

Online Discussion Groups for Bulimia Nervosa: An Inductive Approach to Internet-Based Communication between Patients

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ABSTRACT

Objective: Online discussion forums are often used by people with eating disorders.

Method: This study analyses 2,072 threads containing a total of 14,903 postings from an unmoderated German "pro-recovery" forum for persons suffering from bulimia nervosa (www.ab-server.de) during the period from October 2004 to May 2006. The threads were inductively analyzed for underlying structural types, and the various types found were then analyzed for differences in temporal and quantitative parameters.

Results: Communication in the online discussion forum occurred in three types of thread: (1) problem-oriented threads (78.8% of threads), (2) communication-

oriented threads (15.3% of threads), and (3) metacommunication threads (2.6% of threads). Metacommunication threads contained significantly more postings than problem-oriented and communication-oriented threads, and they were viewed significantly more often. Moreover, there are temporal differences between the structural types.

Conclusion: Topics relating to active management of the disorder receive great attention in prorecovery forums. © 2008 by Wiley Periodicals, Inc.

Keywords: eating disorder; bulimia nervosa; internet; online discussion forum

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Introduction

Eating disorders are chronic illnesses with unfavorable long-term outcomes.^{1,2} The classic interventions for people with eating disorders include self-help groups and group treatments.³ A review by Myers et al.⁴ counted nine controlled studies on the efficacy of self-help groups for eating disorder sufferers, in which only positive effects were demonstrated. The Internet offers a specific form of health-related services. The technology of the Internet permits both autonomous exchange between affected persons and moderator-led group discussions; here communication can take place in synchronous (chat) or asynchronous form (e.g., discussion forums, newsgroups).⁵ Among the frequently mentioned advantages of health-related

online services are the opportunities to make contact regardless of the place and time, which especially helps the integration of socially isolated, chronically sick patients into the community.^{6,7} Writing down their thoughts helps patients distance themselves from destructive or aggressive impulses.⁸ The anonymity of the Internet eases the search for psychological help, especially for persons with eating disorders who are often afraid or ashamed to speak openly about their illness.^{9–11} Another advantage of Internet communication is its public character. The written contributions are freely available on the Internet, which means that they are also available to people who cannot or do not want to actively take part in the discussion: so-called lurkers.¹²

Winzelberg examined 306 postings of an asynchronous online support group for persons with eating disorders over a period of 3 months.¹³ In his content analysis, the author evaluated seven categories of direct and indirect support between the users. He came to the conclusion that the mechanisms of online self-help are similar to those of real-life self-help groups. Online forums for persons with eating disorders can be divided into sites that are oriented "prorecovery" or "prodisorder" ("pro-ana", "pro-mia"). Prodisorder-oriented websites promulgate eating disorders as a lifestyle and

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allow the description of illness-promoting behavior and advice (e.g., purging, dieting). An US-American survey of underage patients found that 51.0% of those surveyed had regularly visited prorecovery websites, 35.5% had visited prodisorder websites and 25.0% had visited both.¹⁴ The potential harm of those websites cannot as yet be estimated.¹⁵ When comparing the ways in which users of proanorexia and prorecovery sites portray themselves, it was possible to observe considerable differences.¹⁶ Prorecovery users, for example, verbalize positive emotions as well as cognitive phrases that suggest reflection on the illness (“know”, “cause”) significantly more frequently. The analysis of a Finnish prorecovery Internet forum concluded that the users found the forum helpful, especially during the early stages of change.¹⁷ One of the dangers of support groups for eating disorders—even if they are prorecovery oriented—is the mutual comparison of appearance and weight. While the disembodied nature of Internet-based communication makes direct comparison between sufferers impossible, the same effect can be achieved by publishing body weight, eating schedules, photos, and videos on the Internet.¹⁸ Johnson et al. compared three Norwegian Internet forums about different types of disorders (psychiatric disorders in general, weight and eating disorders, sexual abuse).¹⁹ The postings in those forums were divided into four categories (constructive/positive, neutral, negative, destructive). Particularly in the forum for eating disorders, the authors found a large number of destructive postings. Underlying aspects of content and structure as well as the temporal aspects of the communication of eating disorder sufferers in online discussion forums have until now remained largely unexplored. This primarily inductive examination aims to identify the fundamental structures of such discussion forums, and this will then form the basis of application-related questions—for example, the benefits of such services.

