

Pro-Eating Disorder websites: users' opinions

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Key words: Pro-Anorexia, Internet, Websites, Recovery, Interaction

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RUNNING HEAD: PRO-EATING DISORDER WEBSITES

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Abstract

The phenomenon of 'pro-eating disorder' websites remains relatively unexplored by researchers in published formats. Supporters of the sites claim beneficial effects but health professionals worry that the sites propagate disordered behaviours. The present study addressed visitor characteristics and perceived impact of visits. A 24-item questionnaire supplemented with the Eating Attitudes Test-26 was developed and posted on the website of the UK mental health charity SANE. Participants who interacted with others on the sites and sought emotional support reported improved mental state after visiting, and for them, evidence was found of reduced impact from potentially damaging content. 'Silent browsing' in order to sustain a disorder was found to be mainly harmful. 'Silent browsers' may be particularly vulnerable to a worsening of their symptoms in the absence of beneficial effects from emotional support, but those who interact and find support could face a danger of a different sort.

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INTRODUCTION

Over the past decade support groups have proliferated over the Internet. One type of online community, run by individuals who themselves have an eating disorder, has attracted a significant amount of criticism. The criticised sites are commonly known as 'pro-anorexia/pro-bulimia' or 'pro-ana/pro-mia' sites. The media has focused on the possible dangers these sites pose to visitors (BBC News UK Edition, 2005). Concern has been expressed that individuals are visiting these sites in order to 'learn how to be anorexic' or to sustain disordered eating behaviour (Jackson & Elliott, 2004). Another issue raised is the concept of the 'anorexic/bulimic lifestyle'. Steve Bloomfield of the Eating Disorders Association (UK), quoted in the Times, has said that "we are very concerned about the danger these sites pose to young people who may be in the early stages of anorexia and could be misled into believing that it is an acceptable lifestyle" (Kemp, 2002). Health professionals have generally supported this view and in 2001 the 'National Association of Anorexia Nervosa and Associated Disorders' and the 'National Eating Disorders Association' in the United States requested that Yahoo shut these sites down (National Association of Anorexia nervosa and Associated Disorders, 2001). Yahoo complied, and MSN soon followed. This forced the sites to move to different servers, and although driven somewhat underground, they still exist.

How do these sites differ from other eating disorder related sites? This question is harder to answer than it seems. In general, they are more accepting of an individual's desire not to seek treatment than sites run by professional organisations or 'recovery sites'. Eating Disorder websites can be categorised loosely into four

main types: those run by health professionals/associations (e.g., the Eating Disorder Association website); 'recovery sites' run by those with eating disorders (e.g. 'Something Fishy'); moderate pro-ED sites (e.g. Blue Dragonfly) and the more uncompromisingly pro-ED sites (E.g. Ana's Underground Grotto; Starving for Perfection). To further complicate matters, many of these sites contradict each other, while being connected to one another via links and web-rings.

What does 'pro-eating disorder' mean? Using a liberal interpretation, the term implies a willingness to accept that an individual has an eating disorder without seeking to encourage that individual to find treatment, and may imply an aim to motivate or enable continuation of disordered eating behaviour. Understood in this way, the term encompasses a wide range of websites, views and individuals. More narrowly defined, the term suggests an understanding of eating disorders that views them as lifestyles rather than disorders. The focus in the lifestyle/disorder debate is the presence or absence of choice: to think that an eating disorder is a lifestyle is to think that one can *adopt* it, and then discard it at will. In the minds of those who think of their eating disorder as a lifestyle, the association with choice and freedom appears to run deeper still. One website contains a well-written and thoroughly thought out statement of a pro-anorexia philosophy. Not only is anorexia viewed as a lifestyle choice, but those who embrace it are praised for the desirable qualities involved in being a 'successful' anorexic: control over oneself, self-discipline and the denial of pleasure and nourishment. This particular site makes a further connection between anorexia and the notion of free will: overcoming the impulse to eat is reconstrued as an exercise of volition over a deterministic, reflex-like impulse. The philosophical underpinnings are somewhat Kantian: it was his thought that in order to be free, human beings must transcend the domain of natural causation to which appetites belong (Kant, 1785). Of course for Kant the transcendence meant acting

from pure reason alone, whereas to the author of the said site suppressing the impulse itself is an exercise of freedom.

Contents of the sites

Calorie charts, exercise advice and BMI calculators can be found on nearly all sites along with factual information. Advice is also often given on how to hide eating disorders. One can find warnings about dangerous practices such as the use of ipecac and advice on how to be anorexic 'safely'. Nearly all contain "Thinspirations" that can be anything from quotes, songs/films about eating disorders and most commonly, pictures of fashion models. Most of the pictures on these websites are of famous actresses and models, the same one finds in fashion magazines. Models involved in the recent 'size zero' media debate arising from the autumn 2006 European fashion shows (BBC News UK edition, 2006) are particularly well represented. However, some sites are more deeply immersed in the anorexic aesthetic, and contain images that appear to have been altered to make even the thinnest models thinner, or depict anorexia sufferers themselves in extreme states of emaciation. These are usually called 'bones' pictures and can be quite shocking to see.

