

Eating Disorders and the Internet: The Therapeutic Possibilities

Theresia Laksmana

With the advent of the Internet era, some mental health researchers have turned to the Internet as a practical, cost-efficient tool for the implementation of Internet-based therapies and prevention programs. Eating disorders have become a prime target for these programs. Chat-rooms and newsgroups have been formed by individuals to learn how to cope with and get over this disorder. Unfortunately, very few studies have examined their efficacy, and the few studies that do exist have been lacking in several areas. Nevertheless, the findings thus far suggest that the Internet can be made very useful in the treatment and prevention of eating disorders. This article will describe the state of the literature thus far and hopefully promote further research in this area.

INTRODUCTION

Over the past few decades, the increasing amount of eating disorders has become a topic of concern. Many attribute this "phenomenon" to societal factors, such as the standards of beauty set by the media, fashion and entertainment industries. However, most people today are misinformed about eating disorders and underestimate the life-threatening dangers involved. Many people do not realize that the mortality rate of anorexia nervosa has been found to be between 5-20% (Nielsen, 2001). Funding for health care services, especially eating disorder programs, has decreased over the past few years. Thus, it has become even more important to develop efficient and cost-effective ways to inform, treat, and prevent eating disorders. The emergence of the Internet has become a hopeful medium for the implementation of these programs.

Eating Disorder Websites

The advent of the Internet has given individuals the ability to access all kinds of information from the comfort and privacy of their homes and offices. Not only does the Internet supply a limitless range of information, but it also introduces us to millions of other users from around the globe, allowing us to talk to anyone, anywhere, at any time. Clearly, with the Internet's fast-paced growth, it was only a matter of time before

the mental health world would begin taking advantage of its resources. Amidst the wealth of information the Internet offers, thousands of websites have been devoted to the issue of eating disorders.

It has been difficult to make people fully aware of the dangers of eating disorders because of society's misconceptions and ignorance about them. Although the Internet can educate individuals about eating disorders, vast amounts of false information on this subject also exist, as is the case with most everything else on the internet. Sites that may seem to be educational can sometimes be damaging to uninformed individuals. In allowing for fast distribution of information, the Internet also allows for fast circulation of inaccurate information. Because the freedom of the Internet allows any individual to post a website, there are also websites that advocate eating disorders. (Christensen and Griffiths, 2000). While most eating disorder sites have been developed to help individuals learn the truth behind eating disorders, there exist "Pro-Anorexia Websites" which blatantly and shamelessly advocate anorexia (Shafran, 2002). "Inspirational quotes" are posted to keep girls on the path of anorexia to the supposed "ideal body." It is unknown how many sites exist that promote eating disorders, but it is obvious that there is a need to evaluate Internet-based health information with what is known to be scientifically accepted. Nevertheless, although ensuring the accuracy of information on the Internet is a recurring problem, indi-

viduals can find comfort in knowing that information provided by government mental health websites and sites run by eating disorder organizations is most often reliable (Shafran, 2002).

Online Eating Disorder Support Groups

Along with many of the misconceptions about eating disorders, a great deal of stigmatism also exists regarding eating disorders. Having illnesses that are perceived as embarrassing or socially disgracing, such as eating disorders often are, lead people to seek support of others who share their condition. Thus, it is no wonder that eating disorder support groups have evolved over the Internet. Online support groups can be accessed through all sorts of services such as AOL and USENET (Finfgeld, 2000). In chat rooms people can come together to talk and share stories about their common disorder. They often find support from those who can sympathize with their experiences, and they can pass on information about the best treatments and how they and their families can best cope with it. Today, several eating disorder newsgroups and chat rooms exist for individuals to share their personal experiences and learn information on how best to deal with the disorder.

Advantages and Disadvantages of Online Eating Disorder Support Groups

The Internet is accessible at any time of the day, all year round. Messages can be posted and e-mails can be sent at any time, by anyone in the world, from the privacy of one's own home. It is relatively cost efficient and easy to use. There is no set time that people must write e-mails or enter chat rooms, and individuals do not have to work their schedule around online group sessions as they do for face-to-face sessions. In one study on an eating disorder newsgroup, Winzelberg (1997) found that two thirds of the messages were posted between 6pm and 7am, a time when support from healthcare professionals or face-to-face support groups would have been least accessible.