The aim of this pilot study was to carry out

- a. a *structural* analysis of the communication threads in an online discussion forum for people suffering from bulimia (Question: What are the aims of communication and how does it take place within the forum?) and
- b. a *quantitative comparison* of structural types with regard to their main characteristics, such as the length of communication units, the number of users, and temporal criteria.

Method

The data used consisted of postings in an open, unmoderated, asynchronous online discussion forum for persons affected by bulimia, maintained by the Information and Support Server of the Deutsche Forschungsinitiative Eßstörungen e.V. (German Research Initiative into Eating Disorders; <http://www.ab-server.de>). Fourteen thousand nine hundred and three postings in a total of 2,072 discussion units (“threads”) during the period from October 2004 to May 2006 were examined. This time period was randomly selected from a total time period of forum use from January 2000 to April 2007. The method chosen to access the data was the inductive approach of *grounded theory*.²⁰ The data relevant to the analysis was collected, coded, and categorized with regard to its structure and content. The criteria for the categorization were not set prior to the analysis, but rather developed from the data. Threads, i.e., self-contained discussion units, were chosen as the basis for the analysis.

1. These threads were analyzed with regard to the objective in creating the thread and how the discussion developed with regard to that objective. The approach used here was that of theoretical sampling. First, individual threads that were very different from one another in terms of characteristics, such as the number of postings, time of day, title, etc., were compared with one another and hypotheses were put forward regarding the reasons for these differences. For the purposes of this comparison, other threads continued to be included in the study successively, until the hypotheses regarding the underlying characteristics had been established (“theoretical saturation”). Only during the second stage were all the threads within the analysis period coded using the categories (types) identified from the data itself. In order to assess the reliability of this categorization, 100 randomly chosen threads were cross-rated by a second person (A.G.). This selection yielded an average Cohen’s κ of 0.768 as a measure of inter-rater reliability.
2. These structural types were then quantified with regard to temporal (month, day, time of day of thread creation) and user-related (number of users) parameters. The structural types identified were analyzed statistically for differences in those attributes, using SPSS 14.0 for Windows. With interval-scaled data (concerning the variables relating to number of users, number of postings and number of hits), the differences between thread types were analyzed using one-way ANOVA. With data that were ordinal-scaled (time of day, month of thread

creation), the differences were analyzed using χ^2 tests.

Results

Structural Analysis of the Threads

Following the analysis of the threads with regard to structural criteria, five types of discussion units were distinguished:

- a. Problem-oriented threads (PRO-T)
- b. Communication-oriented threads (COM-T)
- c. Threads for metacommunication (ME-T)
- d. Mixed (MIX-T)
- e. Other.

In Problem-Oriented Threads. (PRO-T), communication between users is initiated by a central question or problem that is introduced by a user at the start.

The initial question or problem at the beginning of the thread is introduced after the “problem carrier” has greeted the other forum members. Often—particularly where new forum members are concerned—the problem carrier also discloses personal details, such as their age, the type and duration of their eating disorder, their location or such like. The problem carrier tries to stress their personal dismay or describe their current mood in order to encourage the other forum members to react. Usually they express thanks for replies in advance and leave. Typically, one or more users react to the initial question from the problem carrier, whereby the content and structure of the discussion are determined by whether or not the question or problem is accepted by the other users. If the question is accepted, the users describe their own experiences with the problem, share information about this particular problem and give emotional support or request details of the problem. After one or more replies, the problem carrier reacts with thanks, stating whether they have found the replies useful or reacting to inquiries/asking further questions of their own. In this way, a conversation about the problem unfolds.

Example:

Thread no.: 57014005

Title: Having bulimia and being a mum

Anne: Hi everyone, you don't know me because I've not registered and I don't contribute to the forum or anything. I just sit here quietly reading

all the posts and I've been doing this for some time—about 8 months. So why am writing this? Well, I don't know exactly why either, because only I can help myself, but I'm hoping to get an opinion from someone who is perhaps in a similar situation. Mmm, well perhaps I also just want to get something off my chest. I'm 24 years old and I've got a 5-year-old daughter. I suffer from bulimia. [...] I want to be able to be there for my child, play with her, be a good mother and comfort her for the fact that her daddy has left us, but this blasted bulimia takes over my life, of course there are good days too but the situation overall is not what it should be for a child so that it can develop properly. I've been wondering: should I go into hospital now while I'm unemployed BUT can my child manage for so long without her mummy? She would live with her grandparents who love her, but how can I explain all this to my baby? [...] Sorry if I sound confused. Love Anne.

