

## **International multisite survey on the use of online support groups in bipolar disorder**

Running title: Online support bipolar disorder

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## **Abstract**

*Background:* Peer support is an established component of recovery from bipolar disorder, and online support groups may offer opportunities to expand the use of peer support at the patient's convenience. Prior research in bipolar disorder has reported value from online support groups.

*Aims:* To understand the use of online support groups by patients with bipolar disorder as part of a larger project about information seeking.

*Methods:* The results are based on a one-time, paper-based anonymous survey about information seeking by patients with bipolar disorder, which was translated into 12 languages. The survey was completed between March 2014 and January 2016 and included questions on the use of online support groups. All patients were diagnosed by a psychiatrist. Analysis included descriptive statistics and general estimating equations to account for correlated data.

*Results and conclusions:* The survey was completed by 1222 patients in 17 countries. The patients used the Internet at a percentage similar to the general public. Of the Internet users who looked online for information about bipolar disorder, only 21.0% read or participated in support groups, chats or forums for bipolar disorder (12.8% of the total sample). Given the benefits reported in prior research, clarification of the role of online support groups in bipolar disorder is needed. With only a minority of patients using online support groups, there are analytical challenges for future studies.

## **Background and aim**

Peer support groups are a key component for recovery from mental illness providing supportive relationships, encouragement, a sense of belonging to a community, and recognition of experiential expertise (1). The Internet offers the potential to greatly expand the self-help movement with online support groups, including for patients with bipolar disorder. Online support groups allow participation on the patient's schedule from any location with Internet access, can draw members from a wide audience, and may be preferable to face-to-face groups for those who are socially fearful (2, 3). Online support groups may also increase the participation of those living in rural or sparsely populated areas (4). Patients may be particularly interested in online support groups if they are concerned about stigma, or about what behavior is "normal" in the context of a mental illness (5,6). There is still considerable stigma associated with mental illness, including from the general public, healthcare providers and social service workers (7-9). With the increasing importance of the Internet in the long-term care of bipolar disorder, patient online information seeking activities need to be understood, including participation in support groups.

To clarify online information seeking by patients with bipolar disorder, 1222 patients in 17 countries were surveyed. As reported previously, the patients used the Internet at a percentage similar to that of the general public (10). The Internet users who looked online for information about bipolar disorder also consulted a physician, and most sought traditional sources such as books, handouts and other patients with bipolar disorder (10). The main reasons patients looked online were to obtain information

about drug side effects, to learn anonymously, and for help coping (11). The current analysis will focus on the important question of whether the patients participated in online support groups, chats or forums.

## **Methods**

The treating psychiatrist provided the diagnosis, age of onset, and years of education. All other data came from an anonymous, one-time, 39-question survey completed by the patient that took about 20 minutes to finish. All participants were outpatients. All were recruited locally by their psychiatrist, with no online recruitment, and no incentives to participate. The clinical settings included private practice, community mental health centers, and university clinics. To maximize participation and minimize bias, the survey was paper-based and translated into the local language. The use of paper-based surveys allowed those without Internet knowledge to participate. The survey topics included questions about demographics, living with bipolar disorder, Internet use, online information seeking, as well as participation in online support groups. The clarity of the survey questions was validated during a pilot phase in Dresden. The study was approved by institutional review boards according to local requirements.

The survey was completed between March 2014 and January 2016 by 1222 patients with a diagnosis of bipolar disorder who resided in 17 countries. The survey was translated into 12 local languages: Chinese, Danish, Finnish, French, German, Hebrew, Italian, Japanese, Polish, Portuguese, Spanish, and English (versions for US/Canada, UK and Australia). The 1222 surveys were received from: Australia (N=22), Brazil



(N=100), Canada (N=109), Denmark (N=209), Finland (N=16), France (N=50), Germany (N=82), Hong Kong (N=91), India (N=30), Israel (N=46), Italy (N=80), Japan (N=35), Malaysia (N=25), Poland (N=125), Spain (N=82), UK (N=50), and the US (N=70).

