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Online consulting service for eating disorders—analysis and perspectives

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Abstract

The analysis of the use of a free online consulting service for eating disorders at the German “Information and Consulting Server for Eating Disorders” (<http://www.ab-server.de>) revealed that there exists a considerable demand for advice and information. The anonymity of the Internet supports those persons affected with an eating disorder, who turn to qualified personnel in the sense of a first contact. The online consulting service was predominantly used by persons suffering from bulimia nervosa, their families, and friends. The most frequent questions were asked by affected persons, their families, and friends about behavior patterns in dealing with the illness. They were followed by inquiries seeking for help in finding specialized clinics/therapists and places in therapies. The frequent use of the online consulting service illustrates that respective offers are indispensable components not only of the information structure but also of the supply network. To increase the efficiency of the existing online consulting service it is necessary to realize the service in a consulting network with competent partners (specialized clinics, organizations, self-help groups). Furthermore, a service for procurement of available places in therapies for patients with eating disorders will be installed by network and cooperation structures. The online consulting network as well as the therapy procurement network in Germany are available to the public on the web-site of the *ab-server*. © 2003 Elsevier Science Ltd. All rights reserved.

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1. Introduction

Besides detailed medical presentations of nearly all illnesses (diagnostic criteria, symptoms, causes, treatment, prophylaxis etc.) various forms of online consulting

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have been established on the Internet. Doubtlessly, there are more static information services than dynamic information services in the form of online consulting. Here, online consulting means that it is possible for an Internet user to formulate his or her problems in an e-mail exchange or in chat connections, and thus, the user is enabled to communicate with other persons—the consultants. In Germany, different forms of online consulting services are offered especially by self-help groups and organizations, and more and more by public institutions of the counties and the state as well as by health insurances and clinics (Ott, *in press*; van Well, *in press*).

Already a study about patients with eating disorders (Yager, 2001) and a study about patients with diabetes (Razeghi et al., 1998) have shown that accompanying competent consulting via the Internet has a positive effect on the course of illness and healing processes. Experiences of similar Internet projects underline the high acceptance of this form of consulting by affected persons, their families, and friends, which is determined by the following factors:

1. anonymity of communication on the Internet;
2. rapidity of exchange of information;
3. independence of time and place of participants in communication; and
4. low costs for keeping up communication.

The opportunity to communicate anonymously over the Internet supports the overcoming of inhibitions. This is especially reflected in the intensive use of information and advisory services for mental disorders on the Internet and the connected coming up to terms with current every day problems (Christl, 1998; Grohol, 1997; van Well, *in press*). The clientele of these online consulting services consists naturally of affected persons, their families and friends.

On the Internet, information and consulting services are not only offered on general health servers but also on sites specializing on a certain disease. Respective online consulting services for patients with eating disorders had not existed in Germany before 1998. Therefore, the “Information and Online Consulting Service for Anorexia nervosa and Bulimia nervosa” (<http://www.ab-server.de>) had been the first special server for eating disorders with an anonymous online consulting service in Germany. Furthermore, general information on eating disorders, addresses of self-help groups in Germany, special research results of eating disorders and international links are provided on the *ab-server*. The so-called *ab-server* was founded by the author in cooperation with the *Deutsche Forschungssinitiative Eßstörungen e.V.* (DFE) [German Research Initiative for Eating Disorders], the Clinic of Psychiatry, University of Leipzig and the *Rechenzentrum* [Computer Centre], University of Leipzig.

The DFE is a non-profit association supporting research and spread of knowledge in the field of eating disorders. The support and realization of basic research to biological causes of eating disorders are thereby of crucial interest.

This article presents and discusses results of a quantitative and qualitative analysis of incoming e-mails to an online consulting service. A respective pre-analysis has already been published by Grunwald, Richter, Assman, Etrich, and Gertz (1999).

2. Analysis

Between October 1998 and January 2001, 619 e-mails were posted to the *ab-server*. Two persons (psychology students) rated the e-mail messages, and there were no significant discrepancies between the two raters.

