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Cross-sectional survey of users of Internet depression communities

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Abstract

Background: Internet-based depression communities provide a forum for individuals to communicate and share information and ideas. There has been little research into the health status and other characteristics of users of these communities.

Methods: Online cross-sectional survey of Internet depression communities to identify depressive morbidity among users of Internet depression communities in six European countries; to investigate whether users were in contact with health services and receiving treatment; and to identify user perceived effects of the communities.

Results: Major depression was highly prevalent among respondents (varying by country from 40% to 64%). Forty-nine percent of users meeting criteria for major depression were not receiving treatment, and 35% had no consultation with health services in the previous year. Thirty-six percent of repeat community users who had consulted a health professional in the previous year felt that the Internet community had been an important factor in deciding to seek professional help.

Conclusions: There are high levels of untreated and undiagnosed depression in users of Internet depression communities. This group represents a target for intervention. Internet communities can provide information and support for stigmatizing conditions that inhibit more traditional modes of information seeking.

Background

The Internet is increasingly used for health information and advice [1]. Mental health topics are especially popular [2]. Internet communities provide users with information and a platform for peer-to-peer communication that may be synchronous (e.g. chatrooms) or asynchronous (e.g. messageboards). Previous studies of health-related online communities have shown that they can provide social support [3,4], reduce isolation [5], and can help people cope more effectively with their disease [6]. In a review article White & Dorman highlight the fact that anonymity

and convenience can facilitate use by those with stigmatizing and disabling conditions [7]. These authors also discuss the possible disadvantages of online social support, including the exclusion of certain groups through the 'digital divide'; the misinterpretation of online messages lacking in visual or aural cues; and the dissemination of inaccurate information [7].

We are aware of three previous studies investigating Internet depression communities [8-10]. One of these investigated a community (in Sweden) used in our study, but

was a separate investigation of user-perceived benefits [8]. These studies showed that four out of five users were female and that many users found it easier to discuss mental health topics online rather than in person [8-10]. Users reported benefits in terms of information, social support and contact [8-10]. However the only study including a formal measure of social support found no change over six to twelve months [9]. Some users reported revealing their depression on an Internet community having not disclosed it elsewhere [8].

The aims of this study were to identify the level of depressive morbidity among users of Internet depression communities in six European countries, investigate whether the individuals that are actively seeking help online are in contact with formal health services and receiving treatment, and to assess user-perceived effects of these communities.

Methods

Design

Online cross-sectional survey of Internet depression communities. A twenty-nine item questionnaire was offered to all community visitors as a pop-up window during a four week period in May/June 2002. Visitors were able to access the community if the survey was declined. The questionnaire was designed for this study by the authors and partly derived from an earlier study of the Swedish Netdoktor community [8]. It contained questions covering demographic characteristics (age, sex), reason for visiting the community (e.g. for self, for friend or family member), history of depression and consultations, and attitudinal statements regarding self-perceived effects of community use. The questions regarding self-perceived effects asked respondents whether they agreed, disagreed or had no view on certain statements. The questionnaire also contained the Major Depression Inventory, a 12-item self-completion scale validated against DSM-IV criteria for major depression [11]. Questionnaire responses were entered in to a database automatically using computer software linking the online survey and the database. Internet cookies were used to prevent multiple responses from the same Internet connection.

Study sample

The study sample consisted of individuals recruited from one of six Internet depression communities run by the European company Netdoktor. Netdoktor is an independent consumer e-health company financed by advertising and licensing of content. It hosts several Internet communities. The depression communities are similar to other health-related virtual communities in Europe and the United States. They provide registered members with health information, news stories on depression, the facility to email questions to an expert panel, and peer-to-peer

communication via messages and shared personal experiences posted on discussion boards. Registration is free. The communities are hosted in Austria, Denmark, Germany, Norway, Sweden, and the United Kingdom, in the official language of each country using a common format. Users are likely to be from the host country, with the possible exception of the English-language UK site, although usage statistics show that 90% of page impressions of the UK site are accessed from UK servers.

