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ARTICLE

Surfing for Thinness: A Pilot Study of Pro–Eating Disorder Web Site Usage in Adolescents With Eating Disorders

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ABSTRACT

OBJECTIVE. Pro–eating disorder Web sites are communities of individuals who engage in disordered eating and use the Internet to discuss their activities. Pro-recovery sites, which are less numerous, express a recovery-oriented perspective. This pilot study investigated the awareness and usage of pro–eating disorder Web sites among adolescents with eating disorders and their parents and explored associations with health and quality of life.

PATIENTS AND METHODS. This was a cross-sectional study of 698 families of patients (aged 10–22 years) diagnosed with an eating disorder at Stanford between 1997 and 2004. Anonymous surveys were mailed and offered in clinic. Survey content included questions about disease severity, health outcomes, Web site usage, and parental knowledge of eating disorder Web site usage.

RESULTS. Surveys were returned by 182 individuals: 76 patients and 106 parents. Parents frequently (52.8%) were aware of pro–eating disorder sites, but an equal number did not know whether their child visited these sites, and only 27.6% had discussed them with their child. Most (62.5%) parents, however, did not know about pro-recovery sites. Forty-one percent of patients visited pro-recovery sites, 35.5% visited pro–eating disorder sites, 25.0% visited both, and 48.7% visited neither. While visiting pro–eating disorder sites, 96.0% reported learning new weight loss or purging techniques. However, 46.4% of pro-recovery site visitors also learned new techniques. Pro–eating disorder site users did not differ from nonusers in health outcomes but reported spending less time on school or schoolwork and had a longer duration of illness. Users of both pro–eating disorder and pro-recovery sites were hospitalized more than users of neither site.

CONCLUSIONS. Pro–eating disorder site usage was prevalent among adolescents with eating disorders, yet parents had little knowledge of this. Although use of these sites was not associated with other health outcomes, usage may have a negative impact on quality of life and result in adolescents' learning about and adopting disordered eating behaviors.

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Key Words
adolescents, Internet, eating disorders, pro–eating disorder, pro-anorexia

Abbreviation
ED—eating disorder

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THE INTERNET IS a popular form of communication and self-expression for adolescents, with higher use among 13- to 19-year-olds than any other age group. Many popular online journal ("blogs") sites report a heavy skew toward younger users.[1] Up to two thirds of adolescent girls seek health information online, and many of them change their behavior as a result of the information that they find.[2,3] Of these Internet health searchers, nearly one half are looking for ways to lose weight and nearly one quarter are seeking information about eating disorders (EDs).[4] This is of particular concern considering the high prevalence of disordered eating among youth, with up to 13% of adolescent girls engaging in binge eating and purging.[5]

As youth become progressively "Web-savvy," adolescent-developed Web sites that promote anorexia and bulimia are increasingly prevalent. These pro–eating disorder (pro-ED) sites are communities of individuals who engage in disordered eating and use the Internet to discuss and reinforce their activities. Some pro-ED sites indicate that they promote EDs as a lifestyle choice rather than an illness; others accept EDs as illnesses. However, most share similar content, including "thinspiration" (images of thin and cachectic women), poetry, weight-loss advice, methods for avoiding detection by family and health care providers, forums, merchandise, and links to other, related sites.[6] Web sites that promote recovery from EDs provide a balance to these sites but are far less numerous. In 2003, there were ~500 pro-ED sites in existence, outnumbering pro-recovery sites 5:1.[6] Although qualitative studies have begun to explore content and experiential data from pro-ED sites,[7–11] no extant literature examines associations of pro-anorexia and pro-bulimia Web site use with clinical or behavioral parameters.

Pro-ED sites are not unique: numerous other Web sites that may have an adverse impact on health exist.[12] For example, the Internet has been shown to influence drug use in youth and promote antihealth behaviors such as self-injury, suicide, and smoking.[13–17]

The use of media images in pro-ED sites is a likely mechanism of worsening EDs among users. The sites adopt this phenomenon through "thinspiration," in which thin models and even severely cachectic individuals are featured positively for the purpose of maintaining disordered eating. Media images are known to have an impact on body dissatisfaction.[18] A meta-analysis of 25 studies on the effects of media images on ED symptoms found that viewing thin media images was more predictive of a lower body satisfaction than viewing control images.[19] A prospective study of nearly 3000 12- to 21-year-old girls found that reading "teen magazines" was significantly associated with the development of an ED.[20] Furthermore, recent longitudinal and cross-sectional data show that attempts to look like female individuals who are portrayed in movies, in magazines, or on television is predictive of purging behavior.[20–24]

