

# Social support in a wired world

## Use of online mental health forums in Norway

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This study explored the use of the four major Norwegian mental-health-related online discussion forums; who participate, why, and what implications use may have. The objective was to provide a basis for proposing relevant research questions and issues for public policy attention. A total of 492 responses to a web-based questionnaire were received. The respondents, predominantly women (78%) in the age range 18–35 years, found forum participation useful for information, and social contact and support. A majority (75%) found it easier to discuss personal problems online than face-to-face, and almost half say they discuss problems online that they do not discuss face-to-face. A majority would not have participated had they not had the option of using a pseudonym. Respondents perceive discussion groups as a supplement rather than a replacement of traditional mental health services, reporting no change in the amount or type of service used. A clear majority want professionals to take an active role in these types of forum. Comments from respondents indicate that forums may have an empowering effect. We believe that online interaction can have unique benefits for people suffering from mental disorders. Professionals will need new knowledge and perceptions of their roles, and public authorities will have to decide their role in influencing the quality of services offered, and the social values conveyed, to those who seek help through the Internet.

• *Discussion forums, Internet, Mental health, Social support, Telehealth.*

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People with mental health problems are discovering the Internet, where they find a wide range of applications and services, including information sites, diagnostic tools, counselling and therapeutic services (1). Among the services available are online support groups. These are arenas (web-based discussion forums, bulletin-boards, email lists, newsgroups) where people congregate to discuss common problems and exchange mutual support. Today there are thousands of online support groups for all kinds of health problems, many of which specifically address mental health issues (2).

Online support groups have varying degrees of professional facilitation, structure and ideology. Despite these differences, their emergence and character appear to reflect the needs and purposes common to the self-help movement, e.g. empowerment, peer support and experiential knowledge (3–5). They may also be examples of the combined potentials of self-help and the unique characteristics of online communication, e.g. access through transcendence of time and space and anonymity (6, 7).

The majority of online groups use English and originate in the US. In small countries like Norway, similar services are now growing in number. Norway, with its traditionally strong public health and welfare system, lacks the self-help traditions embedded in Anglo-American culture dominating online support groups today. While few Norwegian discussion forums use the term self-help or mutual support to describe themselves, we believe that they share the characteristics of online support groups mentioned above. At the same time, Norwegians are among the most active Internet users in the world, with about 70% of the population between 13 and 40 having used the Internet in the past month (8).

This study explores the use of the four major Norwegian mental-health-related online support groups; who participate, why, and what implications use may have. Our objective is to expose a phenomenon many in the mental health community are unaware of, as well as provide a basis for proposing relevant research questions and issues for public policy attention.

## Material and Methods

The two major health-related websites in Norway were selected for the study, both containing mental-health-related discussion forums. At the time of the study, Doktor Online (<http://www.doktoronline.no>) was the largest health-related Internet site in Norway and hosts many discussion forums, three of which were selected for study: “general psychiatry”, “sexual abuse” and “eating disorders”. The other site – SOL Helse ([http://www.sol.no/helse\\_og\\_samliv](http://www.sol.no/helse_og_samliv)) – hosted “anxiety and depression”, which was the only mental health forum on the site at the time of the study.

While the forums are primarily meeting places for peers, where anyone can read and write messages – or postings – professionals monitor the activity and are available for answering a limited number of questions from participants. Professionals also have the right to delete postings which are not in accordance with the guidelines for use explicitly stated at the site. The degree of professional activity varies considerably between the forums. The forum with least professional involvement was “anxiety and depression”, which primarily was supervised by an experienced user from a self-help organization, although professionals were on call.

### Instrument and procedure

A web-based questionnaire, covering issues related to who, why and implications for use, was available to all forum participants during a 3-week period beginning 24 November 1999. It was accessed through a link on the start page of the forums. An introductory statement informed users that this was a study of online mental health services in Norway, that relatively little was known about how users experienced such services and that the results could be of importance for designing such services in the future. Also, they were told that the questionnaire would take 15–20 min to complete, that their anonymity would be ensured and that the results of the study would be made available online. The questionnaire was partly interactive, posing follow-up questions based on responses. Thus, the number of questions posed varied depending upon the answers given. The typical respondent answered between 50 and 60 of a total of 80 items.