Cindy: Hi Anne!

I don't think you sound confused, more like you're being honest.

I can understand you only too well. Bulimia has taken over my life completely too, not only physically. I always used to be going out but now i sit here at home without any friends any more, I can't concentrate on filling in my application forms, I'm ocd about tidiness if I don't throw up and its shit, and i found the worst thing was that i couldn't resist. It was like my hands were simply pushing the food into my mouth. Always keeping up appearances to the outside world (well, yes, unfortunately—or rather luckily—couldn't hide my skin-and-bone figure or rather a good thing)! Your kid is a reason to fight. I had nothing, broke up with my boyfriend, just sat at home and this constant lying. Do go to the advice center cos if you fight against it now it will also be easier for your daughter, when she's older she will understand and won't be upset by it any more. It sound like your parents will stand by you, the worst thing is always just how misunderstood you feel. Have a hug from me. Where there's a will there's a way. Even if it takes a while to find the way. (Extract; names have been changed).

If the problem or question is not accepted by the other forum members (e.g., because it is thought to be prodisorder), in their replies they react with open criticism, concern, or information on the problem.

Example:

Thread no: 57008101

Title: Website with tips on throwing up! ~> Pro-ana.

Manuela: Could anyone here give me the name of a PRO-anorexia website? One with tips on throwing up and so on? Thanks, Manuela.

Diggy: hey, why do you want that? and you're in the wrong place here, this is an anti forum, people here want to be helped. What do you want to achieve by vomiting?

Bonita: sorry but I don't think anyone here will give you tips on throwing up ... and that's how it should be...

(Extract; names have been changed).

Problem-oriented threads form the majority of the threads examined, making up 78.8% of the 2,072 threads that were examined. Because of the large proportion of PRO-Ts, a second categorization of $n = 383$ randomly selected PRO-Ts was carried out within the analysis period, oriented more strongly toward the opening question. Of these, the categories with the highest proportions are given here as examples. A total of 44 postings (11.5%) included a question on patterns of behavior against the eating disorder; another 44 asked about quantities of food, calories, or weight, 43 (11.2%) described the emotions that people were feeling at that moment, and 30 (7.8%) asked for information on therapists, interventions, clinics or self-help groups. Thus, a large number of the queries can be put down to problem-oriented or emotional coping. Other questions show a stronger reference to eating disorders by the way they refer to quantities of food eaten and weight.

In Communication-Oriented Threads. (COM-T), it is not the factual problems that are the focus of the communication, but the conversation itself and the discussion about private or everyday topics. Structurally heterogenic, informally oriented threads fall into this category. Users who want to communicate with a particular person frequently write the user's name in the header (for example, "@minchen"). These threads were of an extremely private character, regularly referring to information that was not known to outsiders. There was frequent use of Internet-typical expressions using emoticons and smileys. Also typical of those threads was the arrangement of later face-to-face meetings, telephone calls, or Internet chats.

Example:

Thread no.: 57046822

Title: painting??

Lotta: Hello can any of you draw/paint?? I can't! I'd really love to sit down and paint something, only then I would only do a few little lines and flowers because I simply don't know how. It's not fair when you're not creative. So what do you paint?

Queen: hi there... well I draw whatever I feel like at the time! My fave is an underwater world... sometimes I paint something bright and jazzy or sometimes I just use pencil... i've already won something in a European art competition =).

(Extract; names have been changed).

COM-Ts were rarer than PRO-Ts, comprising only 15.3% of threads examined.

Threads for Metacommunication. (ME-T) were those in which the users took the forum and the forum communication itself as the topic. Three principal topics/aims of these threads were identified:

- General appeals to all forum members and encouragement to fight the illness.
- Dealing with prodisorder postings or other postings that provoked users.
- Discussion of the methods of communication between members.

ME-Ts were characterized by the verbalization of ideas for coping strategies, the effectiveness of these, and subjective theories relating to illness and health. In ME-Ts the users negotiated their self-images.

Example:

Thread no.: 57001136

Title: triggering - what does it mean?

Arielle: sorry, but the word trigger keeps cropping up and somehow I have absolutely no idea what this means, or rather, I haven't sussed out what it means here, can someone help me? that is, explain the word to me? TIA! XXX.

