

Individual Use of Online-Consulting for Persons Affected with Eating Disorders and their Relatives—Evaluation of an Online Consulting Service

Martin Grunwald* and Dorette Wesemann

University of Leipzig, EEG-Research Laboratory, Department of Psychiatry, Germany

This paper describes an independent online consulting service for persons affected with eating disorders and their relatives (<http://www.ab-server.de>) which was developed by physicians and psychologists in Germany. This study aims to understand the individual use of the online consulting by affected persons and their relatives. In order to do this, two online questionnaires were developed: one for affected persons and one for their relatives. These questionnaires were sent digitally to those people who had posted an e-mail to the online consulting service between 1/1999 and 11/2003 ($n = 2760$). Finally, 240 data sets of affected persons and 85 of relatives were included in the analysis. Respondents said that the online consulting had had important effects on their lives: (a) 22.5% of affected persons and 49.4% of relatives stated that the answers provided by the online consultants led to a better understanding of the disease; (b) 32.1% of affected persons and 52.9% of relatives experienced that they had been talking more about the disease since they had contacted the online consulting service; (c) 20% of affected persons went to see a therapist as a consequence of the online consultation. 55.4% of affected persons and 81.2% of relatives had not turned to professional help before they contacted the online service. The results of the evaluation suggest that people seeking help are made sensitive to their existing problem and that they have been encouraged by the online consultation to seek further professional help. Copyright © 2006 John Wiley & Sons, Ltd and Eating Disorders Association.

Keywords: eating disorder; online consulting; relatives; internet; evaluation

*Correspondence to: Dr Martin Grunwald, University of Leipzig, Department of Psychiatry, EEG-Research, Laboratory, Johannisallee 34, 04103 Leipzig, Germany. Tel: 0049-341-9724502. Fax: 0049-341-9724305. E-mail: mgrun@medizin.uni-leipzig.de

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THEORETICAL BACKGROUND

Eating disorders are severe psychological diseases with psychological, physical and social implications. Moreover, eating disorders may end fatally. (Sullivan, 1995; Steinhausen, 2002). There are indications that the prevalence of eating disorders has increased over the last decades (Hoek & van Hoeken, 2003; Nielsen, 2001). Even with treatment the prognosis still remains poor and this is especially so if there is associated personality disorder. (Garfinkel Kennedy, & Kaplan, 1995) This holds true for bulimia nervosa (Hay & Bacaltchuk, 2000; Wells & Sadowski, 2001) as well as for anorexia nervosa (Ben-Tovim et al., 2001; Kaplan, 2002) and difficulties with classification complicate the evaluation of treatment. (Bulik, Sullivan, & Kendler, 2000; Fairburn & Harrison, 2003). There is always the danger that the eating disorder could develop into a chronic form (Bulik, Sullivan, Fear, & Pickering, 2000). Therefore, helping the affected turn to professional help as early as possible is thought to be of great importance. However, patients with an eating disorder often have a high threshold to seek help due to features of the disease together with characteristic processing mechanisms such as shame, the tendency to avoid conflicts and to deny the seriousness of their state of health and pathological behaviour (Bulik, et al., 2000; Wells & Sadowski, 2001). It may therefore, be useful to complement existing inpatient and outpatient treatment facilities with a service which makes it easier for patients to turn to professional help and which at the same time motivates patients. To motivate affected persons to undergo treatment is an essential part of the intervention for eating disorders (Fairburn & Harrison, 2003).

Internet based services may contribute to such early intervention. The access to professional help on the internet allows those seeking help to be in control of the situation and to remain anonymous at the same time. Therefore, online services are highly acceptable: especially to young patients (Fenichel et al., 2002). These particular features of online services may be especially valued by patients with eating disorders. On the internet, messages from patients with an eating disorder to their therapists are quicker and problems are more openly spoken about (Yager, 2001). Due to missing psychological stimuli (visual, acoustic) on the internet, communication over concerns about body shape, attractiveness and weight are reduced and, moreover, persons are in control of the communication (Walstrom, 2000).

