Comparison of chronic fatigue syndrome/myalgic encephalopathy with other disorders: an observational study

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Summary

Objectives To examine the level of activity in online discussion forums for chronic fatigue syndrome/myalgic encephalopathy (CFS/ME) compared to other disorders. We hypothesized the level of activity to be higher in CFS/ME online discussion forums.

Design Observational study

Setting Norway, which has more than 80% household coverage in internet access, September 2009

Participants Twelve Norwegian disorder-related online discussion forums

Main outcome measures Number of registered users and number of posted messages on each discussion forum

Results Two forums were targeted towards individuals with CFS/ME. These forums had the highest number of registered users per estimated 1,000 cases in the population (50.5 per 1,000 and 29.7 per 1,000), followed by a site for drug dependency (5.4 per 1,000). Counting the number of posted messages per 1,000 cases gave similar indications of high online activity in the CFS/ME discussion forums.

Conclusions CFS/ME online forums had more than ten times the relative activity of any other disorder or condition related forum. This high level of activity may have multiple explanations. Individuals suffering from a stigmatized condition of unknown aetiology may use the internet to look for explanations of symptoms or to seek out alternative treatments. Internet forum activity may also be reinforced by the creation of in-group identity and pre-morbid personality traits. More knowledge on the type and quality of information provided in online forums is urgently needed.

DECLARATIONS

Competing interests
None declared

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Ethical approval
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Contributorship
AKK contributed to the design of the study, analysis and interpretation of the data, literature

review, and critical revision of the article for important intellectual content. LVL contributed to the analysis and interpretation of the data, literature review, and writing out the first draft of the article. SBH contributed to the design of the study, interpretation of the data, literature review and critical revision of the article for important intellectual content. CMSL contributed to the interpretation of the data and critical revision of the article for intellectual content. ANO contributed to the interpretation of the data and reviewing and revising the article critically for intellectual content. AM contributed to the conception and design of the study, analysis and interpretation of the data, and critically revision the article for important intellectual content. All authors have given their approval of the final version of this manuscript

Background

Chronic fatigue syndrome (CFS), also known as myalgic encephalopathy (ME), is a disorder characterized by unexplained persistent or relapsing fatigue and considerable functional impairment.[1,2] Evidence across several domains suggests that CFS/ME is a heterogeneous condition of complex and multifactorial aetiology.[3] There is no objective test to determine the presence of the disorder, and the diagnosis is based on symptomatology and the exclusion of other diagnoses.[4,5] These uncertainties, together with an ongoing debate regarding the relative contributions of biological and psychosocial risk factors, have contributed to the controversy and conflict surrounding CFS/ME.[6,7] Practitioners are often dissatisfied with the quality of care they are able to provide to individuals with CFS/ME, at times leading them to feel frustrated and question their professional role.[8,9] Such doubts are not without basis, as many patients also report feeling dissatisfied and having negative experiences in dealing with health services.[10,11] Recent high profile cases have demonstrated how the mass media's portrayal of CFS/ME is also often inaccurate or misleading.[12]

Over the last decade, the use of the internet as a resource for retrieving health-related information has increased, with patients now much less reliant on the information provided by either the mass media or health professionals.[13,14] A growing number of health related online support groups and discussion forums are emerging on the internet.[15] This new way of acquiring knowledge has made researchers raise questions about the quality of the information available,[16] the effect of online communication,[15] and more specifically, the relative use of the internet for different patient groups.[17,18] The internet can ensure anonymity for people experiencing stigmatization, and gives access to social relations and group identity for people restricted in their mobility or social connections.[19] There are anecdotal reports and some limited research evidence suggesting that sufferers of CFS/ME may be very active on the internet,[20] possibly due to the unique challenges they experience in the health care system.

The aim of this study was to examine the level of activity in online discussion forums for CFS/ME compared to online discussion forums for other mental health and somatic conditions. The geographic restrictions in the use of the Norwegian language makes Norway particularly well suited for this type of study. The study hypothesis was that the level of online activity would be higher in CFS/ME forums compared to forums for other conditions.