Many hospitals and community clinics offer support groups, yet many individuals turn to Internet support groups. Internet support groups offer anonymity; and in cases like eating disorders, being able to seek support for a disease while still being able to remain anonymous is highly desirable. For some, remaining anonymous is a way of reaching out for help while not having to admit to those close to them that they have a problem. Girls can share their similar experiences and can often help one another, regardless

of whom they are talking to.

Anonymity also allows for elimination of socio-demographic factors like age, race, and socioeconomic status (Finfgeld, 2000). As a result, differences in social status, which are normally more visible in face-to-face sessions, can be minimized, and issues of physical attractiveness and social skills are neutralized (Davison, 2000). Anonymity reduces the shame and embarrassment that people sometimes associate with their eating disorders.

Though many make use of the online support groups available, much controversy has surrounded their efficacy and validity. There have been claims that online chat groups can have harmful or even dangerous effects on individuals (Christenson and Griffiths, 2000). Accuracy of the information shared is a big concern because it is unknown how many individuals rely on the information they learn in these support groups.

Newsgroups and chat rooms without moderators fall under greater scrutiny because of the increase of risks they project. Wanderers can enter newsgroups, sometimes making negative comments and causing more damage on group participants than would otherwise have been there. False information is not always corrected, and while this is not exclusive to newsgroups about eating disorders, inaccurate information is more dangerous in these groups because of the lack of knowledge most individuals have about eating disorders. Thus, inaccurate information about eating disorders is more likely to be accepted as truth.

Allowing people to join whenever they choose also lets people leave whenever they choose. Even with moderator-led newsgroups, the moderator cannot control the regularity or length of a member's participation. They also cannot control what goes on in the privacy of each person's home. Distractions, such as television, radio and other people, which are not present in face-to-face sessions, are out of the control of the moderators (Zabinski, 2000).

Internet-based Eating Disorder Therapies

The difficulty in treating eating disorders and the amount of relapse (for review, see Herzog, Nussbaum, & Marmor, 1996) has led physicians to start using e-mail as an adjunct to therapy. Its uses can range from the simple task of scheduling appointments to more in depth correspondence in which weekly e-mail reports are required of the patient.

A case study done by Yager (2000) illustrates the correspondence between him and four of his patients. After each treatment, patients submitted eval-

uations of the mandatory use of e-mail to supplement treatment. All the patients found it helpful, most importantly because it met a "demand feeding" schedule, meaning they were able to write whenever they felt the need to "speak" to the doctor. They could write the mandatory e-mails as their schedules permitted, and having to do them almost daily kept them in constant awareness of their behaviors. The constant contact via e-mails increased the frequency and amount of time with their clinician, forging a stronger relationship with the doctor and making it more comfortable for them to say whatever they wanted either in the e-mails or in the therapy sessions.

Though the simplicity of e-mail as an adjunct to therapy limits the dangers of its usage, some risks can be noted. On the part of the physician, failure to respond to patient's e-mails in a timely or sufficient manner can hurt the doctor-patient relationship, prompting the patient to lose trust in the doctor and causing unnecessary damage to the relationship and negatively affecting the therapy. The use of e-mail also increases the risk of violation of privacy. One of the hallmarks of therapy is the doctor-patient confidentiality, but as discussed earlier, improper logging out of e-mail accounts enables others to read physician's e-mail responses, thus breaching one's privacy.

A more risky venture has been for physicians to use e-mail or chat rooms as the only means of therapy and communication. One might ask, why offer eating disorder therapy over the Internet? Eating disorders generate a significant degree of shame and denial, and often, because of this, many sufferers do not seek treatment (Muscari, 1998). What many do not know is that for some girls, this disorder can be effectively treated using self-help treatments. Cognitive Behavioral Therapy is a sound candidate for online treatment because its effectiveness has been proven in face-to-face sessions as well as self-help formats (Zabinski et al., 2000).

One study done by Robinson and Serfaty (2001) studied the effectiveness of therapy delivered entirely by e-mail to 23 female students from the University of London. These students, recruited online by an e-mail sent only one time to the student and faculty members of the University of London, exhibited Bulimia Nervosa, Binge Eating Disorder or Eating Disorder Not Otherwise Specified, initially measured by BITE (Bulimia Investigatory Test Edinburgh) and BDI (Beck Depression Inventory). Half of the subjects were treated with CBT, Cognitive Behavioral Therapy, and the other half were treated with a more traditional

treatment, using diet records, advising on regular eating habits and confronting of cognitive determinants of the eating disorder. At the 3 month follow up, subjects from both groups returned questionnaires which showed there was an overall significant reduction in scores of depression and of bulimic symptoms and severity.

