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Special Online Consulting for Patients with Eating Disorders and Their Relatives: Analysis of User Characteristics and E-Mail Content

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ABSTRACT

In the treatment of chronic diseases, programs that use the internet as a medium are becoming more and more important as a complement to classical intervention techniques. Since 1998, a non-profit information and online consulting service for patients with eating disorders and their friends and relatives (www.ab-server.de) has existed. This was established by members of the Deutsche Forschungsinitiative Essstörungen e.V. (DFE) [German Research Initiative for Eating Disorders] and members of the Clinic of Psychiatry, University of Leipzig, Germany. For the present study, 2,176 e-mail requests from users of the online consultation service were analyzed qualitatively and quantitatively in order to better understand the differences between different types and groups of users. The analysis was related to the social field of the person requesting the consultation, the type of disorder reported, and the content of the e-mail request. Three main user groups could be identified: people who described themselves as having an eating disorder (57.2%), people who were related socially to the affected person (32.4%), and interested persons (9.8%). The consulting service was predominantly used by persons suffering from bulimia nervosa or their families and friends (63.1%). One third (33.3%) of the posted e-mails were related to behavioral patterns in dealing with the illness and the affected person. They were followed by inquiries for information about the disease (18.7%) and by those seeking help in finding specialized clinics/therapists and places in therapies. The increasing use of the online consulting service indicates that there is a substantial need for information and help in persons with eating disorders and in their relatives, who are able to easily contact professionals using this online service. Online consulting has a high potential for complementary care of affected people.

INTRODUCTION

Eating disorders are a psychological illness with considerable psychological, physical, and social consequences for the affected person.[1] The prognosis for the different forms of eating disorders continues to be unfavorable,[2,3] with success in therapy being shown in only a percentage of cases.[4] One of the most important tasks for consultants/therapists in the field of eating disorders is to motivate the patient to seek professional help.[5] People affected by eating disorders often show a low level of interest in seeking this treatment. This is caused by several factors such as, for example, feelings of shame, the tendency to avoid conflict, and the denial of the seriousness of their disease.[6,7]

Internet-based forms of intervention attempt to deal with these problems. Online consulting can

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help reduce resistance to making contact with professional help, caused by the following advantages of the Internet.[8] (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.[8]

Online consulting can, in this way, supplement and extend the classical (face-to-face) treatment options; however, the demands of the Internet and the specifics of Internet-based communication must be adequately considered.

Related literature cites the following advantages of Internet-based intervention processes; the problem of the affected person is more quickly verbalized[9]; and aided by anonymity and because of the absence of nonverbal prompting online, the process of exchange and information transfer is faster and more direct.[10] The target group of people affected by eating disorders comments that the nonphysical communication ("bodiless communication") is strongly accepted because, in this way, the counterproductive preoccupation with the effect of their own appearance (attractiveness, weight) on their communication partner can be avoided.[11]

The peculiarities of the medium also put high demands on the intervention process as well as the consultant/therapist themselves. For one thing, the absence of nonverbal communication contributes to the fact that the consultant/therapist has access to less information which they can use for the intervention. This, as well as the delayed communication can lead to inadequate intervention. Specifically, the tone or degree of the problem of the affected can be incorrectly estimated or the problem is no longer current at the time of the answer from the consultant/therapist. Online consultation is not enough in the case of crisis intervention or in the case of a user using the online service because they can more easily discontinue the therapeutic intervention. In such a situation a coupling with face to face options should take place.[9]

Initial studies into e-mail and internet based therapies in the field of eating disorders have shown positive results on the attitude towards the eating disorder and a reduction in emotional stress[12–14] as well as the acceptance of continued therapy.[15]

The Information and Online Consulting Service for Patients with Eating Disorders (www.ab-server.de) was the first special server for eating disorders with an anonymous online consulting service in Germany, founded by the author in cooperation with the *Deutsche Forschungsinitiative Eßstörungen e.V. (DFE)* [German Research Initiative for Eating Disorders], the Clinic of Psychiatry, University of Leipzig and the Computer Centre of the University of Leipzig.