Methods

Online discussion forums

For the purpose of the current study, an 'online discussion forum' was defined as an internet website for lay persons with particular symptoms, where information and support were exchanged. Such forums target people with symptoms that are related to particular disorders and conditions, their relatives and other carers. Norwegian online discussion forums for different disorders and conditions were assessed through the search engine *Google* during September 2009. Disorders and conditions for which online discussion forum activity in CFS/ME were to be compared, were predefined and targeted towards disorders that are relatively common in the young adult population,[21] who are more likely to be active users of the internet. The searched disorders thus consisted of CFS/ME, fibromyalgia, whiplash, electromagnetic hypersensitivity, diabetes, cancer, anxiety, depression, drugs and alcohol dependency, neck and back conditions and chronic pain. Each search consisted of a Norwegian keyword for one of the predefined disorders or conditions together with the Norwegian word for discussion forum i.e. *myalgisk encefalopati* and *diskusjonsforum*. A total of 44 searches were performed and resulted in the identification of 203,111 potential websites. Searches were limited to the first ten results of each search with links from these ten again examined for possible discussion forums. The limitation to the first ten results was based on initial investigations, revealing that results beyond the first ten were less likely to be of relevance to the entered keywords and often linked back to pages obtained among the first ten results.

The inclusion criteria for this study were that the online discussion forums should make use of Norwegian language, have electronic messages

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posted in delayed time and target the adult population. In addition, the forums included needed to be directly accessible from the sample of Google hits. Exceptions were made for results that gave access to an association website which had a forum in relation to their website, or other similar websites with a forum. Forums that represented more than one specific disorder or condition were included, for instance forums targeted towards both anxiety and depression. Forums from websites of general health, newspapers, blogs and other commercial sites, and forums targeting adolescents or with synchronous communication, like a chat forum, were excluded. The included forums are displayed in the second column in Table 1.

Registered activity

Both numbers of registered users and numbers of posted messages on the online discussion forums were defined as indicators of activity, and are presented in Table 1. The monitoring of activity was performed in a one week period from September 16th to 23rd 2009, except for one forum for mental disorders (*Bluemood)*, which was observed from October 7th to 14th 2009. During the selected week of online monitoring there were no major health stories in the media which could have lead to an increase in internet activities. For the majority of the forums, the total number of posted messages at a certain time could be read from a counter on each forum's main website. Exceptions were for the forums for obsessive-compulsive disorder (*Tvang)* and chronic pain (*Sunshine)*. For these two forums, calculation of posted messages was based on information from the main webpage on total numbers of messages posted in several subgroups. The number of registered users on each forum was gathered at the last day of monitoring. The majority of forums had statistics that yielded this information, but for three forums (*Tvang, Prostatakreft* and *Bluemood)*, this information was retrieved by contacting the forums by e-mail. The total number of users of the forum *Sunshine* was estimated based on information from the forum's website that about 60 percent of the users are Norwegian. Each forum's year of launching is listed in Table 1.

Prevalence estimates of the disorders and conditions

To allow for comparison of relative rates of online activity between various conditions, we used point prevalence estimates of each disorder. Information on prevalence estimates were gathered from scientific articles retrieved through the search engine *ISI web of science.* Terms of the different disorders and conditions were combined with the following keywords; prevalence, epidemiology, burden of disease, review, meta-analysis and population-based study. A range of prevalence estimates of the disorders and conditions were collected from various studies, and the prevalence of each targeted forum population was based on the mean value of this range. If the prevalence estimates of the targeted disorder were not found in scientific articles, other relevant sources of information were used. This applies to the forums *Ryggforum* (prevalence range for neck and back injury derived from a health survey by Statistics Norway),[22] and the cancer forums *FFB* and *Prostatakreft*, where exact number of cases in 2007 with these types of cancer were derived from the Cancer Registry of Norway.[23] For forums targeted at more than one disorder, the prevalence estimates for the wider group were used. The population prevalence estimates for CFS/ME range from 0.24 to 1.4%,[24–26] although estimates based on samples from primary care are as high as 2.6%.[27] However, due to the nature of CFS/ME, there remains some uncertainty in these estimates, with health service data suggesting there may have been a recent increase in the diagnosis of CFS/ME in Norway. In order to minimize the risk of type I error, we used a conservative prevalence estimate for CFS/ME of 1.0%. The prevalence estimates for other disorders and conditions are listed in Table 1.