Outcome measures

The primary outcome measure was depressive morbidity as measured using the Major Depression Inventory (MDI) which was adapted for online use. Other measures were demographic characteristics, history of depression and consultations, and attitudinal statements regarding self-perceived effects of community use.

Statistical methods

Simple percentages were used to describe characteristics of respondents including prevalence of depressive morbidity, and numbers in contact with services or receiving treatment. Between country differences in these characteristics were investigated using chi-square test for heterogeneity. Chi-square tests for differences in proportions were used for pairwise comparisons. Multivariate (logistic regression) analysis was used to investigate whether inter-country differences in depressive morbidity could be explained by differences in age and sex distributions.

Standard ethical review procedures were followed in each country and ethical approval was obtained from the research ethics committees of the academic host institutions of the lead investigators in London and Heidelberg (JP and GE).

Results

Characteristics of respondents

A total of 2037 visitors to the communities chose to complete the survey. In total the pop-window was displayed on 16926 occasions, giving an overall participation rate of 2037 volunteer responses per 16926 pop-up displays (12%). Community users also included friends or family members of people with depression although the number was small (6.7%, 137/2037).

Table 1 shows demographic characteristics of respondents and percentage rated as having major depression. The overall prevalence of major depression was 52.6% for male community users and 51.4% for female community users. There were statistically significant differences between countries in respondent age ($p < 0.001$) and sex ($p = 0.02$) and diagnosis of major depression ($p < 0.001$). Major depression was most common among respondents in the UK (64%, 339/529) and Sweden (57%, 257/453)

Table 1: Characteristics of respondents by country of web community.

	UK*	SE*	DK*	NO*	DE*	AT*	Total	Chi-square†
Number	529	453	382	291	330	52	2037	
Percent men (n)	29 (153)	26 (120)	27 (102)	31 (90)	37 (123)	27 (14)	30 (602)	p = 0.02
Percent by age group (n)								
% <26 years (n)	29 (151)	29 (133)	17 (64)	40 (117)	23 (75)	25 (13)	27 (553)	
% 26–35 years (n)	33 (172)	35 (160)	36 (138)	33 (96)	30 (98)	27 (14)	33 (678)	
% 36–45 years (n)	22 (118)	22 (100)	25 (94)	19 (54)	25 (84)	29 (15)	23 (465)	
% >46 years (n)	17 (88)	13 (60)	23 (86)	8 (24)	22 (73)	19 (10)	17 (341)	p < 0.001
% meeting criteria for major depression (n)	64 (339)	57 (257)	40 (153)	42 (121)	48 (158)	50 (26)	52 (1054)	p < 0.001

* UK = United Kingdom, SE = Sweden, DK = Denmark, NO = Norway, DE = Germany, AT = Austria. † Chi square test for heterogeneity between countries. **Country – country comparisons:** Differences in sex distribution (proportion of women) (Chi square test): SE>DE (p < 0.001); DK > DE (p < 0.01); UK > DE (p < 0.05). Differences in age distribution (rank sum test on 5 year age bands): UK-DK, UK-NO, UK-DE, SE-DK, SE-DE, DK-NO, NO-DE (p < 0.001); SE-NO, NO-AT (p < 0.01). Proportion depressed (Chi square test): UK > DK, UK > NO, UK > DE, SE > DK, SE > NO (p < 0.001); UK > SE, UK > AT, SE > DE, DE > DK (p < 0.05).

and least common among respondents in Denmark (40%, 153/382) and Norway (42%, 121/291). Intercountry differences for major depression remained after adjustment for age and sex in multivariate (logistic regression) analysis.