The main goal of the online consultation is to provide the person seeking advice an awareness of the problem in terms of the disease. Information about the symptoms, manifestation, form, and therapies of eating disorders are provided in response to corresponding requests. Depending on the case, persons affected with an eating disorder are encouraged to seek further help and/or to undergo treatment. Replies from the consultants contain no diagnoses. Regarding the theoretical basis of the online consultation, an eclectic approach is used. The online consultation is not to be thought of as a long term process. It is normally limited to a single contact with the inquiring person. A first analysis of the content of incoming e-mails was conducted on the basis of 619 cases.[16] The majority of requests (54.1%) were from females affected by an eating disorder. More than half of the requests (59%) were related to bulimic symptoms with 14.9% relating to anorexic symptoms. Ten categories were created for the content of the questions. The most common content types were questions regarding behavioural advice when dealing with the disease (36.3%) and factual issues concerning the disease (23.6%).

The goal of the following analysis should be to make differentiated statements about the user groups of the online consulting service using the 2176 requests that are available. It should (a) check the stability of the first analysis of the user characteristics[16] and, as a result of the higher number of cases, and (b) make differentiated statements regarding requests out of the symptom area of anorexia nervosa and bulimia nervosa. This should be done with the creation of subgroups related to question content in the respective areas.

METHODS

Data collection

Between October 1998 and December 2002, 2,176 e-mails were answered by the *ab-server* consulting team. All of the incoming e-mails were taken into account for the study.

Data analysis

In order to analyze the data, a sample was first made. 100 e-mails were randomly selected and categorized by one person (a psychology student) according to qualitative content.[17] For the sake of reliability, the categorization of these 100 e-mails

TABLE 1. CIRCLE OF INDIVIDUALS (WHOLE SAMPLE, ANOREXIA NERVOSA, BULIMIA NERVOSA)

	Whole sample		*Bulimia nervosa*		*Anorexia nervosa*	
Who asked?	*N*	*%*	*N*	*%*	*N*	*%*
Affected person (female)	1203	55.3	1102	58.1	162	39.8
Affected person (male)	41	1.9	31	1.6	6	1.5
Female friend of affected person	231	10.6	224	11.8	46	11.3
Male friend of affected person	211	9.7	226	11.9	38	9.3
Mother of affected person	89	4.2	59	3.1	31	7.6
Father of affected person	25	1.1	7	0.4	11	2.7
Sister of affected person	53	2.4	42	2.2	19	4.7
Brother of affected person	5	0.2	3	0.2	1	0.2
Other relatives	33	1.5	26	1.4	20	4.9
Acquaintance	46	2.1	38	2.0	22	5.4
Teacher	6	0.3	4	0.2	0	0.0
Schoolmate	7	0.3	4	0.2	2	0.5
Colleague from work	14	0.6	8	0.4	4	1.0
Colleague in the field (psychologist/physician)	19	0.9	7	0.4	8	2.0
Interested person (female)	123	5.7	60	3.2	26	6.4
Interested person (male)	26	1.2	14	0.7	6	1.5
Other	44	2.0	43	2.3	5	1.2
Total	2176	100.0	1898	100.0	407	100.0

was rated by a second person. Inter-reliability of this sample resulted in a Cohen's kappa of 0.84 on average.

Because the data is only available in the form of self-description, its meaningfulness is limited. For example, it can be assumed that statements regarding previous therapy experience are not completely truthful. In addition, a large number of details are missing, for instance, regarding age and area of residence. The eating disorders were categorized very roughly; the exact categorization based on clinical standards was not possible given the available data. The analysis material comes from the available e-mails and was not specifically attained for this study. Out of consideration for the anonymity of the senders of the e-mails, question content has, for the most part, not been presented in detail.

Sixteen categories were used for the analysis of the circle of individuals requesting information (e.g., affected persons, family members, and friends of an affected person; Table 1).

Six categories were used to differentiate between different types of eating disorders: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Adipositas, Eating Disorder in General, and Other Disorders. Because of the impossibility of an exact diagnosis based upon the symptom description, the category headings were placed in quotation marks (e.g., "Bulimia Nervosa").

For the analysis of e-mail content, 12 categories were created (Table 2). Because an e-mail could contain an inquiry to more than one theme, of 2.176 inquiries 2.961 reasons for asking were coded. E-mails were classified according to whether the person asking was seeking professional help (clinics, self-help groups, therapists, types of therapy, and alternative types of therapy) or information on the disease (factual issues, diagnostics, literature, brochures and leaflets, research results). The category "behavioral patterns" summarizes inquiries that were concerned with how to cope with the disease and with the affected person. E-mails with no differentiated wish for help were classed to the category "help in general."

Statistical analysis

The remaining data analysis was conducted using SPSS 10.0 for Windows.