Some of the more uncompromising pro-anorexia sites contain a doctrine, often called 'ana psalms' or 'ana creed'. Generally speaking these are 'rules' or beliefs about living an anorectic lifestyle. Some involve rules governing eating behaviour; others involve assertions to the effect that the individual is worthless if the temptation to eat is not resisted. Some have a religious and spiritual flavour to them. On one of the sites the creed is actually written in quasi-biblical style: "I believe in a wholly black and white world, the losing of weight, recrimination for sins, the abnegation of the body and a life ever fasting." These creeds seem to be designed

to keep someone in a low state of mind and self-worth in which disordered eating is perhaps more easily maintained. The spiritual theme is taken to the extreme by one site that describes a ritual to the goddess of anorexia, complete with an altar, candles, incense and incantations.

Chatrooms and Forums

A common defence of these sites is that they provide a community and social support for otherwise isolated individuals, and many of them host chatrooms and forums. Previous studies have found that people suffering from anorexia or bulimia are distressed by the impact of the disorder on their relationships with family and friends (Serpell & Treasure, 2002; Serpell, Treasure, Teadale & Sullivan, 1999). They also tend to report fewer friends and greater loneliness in their childhood when compared with a healthy population (Fairburn, Cooper, Doll & Welch, 1999; Fairburn, Welch, Doll, Davies & Conner, 1997; Karwautz, Rabe-Hesketh, Hu, Zhai, Sham, Collier & Treasure, 2001; Troop & Bifulco, 2002). The fact that chatrooms and forums are common features of pro-eating disorder websites may in part be explained by the opportunity for social interaction that they offer. The topics centre on helping one another stay motivated, sharing information or experiences and supporting one another with problems. Responses to distressed posts seem genuinely supportive and people appear to try to dissuade those who are contemplating dangerous behaviours. Some posts contain 'accountability threads', public accounts of food consumption designed to encourage self-control, and others invite fellow chatters to fast or diet together.

The present study

The authors hoped to explore the phenomenon of pro-anorexia/pro-bulimia websites and to address some of the concerns expressed by treatment providers,

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related organisations and other concerned parties who have expressed their reservations about the existence of the sites. In the authors' view an improved understanding of the function of these sites in the lives of those who use them would provide grounds for a well-informed, moderate debate on the subject of pro-anorexia/pro-bulimia websites.

Hypotheses

1. The websites play a role in providing emotional support and a platform for expressing views and discussing experiences whilst feeling that those views and experiences were being shared and/or understood by members of the Internet community.
2. Individuals visit the sites for the purpose of gaining information, motivation and other support for 'maintaining their eating disorder'.
3. Individuals who visit frequently report both positive and negative effects in greater quantity than those who visit less frequently (dose-response mechanism).
4. Participation (or lack of) in forums/chatrooms is a significant factor in determining the perceived impact of the sites on their users.

In addition, an opportunity was given to the respondents to reflect on whether eating disorders can ever be 'lifestyles': the responses are discussed below.

METHOD

Recruitment and Participants

Working for a charity, the researchers had limited support and funding. As the topic was appropriate for an Internet-based study and the desired participants were individuals already making regular use of the Internet, a questionnaire was developed in-house and posted on SANE's website.

A major debate in 'Internet-mediated research' (IMR) has been the extent to which samples drawn from the Internet are non-biased and representative. The data collection of the present study followed the principles of good sampling and other practices outlined in Hewson, 2003. For example, information about the participants' demographics was gathered in order to assess the nature of the sample. Date and time of response was recorded in order to control for multiple submissions. Repeat responses from participants who completed the survey more than once were deleted. Participants were required to complete several sections of 'free text' and these were compared to ensure that any suspected repeat responders were excluded. Finally, participants were given the option to provide their e-mail addresses if they were willing to take part in further research or wanted the researchers to contact them.

Participants could have potentially been recruited from SANE's helpline, via eating disorder clinics/outpatient departments or through media advertisements. These methods however would have been inappropriate in that they may have brought the existence of the websites to the attention of potential participants. Therefore, it was decided to target only those already surfing the net.

Procedures

Visitors to SANE's website were invited to go to the 'psychology laboratory' where the questionnaire was placed among a number of other surveys. At a later date, due to slow recruitment, links to the questionnaire were posted on the discussion board of the Eating Disorders Association website, the message board on 'The Site' (Internet pages containing information of interest to young people) and two pro-eating disorder websites. From this point onward, 'Where did you find this questionnaire?' was a mandatory question. After being guided to a page containing a standard statement of informed consent and agreeing to it, participants completed and submitted the online survey described below. An example of the consent form can be seen at

http://www.sane.org.uk/public_html/Research/survey/consent_survey1.shtm.

Participants were not screened for eating disorders as there has been no previous research to establish the diagnostic characteristics of visitors to these sites. Rather, the EAT-26 was used to get a sense of the severity of disordered food related behaviours and thoughts.