Results

Twelve online discussion forums were found. The CFS/ME forum, *Me-forum*, had the highest number of registered users per 1,000 cases (50.5) followed by the second forum for CFS/ME, *MENIN* (29.7) and then a forum for drug and alcohol dependency, *Narkoman* (5.4) (Table 1). The highest activity levels, in terms of number of posted messages during a one week period, were

Table 1
Online discussion forum registered users and activity for CFS/ME compared to other somatic and mental disorders and conditions

Disorder/ Condition	*Online forum (year launched)*	*Point prevalence* in percent(range)* ^{references}	*Estimated number of cases in Norway (N)*‡	*Registered users at day seven (N)*	*Registered users per 1,000 cases (N)*	*Posted messages day one (N)/day seven (N)*	*Sum posted messages in a week (N)*	*Sum posted messages in a week per 1,000 cases (N)*
CFS/ME	Me-forum (2005)	1.0 (0.0–2.6)[24–27, 31]	48,000	2,426	50.5	209,362/209,896	534	11.1
CFS/ME	MENIN (2003)	1.0 (0.0–2.6)[24–27, 31]	48,000	1,427	29.7	36,058/36,066	8	0.2
Breast cancer	FFB (2009)	33,889[23]†	33,889	74	2.2	390/402	12	0.4
Prostate cancer	Prostatakreft (2009)	25,611[23]†	25,611	36	1.4	15/16	1	0.0
Chronic pain	Sunshine (2001)	21.7 (19.0–24.4)[32, 33]	1,041,600	1,075	1.0	27,807/28,606	799	0.8
Back and neck conditions	Ryggforum (2008)	20.5 (10.0–30.0)[22, 34, 35]	984,000	367	0.4	875/903	28	0.0
Mental disorders	Bluemood (2008)	21.2 (9.6–32.8)[36–38]	1,017,600	500	0.5	392/394	2	0.0
Mental disorders	Stille-vann (2006)	21.2 (9.6–32.8)[36–38]	1,017,600	404	0.4	63,249/63,502	253	0.2
Anxiety, depression and dependency	Gimmestad-psykoterapi (2009)	12.4 (7.6–17.2)[36–38]	595,200	331	0.6	12/12	0	0.0
Anxiety and depression	Angsten (2009)	12.4 (7.6–17.2)[36–38]	595,200	1	0.0	1/2	1	0.0
Drug and alcohol dependency	Narkoman (2005)	7.6 (3.8–11.3)[36–38]	362,400	1,967	5.4	29,876/29,952	76	0.2
Obsessive compulsive disorder	Tvang (2004)	0.8 (0.5–1.0)[36–38]	36,000	0	0.0	294/294	0	0.0

*The point prevalences are mean values derived from the range of collected prevalence estimates of the disorders, except for CFS/ME where a more conservative estimate was used.
†Exact numbers of cancer cases (2007) obtained from the Norwegian cancer registry
‡Total number of inhabitants ≈4,800,000

found for *Sunshine* (chronic pain) (N = 799), *Me-forum* (N = 534) (CFS/ME) and *Stille-vann* (mental disorders) (N = 253) (Table 1). However, the forum with the highest number of weekly posted messages per 1,000 cases was *Me-forum* (11.1), followed by *Sunshine* (0.8) and *FFB* (breast cancer) (0.4) (Table 1).

Discussion

Individuals suffering from CFS/ME appear to be much more active in their use of online discussion forums than sufferers of other somatic or mental health conditions. CFS/ME online forums had more than ten times the relative activity of any other disorder or condition related forum.