Southmouth: Hello, I'd be happy to do that. Triggering means giving something a boost or reinforcing something. [...] So here it means that as a result of what people write here, something can be set off or reinforced in other people. So if someone writes that I am this tall and

I weigh this much, it can cause someone else to go into or reinforce a hunger phase, because that person is the same height but weighs more and wants to change this as quickly as possible. In terms of content there are several other ways of triggering people, e.g. eating plans and such-like. Best wishes, R.

Constance: Triggering doesn't always have to be negative! But here in this forum everything is made negative or explained one-sidedly... triggering can also bring out positive feelings in people! (Extract; names have been changed).

2.6% of all threads analyzed were included in this type.

Mixed. There were also *mixed forms* of communication, for example in a primarily problem-oriented thread, when two acquaintances met and exchanged messages privately. Mixed forms accounted for 1.8% of the threads examined.

Other. The remaining 1.3% of threads could not be assigned to any of these categories. Mostly these were inquiries from outsiders, such as postgraduates or researchers about recruiting subjects for certain studies.

Comparison of Structural Types

The three most important types of thread were analyzed with regard to times and user-related attributes and compared in order to look for differences in these attributes. **Table 1** shows the results of this analysis.

Number of Postings. On average, 6.8 postings were made in each thread, with numbers ranging from 1 to 211. Threads with a high number of postings were rarer: 75% of threads contained just 8 postings or less. However, there are also several singular threads that have significantly above-average numbers of postings. To illustrate this point, the titles and characteristics of the five threads with the most postings are listed in **Table 2**.

The three structural types differ only marginally in the number of postings of each per thread. In PRO-Ts, an average of 6.8 postings was made; COM-Ts had an average of 6.7 postings, and ME-Ts contained an average of 7.4 postings. The results of the variance analysis did not show any significant differences between the structural types ($F[2,2004] = 0.234; p = .792$).

Number of Users. In the threads that were analyzed, postings were made by an average of four

TABLE 1. Results of the comparison of the three structural types for user-related variables

	N	M	SD	F	p
Number of postings per thread					
PRO-T	1,636	6.8	6.4		
COM-T	317	6.7	10.3		
ME-T	54	7.4	7.8		
Total	2,077	7.1	9.5	.234	.792
Number of users per thread					
PRO-T	1,636	3.9	2.8		
COM-T	317	2.5	2.4		
ME-T	54	4.5	3.2		
Total	2,077	3.8	2.8	39.3	.001
Number of hits/views					
PRO-T	1,636	207	157.7		
COM-T	317	121	189.6		
ME-T	54	231	239.3		
Total	2,077	201	206.1	37.1	.001

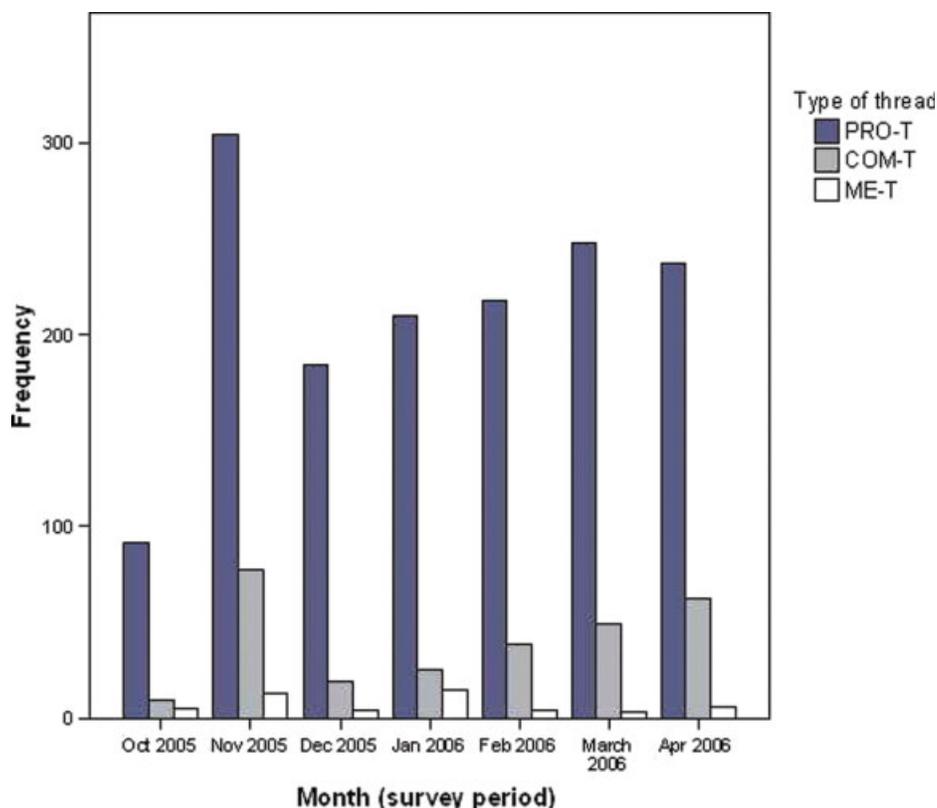
users, the numbers ranging from 1 to 44. Threads that had a large number of users communicating with one another were less common: 75% of threads contained postings from five or fewer users. In ME-Ts, more users were involved: an average of five users posted here, while in PRO-Ts an average of four users and in COM-Ts an average of three users made postings. These differences in numbers of users were highly significant ($F[2,2004] = 39.3; p = .001$).