A number of the items in the questionnaire included open fields inviting free-text responses. Three of the open-ended questions – topics discussed in the discussion groups, the usefulness of discussion groups, and changes in health care use – were analysed by the authors in order to identify recurring themes along the guidelines used in Salem et al. (9). Rather than presenting an objective analysis, these free-text responses were used to illustrate some major issues conveyed by respondents and exemplify these with quotes. The results of this analysis are presented in conjunction with the quantitative responses.

One month prior to the questionnaire being posted, users were informed that individual posts to the forums would be stored for study. For the purpose of the present study, these postings were used as an aid in estimating the population size and in validating some of the responses to the questionnaire. Further analysis of the postings will be published elsewhere.

### Representativity and population size

This study sought responses from low-threshold services where users primarily use nicknames to protect their true identities. Two alternative approaches were considered: 1) We could seek to identify forum participants and make a representative selection, or 2) post an open survey on the web where respondents selected themselves. Choosing the first alternative could mean that those anxious about revealing their true name would be less likely to respond, affecting the reliability of the results. Given the explorative aim of the survey, and our need for responses from the widest possible range of users, we chose the second alternative.

The total survey population is defined as those who visited the forum during the period the survey was conducted. Since the same person can access the sites from different computers, and the same computer can be used by several persons, there is no way of exactly measuring population size. In the sub-population of those that actually posted messages to the forum, this can be measured more accurately. In the 4268 messages posted to the forum, we found 841 unique nicknames. Since 286 of the respondents claimed to have posted to the forum in this period, this indicates a response rate of 34% for this sub-population. A comparison of posting frequency and response rate shows that the response rate is significantly higher for the active posters (39%) than for those that have posted only once (10%). This method cannot be used to calculate the response rate for the total population including those that have visited the forum, but never posted. However, since the material shows a strong correlation between number of posts and the number of visits, it is reasonable to assume that the response rate for the total population is in the lower part of this range (i.e. closer to 10% than 39%).

## Results

A total of 505 completed questionnaires were received. Of these, 13 were deleted from the material for the following reasons: duplicate responses ( $n = 8$ ), incomplete questionnaires with less than 75% of questions completed ( $n = 4$ ), and responses clearly not intending to answer the questionnaire ( $n = 1$ ). The analysed sample therefore consisted of 492 responses.

Women represented 78% of the total number of responses, though with varying gender distributions across the various forums, as shown in Tables 1–3.

Table 1. Percentage of women in the forums

Forum	Women (%)
Eating disorders	92
Abuse	89
Psychiatry	81
Anxiety and depression	65
Total (n = 492)	78

Table 2. How many times did you visit/post to the forum in the past 30 days?

	Visits (%)	Posts (%)
0 times	N/A*	41.8
1 time	36.9	9.6
2-9 times	27.3	32.3
10 or more	35.4	15.4
Not answered	0.4	0.8
Total (n = 492)	100	100

\* Since the questionnaire was posted in the forum, they had to access the forum at least once.

Table 3. How important is it that you don't have to use your real name on the service?

	"I would not use the service if I had to use my real name"	
1	Very important	64%
2		19%
3		10%
4		4%
5	Totally unimportant	2%
	"I would have used the service just as frequently if I had to state my name."	

The majority of the respondents (62%,  $n = 308$ ) were in the age range 19 to 34 years, 16% were 18 or younger and 20% were 35 or older. The age group 55 years and above comprises less than 2% of the total number of responses. The age distribution follows this pattern in all forums, although the under 18 group is significantly larger in the forum "eating disorders" (37%).

### Use of services

Thirty-five percent of the respondents visited the services more than 10 times during the previous 30 days. A total of 42% did not post any messages to the forum in this period. As mentioned in the Methods above, the low-frequency users are probably underrepresented in our material.

### Users of health services

Sixty-five percent said they had been in contact with health care services due to mental health problems. For low-frequency users of the online service (i.e. those that

used the forum only once in the previous 30 days), this percentage was 53. A relatively higher proportion of users of the "Anxiety and depression" forum reported having used traditional health care services (83%,  $n = 55$ ) than users of the other forums.

### Role of online services relative to traditional services

Among those having used traditional mental health care services ( $n = 317$ ), 62% ( $n = 195$ ) perceived the forums primarily as a supplement to traditional services. Seventeen percent ( $n = 54$ ) said it was both a supplement and a replacement. Only 4% ( $n = 13$ ) perceived the forums as exclusively a replacement of traditional health services, while the remaining 16% ( $n = 53$ ) were undecided.