Early studies report positive effects of interventions for eating disorders using new technologies (Myers, Swan-Kremeier, Wlonderlich, Lancaster, & Mitchell, 2004). Their use extends from online prevention programmes to reduce negative body image in female students (Winzelberg et al., 2000) and e-mail contacts as a complement to face-to-face therapy for anorexia patients (Yager, 2003), to e-mail based therapy for patients with bulimia nervosa (Robinson & Serfaty, 2001, 2003) as well as caring for patients with bulimia nervosa after hospitalization using a text messaging service (Bauer, Percevic, Okon, Meermann, & Kordy, 2003). There is some evidence for positive effects on the disorder and on the reduction of emotional stress in patients with an eating disorder (Zabinski, Celio, Jacobs, Manwaring, & Wilfley, 2003; Zabinski, Wilfley, Calfs, Winzelberg & Taylor, 2004; Winzelberg et al., 2000), on the acceptance of further psychotherapeutic treatment (Robinson & Serfaty, 2003) as well as on attitudes of patient's parents (Brown, Winzelburg, Abascal, & Taylor, 2004). Most of the studies have been based upon structured programmes with a cognitive-behavioural orientation and with similar objectives to conventional face-to-face therapies.

The medium of the Internet is suitable for far more than the mentioned treatment options or treatment settings (Carlbring & Andersson, 2004). In contrast to online therapy, internet based consulting services make first contact with professional help easier for those persons who are seeking help. Affected people as well as those who are interested in a certain disease may find information about that disease as well as further treatment options. Thus, the advantages of the internet—rapid communication, easy access, its use independent of time and place and its low costs—support the overcoming of inhibitions in turning to professional help in order to get early treatment of chronic diseases (Döring, 2003).

In Germany, online consulting is offered mainly by associations or self-help groups and sometimes also by private institutions. Among these, the *Informations- und Beratungsserver für Patienten mit Essstörungen und deren Angehörige* [Information and Consulting Server for Patients with Eating Disorders and their Relatives] (<http://www.ab-server.de>) is the first professional, non-profit online consulting server for eating disorders in Germany. The so called *ab-server* was founded by the non profit organization *Deutsche Forschungsinitiative Eßstörungen e.V.* (DFE e.V.) [German Research Initiative for Eating Disorders] in cooperation with the Clinic of Psychiatry at the University of Leipzig, Germany.

The online consulting service offers patients with eating disorders, their families and friends, as well as colleagues or other persons interested in eating disorders, the opportunity to contact professionals via e-mail. This service is free of charge. All incoming e-mails are directed to the online consulting coordination centre. Only the content of the e-mail is passed along to an online consultant. The response of the online consultant to this e-mail is then sent back to the online consulting coordination centre which passes the answer on to the inquiring person after its 'intervision' [means a setting of professional interchange among colleagues] and review by the consulting team of the *ab-server* at the University in Leipzig. This procedure guarantees the anonymity of the person asking for advice, because his or her e-mail address remains unknown to the consultant. The time between receiving the e-mail and its being answered by the consultant varies depending on its content. Generally, answers take no longer than two days. The consulting team consists of psychologists and physicians working at the University of Leipzig as well as external professionals (certified psychologists) who have been working with patients with eating disorders for years. External consultants receive a fee per answer given to an e-mail message.

All online consultants of the *ab-server* work according to quality standards and guidelines which describe the purpose and procedures of the online consulting. The answers to inquiries provide information on symptoms and treatment options for eating disorders. Depending on the case, persons affected with an eating disorder will be encouraged to seek further help and/or to undergo treatment. Answers from the consultants contain no diagnoses. Thus, the online consultation serves as a complementary service and not as a long-term treatment in place of conventional consulting and therapy methods. Usually, the communication is limited to a single contact with the inquiring person.

Since 2001, the *ab-server* project has been supported by the central organization of German health insurances. The number of incoming e-mails has increased every year. An average of 24 e-mails were received by the online consultants each week in the year 2003.