Contact with services

Service use analyses were confined to those participants who reported current or past history of depression or low mood and met the criteria for MDI major depression (n = 953). Table 2 shows that 49% (n = 467) of users meeting the criteria for MDI major depression were not currently receiving drug or psychological treatment, and 35% (n = 334) were not known to health services (defined as currently receiving drug or psychological treatment or having had a consultation with a healthcare practitioner in the previous year). There was significant statistical heterogeneity between countries with respondents to the German community survey having substantially lower rates both of consultation with health professionals and of current drug treatment. Swedish and Norwegian respondents reported relatively high consultation rates and relatively low drug treatment rates. UK and Denmark had relatively high consultation and drug treatment rates. Intercountry differences for consultation rates and drug treatment remained after adjustment for age and sex.

The number of respondents who reported a history of depression and who met MDI major depression criteria and who described having revealed their depression on the Internet community despite not having told anyone else about it was 14.4% (137/953). This figure was similar for those identified as having been currently known to services (on treatment or with a recent consultation) (13.8%, 85/619) and those not (15.6%, 52/334) [Chi square test, p = 0.44].

Self-perceived effects of communities

Analysis of self-perceived effects of the communities was restricted to users who had visited more than once (n = 926, 45.5%). Of these 71% (n = 655) reported having learned more about medication from using a community, and 51% (n = 472) of subjects agreed that they were able to discuss subjects that they felt unable to discuss elsewhere (12% disagreed, 113/926). Forty-four percent (n = 307) agreed that they felt less isolated as a result of using a community, while 11% (n = 99) felt lonelier. Of these repeat visitors those who had consulted a health professional within the last year (n = 751) were offered a question about their decision to consult. Of 604 replies only 9% (n = 53) agreed with the statement that the Internet community had delayed their seeking professional help, while 70% (n = 421) disagreed with this statement; and 36% (n = 215) felt that the Internet community had been an important factor in deciding to seek professional help. There were no significant differences by country. Thirty-seven percent (n = 228) reported having used information from the community in their consultations with professionals. Eleven percent (n = 66) of respondents agreed that the Internet community had made them trust their doctor less, while 54% (n = 324) disagreed with this statement.

Discussion and conclusions

A high prevalence of major depression was identified among users of Internet depression communities. Our findings suggest that unmet need exists online as it does in primary care [12]. Many people were seeking help online without presenting to formal health services, and half of them were not receiving treatment.

Compared to the current study, Houston *et al.* found a higher rate of depression among the 103 community

Table 2: Percentage treatment and consultation rates among respondents reporting current or past depression or low mood and fulfilling MDI criteria for major depression.

	UK*	SE*	DK*	NO*	DE*	AT*	Total	Chi-square†
Number with major depression	321	215	133	116	144	24	953	
Consultation in past year (%)	68	63	70	69	44	63	64	p < 0.001
(n)	(219)	(136)	(93)	(80)	(64)	(15)	(607)	
Treatment								
Psychological								
Never	59	57	46	41	53	46	53	
(n)	(189)	(123)	(61)	(48)	(76)	(11)	(508)	
Past	19	19	23	25	22	29	21	
(n)	(60)	(40)	(31)	(29)	(32)	(7)	(199)	
Current	22	24	31	34	25	25	26	p = 0.09
(n)	(72)	(52)	(41)	(39)	(36)	(6)	(246)	
Drug								
Never	32	51		44	50	54	42	
(n)	(102)	(110)	(50)	(51)	(72)	(13)	(398)	
Past	15	14	8	17	19	4	14	
(n)	(47)	(30)	(11)	(20)	(28)	(1)	(137)	
Current	53	35	54	39	31	42	44	p < 0.001
(n)	(172)	(75)	(72)	(45)	(44)	(10)	(418)	
Either								
Never	29	40	30	32	38	33	34	
(n)	(93)	(87)	(40)	(37)	(55)	(8)	(320)	
Past	15	14	10	18	22	17	15	
(n)	(47)	(30)	(13)	(21)	(32)	(4)	(147)	
Current	56	46	60	50	40	50	51	p = 0.01
(n)	(181)	(98)	(80)	(58)	(57)	(12)	(486)	
Consultation or current treatment (n)	69	65	72	70	47	63	65	p < 0.001
	(220)	(139)	(96)	(81)	(68)	(15)	(619)	