Fifty-three percent ( $n = 165$ ) reported that the use of online forums had no effect on their use of traditional health services. Six percent ( $n = 18$ ) reported reduced use of traditional services, while 6% ( $n = 19$ ) reported increased use as a consequence of participating in the online forums. Nineteen percent ( $n = 60$ ) did not know whether this had effected their use of traditional health services. Seventeen percent ( $n = 52$ ) reported a qualitative change of use, or they chose to specify their change of use. The comments from this group indicate that participation in forums increased their knowledge and understanding of mental problems, health care services, their rights and what they could expect from health services. This enabled them to feel more active, prepared and goal-oriented when seeking help. As one respondent put it: "Now I'm better prepared for each consultation (...). Better knowledge about my illness leads to an inner certainty about what kind of treatment is necessary. I feel more self-confident, rather than blindly trusting my doctor."

### Personal problems online and face-to face

Users were also asked to rate on a Likert scale the ease/difficulty of discussing personal problems both online and in face-to-face interaction. Forty-six percent ( $n = 259$ ) reported that it was "difficult" or "very difficult" to discuss personal problems face-to-face, while only 10% ( $n = 40$ ) reported the same for online discussion forums. These results are provided in Fig. 1.

Of those who answered both questions ( $n = 408$ ) (i.e. with respect to online versus face-to-face communication), 75% ( $n = 306$ ) found it easier to discuss personal problems in discussion forums than face-to-face. Fifteen percent ( $n = 62$ ) rated them as equal and 10% ( $n = 40$ ) found face-to-face the easiest way to communicate personal problems.

Of those who had written posts to the forum during the previous month ( $n = 321$ ), 46% ( $n = 146$ ) said they had discussed topics online which they felt unable to discuss offline (15% didn't know, while 39% negated this). Of these, 136 provided examples of what topics

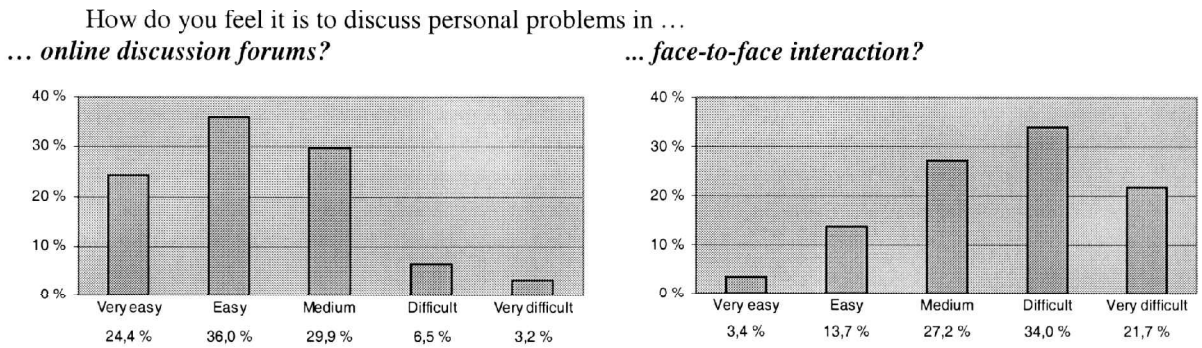


Fig. 1

they discussed. Most responses reflected the topics of the forums themselves (e.g. abuse, eating disorders, anxiety), affiliated topics such as suicide and loneliness, as well as practical questions concerning medication or general information about psychiatric issues. Reported topics were often accompanied by expressions such as “embarrassing”, “guilt” and “shame”.

**Attitude toward professional participation**

Sixty-eight percent ( $n = 334$ ) preferred that professionals should take an active part in these kinds of forums, while 16% ( $n = 78$ ) said that professionals should merely monitor the forums without taking an active part in the discussions. Only 3% ( $n = 15$ ) said that the professionals should not attend the forums.

**Anonymity**

Querying the importance of not using their real name on the service, the response alternatives were given in a five-step Likert scale. Of those who had posted on the forum ( $n = 286$ ), 64% described it as “1 – very important” with the subtext “I would not have used the service if I had to state my real name”.