Individuals who are likely to use pro-ED sites may be the most vulnerable. A meta-analysis demonstrated that individuals who were younger than 19 years and had body image issues were most prone to the negative effects of these images.[19] One study of 219 13- to 17-year-olds found that exposure to *Seventeen* magazine for 15 months increased the negative affect of participants who at the onset of the study felt increased pressure to be thin.[25]

Pro-ED Web sites are interactive and sustain a community of individuals through message boards and chat rooms. This community may act as a clique, a type of social interaction that has been shown to have a negative impact on body image and disordered eating behaviors of adolescents.[26] However, it also is possible that these communities serve a therapeutic role for individuals who are not ready for therapy or who feel rejected by the medical community, by providing the opportunity for individuals to express themselves in a supportive, anonymous setting.[27,28]

Little is known about the effects of pro-recovery sites on adolescents with EDs. One study that examined postings on an ED support forum showed that some site visitors feel more able to express themselves online and find these sites more supportive than face-to-face therapy.[29] However, another study that examined the recovery process by monitoring an online ED recovery forum found that although they provide support in the initial phases of recovery, they may impede the process at later stages.[30] Moreover, content that was displayed on 15 pro-recovery and informational sites for patients with EDs was found to be of "generally poor quality,"[31] suggesting that sites that are intended to promote recovery may not achieve their goal.

With 50% to 90% of adolescents accessing the Internet at home an average of 5 hours per week[2–4] and this age group likely to be the most frequent users of pro-ED sites, it is critical that the impact of these Web sites on adolescent health be better understood. This pilot study aimed to document the awareness of ED Web sites among adolescents with ED and their parents, to examine and describe their use of these sites, and to probe associations between ED Web site use and health and quality of life. This exploration focused on an area in which there has been little research and could serve as a preliminary basis for future investigation into these important realms. We hypothesized that pro-ED Web site use would be widespread in this population and associated with poorer health status and decreased quality of life.

METHODS

Overview

This cross-sectional study used a questionnaire that was sent to parents and patients who were aged 10 to 22 and had previously been evaluated for an ED at Lucile Packard Children's Hospital at Stanford between January 1997 and August 2004. All protocols were approved by the Stanford University Panel on Medical Research in Human Subjects and were compliant with the Health Insurance Portability and Accountability Act of 1996.

Potential participants were identified by medical chart review. An initial single mailing was sent to the parents of 698 patients and each patient who was 18 years or older at the time of the survey. Informed consent was obtained from patients who were older than 18 and from the parents of patients who were younger than 18, with younger patients giving assent. To link patients to their parents while maintaining anonymity, a random, unique number was assigned to each patient/parent questionnaire set. Questionnaires were completed and returned by mail or completed online. Identical questionnaires were offered to a consecutive sampling of parents and patients during regularly scheduled visits at the Eating Disorder Outpatient Clinic if they had not responded by mail.

Questionnaires

Because no validated measure exists for the systematic assessment of Web site use in adolescents, we designed our own survey instrument. Question phrasing was pilot-tested on a small group of patients with ED and their parents in a clinic setting. The parent questionnaire was 3 pages with 46 items, and the patient questionnaire was 3 pages with 56 items. Only English-language versions were used (see Table 1 for questionnaire content). Unique questions on the patient questionnaire addressed the extent of the patient's pro-ED and pro-recovery site use. Unique items on the parental questionnaire assessed parental Internet use and knowledge of patient pro-anorexia, pro-bulimia, and pro-recovery site usage.

Associations were assessed using χ^2 testing, Student's *t* test, and analysis of variance testing, followed by Tukey's test for posthoc comparisons between groups. Significance level was set at .05. Statistical analysis was conducted using SPSS 13.0.0 for Windows (SPSS Inc, Chicago, IL).

RESULTS

Participant Characteristics

Completed surveys were returned by 182 participants: 76 patients (response rate: 10.9%) and 106 parents (response rate: 15.2%). Three parents approached in clinic refused to participate. Eleven questionnaires were completed online. Of the 182 responses, 116 were completed as a part of a patient–parent pair. Demographic and basic clinical characteristics of patient and parent respondents are described in Table 2. Patients who currently were in active treatment did not differ from patients who previously were in treatment with regard to sites visited and online time devoted to those sites. Patients who were recruited by mail did not differ from patients who were recruited in clinic in sites visited and time spent on ED sites.

