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Internet use by patients with bipolar disorder: Results from an international multisite survey

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1. Introduction

Patients with serious mental illness want to learn more about their disease (Giacco et al., 2014; Griffiths and Crisp, 2013; Hallett et al., 2013). For example, patients with bipolar disorder are not satisfied with the information provided about possible medication side effects (Bowskill et al., 2007). Information seeking is increasingly recognized as a key coping strategy (Lambert and Loiselle, 2007), including by those with bipolar disorder who function at a high level (Murray et al., 2011). Patient education may improve self-management skills, increase use of medical services and improve treatment adherence for those with bipolar disorder (Druss et al., 2014; Rouget and Aubry, 2007; Vieta, 2005).

The Internet has been recognized by governmental health authorities, health systems and physicians as a transformative tool for patient education, and may be particularly useful for those with a stigmatized illness (Berger et al., 2005). A website offers an economical way to reach large numbers of patients, who can read about topics of interest on their own schedule from any location. Many health websites attract a global audience (Leon and Fontelo, 2006) and are available in multiple languages. There is considerable international investment in web-based initiatives to improve care for bipolar disorder relating to patient education, self-management, and support forums (Bauer et al., 2013; Hidalago-Mazzei et al., 2015; Leitan et al., 2015; Lauder et al., 2015; Nicholas et al., 2015; Parikh and Huniewicz, 2015).

One concern with online education is whether patients with bipolar disorder use the Internet. For example, the percentage of Internet users in the US general public was 84.2% in 2013 (ITU, 2014), but only 35–70% of patients with serious mental illness were reported to be Internet users, although these studies include patients with diagnoses other than bipolar disorder (Borzewski et al., 2009; Carras et al., 2014; Record et al., 2016; Tsai et al., 2014). Another uncertainty is whether patients with bipolar disorder have the appropriate technical skills to successfully navigate the Internet (Monteith et al., 2013).

This survey project aims to better understand how patients with bipolar disorder obtain information about their illness, to characterize the patients with bipolar disorder who use the Internet, and to understand the experience of those who seek information online about bipolar disorder. Since Internet technology is widely available, and resources are used internationally, surveys were collected from many countries. This initial report will focus on two critical questions: (1) "Do you use the Internet?" and (2) "Do you use the Internet to find out about bipolar disorder?" Subsequent reports will focus on the responses to the remaining questions.
2. Methods

2.1. Sample

Patients with a diagnosis of bipolar disorder confirmed by a treating psychiatrist completed an anonymous, one-time, survey. The survey was paper-based to ensure participation of those who do not have access or the skills to use the Internet. The surveys were translated into 12 languages: Chinese, Danish, Finnish, French, German, Hebrew, Italian, Japanese, Polish, Portuguese, Spanish, and English (versions for US/Canada, UK and Australia), and are available from the corresponding author. No incentives were offered to complete the survey. The surveys were given to patients at 31 sites in 17 countries at settings including private practice, university clinics, and community mental health centers. A convenience sample was collected. In total, 1171 surveys were received: from Australia (N = 19), Brazil (N = 87), Canada (N = 109), Denmark (N = 209), Finland (N = 16), France (N = 50), Germany (N = 82), Hong Kong (N = 61), India (N = 30), Israel (N = 46), Italy (N = 80), Japan (N = 35), Malaysia (N = 25), Poland (N = 125), Spain (N = 82), UK (N = 45), and the US (N = 70). This study was approved by institutional review boards in accordance with local requirements. The surveys were collected between March 2014 and August 2015.

2.2. Survey

The survey contains 39 questions and takes about 20 minutes to complete. The questions covered demographics, living with bipolar disorder, information sources, use of the Internet, and participation in online support groups. The clarity of the questions was validated during a pilot phase in Dresden. Conditional branching was used for efficient survey navigation, so respondents would skip questions that did not apply, and to allow follow-up questions to both Yes and No responses. Questions to measure internal consistency were included. Duplicate data entry was used to prevent data entry errors from paper forms (Kawado et al., 2003; Neaton et al., 1990). Automatic logic checking of numeric fields was implemented as appropriate. The diagnosis, age of onset, and years of education were provided by the physician for each patient.