Measures

Pro-Anorexia Website Survey (PAWS):

A 24-item questionnaire designed to cover a number of topics was developed specifically for this study. Questions were presented in various formats, both free text and rating scale options. The questionnaire is presented in Appendix 1, along with the introduction and directions for completing the questionnaire. Two questions were dropped at the development stage in order to be friendly to participants' concerns. No

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questions were asked about weight or BMI. In addition, the decision was made not to ask individuals the names/addresses of the sites they visited. There appears to be a fear among the users of the sites that anyone not directly involved with the sites wishes to shut them down, and the authors did not wish to deter any potential participants by asking about specific sites.

EAT-26:

The Eating Attitudes Test -26 is a well-known self-report measure used in the research of eating disorders (Garner, Olmsted, Bohr & Garfinkle, 1982). It is freely available to use and has indeed been very widely used. Since the researchers felt that making the survey too long might jeopardise recruitment, not all fields were made mandatory and as the EAT was the longest section of the survey, it was not made mandatory. Scoring can potentially range from 0 to 78. Garner recommends a minimum score of twenty as indicative of a need for further diagnostic interviewing. Of those scoring more than 20, a third have clinically significant eating concerns or weight preoccupations (*ibid.*).

RESULTS

Participants

One hundred and fifty one individuals took part in the study. Most respondents were female (n=147; 97%) with only 4 males responding. Most were residents of either the United Kingdom (n=91; 60%) or the United States (n= 38; 25%). The remaining were from Australia and Canada (n=5; 3.5% each), The Netherlands (n=4; 3%) and one each from Germany, Mexico, Korea, Uruguay, and Puerto Rico. Respondents' ages ranged from 13 years of age to 49 years of age,

with a mean of 22.05 (SD=6.60). The majority of respondents were 22 years of age or younger (69%) with 41% aged between 16 and 19 years of age.

Seventy-eight participants completed the EAT-26 (the EAT was not mandatory). Participants' mean scores on the EAT-26 were 45.34 (SD=15.35). One hundred and twenty seven participants (84%) reported having an eating disorder. Forty-three (29%) reported anorexia nervosa, 22 (15%) reported bulimia nervosa, 26 (17%) reported eating disorder not otherwise specified. Twenty-two participants (15%) reported a combination of AN and BN, 5 (3%) reported binge eating disorder and 7 (5%) reported unspecified eating problems. Ten (7%) reported they were recovered. In addition, 70 (46%) reported experiencing problems with self-harm, 56 (37%) reported anxiety/panic attacks, 36 (24%) reported depression and 36 (24%) reported some form of social difficulty, e.g. social withdrawal, nervousness around people or problematic relationships with friends or family.

As reported in the method section, links to the survey were posted on a number of websites to boost recruitment. From this point on, 'Where did you find this survey?' was a mandatory question. Of the 93 participants completing this item, five (5%) found it via the SANE website, four (4%) via 'the Site', eleven (12%) followed a link from the EDA website, fourteen (15%) found the survey through an unspecified Internet search/search engine, and thirty-four (37%) through an unspecified forum/chatroom. Twenty-three participants (25%) reported finding the survey via a pro-eating disorder forum/chatroom.

Learning about and visiting pro-eating disorder sites

Only nine participants reported having visited an eating disorder site only once. The largest group (n=61; 41%) visit several times a day, and sixteen participants (11%) visit at least once a day. Twenty-six participants (17%) reported visiting a few times a week and another twenty-six reported visiting every few months. Twelve participants (8%) reported visiting a few times a month.

The largest majority of participants (n= 54; 36%) reported initially finding the websites via the Internet or search engines. An almost equally large group (n=51; 34%) found the sites through hearing about them in the media. The remaining participants heard of them through word of mouth (n=16, 11%), word of mouth via the Internet (e.g. chatrooms; n=9; 6%), treatment providers, or awareness materials. Please see Tables 1 and 2 for a summary of the motivations behind visiting the sites and regularly viewed features.

Participants were asked whether the websites helped them or harmed them. Twenty-nine (19.2%) felt that the websites were harmful to them. The websites were perceived to encourage disordered behaviour and competition between users, and it was felt that they had a negative impact on self-affect. Two distinct groups emerged from the “help”-responses to the question. One group responded that the sites helped because they supported them in their quest to maintain restricted eating and other abnormal behaviours related to their illness. Another group described the emotional support that stems from a realisation that there are others who share their experiences and thoughts, and from the ability to express their views. Seventeen percent (n=26) of participants reported the websites helped them maintain disordered eating behaviours, while 43.0% (n=65) reported receiving help in the form

of emotional support by visiting the sites. An additional 2.6% (n=4) responded that they were receiving both sorts of help.