Number of Hits. In addition, an investigation was carried out into the frequency with which the threads were viewed on the Internet from the time of their creation until the start of this analysis (May 2006). On average, each thread was opened 202 times, the totals ranging from 2 to 4,105. The standard deviation was 206, i.e. there was a high margin of deviation in interest in the topics. COM-Ts were viewed less often; on average, 121 viewings were registered here. PRO-Ts were viewed 207 times on average, while ME-Ts attracted far more interest: here the average number of hits was 230. These are significant differences ($F[2,2004] = 37.1; p = .001$).

Month of Thread Creation. The threads were analyzed on the basis of the month in which they were created. Only those months were evaluated where all postings resulting from that time period had already been coded (survey period: October 2005 to April 2006). This revealed distinct seasonal trends. By far, the greater number of threads was created in November (19.7% of threads), followed by April (15.1%), March (14.7%), February (13.3%), and January (12.4%). The lowest numbers of new threads were registered in December (10.4%) and October (5.7%). In addition, the structural types of the threads were analyzed in respect of whether the

TABLE 2. Characteristics of the five most-frequented threads

Thread No.	Title	Number of Postings	Thread Type	Number of Users	No. of Viewings
57005554	Next day	211	4	5	4,105
57001837	@isabela!!!	122	2	2	1,483
57027515	I hate myself. . .	102	4	8	809
57027235	I want to see some photos, pretty please!	89	2	13	2,567
57026969	I'm worried about my dad	66	1	17	915

FIGURE 1. Frequency of thread creations per month. [Color figure can be viewed in the online issue, which is available at www.interscience.wiley.com.]

creation of a new thread was dependent on these temporal influences. A χ^2 test showed significant differences between the three principal thread types ($\chi^2 = 2148.3$; $p = .001$). **Figure 1** illustrates the frequency of thread creations per month, divided into the three structural types.

Especially in November there was a surge in thread creations of all three types. They made up 18.6% of problem-oriented threads, 24.3% of communication-oriented threads, and 24.1% of threads for metacommunication.

Also, offsets were registered in the ratio between the types in certain months, for example in January. In that month, 27.8% of threads for metacommunication were created, but only 12.8% of all problem-

oriented threads and 7.9% of communication-oriented threads.

Time of Day. An analysis of the time of day showed that new threads were created mostly at night between 11.00 pm and 4.59 am (43.3%). More than one-third (35.9%) of thread creations occurred during the afternoon/evening between 5.00 pm and 10.59 pm; they were less frequent during the day between 11.00 am and 4.59 pm (11.5%) or in the morning between 5.00 am and 10.59 am (9.2%).

Comparing the structural types, significant differences were found in the time of day at which a thread was created ($\chi^2 = 713.6$; $p = .001$). COM-Ts were also created in greater numbers in the morn-

ing (11.4%) or during the day (14.2%). Thus, the threads of this type are somewhat more evenly distributed than the other types. However, more than half of the threads for metacommunication (51.9%) were created at night, and only 9.3% in the morning and 7.4% during the day.

Conclusion

The results of the analysis show that the people who are affected visit the forum with different objectives and that the content of their communication varies accordingly.

PRO-T dominated in the forum analyzed, comprising 78.8% of all threads during the time period studied (October 2004 to May 2006). The forum was thus used mainly for dealing with illness-related or personal problems, which leads to the conclusion that the online discussion forum serves a similar purpose to a face-to-face self-help group.¹³ PRO-Ts were created primarily at night between 11.00 pm and 4.59 am (43.3%) or in the evening between 5.00 pm and 10.59 pm (36.8%).