Studies focusing on users of the online consultation at the *ab-server* and on content of incoming e-mails have already been published (Grunwald & Busse, 2003; Grunwald & Wesemann, 2005). So far, there have been no investigations into the individual effect of the online consultation for affected persons with eating disorders and their social environment.

Thus, this study aims to analyse how affected persons and relatives assess their individual use and the efficiency of the online consulting service.

The study focuses on the following questions:

- (a) What are the reasons for people seeking help in the form of online consultation on the *ab-server*?
- (b) Does the online consultation have an effect on their understanding of the illness?
- (c) Does the contact with the online consulting service encourage people to seek further help? Did persons follow the given advice and suggestions?

METHOD

Two online questionnaires were developed (a) one for relatives of persons affected by an eating disorder and (b) one for persons affected by an eating disorder. Questionnaires consisted of 17 items in the form of close-ended questions. Sometimes more than one answer was possible. (Questionnaires can be found at <http://ab-server.uni-leipzig.de/fb.pdf>).

All persons seeking help who contacted the online consulting service between January 1999 and November 2003 were included in the investigation. In this study we used the classification of 'affected persons' and 'relatives' as in a previous study (Grunwald & Busse, 2003). 'Affected persons' say of themselves that they suffer from an eating disorder or they describe symptoms which indicate a clinical relevance or sub-clinical eating disorder. 'Relatives' describe people who have a person with eating disorder symptoms in their social environment. The e-mail message to the subjects informed them of the purpose of the investigation and contained a link to the site with the respective online questionnaire which could be answered anonymously. It was left up to the persons in question whether they wanted to take part or not. Furthermore, people were informed that upon answering of the questionnaire they accepted that their data would be used for scientific purposes.

Data collection took place in two phases, in May 2003 and in November 2003. Two thousand two hundred eight of 2760 e-mails were posted successfully, 1470 e-mails from affected persons and 908 e-mails from relatives. However, 552 e-mails could not be posted successfully because of errors in e-mail addresses or deleted addresses. Two hundred seventy three affected persons (18.6%) and 117 relatives (15.9%) answered the questionnaire ($n = 390$). Only those questionnaires that were completely

Table 1. Response rate of the investigation (based on all received questionnaires, $n = 390$)

Year of inquiry	1998	1999	2000	2001	2002	2003
Response rate	0%	9.7%	9.2%	11.1%	17.6%	20.7%

and correctly filled in were included in the analysis. Thus, 325 data sets, 240 of affected persons and 85 of relatives were included in the descriptive analysis using SPSS 10.0 (Windows).

The rate of return in relation to the year of consultation is displayed in Table 1.

SAMPLE

The majority (95.8%) of participants affected with an eating disorder were female, whereas 43.5% of the relatives are male. The average age of the affected was 23.8 with a margin of error of 6.63. All this is in line with results of our previous study (Grunwald & Busse, 2003) The group of relatives was more varied in age but also tended to be young adults. The average age was 29.6 and 50% of relatives were 26 or younger, although many were people aged from 35 to 55 years. This heterogeneity is due to the characteristics of the group. It consists predominantly of male friends/boyfriends/husbands (29.4%) and female friends/girlfriends/wives (23.5%) followed by mothers (16.5%). Moreover, 'relatives' in this study also includes people who know the affected persons (8.2%), colleagues (4.7%), sisters (4.7%) and teachers (2.4%) as well as other relatives and friends.

The majority of affected persons taking part in the study are those with self-declared bulimia nervosa (70%) and binge eating disorder (14.2%). Only a minority of persons described themselves as having anorexia nervosa (4.6%). Only 2.5% of respondents were concerned with obesity and 8.8% with eating disorders in general.

More than half of the affected and over two-thirds of their relatives had not turned to professional help before they contacted the online consulting service. For 55.4% of affected persons and 81.2% of relatives, the online consulting service had been the first contact with professionals. Some people had sought professional help before but without success (10.8% of affected persons; 7.1% of relatives). Only a few had experienced professional consulting (7.1% of affected persons; 11.8% of relatives), whereas 26.7% of affected persons had already had a therapy.