Immersion and perceived positive/negative effects

Correlational analyses found that visiting the websites frequently was correlated with subjective self-esteem improving ($r = .306, p < .05$), feeling better about oneself after visiting ($r = .304, p < .01$), feeling less lonely following a visit ($r = .551, p < .01$), and motivating each other to diet together etc. ($r = .585, p < .01$). Those who visited frequently also reported being encouraged to seek treatment ($r = .219, p < .05$). Visiting frequently was not associated with changes in attitudes toward the body ($r = .150, p > .05$), checking behaviour ($r = .016, p > .05$), fasting behaviour ($r = .128, p > .05$), comparisons to others ($r = .033, p > .05$) or eating behaviour ($r = .026, p > .05$). Hypothesis 3 was therefore confirmed with respect to positive but not to negative effects (with the exception of motivating to diet together etc.)

Interaction with others

Scores for the question 'Do you participate in chatrooms/forums?' were examined. Those who reported they participated 'all the time'/'a lot' were grouped as Actives (n= 69; 45%) and those who reported they participated 'never'/'hardly ever' as Passives (n= 52; 34%). The middle group was excluded from these analyses.

Actives were found to visit the site more frequently than Passives ($t(1,119)=12.70; p < .01$). Unsurprisingly then, positive perceived effects were present in greater quantity. As hypothesised, Actives believed they had more in common with other visitors than Passive participants ($t(1,119)=5.82; p < .01$), and they felt better

about themselves after visiting the sites ($t(1,119)=3.88$; $p<.01$). The subjective self esteem of Actives reportedly improved after visiting the site more than that of Passives ($t(1,119)=3.68$; $p<.01$). Actives also reported that the sites encouraged them to seek treatment more than Passive participants ($t(1,119)=2.19$; $p<.05$). As responses to the question: 'Does visiting the sites make you feel less alone or isolated?' were not normally distributed for Passives and Actives, the Mann-Whitney U non-parametric test was run. Descriptive statistics indicated that Actives felt less lonely after visiting the sites (median = 1) than Passives did (median = 4). The Mann-Whitney U was found to be 574 ($z=-6.74$) with an associated probability of .00. The differences between the groups with respect to the negative effects were not significant: Actives reported no more checking, measuring etc. behaviour after visiting the sites than Passives did ($t(1, 119)=.019$; $p>.05$). Although there was a trend that Actives reported that the sites helped them to maintain their restricting or other disordered eating behaviours slightly more than Passives did, the difference was not significant ($t(1,119)=1.67$; $p>.05$). No differences were found between the groups on comparisons to others ($t(1,119)=.81$; $p>.05$) or on changing attitudes toward the body ($t(1,119)=1.69$; $p>.05$) after visiting sites.

The viewing habits of the two groups were found to differ in some respects but not in others: Passives reported browsing the 'tips and tricks' sections significantly more than Actives ($X^2=6.77$; $p<.05$), whereas Actives were more likely to be interested in jokes and diversions ($X^2=29.28$; $p<.01$) and essays and other 'cultural' content ($X^2=16.60$; $p<.01$). Both groups were equally likely to view 'thinspirations' (verbal: $X^2=0.01$; $p=1.00$ / picture: $X^2=0.09$; $p>.50$), food information ($X^2=0.27$; $p>.50$) and exercise information ($X^2=0.22$; $p>.50$).

A chi-square test was run to determine whether Actives/Passives were different in regards to using the site for emotional support or to maintain disordered eating (as measured by their response to the 'help or harm' question discussed in section: 'Learning about and visiting pro-eating disorder sites'). It was found that Passives were more likely than Actives to use the sites to maintain disordered eating behaviours, while Actives were more likely to use the sites to gain emotional support ($X^2=17.27$; $p<.01$).

Lifestyle or disorder?

It has been suggested that a distinguishing feature of the pro-eating disorders community on the Internet is the viewing of anorexia/bulimia as lifestyles rather than disorders. The respondents were asked to reflect on this. Examination of 147 free-text answers revealed two distinct conceptions of 'lifestyle'. On the first understanding, a lifestyle is a *chosen* manner of living one's life and entails embracing a set of values that characterise the lifestyle – perhaps even promoting them. Only ten respondents (7%) clearly stated that their eating disorder was a lifestyle in this sense. In addition, six individuals (4%) made the point that although adopting an anorexic or bulimic lifestyle is a matter of choice, it is unsustainable and in the end will develop into a disorder.

According to another perception of the concept, an eating disorder as a lifestyle does not imply a presence of choice. Rather, it is a lifestyle in the sense of 'a way of life' that pervades every aspect of the person's thought, perception and action. This second understanding of lifestyle is compatible with conceiving anorexia/bulimia as disorders, and the majority of respondents who understood lifestyle in this way saw a progression from a disorder to lifestyle ($n=12$; 8% of

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respondents). Eighty-one respondents (54%) simply believed anorexia/bulimia to be disorders.

Twenty-two (15%) respondents were undecided on the issue. Several of them thought that something like a 'healthy anorexia' (a lifestyle in the first sense, see above) could be maintained, e.g. "They can be lifestyles for people that have just enough sanity to walk the line..." It was also thought by some that anorexia was different to bulimia in this respect, e.g.: "Anorexia is more of a controlled exercise, or a 'lifestyle'. I think few bulimics would see their binge eating as a choice or a lifestyle and most are quite disgusted with themselves for it."