Duplicate data entry was completed for quality control with the paper-based surveys. Automated logic checking of numeric fields was implemented as appropriate. An explanatory model to estimate participation in online support groups was created using the generalized estimating equation (GEE) statistical technique due to imbalances in the number of responses from collection sites, and correlation in survey responses within collection sites. The GEE estimates provided the reported odds ratio and confidence intervals for the model. The variables that were significant at the 0.05 level in univariate analyses were included in the multivariate model estimates. Descriptive statistics were calculated for demographic variables using mean values and standard deviations. SPSS version 23.0 was used for all analyses. **More** details about the project methodology were published previously (10, 11), **and the complete survey can be obtained at:**

<https://journalbipolar disorders.springeropen.com/articles/10.1186/s40345-016-0058-0>

## **Results**

Of the total sample of 1222 patients, 81% were Internet users (976 of 1212 valid responses) (11). Of the Internet users, 77% used the Internet to look up information on bipolar disorder (750 of 972 valid responses). The 750 patients who looked up

information on bipolar disorder online were 62.2% female, age  $41.1 \pm 12.5$  years, had  $14.4 \pm 3.0$  years of education, had  $15.6 \pm 11.6$  years of illness, and 53.6% worked full time (11). Of the 750 patients, 59.7% had a diagnosis of bipolar I disorder, 34.7% of bipolar II disorder and 5.6% of bipolar disorder not otherwise specified.

The survey contained the question "Do you read or participate in online patient support groups, chats or forums for bipolar disorder?" Of the 750 patients who looked up information on bipolar disorder online, 21.0% (157 of 746 valid responses) answered yes. The 157 yes responses are 16.1% of the 976 Internet users, and 12.8% of the total sample of 1222.

In the univariate analyses, most patient demographic variables were not significantly associated with using online support groups including age ( $p=0.332$ ), gender ( $p=0.733$ ), years of illness ( $p=0.569$ ), living alone ( $p=0.393$ ), living in an urban area ( $p=0.654$ ), and working fulltime ( $p=0.117$ ). To explain if patients read or participate in online support groups, the estimated coefficients from the best fitting multivariate model suggest that having attended patient support groups or received group or individual therapy will increase the odds by 104%, searching online for information on bipolar disorder monthly or more frequently will increase the odds by 125%, and having a specific mental health site as a favorite source of information will increase the odds by 93%. **If patients did none of these, the estimated intercept suggests that the odds that patients will read or participate in online support groups are small.** See Table 1.

The survey also contained four questions about the online support group experience. However, only 157 patients read or participated in online support groups. Since the maximum possible number of valid responses to these questions was only 157 from patients in 17 countries, there was not enough data from a statistical perspective to report or reach conclusions.

## **Discussion**

A minority of patients who looked online for information about bipolar disorder read or participated in online support groups, chats or forums (21.0%), or 12.8% of the total sample. This finding is consistent with the results of a US national survey of Internet users, in which 23% of those living with a chronic condition looked for peer support online (12). In the current study, the odds of reading or participating in online support groups were increased if patients had attended any support groups or received psychotherapy, or looked online for information about bipolar disorder monthly or more often. In contrast, the majority of patients looked online for information about bipolar disorder just a couple times a year (11).

The limitations of the survey methodology may bias the findings. All data were self-reported and there was no follow-up discussion of responses. The convenience sample does not reflect the demographic composition of the countries, and the translated versions were not checked for construct validity. People living with bipolar disorder who did not seek professional help did not participate. Patients who were poorly educated, had an unstable living situation, or did not understand the local language may also not

have participated. The impact of the clinical setting could not be determined due to the large differences in the healthcare systems. The survey was administered by the treating psychiatrist, which may be a source of bias. No information was collected on whether physicians recommended online support groups. The survey results cannot be used to establish causality.