2.3. Country variables

In addition to individual variables from the survey responses, country specific variables were analyzed to better understand the international sample. These included variables about the telecommunications infrastructure such as the average connect speed, percent Internet users, percent households with computers (ITU, 2014), and the Internet user age gap (ITU, 2013). The Internet user age gap is the ratio of the number of Internet users aged 15–24 years to the number of Internet users in the total population. In a developed country, there is little age gap and the Internet use for the general population is similar to that of the young. In an underdeveloped country, many more young people use the Internet, exaggerated by the demographic youth bulge often present. In this sample, the age gap varied from 1.1 in Canada, Denmark, Finland and UK, to 2.2 in India.

Other country specific data consisted of economic variables including the GDP (gross domestic product) per capita and Gini index of income inequality (World Bank, 2015), education variables including the mean years of education for adults aged ≥ 25 years (UNESCO, 2015), education ratio (for those aged ≥ 25 years, patient years of education compared to the mean years of education for the general population), and cultural variables from the Inglehart world values survey (World Values Survey, 2015).

2.4. Statistical analysis

Generalized estimating equations (GEE) were used to model if patients with bipolar disorder used the Internet, and if the patients who used the Internet searched online for information about bipolar disorder. The GEE approach was selected to account for both the correlation in survey responses among the international collection sites, and the unbalanced numbers of patients. GEE models were estimated using a binomial distribution, independent working correlation matrix and a logit link function. The potential variables from univariate analyses that were significant at a level of 0.05 were entered into multivariate models. Many individual and country specific variables were similar and correlated. The corrected quasi-likelihood independence model criterion was used to assist with multivariate model fitting (Pan, 2001). The odds ratios and confidence intervals generated by the GEEs are reported.

Some of the multiple choice survey responses were dichotomized for analysis (e.g. very confident in one’s ability to live with bipolar disorder versus somewhat and not at all).

Descriptive statistics such as percentages are reported for demographic variables and survey responses. SPSS version 23.0 was used for all analyses.

3. Results

3.1. Demographics

The survey was completed by 1171 patients with a mean age of 44.4 ± 13.9 years. Of the 1171 patients, 62.2% were female and 37.8% were male, and they completed a mean of 14.0 ± 3.2 years of education. The patients had a mean of 17.3 ± 12.2 years of illness with bipolar disorder. The demographic characteristics of the 1171 patients are shown in Table 1. The patients consulted with a mean of 1.8 medical professionals: a psychiatrist (1018, 90.2%), a psychologist (357, 31.6%), a primary care physician (320, 28.3%), a counselor or therapist (134, 11.9%), a pharmacist (79, 7.0%), a religious counselor (64, 5.7%), an alternative medicine practitioner (31, 2.7%), and other (125, 11.1%).

3.2. Sources of information

In addition to professional advice, the patients were asked to identify other sources of information with a general question: “Do you use any of these resources to find out about bipolar disorder? “ 1114 patients responded that they consulted the following sources: the Internet (695, 62.4%), other people with bipolar disorder (423, 38.0%), books (413, 37.1%), pamphlets or handouts from doctors (393, 35.3%), newspaper or magazine articles (384, 34.5%), friends and family (365, 32.8%), television or radio (275, 24.7%), telephone helplines (21, 1.9%), and other (103, 9.2%). The patients who used the Internet consulted a mean of 2.3 sources of information (excluding the Internet), while the patients who did not use the Internet consulted a mean of 1.6 sources.