DISCUSSION

The present study, the authors believe, has been one of the first published studies to explore this modern phenomenon of pro-eating disorder Internet communities. It is hoped that the multi-faceted appeal the sites have for those who visit them has been sufficiently illustrated by the results reported above.

According to the results, majority of the people using these sites are young and female, as expected. A mean score of 45 on the EAT-26 is considerably higher than the minimum score suggested by Garner as an indicator of significant eating concerns, and the majority reported they believed they had an eating disorder. Half of the sample reported visiting such sites at least once a day, and were most likely to have come across them via the Internet itself or the media.

As shown in Table 1, the findings of the current study appear to substantiate the fears of Jackson and Elliott (2004) that individuals visit these sites to sustain or instigate disordered eating: participants reported visiting the sites to obtain food and

exercise information, for 'thinspiration' and 'tips n tricks'. Many participants reported visiting the sites when already in a negative mood, and overall, a trend was found toward a worsening of body image as a result of visiting the sites. Participants admitted that the sites helped them maintain disordered eating and discouraged them from recovery.

On the other hand, the findings suggest that genuine social support is available on these sites and visiting the sites can thereby have a positive effect, perhaps one not expected by mental health professionals. The sense of isolation that appears to be present at the outset for those who later develop eating disorders (Fairburn et al., 1999; Fairburn et al., 1997; Karwautz et al., 2001; Troop & Bifulco, 2002) deepens as the illness progresses (Serpell & Treasure, 2002; Serpell et al., 1999). Of the participants to the present study, 24% reported some form of social difficulty, and statements such as "I kind of lost all of my friends at school and in my neighbourhood but I still have my pro-ana and pro-mia friends" were frequent. Many of the reasons for this isolation are understood, even obvious: social occasions that do not involve food and drink are hard to find, and the individual whose eating habits raise constant criticism is necessarily driven to secretiveness and thereby isolation.

When asked whether they thought that eating disorders were lifestyles rather than disorders, participants of the present study grasped the opportunity to talk about an unorthodox conception of 'lifestyle', one that does not imply willingly adopting or defending a set of values. They spoke of their eating disorder as an existential state that pervades every aspect of the thought, perception and action, and is thus felt to be inseparable from one's identity. This is likely to be an important contributor to the sense of isolation experienced by people with eating disorders. Certainly, in large part this experiential shift concerns food and eating issues: narrowed interests and compulsive thoughts about food are well-documented aspects of eating disorders. In

the Keys, Brozek, Henschel, Mickelson & Taylor (1950; summarised in Garner, 1997) “starvation experiment” during the 1950’s, a radical reduction of calorie intake caused healthy college men with no previous eating issues to become obsessed with food, collecting recipes, hoarding food and cooking elaborate meals they did not eat. However, the experiential similarity among people with eating disorders almost definitely goes beyond food issues, and further research will be necessary to uncover aspects unrelated to food.

Pro-eating disorder chatrooms can function to alleviate the loneliness experienced by those with eating disorders. In the words of one of the participants: “I feel like I belong with these people. They are always voicing my opinions or thoughts.” Among those who share their experience of the world and are interested in the same subjects, even the more unpleasant aspects of eating disorders can be discussed without the fear of the other person turning away in horror or disgust, and obsessions can be indulged without fear of embarrassment. It is also worth noting the fact that on the Internet, all this can take place without physical presence – something that may be assumed welcome among this group of people.

Frequency of visits was found to be a factor in determining the extent of positive but not of negative impact of visiting the sites. This could be explained by the fact that those who were frequent visitors also tended to actively participate in chatrooms on the sites. In fact, there was a clear difference in perceived impact created by this factor: active participants reported a more positive impact on their self-esteem and a greater reduction in their feelings of loneliness as a result of visiting the sites. They were also more likely to feel that they had a lot in common with others who frequented the sites. Active participation was also associated with finding the sites helpful in terms of improving emotional well-being, while passive

participation was associated with finding the sites helpful in maintaining an eating disorder. Accordingly, it was shown that active participation implied using the sites mainly for emotional support and passive, 'silent' browsing implied using them to sustain disordered eating.

The findings suggest that active participation on pro-eating disorder websites and seeking the support and friendship of the other visitors to the sites *can* have a positive perceived impact on mental (and perhaps indirectly physical) well-being. It is the Passive visitors who should cause particular concern not only in that they are trying to become 'better' at an eating disorder, but also in that they fail to reach out of their (probable) isolation. Much of the discussion in the chatrooms is 'crisis resolution', something the Passives do not utilise. This negates any possible beneficial impact, whilst exposing the individuals to the disorder-maintaining content of the sites. For the Actives, it seemed as if increased exposure to potentially harmful elements on the sites such as 'thinspirations' had less of an effect in the climate of the improved mental state created by positive effects (e.g., feeling less lonely), thereby inhibiting the assumed functioning of a dose-response mechanism that gave rise to hypothesis 3.