For some girls, there are advantages to using e-mail as the only means of communication. Using e-mail eliminates much of the status disparity between therapist and patient. Along with this, some patients may feel more comfortable with their therapist and may interact less formally than they otherwise might feel comfortable doing in an office, face-to-face. For some, avoidance of face-to-face confrontation makes it easier for them to be honest about their discussions. Knowing that the physician will not be focusing on their physical appearances is comforting and allows them to feel less pressured. In this experiment, anonymity was maintained, to a great extent. This is very important for sufferers since many do not seek treatment because of shame and guilt. However, it should be noted that in this study, physicians were given their college e-mail addresses so that, in case of an emergency, they would be able to obtain proper medical care for the patient.

As would logically be the case, there are risks to this form of treatment. Because of the difficulty in expressing non-verbal cues across e-mail, failure to perceive urgent communications from troubled patients is a very significant risk. In the case of Robinson and Serfaty's study, attaining valid college e-mail addresses from which proper information of the subjects could be attained, controlled for the risks of complete anonymity. Even in this case, physicians were taking responsibility for patients they had never met before.

However, there are online counseling services such as the Samaritans (www.thesamaritans.co.uk) in which complete anonymity is ensured. This becomes a great risk for patients and physicians. Troubled patients who may be a threat to themselves or others cannot be reached because of their anonymity. This can endanger the patient and can compromise the physician who is liable for the patient.

Another method of Internet-delivered therapy is treatment provided through newsgroups and chat rooms. One study done by Zabinski et al. (2000) studied the potential of IRC-delivered (Internet Relay Chat) treatment. IRC, a form of synchronous chat, is one instrument for people to login to chat rooms. Zabinski and colleagues provided a 7-week program based on a cognitive-behavioral approach to 4 female students

who had high body image dissatisfaction as measured by the BSQ, Body Shape Questionnaire. Students met once a week in a limited access chat room for structured activities; homework was assigned weekly, and responses to the readings were posted in a newsgroup. Questions were e-mailed to the group moderator.

Significant improvements were observed on the EDI-DT (Drive for Thinness Subscale), EDE-Q (Eating Disorders Examination-Questionnaire), BSQ, and RSE (Rosenberg Self-Esteem Scale). Subjects reported high satisfaction with the program, and exhibited positive change in their attitudes about their shapes and weights. They also stated that the intervention helped them to recognize and challenge the thoughts that triggered their negative feelings.

The results of this study give support for moderator-mediated chat room therapy in the treatment of eating disorders. The accessibility of the Internet for so many sufferers makes this treatment a very valuable approach. The IRC-delivered treatment proved to be effective and more helpful for those who otherwise would not have sought treatment.

However, this form of treatment assumes the most risks. Clients must be forewarned of the potential breaches of privacy, such as the interception of Internet transmissions or improper logging out of chat rooms. Practitioners assume great risks in liability in delivering this form of therapy. Unless in complete certainty, practitioners cannot assume that their insurance carrier will cover the "telemetry-mediated services." As with e-mail delivered therapy, the clinician is accepting responsibility for clients he has not actually met, and any mishaps resulting in injury to the patient could leave the therapist vulnerable to civil action. Backup services in case of an emergency can be difficult for the physician to arrange if the patient maintains complete anonymity.

Implications of this Research

In response to the diminishing health care resources, online support groups and therapies have grown rapidly, and yet research in this area remains in its infancy. At first glance at the principal findings, one might be very confident in implementing these cost-efficient treatments. However, the findings of the aforementioned studies, though promising, are not enough to solve the problem of eating disorders. Nevertheless, what they have done is validate further large-scale research to establish the efficacy of these new treatments.