Nearly all incoming e-mails could be classed with a certain form of eating disorder. More than half of the questions (364, 59.0%) were asked to bulimia-related symptoms, whereas only 92 (14.9%) questions were asked to anorexia-related symptoms. The remaining inquiries were related to binge eating disorder (71, 11.5%), obesity (11, 1.8%), and to other illnesses which could not be classified as any kind of eating disorder (5, 0.8%).

Seventy-four messages (12.0%) were general inquiries about eating disorders, but they could not clearly be classed with the above-mentioned symptoms.

2.1. Circle of individuals

Because there had been no instructions for composing an e-mail to the online consulting service, it was up to the person asking which personal details they wanted to give. The analysis of 615 inquiries revealed the following:

The majority of questions (333, 54.1%) was asked by affected, female persons, that means that according to the text of the message it was obvious that the respective person suffered from a form of eating disorder. Of 333 affected, female persons, only 68 wrote that they are receiving treatment for the existing eating disorder.

Two hundred and twelve women (63%) were suffering from bulimia nervosa, 54 (16.2%) from binge eating disorder, 27 from anorexia nervosa, 8 from obesity and 29 from a declared eating disorder without specification. The remaining four messages were posted by persons who suffered from other diseases.

Another circle of persons consisted of male friends of an affected, female person (73, 11.9%) followed by female friends of an affected, female person (57, 9.3%).

Only 13 e-mails were from men suffering from an eating disorder (8 bulimia nervosa, 2 binge eating disorder, 1 obesity, 1 eating disorder without specification, 1 other disease). Few questions were asked by male friends of an affected, male person (16), by teachers (2), by colleagues from work (5), and colleagues in the field—physicians, psychologists (13) (Table 1).

2.2. Gender

The distribution concerning gender shows that noticeably more women (460, 74.3%) have turned to the online consulting service than men (105, 17.0%). In 54 inquiries no gender could be ascertained.

2.3. Age

Only 37.6% gave their current age in the e-mail. Thus, an average age of 21 years could be determined according to the information in hand. But the result must be

interpreted with reservations because of low case numbers. On account of unsystematic observations concerning features of style we assume that the average age of the asking persons must be noticeably below 21.

2.4. Content

Ten categories were determined for the content analysis of the e-mails (Table 2). In more than one third (225, 36.3%) of the 619 analyzed messages it was asked for behavior patterns in dealing with eating disorder. One hundred and three female

Table 1
Circle of individuals

Who asked?	<i>N</i>	%
Affected person (female)	333	54.1
Affected person (male)	13	2.1
Female friend of affected person	57	9.3
Male friend of affected person	73	11.9
Mother of affected person	9	1.5
Father of affected person	8	1.3
Sister of affected person	17	2.8
Brother of affected person	2	0.3
Other relatives	13	2.1
Aquaintance	16	2.6
Teacher	2	0.3
Schoolmate	1	0.2
Colleague from work	5	0.8
Colleague in the field (psych./physician)	13	2.1
Interested person (female)	44	7.2
Interested person (male)	9	1.5
Total	615	100.0

Table 2
Content of e-mail inquiries

Inquiry concerns...?	<i>N</i>	%
Behavioral advice	225	36.3
Factual issues of eating disorder	146	23.6
Search for therapy facilities	27	4.4
Search for self-help groups, organizations, consulting centres	53	8.6
Search for alternative treatment options	10	1.6
Mailing information	52	8.4
Mailing research results	5	0.8
Diagnosis	28	4.5
Search for literature	8	1.3
Help in general	65	10.5
Total	619	100.0

persons with eating disorders were interested in how to cope with the own illness. Male (45) and female (44) friends of affected female persons were asking for behavioral advice in dealing with the person they are friends with. Regarding frequency questions on behavioral patterns were followed by medical and/or psychological factual issues (146, 23.6%). These inquiries were first and foremost from women suffering from a form of eating disorder.

A third group consisted of e-mails in which a critical situation of life had been described (65, 10.5%). Furthermore, it was frequently asked for addresses of self-help groups (53, 8.6%) as well as for mailing information about eating disorders (52, 8.4%).

The results of the content analysis concerning the e-mail-inquiries are presented in Table 2.