However, the above is not to suggest the Actives are safe from harmful effects of pro-eating disorder sites. For one thing, Actives were more likely to motivate each other to fast etc. – behaviour facilitated by the chatroom but not by other sections of the sites. For another, although Actives reported that visiting the sites had in some cases led to their seeking treatment, the reported effect overall was recovery-neutral at best.

In addition, there may be negative effects other than those addressed directly by the PAWS. Despite the fact that participants reported being aware of a disorder-sustaining effect of the sites, they continue to return to them. At the heart of pro-eating disorder movement is the idea that having and retaining an eating disorder can be beneficial to the person who has it. Having a strong Internet community to which you belong reinforcing your identity as an anorectic or a bulimic may make it difficult to break away and seek recovery. Some participants alluded to this in their answers, e.g. "There's the feeling one daren't recover, because then you'd no longer belong". The idea that an eating disorder can be of benefit to the person who has it can lead to recovery being perceived as a *loss*, of control or of a coping mechanism the individual has come to rely on. There is a danger that through this Internet phenomenon the loss of a sense of belonging, of a membership in a community is added to the list. There is also the possibility that competitiveness arises among the individuals with each seeking to become the 'better' anorexic; it was found that the respondents tended to compare themselves to other members of the internet community.

Limitations

The limitations of the method of recruitment/data collection must be acknowledged. First, the authors must acknowledge the possibility that participants were not honest in their representation of the websites. Criticisms directed at these sites have resulted in many of them being shut down, and it may be possible that negative effects were under-reported in an attempt to 'protect' the sites. However, respondents freely reported that the sites enabled them to sustain their restricting and other disordered behaviours. Second, the data are correlational in nature and therefore form no basis for claims about causality. Nevertheless, this study showed a clear association between use of these sites and perceived impact on well-being.

Further studies need to address the extent of the impact on the individual and on seeking recovery.

Conclusion

Although attempts have been made to close pro-eating disorder sites, they have re-appeared and will continue to do so. Unless wholesale censorship of the Internet takes place, Internet savvy individuals will always stay one step ahead of those attempting to shut down the sites. A better approach would be for clinicians to acknowledge the needs these sites fulfil and to address them in conventional treatments for eating disorders.

One of the main therapeutic challenges is to counteract the association between recovery and a sense of losing something valuable. Given that closing down these Internet communities would arguably be a vain and potentially damaging attempt, other ways must be found in order to bring that about in the context of pro-eating disorder websites. The authors recommend further research aimed at unveiling aspects of 'pro-ana/mia identity' *apart* from the disordered eating. If the individuals visiting these sites can be helped to focus away from eating issues as the glue that binds them together, this particular association between recovery and loss should also begin to unravel. The challenge for a person who develops an eating disorder is not just that her identity survives the illness, but that it survives the treatment and the recovery.

Table 1.

What motivates participants to visit the sites?

Reasons for Visiting	Percent answering 'YES' n = 151
Do you regularly look at?	
Food information (calories etc.)	60 % (n=91)
Exercise information	39% (n=59)
Verbal 'thinspirations'	46% (n=69)
Picture 'thinspirations'	59% (n=89)
Tips and Tricks	59% (n=89)
Chatroom/forum/message board	74% (n=112)
Diversions/jokes/artwork	30% (n=45)
Essays/poetry/other cultural/political content	38% (n=58)
What motivates you to visit the sites?	
Feeling Good about yourself	26% (n=39)
Feeling Bad about yourself	69% (n=104)
Feeling Stressed	50% (n=76)
Boredom	37% (n=56)
Need for Information	46% (n=70)
Need for company; to interact with others on the sites	52% (n=79)

Table 2
Mean scores and percentages on PAWS questionnaire

	Mean	SD	Yes/better/ more	Neutral	No/worse/ less
Have attitudes toward your body changed since visiting these sites? 1= greatly improved; 5= worsened greatly	3.12	.84	23%	46%	32%
Has your self-esteem changed since visiting these sites? 1= greatly improved; 5= worsened greatly	2.86	.94	34%	45%	22%
Have you weighed, measured, or checked yourself more often? 1= a lot more; 5= a lot less	2.44	.81	46%	50%	4%
Do the websites help you maintain your restricting,/fasting/purging etc? 1= yes a lot; 5= Not at all	2.77	1.31	50%	15%	35%
Have the sites encouraged you to seek treatment? 1= yes, it led to my recovery; 5= it helped become a better anorexic	3.19	1.14	24%	30%	42%
Do you find yourself comparing yourself to other visitors? 1= yes, all the time; 5= never	2.54	1.65	46%	35%	18%
How do you feel about yourself after visiting a pro-ana/mia site? 1= a lot better; 5= a lot worse	2.68	1.17	46%	29%	25%
Do you feel other visitors have a lot in common with you? 1= yes, they are just like me; 5= no, they aren't like me at all	2.44	.94	58%	30%	12%
Does visiting make you feel less alone or isolated? 1= yes, a lot; 5= never	2.34	1.44	64%	7%	29%
Do you participate in forums/chatrooms or others contact other visitors? 1= yes, all the time; 5= never	2.77	1.59	46%	20%	34%
Do you motivate each other/do things together (e.g. begin a fast)? 1= yes, all the time; 5= never	3.76	1.36	18%	23%	59%
Do you think the sites impact your eating behaviour in any way? 1 = eat a lot more; 5= eat a lot less	3.46	.94	11%	42%	47%

