Amylon, M. (1988). After treatment ends: Psychosocial sequelae in pediatric cancer survivors. *American Journal of Orthopsychiatry, 58*(4), 552-561.
- Hockenberry-Eaton, M., & Minick, P. (1994). Living with cancer: Children with extraordinary courage. *Oncology Nursing Forum, 21*(6), 1025-1031.
- Jamison, R. N., Lewis, S., & Burish, T. G. (1986). Psychological impact of cancer on adolescents: Self-image, locus of control, perception of illness and knowledge of cancer. *Journal of Chronic Diseases, 39*(8), 609-617.
- Jenkins, R. A., & Pargament, K. I. (1995). Religion and spirituality as resources for coping with cancer. *Journal of Psychosocial Oncology, 13*(1-2), 51-74.
- Karian, V. E., Jankowski, S. M., & Beal, J. A. (1998). Exploring the lived-experience of childhood cancer survivors. *Journal of Pediatric Oncology Nursing, 15*(3), 153-162.

- Kelly, K. P., & Porock, D. (2005). A survey of pediatric oncology nurses' perceptions of parent educational needs. *Journal of Pediatric Oncology Nursing*, 22, 58-66.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Koocher, G. P., & O'Malley, J. E. (1981). *The Damocles syndrome: Psychological consequences of surviving childhood cancer*. New York: McGraw-Hill.
- Kvist, S. B., Rajantie, J., Kvist, M., & Siimes, M. A. (1991). Aggression: The dominant psychological response in children with malignant disease. *Psychological Reports*, 68(3, Pt. 2), 1139-1150.
- Kyngas, H., Mikkonen, R., Nousiainen, E. M., Ryttilahti, M., Seppanen, P., Vaattovaara, R., et al. (2001). Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care*, 10(1), 6-11.
- Last, B. F., & van Veldhuizen, A. M. H. (1996). Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. *European Journal of Cancer Care*, 32A(2), 290-294.
- Lyons, E. J., Mehl, M. R., & Pennebaker, J. W. (in press). Linguistic self-presentation in anorexia: Differences in pro-anorexia and recovering anorexia internet language use. *Journal of Psychosomatic Research*.
- Miller, H. (1995). *The presentation of self in electronic life: Goffman on the Internet*. Retrieved September 3, 2002, from <http://ess.ntu.ac.uk/miller/cyberpsych/goffman.htm>
- Nichols, M. L. (1995). Social support and coping in young adolescents with cancer. *Pediatric Nursing*, 21(3), 235-240.
- Noll, R. B., Gartstein, M. A., Vannatta, K., Correll, J., Bukowski, W. M., & Davies, W. H. (1999). Social, emotional, and behavioral functioning of children with cancer. *Pediatrics*, 103(1), 71-78.
- Novakovic, B., Fears, T. R., Wexler, L. H., McClure, L. L., Wilson, D. L., McCalla, J. L., et al. (1996). Experiences of cancer in children and adolescents. *Cancer Nursing*, 19(1), 205-221.
- Pennebaker, J. W., & Beall, S. K. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of Abnormal Psychology*, 95(3), 274-281.
- Pennebaker, J. W., & Francis, M. E. (1996). Cognitive, emotional, and language processes in disclosure. *Cognition and Emotion*, 10(6), 601-626.
- Pennebaker, J. W., Kiecolt-Glaser, J. K., & Glaser, R. (1988). Disclosure of traumas and immune function: Health implications for psychotherapy. *Journal of Consulting and Clinical Psychology*, 56(2), 239-245.
- Ries, L. A. G., Eisner, M. P., Kosary, C. L., Hankey, B. F., Miller, B. A., Clegg, L., et al. (2002). *SEER cancer statistics review, 1973-1999*. National Cancer Institute. Bethesda, MD: National Cancer Institute. Retrieved from <http://seer.cancer.gov/csr/1973-1999/>
- Saillant, F. (1990). Discourse, knowledge, and experience of cancer: a life story. *Culture, Medicine, and Psychiatry*, 14(1), 81-104.
- Seale, J. K. (2001). The same but different: The use of the personal home page by adults with Down syndrome as a tool for self-presentation. *British Journal of Educational Technology*, 32(3), 343-352.
- Seepersad, S. (2004). Coping with loneliness: adolescent online and offline behavior. *Cyberpsychology and Behavior*, 7(1), 35-39.
- Skott, C. (2002). Expressive metaphors in cancer narratives. *Cancer Nursing*, 25(3), 230-235.
- Smith, M. A., Gurney, J. G., & Ries, L. A. G. (1999). *Cancer among adolescents 15-19 years old (99-4649)*. Bethesda, MD: National Cancer Institute, SEER Program.
- Suzuki, L. K. & Kato, P. M. (2003). Psychosocial support for patients in pediatric oncology: The influences of parents, schools, peers, and technology. *Journal of Pediatric Oncology Nursing*, 20, 159-174.
- Tebbi, C. K., Mallon, J. C., Richards, M. E., & Bigler, L. R. (1987). Religiosity and locus of control of adolescent cancer patients. *Psychological Reports*, 61, 683-696.
- Thornton, A. A. (2002). Perceiving benefits in the cancer experience. *Journal of Clinical Psychology in Medical Settings*, 9(2), 153-165.
- Tichon, J., & Yellowlees, P. (2003). Internet social support for children and adolescents. *Journal of Telemedicine and Telecare*, 9(4), 238-240.
- Tichon, J. G., & Shapiro, M. (2003). The process of sharing social support in cyberspace. *Cyberpsychology and Behavior*, 6(2), 161-170.
- Waxler-Morrison, N., Doll, R., & Hislop, T. G. (1995). The use of qualitative methods to strengthen psychosocial research on cancer. *Journal of Psychosocial Oncology*, 13(1-2), 177-191.