* UK = United Kingdom, SE = Sweden, DK = Denmark, NO = Norway, DE = Germany, AT = Austria. † Chi square test for heterogeneity between countries. The results for psychological, drug or either treatment are for heterogeneity among 'never', 'past' and 'current' treatment all combined. **Country – country comparisons (all Chi square tests):** Proportion consulted in past year: UK > DE, SE > DE, DK > DE, NO > DE (p < 0.001). Proportion currently on drug treatment: UK > SE, UK > DE, DK > DE (p < 0.001); UK > NO, SE > DK, DK > NO (p < 0.05). Proportion currently on psychological treatment: UK > NO (p < 0.01); UK > DK, SE > NO (p < 0.05). Proportion consulted in past year or on current treatment: UK > DE, SE > DE, DK > DE, NO > DE (p < 0.001). Proportion currently on psychological and/or drug treatment: UK > DE, DK > DE (p < 0.01); UK > SE, SE > DK (p < 0.05).

users (86%) in their USA study, and 92% were receiving treatment [9]. It is possible that underdetection and undertreatment is greater in Europe, or that differences in recruitment between the studies influenced the results. Houston *et al.* initially recruited volunteers through an advertisement for participation in a study about depression in online communities, and then surveyed them [9]. It is possible that their method of sampling was more likely to recruit individuals with depression than our method of offering a survey to all community users. It is also possible that those people who responded to an advert to register their interest in a research study might be people who were more likely to engage with formal health services compared with our sample.

Our study was conducted in the summer months and seasonal rates of depression will vary, particularly in northern latitudes [13]. As indicated in our background section previous studies have also shown that the majority of users of similar communities are female [8-10]. Women are more likely to suffer from depression [14], and are

more likely than men to use the Internet for health information [15].

One major limitation of web-based surveys is determining the representativeness of results. As users are anonymous and repeat visits to websites are frequent, response rates are difficult to obtain and are typically low. Our study surveyed a convenience sample of a cross-section of users, but volunteer self-completion surveys on the Internet are prone to selection bias [16]. We attempted to minimise this by making the survey brief and explaining the importance of receiving views from all users. However respondents may differ from non-respondents, for example in terms of educational level or reading ability. We were unable to analyse characteristics of non-respondents. The participation rate cannot be directly compared with a response rate to (for example) a postal survey. The difficulties of low participation rates in web-based health surveys are well recognised [17]. While multiple responses from the same individual were prevented using IP addresses it is likely that the denominator of number of

Table 3: Country comparisons for various measures of mental health service provision.

Compare by Countries	United Kingdom	Sweden	Denmark	Norway	Germany	Austria
Rates of consultation in past year in our study	High	Medium	High	High	Low	Medium
Rates of current treatment in our study	High	Medium	High	Medium	Low	Medium
Presence of therapeutic drug policy/essential list of drugs	present	absent	absent	present	not available	absent
Most important method of financing mental health care	tax based	tax based	tax based	social insurance	social insurance	social insurance
Presence of mental health care facilities in primary care	present	present	present	present	present	present
Presence of community care in mental health	present	present	present	present	present	present
Number of psychiatrists/100,000 population	11	20	16	20	7.3	10
Number of psychologists working in mental health/100,000 population	9	76	85	68	not available	36.9
Number of psychiatric nurses/100,000 population	104	32	59	42	52	38.9
Number of social workers working in mental health/100,000 population	58	not available	7	not available	not available	103.4

Source: Department of Mental Health and Substance Dependence. Mental Health Resources in the World. Project ATLAS. 2002. Geneva, World Health Organization. <http://cvdinfobase.ca/mh-atlas>

pop-up displays includes repeat visits from non-respondents and also from some respondents logging-in on a new occasion. We are not aware of other studies of sensitive health topics such as depression that have used an online pop-up technique to both contact and survey users. The Major Depression Inventory has been validated as a sensitive and specific measure in paper-form [11], and there is no obvious reason why its use as an online tool should differ greatly, although a broader issue is the need for online validation of standard psychometric instruments.