The finding that only a minority of patients with bipolar disorder read or participated in online support groups is important. In prior research, some patients with bipolar disorder and other mental illness report considerable emotional support and value from online support groups (2, 3). However, online support groups may also promote unacceptable behaviors (13) and social avoidance (14). The role of online support groups in bipolar disorder, including patient acceptance and participation, and the efficacy, needs to be understood in comparison to alternative approaches. Since only a minority of patients use online support groups, future research will require a much larger sample, along with study of verified participants. Another challenge for future research is that participation in online communities is skewed, following the "90-9-1 rule" such that 90% of participants read but do not create content, 9% rarely create content and 1% of users create the vast majority of content (15). This usage pattern was found in online support groups for bipolar disorder, depression, problem drinking, panic disorder, and smoking cessation (16, 17). In conclusion, only a minority of patients with bipolar disorder read or participate in online support groups. However, positive patient feedback in prior research suggests the need for further study to clarify the role of online support groups in the treatment of bipolar disorder.

## References

1. SAMHSA (Substance Abuse and Mental Health Services Administration - US). National Consensus Statement on Mental Health Recovery. 2004. [cited 2016 Dec 5]. Available from: <http://store.samhsa.gov/shin/content/SMA05-4129/SMA05-4129.pdf>
2. Bauer R, Bauer M, Spiessl H, Kagerbauer T. Cyber-support: an analysis of online self-help forums (online self-help forums in bipolar disorder). *Nord J Psychiatry* 2013;67:185-90.
3. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. *Epidemiol Psychiatr Sci* 2016;25:113-22.
4. Griffiths KM, Christensen H. Internet-based mental health programs: A powerful tool in the rural medical kit. *Aust J Rural Health* 2007;15:81-7.
5. DeAndrea DC. Testing the proclaimed affordances of online support groups in a nationally representative sample of adults seeking mental health assistance. *J Health Commun* 2015;20:147-56.
6. Giles DC, Newbold J. 'Is this normal?' The role of category predicates in constructing mental illness online. *J Comput Mediat Commun* 2013;18:476-90.
7. Jensen KB, Vendsborg P, Hjorthøj C, Nordentoft M. Attitudes towards people with depression and schizophrenia among social service workers in Denmark. *Nord J Psychiatry* 2017 Jan 26:1-6.
8. Mirnezami HF, Jacobsson L, Edin-Liljegren A. Changes in attitudes towards mental disorders and psychiatric treatment 1976-2014 in a Swedish population. *Nord J Psychiatry* 2016;70:38-44.

9. Corrigan PW, Druss BG, Perlick DA. the impact of mental illness stigma on seeking and participating in mental health care. *Psychol Sci Public Interest* 2014;15:37-70.
10. Bauer R, Conell, J, Glenn T, Alda M, Ardaou R, Baune BT, et al. Internet use by patients with bipolar disorder: Results from an international multisite survey. *Psychiatry Res* 2016;242:388-94.
11. Conell J, Bauer R, Glenn T, Alda M, Ardaou R, Baune BT, et al. Online information seeking by patients with bipolar disorder: results from an international multisite survey. *Int J Bipolar Disord* 2016 Dec;4(1):17.
12. Fox S. Peer-to-peer health care. Pew Research 2011. [cited 2016 Dec 5]. Available from: <http://www.pewinternet.org/2011/02/28/peer-to-peer-health-care-2/>
13. Bell V. Online information, extreme communities and internet therapy: Is the internet good for our mental health?. *J Ment Health* 2007;16:445-57.
14. Lawlor A, Kirakowski J. Online support groups for mental health: A space for challenging self-stigma or a means of social avoidance?. *Comput Human Behav* 2014;32:152-61.
15. Nielsen J. The 90-9-1 rule for participation inequality in social media and online communities. Nielsen Norman Group. October 9, 2006. [cited 2016 Dec 5]. Available from: <https://www.nngroup.com/articles/participation-inequality/>
16. Carron-Arthur B, Cunningham JA, Griffiths KM. Describing the distribution of engagement in an Internet support group by post frequency: A comparison of the 90-9-1 Principle and Zipf's Law. *Internet Interv.* 2014;1:165-8.
17. van Mierlo T. The 1% rule in four digital health social networks: an observational study. *J Med Internet Res.* 2014;16:e33.