The forum was thus used mainly at a time of day when "classic" support and self-help structures are not available to the affected persons.¹³ The high level of night-time activity among forum users can also be interpreted from the point of view of disturbed sleeping/waking activities. The connection between certain forms of eating disorders and sleep disorders has been well documented.²⁴ Other systematic studies in this field could incorporate the Internet usage by the affected persons as a medium for nocturnal eating-disorder related thinking, rumination, or coping activities. The issue of the topics shared by the users in the forum as well as the issue of which questions are discussed in consensus and which are discussed confrontationally still have to be explored. 15.3% of threads were COM-Ts. On average, COM-Ts had fewer users (2.5) participating than PRO-Ts, and with an average of 121 hits, they were viewed significantly less frequently. A small but significant part of forum communication is thus utilized by the affected persons for private, leisure-related exchanges and the establishment of informal contacts. COM-Ts are more equally distributed throughout the day, which might result from the fact that these users are mainly of a group that has fewer obligations during the day. COM-Ts appear to meet the need of these users for social contact. Other patient groups—persons affected by schizophrenia, for example—also use online discussion forums to establish social

contact, e.g. to counter isolation.^{6,7} Eating disorders are psychological disorders that combine feelings of shame and guilt with a high amount of social isolation.⁵

There is evidence that contacts in COM-Ts can also lead to offline meetings. It would appear that persons affected with eating disorders may also be using the anonymous online communication that is so important to them as a means of establishing personal contacts.^{10,11} ME-Ts made up 2.6% of all threads in the online discussion forum. ME-Ts serve to broach the issue of forum communication, e.g., in the case of technical problems or communication disturbances, where aspects of subjective concepts of illness were also often communicated. While ME-Ts took up a comparably small amount of space (2.6% of all threads), they were used and read by significantly more users (4.5 users on average) than the other thread types. This might be an indication that the topics discussed in these threads are of particular interest to people with eating disorders. The principal structural types of the threads differ not only according to the users' objectives with regard to the communication but also according to the audience being targeted, as highlighted by the differences in user numbers ("one-to-many", "one-to-one", and "many-to-many").²¹ PRO-Ts thus correspond to one-to-many communication, as here a single user (the problem carrier) addresses a large group of users in order to receive support or advice.

COM-Ts correspond to one-to-one communication, because here a more private form of communication takes place, with specific users being addressed. ME-Ts correspond more closely to many-to-many communication, as here the users discuss a problem among themselves and there is no "problem carrier" to whom the replies are addressed; instead, all users are addressed equally. A specific feature of the Internet lies in the fact that communication can take place at practically any time; thus the temporal structure of the communication is defined by individual preferences and schedules as well as possibly by agreement.²² In the case of a health-related forum such as the bulimia forum examined here, seasonal mood crises are potentially responsible for the increased communication.²³ It was not possible to carry out an analysis of the content of postings at this stage. The typing carried out in this study can only be a first step toward a wider-reaching analysis of forum communication. The use of the inductive approach has proved to be an adequate means of generating further research questions and hypotheses.²⁰ Where PRO-Ts are concerned, the following questions

have been raised for future studies: what problems are discussed by the users, whether the support received online was perceived to be helpful, and whether given information about eating disorders was factual or wrong. COM-Ts might constitute a transition to other means of communication, e.g., chat or offline contacts. It is still unclear under what conditions the users give up their anonymity in part or in full so that they can carry over their social contacts from the Internet to real life. In ME-Ts, discussions take place about illness and communication-related topics, e.g., how to deal with pro-disorder postings. The subjective views of the affected persons on their illness, how they deal with it, the resources and risks can be further analyzed in these threads, and perhaps that will provide new approaches for therapeutic intervention. One of the weaknesses of this method of analysis is without doubt the categorization by only two raters. Furthermore, qualitative inaccuracies may have occurred during classification, which subsequently will also have affected the quantitative parameters. Additional rating will thus be necessary in future.

The results show that the Internet offers persons affected with eating disorders a means of forming groups, communicating and processing their illness. The online discussion forum is used by the affected persons as a medium for and a way of supporting illness- and health-related communication, which is evidenced by the high absolute numbers of postings and viewings of problem-oriented and metacommunication threads. Thus this medium must not only be regarded as a risk,^{6,12} but must also be valued as an additional resource for patients.

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