One of the most interesting questions related to our findings is whether web-based surveys across different countries can elicit useful and valid data for public health and health services research. We found significant differences across countries both in regard to the prevalence of depression on online communities and in health service utilization. To what degree are these differences reflecting true differences in disease prevalence and health care systems between countries, or to what degree are the observed differences the result of self-selection bias of the survey participants? Unfortunately there are few cross-national population-based studies containing prevalence data or service utilization data against which we could compare our results.

If the prevalence variations by country of web community are not due to bias or chance the two most likely explanations are either that it reflects cross-national variation in prevalence of depression or that there are intercountry differences in help-seeking behaviour in relation to online

communities. Population prevalence data for depression in each country are not available and international depression prevalence comparisons are problematic [18]. Previous studies have shown limited variation in depression prevalence between countries, but it is unlikely that wide differences would exist between neighbouring Northern European countries such as Sweden and Norway [19]. Differences in online help-seeking behaviour by country could be related to a number of factors including those related to the penetration of Internet uptake among different sub-populations. Other possible influences include how the communities were marketed in each country, and differences in the timing of community use in relation to the stage of illness or recovery. But this is an area with very little empirical research.

Regarding service utilization, we found intercountry variation in consultation rates and use of drug treatment for depression, with Germany in particular having low rates for both. At the country level there is, as one would expect, a positive correlation between consulting in the past year and currently receiving treatment. One possible explanation is that this reflects the availability of formal health services in each country, but there are very few proxy measures available for each country to investigate this. The ones we identified are shown in Table 3. Variations in numbers of psychiatrists per 100000 population (UK 11; SE 20; DK 16; NO 20; DE 7.3; AT 10) [20], might help explain the low utilization rates in Germany but not other differences. There were no consistent patterns between countries on other measures – for example comparing tax-

based health systems (UK, Sweden, Denmark) with social insurance based systems (Norway, Germany, Austria).

Health-related virtual communities may present an opportunity to integrate online detection of mental health morbidity with other services, with significant implications for worldwide healthcare. The Internet could be used as an adjunct to traditional services, or as a medium for interventions such as online cognitive-behavioural therapy, although such interventions are at an early stage of development [21]. Future research could include controlled trials of Internet communities examining effects on measures of health status and well-being, although such studies are difficult to conduct and face issues of contamination [22].

Limitations of Internet communities include abuse by users offering false stories [23], and concerns over the dissemination of inaccurate information [24]. However our findings do not support a view of the Internet as harmful. Few users reported that Internet community use led to delays in help-seeking while more than a third reported that use of the community was actually a factor in deciding to seek help. Furthermore we did not find evidence that online information reduces the trust patients have in their doctors or that it leads to social isolation [25]. We found that many users felt able to discuss subjects that they were unable to discuss elsewhere and some had revealed their depression for the first time on the community. These findings suggest that Internet communities may be a useful tool in providing support services for stigmatizing conditions that inhibit more traditional modes of information seeking.

Competing interests

Dr Powell and Dr Eysenbach have previously carried out work with Netdoktor as Medical Advisors. They have no current financial arrangements with Netdoktor.

Authors' contributions

JP designed and carried out the study, contributed to the analysis and interpretation of data and drafted the manuscript. NM provided statistical expertise, led the analysis and interpretation of data and revised the manuscript; GE contributed to the concept and design of the study, interpreted the data and revised the manuscript. All authors read and approved the final manuscript.

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