Most importantly, there are three main weak-

nesses which need to be addressed in future studies. First off, much of the research thus far has been case studies. Randomized-controlled trials are almost nonexistent. Given this substantial lack, there has been insufficient data to produce valid conclusions. Secondly, though Internet-based therapies have the potential to reach a vast number of people, the studies so far have only investigated small sample sizes. Unfortunately, what may work on four students may not necessarily work for the population at large. Lastly, none of the studies up to now have assessed the long-term effects of these therapies. The longest follow-up so far has been 10-weeks, in the study done by Zabinski, Wilfley and colleagues (2000). It is a possibility that the positive effects of these treatments may be gone within a year. Given that these follow-up questionnaires are sent via e-mail, this simplified task of administering follow-ups should be very agreeable with physicians. Therefore, it is imperative that future studies incorporate larger sample sizes, randomized-control groups and long-term follow-ups. Until these three limitations are resolved, Internet-based treatment cannot be established as effective therapy in the treatment of eating disorders.

Qualitative Research on Internet Communities

Amid the wealth of information on the Internet, one of the most useful sources of information for physicians comes from support groups created in chat rooms and newsgroups. Qualitative analysis of Internet postings may help to determine peoples' needs and preferences, thereby helping clinicians identify the optimal blend of patient and professional needs to maximize all types of treatment success (Eysenbach, 2001)

There are two kinds of research methods: active analysis, in which researchers actually participate in the group, and passive analysis. In 1997, Winzelberg completed a passive observation study to analyze the content of messages posted in an electronic eating disorder support group. By means of an unobtrusive 3-month observation, Winzelberg collected 306 posted messages. He categorized the postings into seven categories, with "personal disclosure" and "provision of information and emotional support" being the most frequently posted messages. According to Winzelberg, members of the group used helping strategies similar to those found in face-to-face support groups.

While the findings of Winzelberg's study show that online support groups are as effective as face-to-face support groups, his study has many flaws. The length of observation was relatively short, and because

none of the patients were contacted, it is unknown whether this specific eating disorder support group was typical of all eating disorder support groups. In addition, there are many ethical limitations to this kind of research. In particular, privacy of group members needs to be addressed.

In conditions of passive analysis, a big dispute is whether consent is needed for unobtrusive observation and analysis of posted messages. In the case of this study, none of the members of the support group were aware that their messages were being copied, and in some cases, being reproduced in Winzelberg's article. There is a huge risk in doing this because some search engines, such as Google.com, can index newsgroups such that using the direct quote as a query will release the e-mail address of the sender (Eysenbach, 2001). However, Winzelberg did in fact make some changes to the messages to insure the anonymity of the group members, but it must be noted that this action is the very least that must be done to ensure every member's privacy.

In order for researchers to conduct active analysis studies, informed consent must be obtained from each member of the group. This can be done either prospectively or retrospectively. Prospectively, the chat room or newsgroup must be monitored such that upon entry of new members, each can be briefed on the ongoing research. Unfortunately, use of this method may influence the content and manner of discussion because the knowledge of being monitored may affect the members. However, obtaining consent retrospectively can be a hassle since it is unknown how many members may ask to be withdrawn from the analysis.

For future studies, another focus in this area should be to elucidate the differences in communication and disclosure styles between groups with moderators and groups without moderators (Davison, 2000). While it seems that having moderator-led groups is more beneficial in ensuring the accuracy and privacy of discussions, it is unknown how these moderators affect members. Another focus needs to be on the accuracy of postings and discussions, and how best to avoid the spread of false information. In his study, Winzelberg found that almost 12% of the shared information was inaccurate and beyond the accepted standards of mental health care. If this is the case with all chat rooms and newsgroups, it is most imperative that this situation be managed as quickly as possible.

Prevention Programs

Less than 1% of the young adult female popu-

lation suffers from anorexia while about 1-2% of the population suffers from bulimia nervosa. More than 10% of college women are thought to have sub-clinical bulimia nervosa, and 25% of college women are thought to be at risk for developing eating disorders (Winzelberg, 2000). For this reason, it is clear why finding an effective prevention program is imperative. Unfortunately, prevention programs for eating disorders have not had very satisfactory outcomes. Their effectiveness has been questioned, with some studies showing that it can in fact be more harmful than beneficial for individuals. Furthermore, funding for prevention programs has been scarce because, even as eating disorders is a widespread mental health problem, its prevalence is not comparable to such disorders as depression or drug abuse.