Because this was an anonymous survey, we could not compare the demographics of responders with nonresponders. However, responders were compared with the entire set of patients who were sent surveys. In comparison with the collective averages, responders were younger (16.7 vs 17.7 years), were less likely to be white (82.4% vs 77.9%), and were more often female (94.7% vs 91.0%). Because the responders are a subgroup of the overall population, statistical significance of the differences between these groups could not be determined.

We compared parents who allowed their child to complete a questionnaire with parents who did not. The 2 groups of parents did not differ by ethnicity or gender; however, parents who did not return a patient question-

TABLE 1 **Patient and Parent Questionnaire Items**

Patient Questionnaire	Both Questionnaires	Parental Questionnaire
Patient demographics	Patient current height and weight	Parent demographics
Source of ED information	Patient high and low weights	Concern about child's ED information
Pro-recovery and pro-ED sites:	Treatment status and length	Parent internet access
Sites visited	Length of ED	Parent time on the internet
Introduction to sites	Hospitalizations	Pro-recovery and pro-ED sites:
Frequency of visitation	Impact of ED on activities	Parent usage of sites:
Reasons for visitation	Diagnosis of low bone density	Awareness of sites
Site features used	Missed menses	Introduction to sites
Utility of site features	Patient time on the internet	Sites visited
Supportiveness	Parent restriction on web use	Child usage of sites:
ED techniques learned/used	Perception of patient's ED	Awareness of child's site usage
	Role of ED sites in patient's ED	Discovery of child's site usage
		Discussion of sites with child

TABLE 2 **Sample Characteristics**

	n	Valid, %	Mean	SD
Patients (*n* = 76)				
Gender				
Female	72	94.7		
Male	4	5.3		
Ethnicity				
White	56	82.4		
Asian American	6	8.8		
Latino	3	4.4		
Black	0	0.0		
Other	3	4.4		
Age, y			16.7	2.5
Disease length, y				
≤1	33	44.0		
1–2	15	20.0		
≥2	27	36.0		
Treatment length, y				
≤1	39	51.3		
1–2	17	22.4		
≥2	20	26.3		
No. of hospitalizations				
0–1	39	52		
2–3	27	36		
≥4	9	12		
No. of missed menses				
≤6	28	43.7		
>6	36	56.3		
Parents (*n* = 106)				
Gender				
Female	83	81.4		
Male	19	18.6		
Ethnicity				
White	82	82.0		
Asian American	9	9.0		
Latino	5	5.0		
Black	0	0.0		
Other	4	4.0		
Age, y			48.7	5.4

naire were older by 2.3 years ($P < .05$), a difference that may reflect the older age of their out-of-home children. Parents who were recruited in clinic and whose children currently were in treatment were more likely to allow their child to respond ($\chi^2 = 11.6$, $P < .005$; $\chi^2 = 4.8$, $P < .05$). There was a trend toward parents who allowed participation to be more likely to consider their child sick ($\chi^2 = 3.2$, $P = .074$), but their children did not differ on major outcome variables by the parents' report (eg, percentage ideal body weight, number of missed menses, low bone mineral density). Parents who allowed their child to complete a questionnaire may be the set of parents who have already communicated with their child about pro-ED sites: they were more likely to be concerned about the ED information that their child was receiving from the Internet ($P < .05$), to know about pro-ED sites ($\chi^2 = 4.4$, $P < .05$), to say that their child visited pro-ED sites ($\chi^2 = 6.5$, $P < .05$), to have discussed pro-ED Web sites with their child ($\chi^2 = 10.1$, $P < .005$), and to have discouraged their child from visiting these sites ($\chi^2 = 12.6$, $P < .0005$).

To examine concurrence between parent and patient responses on items that were identical in respective questionnaires (eg, questions about patient's number of hospitalizations), we compared responses among the 58 parent–patient pairs. As expected, we found few significant differences between parent and patient report. However, parents and patients differed in their reports of highest weight, with patients reporting weighing an average of 1.1 kg more at highest weight than their parents' report ($t = -2.6$, $P < .02$). In addition, in response to whether parents restricted the Web sites that their children accessed, parents were more likely to say that they restricted site use as compared with their children ($\chi^2 = 4.4$, $P < .05$).