Note. To calculate percentages, scores of 1 & 2 were combined to form the category 'yes/better/more', 3 was named 'neutral' and 4&5 were combined to form 'no/worse/less'

Appendix 1

Directions and explanations for Completing the PAWS*Introduction to potential participants*

We have noticed that the so-called pro-ED sites have had a lot of often unkind media attention, but the interviewees have typically been either people who run the sites ('the defence') or health care professionals and parents ('the prosecution'). The views of the majority of the people who actually use the sites have gone largely unheard. Our aim is to give voice to the users of these sites.

We have posted a questionnaire on our website that we'd like to invite you all/those of you who have visited the sites to fill in. You can find it at this address: http://www.sane.org.uk/public_html/Research/survey/instruct.shtm - it's the third one down on the list.

We realise that the term 'pro-ED' now has different meanings depending on who uses the term. Some take it to imply 'anti-recovery', others non-judgemental support, others something else. We are using the term for any sites which contain 'tips and tricks', 'thinspirations' and writings about Ana creed, beliefs etc. regardless of what the site's general take on recovery is, if there is one. We hope you find the survey adequate in allowing your views to be expressed. There are plenty of opportunities for writing free text (it's not just ticking boxes!), and if you'd like to, please use the 'further comments' field at the end of the survey to express your opinion on the survey itself if. Most of all, thank you for your time!

General instructions

We have noticed that a lot of media attention has focused on 'pro-eating disorder' websites sometimes known as 'pro-ana' and 'pro-mia' websites. These websites often have things like forums/chatrooms and often offer information related to eating disorders. These websites have been criticised for their content as 'promoting' eating disorders, but the creators of the websites say they are meant to be a place to find support. Articles about these websites discuss the views of health professionals and parents, and sometimes of the creators of the websites, however what seems to be missing is what those surfing such sites think of them. SANE wants to know the views of those who visit these sites, and has devised a survey that takes 10-15 minutes to complete.

So, now it's your turn, we'd like to know what you think!

Pro-Anorexia/bulimia Website Survey (PAWS)

1. Where did you first hear about such websites?
2. How often do you visit such sites?
 - 1 = Several times a day
 - 2 = Once a day
 - 3 = Few times a week
 - 4 = Few times a month
 - 5 = Every few months
 - 6 = Just once

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3. If you only visited once why didn't you go back again?
4. What sorts of features do you regularly look at? (Tick all that apply)
 - Food information (calories etc.)
 - Exercise information
 - Verbal 'thinspirations'
 - Picture 'thinspirations'
 - Tips and tricks
 - Chatroom/forum/message board
 - Diversions/jokes/artwork
 - Essays/poetry & other cultural/political content
 - Other (Free text)
5. What motivates you to visit the sites? (Tick all that apply)
 - Feeling good about yourself
 - Feeling bad about yourself
 - Feeling stressed
 - Boredom
 - Need for information
 - Need for company; to interact with others on the sites
 - Other
6. Do you think your attitudes toward your body have changed at all since visiting such websites?
 - 1 = Greatly improved
 - 2 = Improved somewhat
 - 3 = No change
 - 4 = Worsened somewhat
 - 5 = Worsened greatly
7. Do you think your self-esteem has changed at all since visiting such websites?
 - 1 = Greatly improved
 - 2 = Improved somewhat
 - 3 = No change
 - 4 = Worsened somewhat
 - 5 = Worsened greatly
8. As a result of visiting these websites, have you weighed, measured, or checked yourself more often?
 - 1 = A lot more
 - 2 = Somewhat more
 - 3 = Not at all
 - 4 = Somewhat less
 - 5 = A lot less
9. Does visiting these websites help you maintain your restricting, fasting, purging etc?
 - 1 = Yes, a lot
 - 2 = Yes, sometimes
 - 3 = Somewhat
 - 4 = Not really
 - 5 = Not at all

10. Has visiting these websites (or the people on the websites) encouraged you to seek treatment or go into recovery of any kind?