This study has several strengths. A range of comparison groups across a variety of different disorders and conditions has been sought in order to have a broad basis for comparison. Furthermore, each forum's level of activity has been monitored without interventions or approximated judgments. The study also has some potential limitations. The prevalence estimates for each disorder were based on a detailed search of the current literature. However, these searches were not systematic and all prevalence estimates are an approximation, which may have led to inaccuracies in the calculation of relative activity levels. As this issue is relevant for all of the forums, the risk should be of random error rather than bias. Secondly, the forums are open to all and therefore may be used by self-diagnosed sufferers who would not meet standard diagnostic criteria for the disorder in question. Thirdly, forums might be used by relatives or other interested parties, but again this constraint should apply to all diagnostic categories. Fourthly, it is possible that the sample in study is biased in its selection. The internet is assumed to be an arena for younger people, and disorders that affect the elderly or those from a lower socioeconomic position may be less likely to have active internet forums. In this study we attempted to limit this potential bias by excluding forums targeting adolescents and by using the most common disorders in the young adult population as comparison groups.[21] Disorders that are highly prevalent in the elderly, such as coronary heart disease and dementia, were excluded. Further, as more than 80% of households in Norway have internet access, the possibility of online participation across different socio-economic positions is high. We also acknowledge that limiting our search for internet support groups to websites listed on or linked to the first ten results may have led to some support groups not being identified, although as noted above, initial investigations of more extensive search strategies suggested they were unlikely to yield any additional sites. Finally, as with most studies, our findings may be limited in their generalizability. The study was performed within Norwegian online discussion forums only, and as such the findings may not be representative of forum activity in other countries. However, this may also be viewed as a strength. The prevalence of functional somatic syndromes is often unevenly distributed between countries.[28] The geographic restriction in the utilization of the Norwegian language ensures that the relative levels of online activity between different forums could be accurately compared.

The finding of high online activity among CFS/ME sufferers raises a number of important issues. Firstly, it highlights the increasing use of the internet as a source of medical information amongst certain patient groups. Secondly, it suggests there is something specific about those suffering from CFS/ME and their experiences within the traditional healthcare system which drives them to seek alternative sources of support and information. Thirdly, it raises the possibility that some specific characteristics of the ongoing activity within CFS/ME forums encourages repeated and ongoing use. Despite its increasing importance, very little is known about the way in which various patient groups utilize the internet. The results from this study are in line with findings from Davison *et al.*,[20] who found CFS to have the second highest level of online activity, after multiple sclerosis. The internet is a medium which is developing rapidly, with more people searching for health related information and support.[13,14] It is important for health professionals to generate knowledge in this emerging field, as information gathered from internet sources might have both beneficial and harmful influence on health behaviour. Both the level of activity as well as the quality of the information provided should be examined. The findings from this study indicate that the internet is a particularly important medium for CFS/ME.

There are a number of potential explanations for the high level of activity on CFS/ME forums. The ease of access and anonymous nature of the internet might be particularly appealing for those feeling stigmatized and suffering restricted mobility.[19] Internet forums may also be helpful when CFS/ME sufferers report feelings of frustration and dissatisfaction with the treatment offered by the medical profession.[10,11] Despite the potential benefits of online support, the high level of activity observed in the CFS/ME group may seem contradictory given their core symptoms of fatigue and lack of energy. However, this apparent contradiction may be explained by emerging evidence regarding the pre-morbid personality risk factors for CFS/ME. Research has suggested that many CFS/ME sufferers are 'action prone'; with a tendency for lifelong traits of over-activity.[29] It has been suggested that action-prone personality traits may contribute to the risk of CFS/ME via their promotion of 'boom and bust' cycles of activity.[5] High levels of online activity might be an alternative, less physically exhausting, expression of this 'action-prone' tendency, but whether high online activity also increase the risk of CFS/ME remain unknown.

Research on support group participation for CFS/ME sufferers indicates that active members report greater symptom severity and less improvement of the disorder than inactive members.[30] Norwegian online discussion forums share many of the underlying self-help traditions that characterize traditional support groups.[17] While it is likely that the support provided within online groups may have some benefits, there is a also a risk that strong in-group identity within discussion forums may lead users away from 'real life' social support, therapeutic engagement and effective, evidence-based interventions. Given the very high use of internet forums by CFS/ME sufferers, a greater understanding of these potential risks and benefits is essential.

Conclusion

CFS/ME online forums had more than ten times the relative activity of any other disorder or condition related forum. This high level of activity may have multiple explanations. Individuals suffering from a stigmatized condition of unknown aetiology may use the internet to find explanations of symptoms or to seek out alternative treatments. Internet forum activity may also be reinforced by the creation of in-group identity and pre-morbid personality traits. More knowledge on the type and quality of information provided in online forums is urgently needed.

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