Patient Survey Responses

As an index of the importance of Web-based resources on ED relative to other sources, patients were asked to indicate where they received information about ED. Most participants reported receiving information about ED from physicians ($n = 64$ [84.2%]) and parents ($n = 47$ [61.8%]) but not friends ($n = 35$ [46.1%]). With regard to print media, a large portion of the sample indicated that they sought information about ED from books ($n = 59$ [77.6%]) and magazines ($n = 53$ [69.7%]), whereas only approximately one third of patients reported reading newspapers for ED information ($n = 26$ [34.2%]). Finally, television ($n = 47$ [61.8%]) and Internet Web sites ($n = 57$ [75.0%]) were sources of information for a majority of patients. However, fewer than half reported that they received information on ED from Web sites that are dedicated to pro-recovery ($n = 25$ [32.9%]), pro-anorexia ($n = 25$ [32.9%]), or pro-bulimia ($n = 13$ [17.1%]) content.

Patients were asked about their general Internet use. The majority of participants ($n = 51$ [68.0%]) reported spending <1 hour per day using the Internet. Most patients indicated that their parents place no time restrictions on Web use ($n = 62$ [89.9%]) and do not restrict access to Web sites ($n = 64$ [91.4%]). Patients whose parents restricted the time that they spent on the Web were significantly younger (17.2 vs 14.4 years; $P < .005$). With regard to ED sites, 31 (40.8%) patients reported visiting pro-recovery sites, and 27 (35.5%) stated that they visited pro-ED sites. It is important to note that 19 (25.0%) patients reported using both pro-recovery and pro-ED Web sites, and 37 (48.7%) patients had not visited either type of site. Many patients noted that they found either pro-recovery or pro-ED Web sites through chance searches ($n = 13$ [56.5%] and 11 [47.8%], respectively). Four (5.3%) patients reported running their own pro-ED site, and 1 (1.3%) of these patients also reported establishing a pro-recovery site.

The number of hours that users spent at pro-recovery sites ranged from 0 to 7 per week (mean: 1.3; SD: 1.4). Compared with nonusers of pro-ED sites, pro-ED users spent significantly more time on the Internet each day ($\chi^2 = 6.0$, $P < .05$). The amount of time spent on pro-ED sites varied widely, with a mean site usage of 2.8 hours per week (SD: 4.5) and some patients using the sites up to 20 hours per week (Table 3).

When asked to give reasons for visiting pro-recovery sites, 59.3% ($n = 16$) of patients reported visiting the sites for support, and 48.1% ($n = 13$) reported visiting the sites to meet others with EDs. With regard to pro-ED sites, most users reported visiting these sites to maintain motivation for weight loss ($n = 17$ [70.8%]). Nine (37.5%) patients visited pro-ED sites for support, and 37.5% ($n = 9$) visited to meet others with EDs. Patients who visited pro-ED sites for support spent more time on the sites themselves than those who were not looking for support (mean: 5.4 vs 1.6 hours/week), although this result was not statistically significant owing to a high variance in hours of site visitation among patients.

When visiting pro-ED sites, 96.0% ($n = 24$) learned new weight loss or purging methods; 64.0% ($n = 16$) learned about diet pills, laxatives, or supplements; and 69.2% ($n = 18$) reported using new weight loss or purging methods as a result of visiting pro-ED sites. However, pro-recovery site users also reported learning high-risk eating behaviors online, with nearly half reporting that they learned new methods of weight loss or purging at pro-recovery sites ($n = 13$ [46.4%]) and a smaller percentage learning of new diet aids (ie, pills, laxatives, or supplements; $n = 11$ [39.3%]) and how to obtain them ($n = 5$ [17.9%]).

Parent Survey Responses

Parents were asked to indicate whether they placed time or specific site limitations on their child's Internet use. The majority ($n = 80$ [79.2%]) of parents reported placing no time limits on their child's Internet use, and a similar percentage ($n = 81$ [78.6%]) imposed no restrictions on sites that their child visited.