The analysis concerning the geographical distribution of e-mails shows that 90% of inquiries came from Germany and 5% from Austria. The remaining 5% were distributed among other European countries.

The analysis concerning the annual distribution revealed that the online consulting service had formost been used in January, February and March.

Although it is possible to communicate almost completely anonymous 207 inquiries were “signed” with name and surname, and an address was given. Four hundred messages contained a surname and only in 12 e-mails no name or an abbreviation of name was given.

3. Discussion

The descriptive analysis revealed that the majority of inquiries was concerned with the field of bulimia nervosa. The frequent use reflects, on the one hand, the existing distributional relation between anorexia nervosa and bulimia nervosa in the total population in Germany¹. On the other hand, it makes clear that the need for advice exists not only in persons with a specific form of eating disorder.

The online consulting service is mainly used by bulimic patients which seems to be in line with typical strategies of bulimics in coping with their suffering. In contrast to anorectics, bulimics experience their illness and connected restrictions with a strong sense of suffering. On this background, especially bulimic patients accept their need for professional help and thus, they are seeking for consulting services and treatment options. Whereas anorectics usually reach this state of critical reflection on the own body only after years of psychotherapeutical intervention. Affected persons asked mainly for physical side effects, “advice” on how to get over an eating disorder without therapy, and for special medication as well as treatment options abroad.

A large number of e-mails described eating attitudes and behaviors in detail, weight etc. Those inquiries were focusing on a diagnosis by the consulting team or an assurance, that the described features have no critical or clinical relevance. In this

¹ According to the Federal Centre of Health Information (July 2001) about 600,000 women between 15 and 35 years are suffering from bulimia nervosa, and about 100,000 women are suffering from anorexia nervosa.

connection, we have to point out to those mainly young women who think of their eating habits of being worth observing. By turning anonymously to advisory services—in a sense of first contact—they wanted to know whether their eating habits and their weight is classified as “normal” or as “disturbed”. Additionally, they wrote that they have not wanted to entrust (or that they could not have entrusted) someone with their questions, yet. Those e-mails have to be seen as first contacts of persons with a beginning or with a recently existing eating disorder. Thus, it becomes obvious which landmark potentials the answer may have. Therefore, the answer has to be formulated very sensitively. It is very difficult for the consulting team to decide the right way on the basis of spontaneous information given by the inquiring person. Nevertheless, it has to be found a way to assess critically possible relevant remarks and to give practical advice at the same time without stampeding the person asking. Some studies (Winzelberg, 1997; Winzelberg et al., 2001; Zabinski et al., 2001) have already referred to the special significance of consulting situations on the Internet especially to first contacts and first interventions of persons with beginning eating disorders.

Beside affected women and men (56.2%) a surprisingly large number of persons (>40%) who are confronted with eating disorders in their social environment (friends, relatives, colleagues) turned to the consulting team. Analyses revealed that relatives and friends suffer considerably from a feeling of helplessness towards the disease and from its consequences for social every day communication. Therefore, relatives and friends seek advice concerning strategies

1. to improve life for the affected person or to make it at least more tolerable, and
2. to convince the affected person of the necessity of treatment.

E-mails by relatives and friends are characterized by the will for changes regarding the existing situation, and by the illusion that the symptomatic would increase only by behaving the right way. They want no theoretical advice but quick practical help. This shows that relatives and friends hardly understand the mental dimensions of the diseases or the specific way of perception and experience of the affected persons. It is difficult for them to accept the state the beloved person is in as an existing disease with a prolonged and individual course. Many relatives and friends described beside the will for change a state of resignation in dealing with the affected person. Social and emotional resources have run out, life with the affected person has become unbearable, because of the unchanging state of illness.

In spite of strong feelings of guilt, some friends considered to break up the deep relationship with the affected person. To make this decision they wanted the implicit support of qualified personnel. Mainly relatives and friends demanded understanding for their own great strain.