**Usefulness**

The respondents were asked to provide examples of how they found the service useful. A total of 336 persons provided a free-text comment, varying from single words to several paragraphs. The most dominating theme expressed was the usefulness of the forum in providing information. This included both practical/factual information (particularly concerning medication) and experiential knowledge from peers on how to cope with disorders or stressful situations: “I’m a borderliner, and I’ve found it useful to hear of the experiences of others with this diagnosis.” “Doktor Online has been useful to me because I can meet people [here] [...] that tell me of their own problems, so I can see for myself whether what I am going through is normal/abnormal, and see how they cope with it.”

Another dominant theme was the need for support and the sense of receiving support from other partici-

pants in the discussion group. One example reads: “[I have] received responses from people who care for and understand me. [I] have obtained lots of good advice and support.”

Apart from the recurring themes sited above, several reiterated the value of discussing topics online that would have been impossible for them to discuss offline. Some expand on their positive appraisal of the groups: “[the discussion group] prevented me from executing a carefully planned suicide. I intended to write suicide letter on the forum. That became the turning point of my life. [...] It has helped me want to fight for my life. Now, for the first time, I feel like I’m alive.” In fact, as many as eight conveyed testimonials claim that forum participation prevented suicides. On the other hand, a few describe participation as merely an entertaining pastime: “Useful? Surely for others, but personally I have not found it useful.... Entertaining? Yes.” These examples serve to illustrate the wide range of experiences regarding usefulness.

**Discussion**

The 492 respondents were self-selected for this study, which may have created a bias toward positive evaluations of the online forums. With this in mind, the respondents find forum participation useful first and foremost because it fulfils a need for information – both practical/factual information (particularly concerning medication) – and the experiential knowledge of others in how to cope with disorders or stressful situations. Secondly, forums provide social contact and support, indicating that forums fulfil basic needs that are unavailable, or inappropriate, within their immediate social network. Furthermore, forums are perceived as a supplement to – rather than a replacement of – traditional health services, and online professional involvement is valued by users.

Despite claims of the Internet being a male-dominated medium, the majority of the respondents to this study were women (78%). All the forums have a majority of women, but the female proportion is especially

high in the two forums that address issues traditionally associated with women, i.e. eating disorders and abuse. The relatively high proportion of female users in our study may reflect the fact that women are traditionally far more likely to seek help for mild psychiatric problems than men (11). Also, user statistics indicates that Internet use in Norway is no longer clearly gender-specific, with 44% female users in 1999 (10). Thus, the gender distribution may be said to mirror the consumer patterns of traditional health care services. This also appears true when looking at the age distribution, with one clear exception: Those above 55 years are practically missing from our material, a fact that is reflected in the general population of the Internet users in Norway (12).

A great majority of our respondents find it easier to discuss personal problems online than face-to-face, and almost half say that they discuss problems here that they do not discuss offline. Forums can lower thresholds for self-disclosure in several ways. The users themselves indicate that they would never have used the service if they had to reveal their true name. In forums, users have an opportunity to "test" social reactions to difficult issues without fearing social sanctions or obligations. Furthermore, reduction of social cues facilitates contact with peers by overriding differences that might alienate them from each other in face-to-face social settings (ethnicity, gender, disabilities, etc.). Perhaps this role-playing activity might also be understood as an integral part of experimenting with identities, as pointed out in other studies (13).

McKenna and Bargh (14) suggest that individuals who have a "concealable stigmatized identity" will experience a disproportionate degree of anxiety when seeking social support. According to McKenna and Bargh, such individuals will have strong motivations for belonging to a group of similar others, but are unable to do so because of the concealable and potentially embarrassing nature of their identity. They argue that anonymous participation in online support groups is motivated by a series of very basic needs, such as gaining self-esteem, reducing uncertainty about oneself, and fulfilling the need to belong. This is also supported in our material by comments such as "embarrassing", "don't dare talk about" when providing examples of topics they only discuss online (eating disorders, abuse, suicide, etc.).

### ***Implications for persons with mental disorders***

In light of the above, it may be argued that forums lower the threshold for acknowledgement and discussion of mental health issues. Those who are confused and have fears about mental health disorders and psychiatric services can find a non-threatening environment to express their concerns and pose their questions. For many, this may represent an important first step in the help-seeking process.