RESULTS

Motives for the Use of Online Consulting

Participants were asked to express agreement to several reasons of motivation on a scale divided into five grades ('strongly agree', 'mainly agree', 'agree', 'hardly agree', 'strongly disagree').

The following percentages refer to frequencies of 'I mainly agree' and 'I strongly agree' combined together.

The quick exchange of e-mail and the easy approach was the predominant reason for the use of online consulting given by 90.9% of affected persons and by 95.1% of relatives. 88.8% of affected persons and 90.6% of relatives stated the special competence for eating disorders of the consulting team to be the reason to contact the online consulting service. This seemed to be another essential criterion for the participants.

Anonymity was important to relatives (45.8%) and especially for affected persons (85.4%).

Independence of place when using the online consulting was essential for 69.9% of affected persons and 60% of relatives.

There were two other reasons for a majority of affected persons to turn to the online consulting service, that it is free of charge (66.2%), and that they preferred the written form of the inquiry (61.2%). Relatives gave these reasons less frequently (free of charge: 55.3%; written form of inquiry: 42.3%).

For 46.3% of affected persons and 47% of relatives, independence of time was a reason to contact the online consulting service of the ab-server.

Changes Due to Online Consultation

A crucial aim of the investigation was to find out whether the online consulting had an influence on attitudes towards the eating disorder.

67.1% of relatives and 65.8% of affected persons stated that the answer received during the online consultation had made them think. Another issue was whether the answers given by the online consulting service resulted in any changes concerning the attitude towards the problem and, if so, which kind of changes these were. Answers of affected persons are represented in Figure 1. Most often, affected

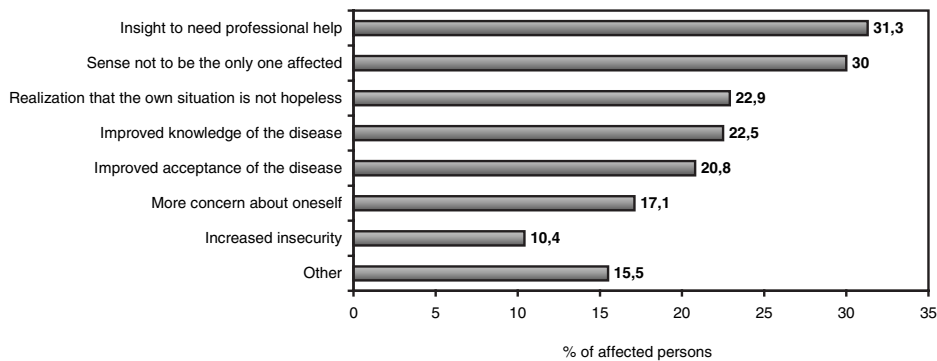


Figure 1. Affected persons: Has the online consulting had an influence on your attitude towards the disease? (Multiple answers were possible)

persons are said to have gained an *insight that they need professional help* (31.3%).

Further responses were related to *the sense of not to being the only one affected with an eating disorder* (30.0%) and to the fact that affected persons *realized that their situation is not hopeless* (22.95). Relatives referred to the same issues in similar frequency (*insight that they need professional help*: 30.6%; *sense, not to be the only one with this problem*: 22.4%; *realization that their situation is not hopeless*: 30.6%). Nevertheless, other criteria were more important for relatives. The contact to the online consulting service resulted in a *better understanding of the affected person* (49.4%) and in an *improved knowledge of the disease* (48.2%). The aforementioned issues occurred less frequently in answers of affected persons (*improved knowledge of the disease*: 22.5%; *improved acceptance of disease*: 20.8%).

17.1% of affected persons and 14.1% of relatives expressed that they were *more concerned* about themselves or about the affected persons as a consequence of the online consultation. 10.4% of affected persons and 1.2% of relatives had a *feeling of insecurity* concerning their own attitudes towards the illness after the online consulting.