Parents were asked about their knowledge of pro-recovery and pro-ED sites. The majority ($n = 65$ [62.5%]) of parents had no knowledge of pro-recovery sites, and fewer than one third ($n = 31$ [29.5%]) of parents reported visiting a pro-recovery site. Parents generally were unsure of whether their children had visited pro-recovery sites during their treatment ($n = 59$ [56.2%]). Moreover, only a minority ($n = 16$ [15.7%]) of parents had discussed pro-recovery site use with their children.

In contrast to parent-reported knowledge of pro-recovery sites, more than half ($n = 56$ [52.8%]) of parents reported that they were aware of pro-ED sites, although only 16.0% ($n = 17$) had visited pro-ED sites themselves. The majority ($n = 55$ [52.4%]) of parents indicated that they were unaware of whether their children visited pro-ED sites, with only 10.5% ($n = 11$) indicating knowing that their child had visited these sites. Relatively few parents reported that they had discussed ($n = 29$ [27.6%]) or discouraged ($n = 30$ [30.6%]) pro-ED site use with their children. Half of parents of pro-ED users ($n = 16$) either did not know ($n = 6$ [37.5%]) whether their child visited pro-ED sites while in treat-

TABLE 3 Frequency of Online Activities of Pro-recovery and Pro-ED Website Users

	Pro-recovery Site Users ($n = 28$)		Pro-ED Site Users ($n = 27$)	
	n	Valid, %	n	Valid, %
Frequency of visits				
≤1/mo	15	55.6	6	26.1
1/wk	4	14.8	7	30.4
1/d	6	22.2	5	21.7
>1/d	2	7.4	5	21.7
Motivation for visit[a]				
Weight loss	12	44.4	17	70.8
Support	16	59.3	9	37.5
Meet others with ED	13	48.1	9	37.5
Curiosity	20	74.1	22	91.7
Activity at sites[a]				
Read posts	17	60.7	14	56.0
Visit chat room	7	25.0	6	24.0
Post messages	4	14.3	10	40.0
Read diaries	16	57.1	20	80.0
Learn method of weight loss/purging	13	46.4	24	96.0
Learn about diet aids	11	39.3	16	64.0
Learn about obtaining diet aids	5	17.9	10	40.0
Post-use activity[a]				
Used new weight loss/purging method	11	39.3	18	69.2
Used new diet aid	5	17.9	9	34.6

[a] n = number of users endorsing that motivation/activity.

ment or thought that their child did not use these sites ($n = 2$ [12.5%]).

Site Use and Health Outcomes

Compared with nonusers, users of pro-ED Web sites had been ill significantly longer ($\chi^2 = 7.2$, $P < .05$), although there was no difference between groups with regard to length of time in treatment ($\chi^2 = 1.1$; P = not significant; Table 4) or age. Of note, none of the 4 male patients had visited pro-ED sites. In contrast to expectations, there was no significant difference between groups in health outcomes, including percentage ideal body weight, incidence of low bone mineral density, number of hospitalizations, or number of missed menses.

In terms of psychosocial and behavioral outcomes, there were no significant differences between pro-ED site users and nonusers with regard to the impact that the ED had on patients' reported time spent in extracurricular activities or with friends (Table 4). However, pro-ED users reported significantly less time spent on schoolwork and activities as a result of their ED ($\chi^2 = 12.0$, $P < .005$). Finally, there were no significant differences in terms of patients' self-health appraisals. That is, users of pro-ED sites were as likely as nonusers to consider themselves healthy, sick, or recovering. Whereas 14.8% of pro-ED site users considered themselves ED by choice, in comparison with 4.4% of those who were not using these sites, this difference was not significant ($\chi^2 = 2.4$, $P = .12$).

Given the considerable and unexpected overlap between pro-ED site users and pro-recovery site users, we decided to perform posthoc analyses to examine further

TABLE 4 **Medical and Psychosocial Characteristics Across Web site Usage Groups**