One Internet-based prevention program, however, has been shown to be effective and cost-efficient. Participants in an Internet-delivered computer assisted health education program (CAHE) called Student Bodies have exhibited significant decreases in body image dissatisfaction. The Student Bodies program, modeled from self-help treatments for eating disorders, incorporates a moderator-mediated electronic newsgroup used as a forum by participants to discuss readings and assignments. It was designed to decrease body image dissatisfaction, a probable risk factor for the development of eating disorders. Developed by eating disorder researchers at Stanford University, the program was first run as four separate trials between 1995 through 1998. Each successive trial, using a modified version of the program, showed improved results in the reduction of body image concerns and eating disorder psychopathology (Dev et al., 1999). After these first trials, researchers conducted more studies to provide more proof of the efficacy of the program.

Zabinski and colleagues (2000) did a controlled study to assess whether an 8-week intervention of the Student Bodies program would significantly decrease body image dissatisfaction and disordered eating in college women. The 8-week program consisted of weekly assignments and mandatory postings to the discussion group in response to the readings. The control group was put on a wait-list and given the opportunity to participate in the Student Bodies program after the follow-up period. Results of the 10-week follow-up assessment completed by 56 students showed that the intervention significantly decreased measures of body image dissatisfaction and eating disorder pathology, with students reporting that they felt most supported by

the electronic newsgroup component of the program. Winzelberg and colleagues (2000) also did a study evaluating the Student Bodies program. Using the same structure as the study done by Zabinski et al. (2001), Winzelberg and colleagues conducted an 8-week intervention on 60 college women. Questionnaires completed at the 3-month follow-up showed that participants in this study also exhibited significant changes in body image satisfaction as determined by the BSQ, EDI-DT and EDI - Bulimia scale.

Winzelberg and colleagues (2000) conducted another controlled study this time comparing the Student Bodies program with a classroom-delivered intervention program called Body Traps. The Body Traps program consisted of eight two-hour class meetings, weekly assigned readings and written reflections in response to the readings. A significant alteration was made to the Student Bodies program such that, in addition to the 8-week program, it included three two-hour face-to-face sessions with the same moderator who led discussions on the on-line discussion group. Measures of the EDE-Q Eating Concerns subscale, EDE-Q Restraint subscale and the EDE-DT by fifty-eight students at the 4-month follow-up assessment revealed significant differences between the Student Bodies condition and the wait-list and Body Traps conditions, with participants in the Student Bodies program showing the most progress. Significant improvements in body image satisfaction and disordered eating attitudes and behaviors were demonstrated by the Student Bodies program while no significant effects were produced by the Body Traps in comparison with the wait-list condition.

The data to support the efficacy of this program have been overwhelming. Modifications made after each trial, in accordance to the feedback of the students, proved to be even more effective than each revision before it. Nevertheless, trials of the program need to be implemented in more areas, particularly where the girls are at high risk. Eighty-five percent of anorexics are diagnosed between the ages of 13 to 20 years old with peaks occurring in the years when high school and college begin. For this reason, the Student Bodies program should also be introduced to high school students, especially those in boarding schools who are at even higher risk. The method should follow the studies already done by Zabinski et al. (2000) and Winzelberg (2000). Finally, it is imperative to determine the long-term effects of this program. By doing a prospective study with long-term follow-ups, researchers will be able to determine for whom the pro-

gram works best and if those improvements are sustained.

Suggestions for Future Research

A randomized-controlled-trial of the Student Bodies program should be conducted on the students of a different university and another trial should be conducted on high school students. For each trial, a sample of about 400 female students should be randomly assigned to the Student Bodies program or a wait-list control. Much like the earlier trials, an 8-week intervention should be administered with the following modifications. Measures should be taken at baseline, post-treatment, 4-month follow-up and 12-month follow-up. Online questionnaires should include the BSQ, EDI Bulimia, EDI Drive for thinness, and EDE-Q: Global, Weight, Shape, Eating and Restraint. Analysis of the data should be done using analyses of variance (ANOVA).

It is obvious that the technologies of the Internet offer a very useful tool for mental health care providers to reach a wider range of girls suffering from or at risk for eating disorders. Perhaps the most important development is the success of the Student Bodies prevention program. Determining the factors that are most effective in the program will allow physicians to better understand the pathology of the disorder and perhaps aid them in modifying the current treatments. Hopefully, if this program can be safely provided to girls all around the country, the epidemic of eating disorders might come to a halt, or at the very least, exhibit a decrease in the number of incidences.

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