30.4% of affected persons and 23.5% relatives experienced no changes at all after the online consultation.

Actual Activities as a Consequence of the Online Consultation

For assessing the quality and utility of the online consultation it is of great importance to know whether people asking for help could be motivated to any activities by the online consultation. Thus, we asked in the questionnaire whether people were

encouraged by the online consultation to seek further help and to turn to other resources for more information. Affected persons expressed most frequently to have looked for *more information on the disease* (27.9%) and for *therapists/treatment facilities* (27.1%) as a consequence of the online consultation. Similarly, relatives claimed to have looked for *more information on the disease* (30.6%) and on *therapists/treatment facilities* (24.7%). Additionally, many affected persons (21.7%) were also seeking information on alternative treatment options after the online consultation.

Less frequently, affected persons (15.8%) and relatives (21.2%) were looking for a *self-help group or a consulting centre*. 4.6% of affected persons and 4.7% of relatives sought a self-help group for themselves and 12.9% of relatives sought one for an affected person. 32.1% of affected persons and 37.6% of relatives gave a negative response to the question.

Regarding actual activities as consequences of the online consulting affected persons answered most frequently that they were encouraged to *talk to their parents, friends and relatives* (32.1%) and relatives to *talk to the affected person* (52.9%) (Figure 2). An *improvement in coping with the illness* was another consequence of the online consultation for 24.6% of affected persons and 29.4% of relatives.

In contrast to relatives, affected persons were encouraged to seek further professional help and to get in contact with other affected persons. Twenty percent of affected persons, but only 5.9% of relatives claimed to have *undergone treatment* as a result of the online consultation. 10.8% of affected persons and 7.1% of relatives said that they had *turned to a consulting centre*. 3.8% of affected persons *changed the therapy* and 2.1% of affected persons *changed their therapist* after the online consultation. 12.9% of

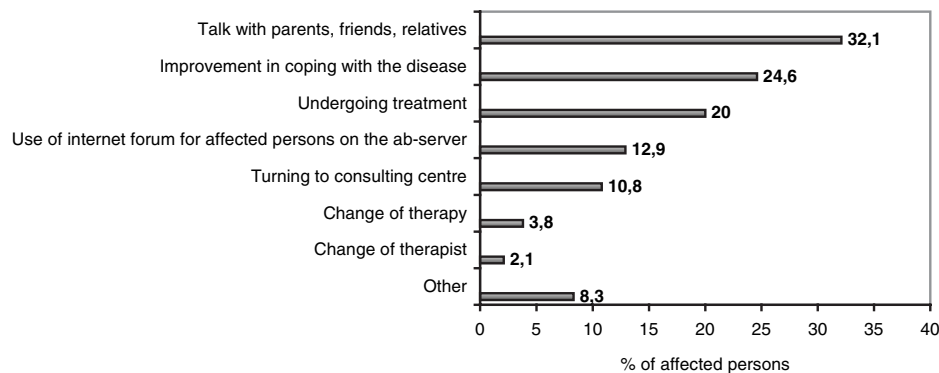


Figure 2. Affected persons: Has the online consulting had any effect on your personal behaviour? (Multiple answers were possible)

affected persons and only 3.5% of relatives *joined an internet forum* for their problems. Furthermore 3.5% of relatives were encouraged *to join a self-help group*.

For 34.6% of affected persons and 29.4% of relatives, the online consulting had no influence on their behaviour.

We asked the users regarding their current utilization of professional help. Twenty seven percent of the affected were, according to their own statements, taking part in an out-patient treatment, 1.7% in-patient therapy, a small part were waiting for a place in therapy (5.4%), 7.9% had broken off treatment and 3.9% claimed to be members of a self-help group.

Roughly one-third stated that they were not taking part in a form of professional help (32.1%). 9.6% of affected persons described themselves as cured. Some additional comments help to understand the background behind this statement: 'I have the feeling that I am no longer sick despite Bulimic attacks', 'I managed it on my own. The symptoms are gone!' and 'I have new things in my life, I recently became a mother'.