Patient Characteristic	Users of Pro-ED sites ($n = 27$)		Non-users of Pro-ED sites ($n = 49$)	
	n	Valid, %	*n*	Valid, %
Age mean (SD), y	17.3	1.9	16.4	2.7
% IBW, mean (SD)	95.4	14.0	93.4	10.5
No. of hospitalizations, mean (SD)	2.8	3.9	1.6	1.1
Length of Disease, y[a]				
≤1	9	33.3	24	50.0
1–2	3	11.1	12	25.0
≥2	15	55.6	12	25.0
Treatment				
Currently in treatment				
Yes	18	66.6	30	61.2
No	9	33.3	19	38.8
Treatment length, y				
≤1	12	44.4	27	55.1
1–2	5	18.5	12	24.5
≥2	10	37.0	10	20.4
Total length hospitalized, d				
≤ 60	21	77.8	44	89.8
> 60	6	22.2	5	10.2
Medical				
No. of missed menses				
≤ 6	10	41.7	18	45.0
> 6	14	58.3	22	55.0
Low bone mineral density				
Present	10	37.0	16	32.7
Absent	17	63.0	33	67.3
Impact of disease on quality of life				
Time spent with friends				
Some or a lot less time	20	74.1	33	67.3
No change	3	11.1	8	16.3
Some or a lot more time	4	14.8	8	16.3
Time spent on extra curriculars				
Some or a lot less time	21	77.8	31	64.6
No change	5	18.5	8	16.7
Some or a lot more time	1	3.7	9	18.8
Time spent on schoolwork[b]				
Some or a lot less time	17	63.0	12	25.0
No change	8	29.6	20	41.7
Some or a lot more time	2	7.4	16	33.3

[a] $P < .05$

[b] $P < .005$

the observed differences between pro-ED site users and nonusers. Patients were divided into 4 categories: pro-ED site users only ($n = 8$), pro-recovery site users only ($n = 12$), users of both sites ($n = 19$), and users of neither site ($n = 37$). Although small cell sizes prevented us from conducting meaningful χ^2 analyses on the categorical data, analyses of variance were performed on all continuous outcome variables. There were no differences in percentage ideal body weight, but significant differences were found in number of hospitalizations ($F_{3,71} = 2.76$, $P < .05$), such that users of both pro-ED and pro-recovery sites reported significantly more hospitalizations than users of neither site (mean: 3.4 [SD: 4.5] vs 1.6 [SD: 1.1], respectively; Fig 1).

DISCUSSION

This study was designed as a pilot investigation of pro-ED Web site use among adolescents with EDs. It is the first to examine pro-recovery site use in this population and to examine parental awareness and use of both types of sites. Use of these sites was prevalent among adolescents with EDs, with parents often having little knowledge of the sites or of their children's use of the sites. Pro-ED Web site use was correlated with a longer disease duration and also with less time devoted to school-related activity. Use of both pro-ED and pro-recovery sites was correlated with more hospitalizations. Although using these sites was not associated with other major health outcomes, use may have a negative impact on quality of life and result in adolescents' learning about and adopting disordered eating behaviors.

Our results elucidate some basic motivations for site visitation. Pro-ED users visit sites more frequently and are more likely to report motivation for weight loss as a reason for visitation than pro-recovery users. Users of both sites most frequently reported curiosity as a motivation for usage. Pro-recovery users were more likely than pro-ED users to report visiting the sites for support and to meet other people with EDs.

These results highlight potential hazards of Web site visitation that deserve attention. An adolescent does not need to be directed to find these sites; our patients usually found them by chance. Most pro-ED visitors report learning about new weight-loss or purging techniques from the sites, and many use new methods after visiting pro-ED sites. Pro-recovery sites also may not be benign: a substantial percentage of pro-recovery site users also reported learning about new weight-loss or purging techniques and diet aids as a result of pro-recovery site visitation and later implementing these techniques. This underscores the dangers of online forums where, regardless of original intent, teens can share useful or harmful information with ease.

Given the activities that their children are reporting adopting after visiting both pro-ED and pro-recovery sites, it is important to educate parents further on how to be constructively but actively involved in their children's Internet use. In general, few parents placed limitations on Internet use in either time or site restrictions, and only approximately one quarter of parents had discussed pro-ED Web sites with their children, despite that more than half of parents had knowledge of these sites in general. Moreover, a fair number of parents of pro-ED users were not aware that their own children were visiting these sites while in treatment. Relatively few parents knew of pro-recovery Web sites or had visited them themselves.

In this pilot investigation, we began to explore associations between pro-ED Web site use, ED severity, and quality of life. Although we found no associations between most health outcomes, we did find that pro-ED users had a longer length of illness and spent less time on their schoolwork as a result of their ED. These preliminary findings suggest that pro-ED use may have an impact on the quality of life of users with ED, a finding that merits additional study.