Respondents who have used traditional mental health care services (65%) describe forums as a supplement to such services. Forums help some users towards a more selective and goal-oriented use of health care services, in part through provision of second opinions. It may be assumed that the respondents' perception of forums as a supplement, in part, refers to the facilitation of information and social support. These are factors assumed important in coping processes, but are not traditionally facilitated as an integral part of psychiatric treatment (16). Patient groups in other fields are pioneering new models for patient-health care partnerships (17). These build on the complimentary nature of experiential knowledge and social support in alliance with the more evidence-based medical community. Davidson, Pennebaker and Dickerson (18) argue that the self-help movement has tremendous therapeutic potential, especially because institutional health care is still far from embracing psychological support into health care delivery. This type of model may be particularly useful in psychiatry and is worth looking into by consumer organizations.

Ongoing debates in the media warn us of potential dangers, such as Internet addiction and deterioration of social ties – debates similar to those surrounding the introduction of the telephone and television. Despite failure to demonstrate the Internet as a causal factor – (and not just a new medium for previously existing problems/symptoms) (18–22) – these concerns should be taken seriously and warrant further research.

In light of the results discussed so far, we believe that computer-mediated communication can have unique benefits for persons suffering from mental disorders. These disorders are often stigmatizing and accompanied by social anxiety – factors typically activated in face-to-face interactions. The positive effects of social support on quality of life and mortality for this group are well documented (23). The challenge lies in finding out whether or not social support can be facilitated online in ways that have similar effects. A pilot study with persons suffering from serious mental disorders found that social use of the Internet was associated with crisis prevention and improved quality of life due to social contact without provoking anxiety (24). It is interesting to note, however, that some of the users – users who have been psychiatric patients over many years – appeared more interested in participating in forums of general topics (e.g. music, chess), than those focusing on their disorders (e.g. forums in this study). For these, the experience of making friends in online communities with "normal" topics was uniquely new and challenged their negative self-image as "crazy" and incompetent.

### ***Implications for professionals and health services***

Respondents clearly encourage professionals to take an active role in these forums. This might indicate that a

growing number of future patients will want their on-line activity treated as an integral part of their health care use. Some psychiatric patients have argued in favour of email-based interaction, also with their therapist (24). They felt it gave them the calmness and concentration necessary in formulating themselves – and perceiving the responses of others – on issues they find difficult to discuss face-to-face. This, along with the lowered threshold for self-disclosure that allows participants to speak and be heard about issues that may be more difficult for them to address in the face-to-face setting of traditional health care, represents an interesting issue for clinical research.

Professionals should not be unaffected by the signals conveyed by these studies even if they choose not to actively engage in online mental health activities.

Professionals will need to acquaint themselves with online services in an effort to understand potential benefits and pitfalls, and discuss these with their patients. Professionals who choose to go online will need to learn how to convey their expertise within the constraints of the written word, and to reassess current relationship theories that implicitly depend upon the physical and spatial aspects of interaction (25). All these issues should become subject to evaluative research in the process assuring the quality of education and future combinations of online and face-to-face services.

Perhaps an increase in knowledgeable and demanding patients will fuel quality improvements in the health services provided. Interaction with “empowered patients” may encourage health care professionals to develop new kinds of communicative skills and perceptions of their roles (26–29) – developments which might also be useful in interaction with less resourceful patients.

### *Issues for public authorities*

If those predicting the future of the Internet and health care are right (30, 31), online support groups are among the “leading-edge applications” of Internet-based health care (32). These interactive environments for peers and professionals provide uniquely powerful arenas for influencing attitudes and behaviour – for better or worse. Today, professionals attending forums are funded by a myriad of private funds, typically through pharmaceutical sponsors and ideal organizations having their respective agendas. The pharmaceutical industry may gain considerable power over patients through these types of forums, a fact which should cause concern. New alliances between private and public service providers should be examined. Public authorities will need to relook at national public health promotion strategies (33) in light of the potentials this global medium has for promoting health in ways conducive to local social and cultural values.

## **Conclusions**

Online support groups should not be written off as yet another aspect of the “hype” surrounding technological innovations, and the Internet in particular. While waiting for more substantial research, we should keep in mind that persons with mental disorders are going to participate in online communities regardless of whether it is good or bad for them. It is our contention that online interaction can have unique benefits for persons with mental disorders, especially due to the limitations in non-verbal and social cues which dominate face-to-face interaction. For some, these limitations allow access to information and social support otherwise inaccessible in local settings. Perhaps the shortcomings of traditional scientific methods in studying anonymous communities will invite greater dialogue with those we’re trying to understand. In the meantime, professionals will need to reassess their roles. Public authorities will need to decide what role they will play in influencing the quality of services offered, and the social values conveyed, to those who seek help through the Internet.(15)

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