DISCUSSION

The aim of the study was to comprehend variables of individual use of online consultation for persons affected by an eating disorder and their relatives using an online questionnaire among users of the online consulting service.

The predominant user group of the online consulting service are adolescents and young adults. The majority of relatives are male friends/partners (29.4%) and female friends/partners (23.5%) of affected persons. Thus, the sample of participating users of the online consulting service is in line with

a previous analysis of incoming e-mails (Grunwald & Busse, 2003).

One crucial result of the investigation is that a majority (55.4% of affected persons and 81.2% of relatives) said that they had not yet turned to professional help at the time of contacting the online consulting service. That means that people who turned to the consulting service of the *ab-server* had not been reached by any other intervention services before that time. These first contacts with professionals were supported by the characteristic advantages of online intervention (easy and quick access, maintaining of anonymity) as well as by the special competence of the online consulting team.

Respondents reported predominantly positive effects as a result of the online consultation. Results are not easy to compare with previous investigations into Internet-based or e-mail based treatments because they differ distinctively in setting, sample and method. In general, reported effects regarding a new way of coping with the illness or with the affected person, the reduction of emotional stress and an increased acceptance of the illness as such by relatives are in line with results of previous studies (Brown et al., 2004; Winzelberg et al., 2000; Zabinski et al., 2003).

Furthermore, a large percentage of affected respondents (31.3%) gained insight into the need to seek further professional help after the online consultation. Robinson and Serfaty (2003) published similar results of an analysis concerning online treatment of bulimia nervosa by e-mail. This analysis revealed that 53% of participants in study 1 would accept a further face-to-face treatment, 26% would like to carry on with the online treatment whereas 29% of participants had experienced professional help before. Results of this study show that even

infrequent contacts with an online consulting service can be enough to increase the motivation among affected persons to undergo further professional treatment.

Additionally, respondents expressed further individual effects of the online consultation which indicate an improvement of their own self-help potential. These include improved knowledge of the disease (22.5% of affected persons; 48.2% of relatives), increased searching for more information on the disease (27.9% of affected persons; 30.6% of relatives), and frequent conversations about the disease in their social environment (32.1% of affected persons; 52.9% of relatives).

It can be concluded from the results, that users of the online consulting service of the *ab-server*—especially those without any experience concerning professional help—are encouraged to continue dealing with the disease. Therefore, an online consulting service with its specific features may serve as a first step in coping with eating disorders. Due to the small sample and its heterogeneity, more detailed analyses of effects of the online consulting should focus on, among other things, different situations in which persons turn to help, on different forms of eating disorder or on the number of contacts.

One considerable reason for the low number of returns of the surveys carried out is partially due to the lag of time between the consultation itself and the accompanying questionnaire. The consultations occurred between January 1998–November 2003. The total survey returns after a longer time (1998–2001) was lower than when the span of time was shorter (see Table 1). This lag is certainly also responsible for the fact that 25% ($N = 552$) of cases were no longer reachable at the e-mail address that they had originally provided.

Therefore, it should be seen to that the time gap between counseling and the questioning does not exceed more than 4–6 months in future studies.

Another factor for the low percentage of survey returns could be accounted for by the fact that the online counseling service is primarily used by people with a greater need and desire for anonymity. These people quite possibly do not wish to engage in continuing communication with experts. It is possible that those affected persons who took part in the survey are, in the main people who have an active attitude to the disease. As a result of these methodological limitations and the low representative qualities of the samples the results of the existing survey must be interpreted with caution.

In future studies the above named methodological shortcomings will be corrected and data will be sys-

tematically ascertained for purposes of evaluating the online consultation. Every inquiring person who agrees to take part in a scientific study will automatically be sent a survey after four weeks. It is expected that, as a result, it will be possible to combine the results of future studies into the online consultation of those affected by eating disorders and their relatives with existing ones in a most precise way.

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