RESULTS

Participants

First, 2,176 e-mails were analyzed with regards to their demographic data. The mean age of inquiring persons was 21.9 years with a range of 11–51 years. Only 834 people gave their current age.

TABLE 2. CONTENT OF E-MAIL INQUIRIES (WHOLE SAMPLE, ANOREXIA NERVOSA BULIMIA NERVOSA)

	Whole sample		*Bulimia nervosa*		*Anorexia nervosa*	
Inquiry concerns ... ?	*N*	%	*N*	%	*N*	%
Behavioral advice	986	33.3	663	34.9	126	31.0
Factual issues on eating disorder	554	18.7	365	19.2	86	21.1
Help in general	330	11.1	214	11.3	35	8.6
Search for therapists/clinics	293	9.9	192	10.1	32	7.9
Questions about types of therapies	186	6.3	135	7.1	25	6.1
Search for self-help groups, organizations, consulting centres	176	6.0	113	6.0	12	2.9
Diagnosis	149	5.0	88	4.6	26	6.4
Mailing information	139	4.7	60	3.2	23	5.7
Search for therapy facilities	53	1.8	20	1.1	20	4.9
Search for alternative treatment options	48	1.6	28	1.5	10	2.5
Search for literature	36	1.2	15	0.8	11	2.7
Mailing research results	11	0.4	5	0.3	1	0.2
Total	2961	100.0	1898	100.0	407	100.0

Nearly two thirds of the inquiring persons gave a surname and more than one third also gave a family name. The majority of e-mails to the consulting team were from Germany (85.5%). Of the inquiring persons, 16.2% had experience with therapy, and 5.5% of them wrote that they are receiving treatment at present.

Form of disease

The requests are not uniformly distributed among the various disorders. By large the greatest percentage of the 2176 requests could be placed in the category "Bulimia Nervosa" (63.1%). Only 12.9% of the requests fall into the category of "Anorexia Nervosa." Another part was related to eating disorders in general (16.2%) and the other questions were distributed over binge eating disorder (4.7%), obesity (1.8%), and other illnesses (0.6%).

Circle of inquiring persons

It was possible to classify three subgroups. These are, firstly, those affected by an eating disorder and, secondly, people socially related to the affected. Females made up the largest percentage of the group of affected persons. More than half of the total requests came from female persons with a self declared eating disorder (55.3%) Of the people related socially to the affected, those turning to the consulting service were mainly friends (female 10.6% and male 9.7%) A third group of inquirers was made up of people interested and colleagues from the field. The largest group among these last two was interested female persons making up 5.7% of the requests. The descriptive results are shown in Table 1.

Additional separate analysis was conducted on both of the groups "Bulimia nervosa" and "Anorexia nervosa." Analyses revealed for both subgroups that most of the e-mails came from female persons suffering from an eating disorder and from female and male friends of an affected person. Nevertheless, differences relating to tendency between the two forms of diseases could be determined. Requests were more often sent to the consulting team by females affected by "Bulimia nervosa" (58.1%) than from those affected by "Anorexia nervosa" (39.8%). Inquiries concerning anorexia-related symptoms often came also from mothers of affected persons as well as from friends and interested female persons.

Content of inquiries

While analyzing the 2961 "reasons for sending an e-mail request," it was possible to identify four categories which depict the most common problem areas in the e-mails sent to the consultant team.

A large percentage of the questions were concerned with behaviour patterns in coping with the illness or the affected person (33.3%). Further

e-mails were related to factual issues on the disease (18.7%), to questions about help in general (11.1%), and to requests for support in search of a therapist or a clinic (9.9%). Content of inquiries with related frequencies is represented in detail in Table 2.

Additionally, separate analysis was conducted on the question content in both of the groups "Bulimia nervosa" and "Anorexia nervosa." Inquiries of bulimia-related symptoms were mainly concerned with requests for behavior patterns, with the search for general help and addresses of therapists, for clinics or special advisory centers. Inquiries of anorexia-related symptoms were mainly concerned with factual issues regarding the disease, with requests for mailing information and literature as well as with questions focusing on a diagnosis by the consulting team. A classification of content of inquiries according to bulimia-related symptoms and anorexia-related symptoms is represented in Table 2.

DISCUSSION

Comparison with the first analysis

The analysis of the data generally shows that the online consulting service was widely accepted. The online consultation is used, for the most part, by people in their youth and by young adults.