Furthermore, physicians sought information about existing treatment options and therapy facilities via the online consulting service. In 90 e-mails it was asked (a) for methods of treatment, (b) for addresses of consulting centres and self-help groups at the place of residence, or (c) for alternative therapy facilities. In some cases, affected

persons asked for help in taking up contact with clinics. Thus, the consulting service developed into a service for procurement. Those procurement inquiries demonstrate that many affected persons know neither sufficiently about the course of in-patient and out-patient treatments nor where to find specialized clinics in Germany. In other cases (9) physicians of intensive care units asked the consulting service for clinics which offer treatment for anorectic patients with extreme underweight in Germany. Those physicians thought it necessary to refer an anorectic patient having received intensive medical care to a specialized clinic for eating disorders for undergoing psychotherapy.

4. Network perspectives

On the basis of our experiences with the *ab-server* online consulting service so far, it can be concluded that this specific form of Internet-based consulting is well accepted by affected people, their families, and friends. Celio et al. (2000) already showed that the acceptance of Internet-delivered help and information was significantly higher compared to face-to-face meetings. From the tendency of increasing e-mail-inquiries follows the need of reorganizing the consulting management. In the following, perspectives of a future consulting management in a consulting network will be shown. As a result of the e-mail analysis, a procurement network concerning available places in therapy will be installed to meet the expressed need of patients.

For the *ab-server* consulting team does not use text modules for their answers, it is a relatively heavy burden for the consultants. But we take the view that inspite of a high repeat rate of questions one should respond individually to e-mails expressing individual ways of life and suffering. Therefore, the danger exists of answering overhastily or of extending inadequately the time for answering. Another problem follows from the structure of the consulting team, which, in our case, is characterized by scientific-clinical work at the clinic of the University of Leipzig. Inherently, the competence of a small group is lower compared to the competence of a network of experts with different experiences and specializations. In difficult or unique critical cases² it had been indispensable to consult colleagues of other fields at the clinic. Because of the always positive experiences concerning those short, case-related “consulting or competence networks” we now see a principle aim of our work in increasing the advisory competence by constant cooperation with colleagues of specialized clinics, organizations, self-help groups and advice centres. In such a consulting network, the *ab-server* team will take on an advisory function as well as the function of an information transmitter while forwarding specific problems and questions to network partners. Inquiries answered by partners will finally be concluded in an answer e-mail and then forwarded to the person asking. By this

² Example: A 42-year-old man, who had been suffering from Bulimia nervosa for 15 years, asked, whether the deposited water in his testicles—as a consequence of his disease—should be removed operatively or not. Although his urologist advised the operation, he was still unsure about it.

procedure we expect that the quality and case specific precision of the advice statement increases significantly, and that the period of time needed for answering will decrease at the same time.

We have already mentioned that the consulting service was used as an procurement service for available places in therapies. To respond to these inquiries it was not only essential to find out about available places in clinics, but we had also to decide beforehand which clinic we should contact. Necessarily, possible clinics were asked sensitively for therapy facilities and treatment quality, because we thought it not sensible to procure someone for any clinic. Because experiences of the clinical routine show again and again that especially patients with severe forms of eating disorder (i.e. anorexia nervosa) undergo only “compromise treatments” in sanatoria and rehabilitation centres without perceptible therapeutical effect. It becomes obvious that, on one hand, there is a need for quick and competent procurement of places for therapies—especially for in-patient treatments—but, on the other hand, neither respective network information about specialized clinics or psychotherapeutics nor objective assessments of therapy concepts are available. Thus, beside founding an online consulting network we want to install a procurement network for available places in therapies for patients with eating disorders. The capacity of actual available places in therapies for in- and out-patient shall be collected in the so-called therapy procurement network which will be published on the *ab-server*. The up-dating of the capacities will be done in short intervals via e-mail or fax. Thus, each person who visits the web-sites of the *ab-server* can inform herself or himself about existing therapy options and capacities in Germany. He or she may as well turn to the consulting team for help in search for treatment offers or in matters of organization. In this way, the network should contribute to shorten referral procedures, while patients are getting the most effective treatment as direct as possible.

Since July 2001 the founding and installation of the online consulting network and the therapy procurement network as well as Internet-based analyses of qualitative aspects in therapies of eating disorders have been supported by the central organization of German health insurances with \$450,000 in a sense of knock-on financing (3 years).

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