3.3. Use of the Internet

The survey also contained a specific question “Do you use the Internet? “ Of the 1171 patients, 941 (81.1%) responded that they used the Internet. These patients completed more years of education than the mean years of education in their country (education ratio 1.3 ± 0.4 for those over ≥ 25 years). In univariate models, gender was not significant, but many country telecommunications, educational and cultural variables, and some survey responses were significant. In general, telecommunications
variables had more impact than cultural variables. The best fitting model for the use of the Internet is shown in Table 2, and includes age, years of education and age gap. The estimated coefficients suggested that a one year increase in education will decrease the odds of using the Internet by 27%, while a one year increase in age will decrease the odds of using the Internet by 10%. A one unit increase in the age gap will decrease the odds of using of the Internet by 27%, while a one year increase in education will increase the odds of using of the Internet by 14.0%.

### Table 1
Patient demographics (N=1171).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>BP I</td>
<td>728</td>
<td>63.2</td>
</tr>
<tr>
<td></td>
<td>BP II</td>
<td>372</td>
<td>32.3</td>
</tr>
<tr>
<td></td>
<td>BP NOS</td>
<td>52</td>
<td>4.5</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>726</td>
<td>62.2</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>441</td>
<td>37.8</td>
</tr>
<tr>
<td>Area of residence</td>
<td>Urban</td>
<td>699</td>
<td>60.0</td>
</tr>
<tr>
<td></td>
<td>Suburban</td>
<td>286</td>
<td>24.5</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>180</td>
<td>15.5</td>
</tr>
<tr>
<td>Employment status</td>
<td>Full-time</td>
<td>321</td>
<td>27.9</td>
</tr>
<tr>
<td></td>
<td>Part-time</td>
<td>135</td>
<td>11.7</td>
</tr>
<tr>
<td></td>
<td>Student</td>
<td>85</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>146</td>
<td>12.7</td>
</tr>
<tr>
<td></td>
<td>Receives disability</td>
<td>198</td>
<td>17.2</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>169</td>
<td>14.7</td>
</tr>
<tr>
<td></td>
<td>Not in work force</td>
<td>96</td>
<td>8.3</td>
</tr>
<tr>
<td>Marital status</td>
<td>Single</td>
<td>404</td>
<td>34.8</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>432</td>
<td>37.2</td>
</tr>
<tr>
<td></td>
<td>Living with partner</td>
<td>139</td>
<td>12.0</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>126</td>
<td>10.9</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>25</td>
<td>2.2</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>35</td>
<td>3.0</td>
</tr>
<tr>
<td>Income group</td>
<td>Upper income</td>
<td>79</td>
<td>6.8</td>
</tr>
<tr>
<td></td>
<td>Middle income</td>
<td>578</td>
<td>49.9</td>
</tr>
<tr>
<td></td>
<td>Lower income</td>
<td>501</td>
<td>43.3</td>
</tr>
<tr>
<td>Live alone</td>
<td>Yes</td>
<td>293</td>
<td>25.2</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>868</td>
<td>74.8</td>
</tr>
<tr>
<td>Mood in last six months</td>
<td>Mostly normal</td>
<td>555</td>
<td>47.8</td>
</tr>
<tr>
<td></td>
<td>Mostly depressed</td>
<td>299</td>
<td>25.7</td>
</tr>
<tr>
<td></td>
<td>Mostly manic</td>
<td>41</td>
<td>3.5</td>
</tr>
<tr>
<td></td>
<td>Mostly manic and depressed</td>
<td>267</td>
<td>23.0</td>
</tr>
<tr>
<td>BP interfered with regular activities</td>
<td>Frequently</td>
<td>391</td>
<td>33.6</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>342</td>
<td>29.4</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>229</td>
<td>19.7</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>203</td>
<td>17.4</td>
</tr>
<tr>
<td>Confident managing living</td>
<td>Very confident</td>
<td>441</td>
<td>38.0</td>
</tr>
<tr>
<td></td>
<td>Somewhat confident</td>
<td>567</td>
<td>48.9</td>
</tr>
<tr>
<td></td>
<td>Not confident at all</td>
<td>152</td>
<td>13.1</td>
</tr>
<tr>
<td>Confident when to see doctor</td>
<td>Very confident</td>
<td>677</td>
<td>58.1</td>
</tr>
<tr>
<td></td>
<td>Somewhat confident</td>
<td>426</td>
<td>36.6</td>
</tr>
<tr>
<td></td>
<td>Not confident at all</td>
<td>62</td>
<td>5.3</td>
</tr>
</tbody>
</table>

* Missing values not included.