- 1 = Yes, it led to my recovery
- 2 = Yes, it encouraged me to seek help/help myself
- 3 = It both encouraged and discouraged me
- 4 = No, it helped to maintain my state of mind
- 5 = It helped me to become a 'better anorexic'

11. Do you find yourself comparing yourself to other visitors on the sites?

- 1 = Yes, all the time
- 2 = Yes, a lot
- 3 = Sometimes
- 4 = Hardly ever
- 5 = Never

12. How do you feel about yourself after visiting a pro-ana/pro-mia site?

- 1 = A lot better
- 2 = A little better
- 3 = No change
- 4 = A little worse
- 5 = A lot worse

13. Did you feel that the other people who visit/maintain the sites have a lot in common with you?

- 1 = Yes, they are just like me
- 2 = Yes, they are like me in many ways
- 3 = We share some things in common, like we share with anybody
- 4 = No, they aren't much like me
- 5 = No, they aren't like me at all

14. Does visiting the sites make you feel less alone or isolated?

- 1 = Yes, a lot
- 2 = Yes, sometimes
- 3 = Somewhat
- 4 = Not really
- 5 = Never

15. Do you participate in forums or chatrooms or otherwise make contact with others at the sites?

- 1 = Yes, all the time
- 2 = Yes, a lot
- 3 = Sometimes
- 4 = Hardly ever
- 5 = Never

16. Do you motivate each other/do things together (e.g. begin a fast on the same day)?

- 1 = Yes, all the time
- 2 = Yes, a lot
- 3 = Sometimes
- 4 = Hardly ever
- 5 = Never

17. Do you think the sites impact your eating behaviour in any way, for better or worse?

- 1 = Eat a lot more
- 2 = Eat a little more
- 3 = No change
- 4 = Eat a little less
- 5 = Eat a lot less

18. Do you believe Anorexia/Bulimia to be lifestyles or disorders? Please explain.

19. There has been a lot of controversy in the media about pro-ana/mia sites and many have been shut down. What's your opinion? What do they do for you?

20. Do you believe these websites harm or help you? Why?

21. Do you consider yourself to have an eating disorder?

- 1 = Yes
- 2 = No

22. If yes, which one?

23. Are there any problems you face (e.g. anxiety, self-harm, relationship difficulties) that you feel are important? Please explain.

24. Please say how you found this survey.

References

BBC News UK Edition Online, (2005). *BBC probe into anorexia websites*. Retrieved Tuesday, 8 February 2005 from: <http://news.bbc.co.uk/1/hi/wales/4245109.stm>. See also Ref. 6 below.

BBC News UK Edition Online (2006). Madrid bans waifs from catwalks. Retrieved Friday, 20 October 2006 from: <http://news.bbc.co.uk/1/hi/world/europe/5341202.stm>

Fairburn, C.G., Cooper, Z., Doll, H.A. & Welch, S.L. (1999). Risk factors for anorexia nervosa: Three integrated case-control comparisons. *Archives of General Psychiatry*, 56, 468-476.

Fairburn, C.G., Welch, S.L., Doll, H.A., Davies, B.A. & Connor, M.E. (1997). Risk factors for bulimia nervosa. A community-based case-control study. *Archives of General Psychiatry* 54, 509-517.

Garner, D.M., Olmsted, M.P., Bohr, Y. & Garfinkel, P.E. (1982). The Eating Attitudes Test: psychometric features and clinical correlates. *Psychological Medicine* 12 :871-878.

Garner DM. (1997) Psychoeducational principles in the treatment of eating disorders. In: Garner DM, Garfinkel PE, editors. Handbook for Treatment of Eating Disorders. New York: Guilford Press; pages 145-177.

Hewson, C. (2003). Conducting research on the internet. *Psychologist*, 16(6): 290-293.

Jackson, M. & Elliott, J. (2004). Dangers of pro-anorexia websites. BBC News International Edition (Online) Retrieved: August 21, 2004. from: <http://news.bbc.co.uk/2/hi/health/3580182.stm>.

Kant, I. (1981). *Grounding for the metaphysics of morals* (J. W. Ellington, Trans.; 2nd Ed). Indianapolis/Cambridge: Hackett Publishing Company, Inc. (original work published 1785).

Karwautz, A., Rabe-Hesketh, S., Hu, X., Zhao, J., Sham, P., Collier, D.A. & Treasure, J.L. (2001). Individual-specific risk factors for anorexia nervosa: A pilot study using a discordant sister-pair design. *Psychological Medicine*, 31,317-329. DOI: 10.1017/50033291701003129

Kemp, B. (2002). I used to think I was the only girl who didn't see anorexia as a bad thing. *The Times* Online (London) Retrieved: April20, 2002.

Keys, A., Brozek, J., Henschel, A., Mickelsen, O. & Taylor, H.L. (1987). *The Biology of Human Starvation* (2 volumes). Minneapolis:University of Minnesota Press 1950. Summarised in

National Association of Anorexia Nervosa and Associated Disorders. (n.d.) *Eating disorders and websites that encourage them*. Retrieved February 3, 2001 from: <http://www.anad.org/site/anadweb/content.php?type=1&id=6979>

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Serpell, L., & Treasure, J. (2002) Bulimia nervosa: friend or foe? The pros and cons of bulimia nervosa. *International Journal of Eating Disorders*; 32, 164-170.

Serpell, L., Treasure, J., Teasdale, J., & Sullivan, V. (1999). Anorexia nervosa: friend or foe? *International Journal of Eating Disorders*, 25(4),177-186. DOI 10.1002/eat.10076

Troop, N.A. & Bifulco, A. (2002) Childhood social arena and cognitive sets in eating disorders. *British Journal of Clinical Psychology*, 41,205-211.