Given the purported messages of pro-recovery and pro-ED Web sites, we were surprised by the significant overlap in use of these sites. This may represent a unique subset of patients who have ED and are more curious about their disease. Pro-ED users and pro-recovery users also were more likely to seek information about EDs from other media sources and their physicians than those who did not use these sites. This group may be of clinical significance because they were hospitalized more often than users of neither site. Our study design was

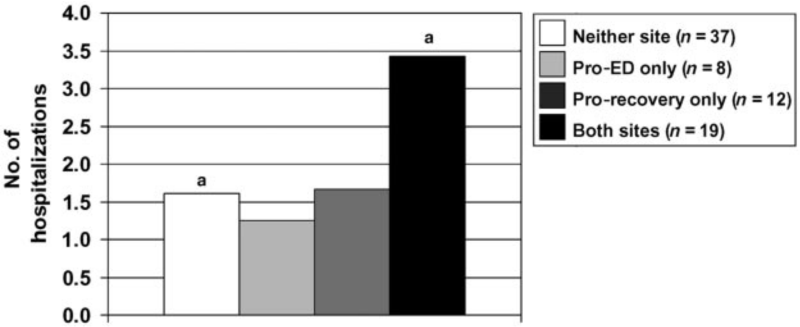

FIGURE 1
Number of hospitalizations among users of neither pro-ED nor pro-recovery sites, users of pro-ED sites but not pro-recovery sites, users of pro-recovery but not pro-ED sites, and users of both sites.
[a] $P = .05$ as determined by posthoc analysis.

limited with regard to this overlap between groups; therefore, additional analyses to discriminate between users of both sites and users of only pro-ED sites currently are not possible. This overlap requires special attention in future study designs.

Another issue is that some pro-ED sites downplay the idea that EDs are a true disease, potentially making them seem less serious to site visitors. As a result, asking questions about health outcomes in users of these sites may elicit a different perspective than would be found if examining clinical patient data from a more objective source, such as the medical chart. Because all questionnaires were anonymous, we could not verify responses to items such as number of hospitalizations. This study also is limited by a recall bias, in that we were asking some patients to remember their earlier activities while ill with an ED.

Obtaining high response rates was challenging and represents a significant limitation to this study. Discussion of pro-ED Web site use is potentially volatile for families, and adolescent patients may be reluctant to engage in these topics with their parents. There are many understandable concerns that parents have regarding this research, the most prominent being whether allowing their child to participate would introduce them to potentially harmful Web site content. Research on other types of adolescent risk behaviors indicate that surveying teens for behaviors does not ultimately make them more likely to engage in these behaviors.[32–34]

However, this fear may have limited the number of parents who were willing to give consent for their child. This concern is reflected in the characteristics of the parents who allowed their children to complete questionnaires; they were more likely to know about pro-ED Web sites and to have discouraged their children from visiting them. Their children also were reported to have a longer treatment length. We cannot assess the true impact of surveys of pro-ED Web site visitation on usage patterns until more is known about these sites and their possible dangers through rigorous study. As with any study design that involves human subjects, informed consent was obtained from parents for their child's involvement. However, such consent procedures do limit our response pool to the children of parents who are comfortable with this investigation and with potential exposure to these sites, and this is an inherent study bias that cannot be avoided.

Another challenge to obtaining responses was that many of the patients whom we were recruiting were seen clinically many years ago and were less likely to respond owing to the time that elapsed since their treatment and that patients with ED are a notoriously difficult population to capture because of the nature of the illness.[35] In addition, mailed surveys often result in poor response rates.[36] Still, other studies with low response rates have produced valuable results,[37–39] and responders in this pilot were comparable in basic demographics to the entire group of patients who were sent surveys.

This study was a preliminary foray into the world of pro-ED Web sites that was designed to understand better the profiles of their adolescent users and to probe associations between their use and outcomes. Although our findings must be interpreted in the context of a low response rate and may not apply to all adolescents with EDs, this remains an informative initial examination of pro-ED site use in a clinical sample. Until we know more about the usage patterns and health outcomes in patients who use pro-ED sites, we will not be able to assess whether true harm results from their use or which patients may be particularly vulnerable to the content displayed in these Web sites. However, these results suggest that both pro-ED and pro-recovery Web sites are frequented by adolescents with EDs, with their parents often unaware, and that their use may lead some youth to adopt unhealthful dieting practices. Future prospective studies that more objectively measure health outcomes and Internet use in these potentially vulnerable populations are indicated.

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