Almost two thirds of the requests could be placed into the category of bulimic symptoms (63.1%) A considerably smaller percentage can be assigned to the area anorexia nervosa (12.9%). This confirms the results of the first analysis,[16] in which the relations of the two symptom categories were similar (63% and 4.4% of requests). This imbalance reflects the distribution of these disturbances but, at the same time, shows that there exists a need for consultation for both the bulimic as well as the anorectic fields.

As expected, the main percentage of users was the affected persons themselves. Mainly female affected persons used the consulting service which is in accordance with the typical distribution of eating disorders among the sexes.[19,20]

The main percentage of inquiring persons was made up of females affected with bulimic disorders (57.4% of the affected). Also here the result of the first study (54.1%) had only to be minimally adjusted. One possible explanation is the higher mental trauma and the more common awareness of the disease among bulimic patients in comparison to anorexic patients.[7]

A large number of questions were asked by people from the social circle of the affected persons. This supports the hypothesis that a considerable emotional pressure weighs on the family and friends of the affected—especially on peers, who play such an important role in the younger age groups. It is possible that online consultation represents an adequate and accepted consultation option for this subgroup.

Bulimia nervosa versus anorexia nervosa

For the categories "Bulimia Nervosa" and "Anorexia Nervosa," investigations were made into which groups of people in the categories made the most inquiries and which differences could be determined regarding the contents of the inquiries from the two different eating disorders. People affected by "Bulimia Nervosa" tended to be looking for professional help. They requested information about therapy options and treatment centers more commonly. They also often asked about actions that would make dealing with the disorder easier. A desire to change, which brought them to actively seek help, was representative for this group. For example:

> Dear consultation team, My name is A. and I'm 29 years old. I have had bulimia for 10 years. I did a 15-week cure in 1999. My time in this clinic did me a lot of good and I was able to live for a year without any symptoms until I broke up with my last boyfriend. Now, I'm back where I was 3 years ago. I'm totally desperate and don't know how I can get a grip on myself. Three or 4 times a week I have attacks where I binge eat and then throw it all back up. . . . Please help me. I want to be able to eat normally again and lead a normal life. How can I do this? I know I can do it. I just haven't been able to figure out how.

The ab-server consulting service received fewer requests from affected people in the category "Anorexia Nervosa." Requests in this category regarded, next to, behavior in dealing with the disease, often factual questions about the disorder, requests for Informational materials and brochures, and they contained the request for a diagnosis. Many of the requests are looking for reassurance that the described symptoms don't contain any critical relevance. For example:

> Hello. I'm 15 and I have a question. How do I tell if I'm anorexic. I took a test once and it told me that I am anorexic. It had questions like "do you think about your weight every time you eat something and that it could make you gain weight.?" With me it's so, I think about how many calories it has. Is that bad? My mother says that I eat way too little

> anyway. I feel too fat, though and want to lose more weight. In the last two months I've gone from 73 k to 60 kg which for someone who's 1.66 meters is still quite a bit, isn't it . . . ?

An explanation for the different frequencies in question content between both categories can be found in clinical experiences and the results of intervention research in the field of eating disorders. According to this, critical reflection over the condition of ones body in cases of Anorexia Nervosa is commonly only after years of psychotherapy. The mental trauma of most anorexics is less pronounced than in other types of disorders.[6]

The consideration of the available results leads one to believe that there exists a considerable need for factual and treatment-related information among people affected by an eating disorder and among those socially associated with them. Online consulting can be useful as an option which contains fewer factors that inhibit the person seeking the information.

It has already been documented elsewhere that online intervention in its many forms is readily accepted and seen as a valuable addition by many who are strongly affected.[9,11] Online intervention can raise, among the affected, the acceptance of the need to seek additional therapy.[15] In this way, it is not an alternative method but rather a complementary which helps to enrich classical intervention measures. This makes sense especially in the field of eating disorders because there are still many gaps in the caring for of this patient group. The linking of classical in- and out-patient interventions with innovative methods including new mediums—be it the motivation to start a secondary therapy or as a follow up to an inpatient therapy—has already shown encouraging results.[21,22] Online consultation—with its low number of inhibiting factors—has, for example, in the making of first contact, the potential to contribute to the better care of these patients in the health care system. As a result, the possible consequences which come about as a result of responses to e-mail requests should be evaluated in a detailed manner in future examinations of the online consultation of the ab-server.

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