### Table 2
Model of patient Internet use (N=1138).

<table>
<thead>
<tr>
<th>Data</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categorical data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use the Internet?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>922</td>
<td>81.0</td>
</tr>
<tr>
<td>No</td>
<td>216</td>
<td>19.0</td>
</tr>
<tr>
<td>Continuous data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1138</td>
<td>44.4 (13.8)</td>
</tr>
<tr>
<td>Years of education</td>
<td>1138</td>
<td>14.0 (3.2)</td>
</tr>
<tr>
<td>Age gap</td>
<td>1138</td>
<td>1.3 (0.2)</td>
</tr>
</tbody>
</table>

* Missing values not included.

**3.4. Seeking information online**

For those who use the Internet, the survey contains another specific question: “Do you use the Internet to find out about bipolar disorder?” Of the 941 patients who used the Internet, 728 (77.7%) used the Internet to find out about bipolar disorder. In a follow-up question of the 220 patients who did not use the Internet, the reasons were: they never learned (105, 52.8%), it’s too technical (27, 13.6%), lack of access (72, 36.2%), friends go online for them (40, 20.1%), anxiety (15, 7.5%), and other reasons (40, 20.1%).

**4. Discussion**

With 81% of this study population using the Internet, the percentage of people with bipolar disorder who are Internet users is Internet by 96%. Most of the patients who did not use the Internet lacked technical skills. In a follow-up question of the 220 patients who did not use the Internet, the reasons were: they never learned (105, 52.8%), it’s too technical (27, 13.6%), lack of access (72, 36.2%), friends go online for them (40, 20.1%), anxiety (15, 7.5%), and other reasons (40, 20.1%).

There was internal consistency between responses to the questions about the Internet and age, years of education, and the age gap. The estimated coefficients suggested that a one unit increase in education ratio will decrease the odds of using the Internet by 27%, while a one year increase in age will decrease the odds of using of the Internet by 27%, while a one year increase in education will increase the odds of using of the Internet by 14.0%.
Table 3
Model of seeking information on bipolar disorder by Internet users (N=833).a

<table>
<thead>
<tr>
<th>Survey question: Do you use the Internet to find out about bipolar disorder?</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categorical data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use the Internet to find out about bipolar disorder?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>641</td>
<td>77.0</td>
</tr>
<tr>
<td>No</td>
<td>192</td>
<td>23.0</td>
</tr>
<tr>
<td>Ever attended any patient support groups?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>483</td>
<td>58.0</td>
</tr>
<tr>
<td>No</td>
<td>350</td>
<td>42.0</td>
</tr>
<tr>
<td>Very confident about managing living with BP?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>312</td>
<td>37.5</td>
</tr>
<tr>
<td>No</td>
<td>521</td>
<td>62.5</td>
</tr>
<tr>
<td>Continuous data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education ratioc</td>
<td>833</td>
<td>1.3 (0.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Significance</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education ratio</td>
<td>0.024</td>
<td>0.536</td>
<td>0.312, 0.923</td>
</tr>
<tr>
<td>Attend support group</td>
<td>0.027</td>
<td>1.419</td>
<td>1.040, 1.937</td>
</tr>
<tr>
<td>Confident managing BP</td>
<td>0.001</td>
<td>0.686</td>
<td>0.547, 0.859</td>
</tr>
</tbody>
</table>

a Only includes responses if the patient used the Internet.
b Very confident as compared to somewhat confident or not confident at all.
c Ratio of patient years of education to the mean country years of education.
d Model estimated using GEE with binomial distribution, a logit link function and an independent working correlation matrix.

about the same as for the general public (ITU, 2014). For background comparison, the mean percentage of Internet users in 2013 for the European Union, North America, Australia and Japan ranged between 76–86% (ITU, 2014). Additionally, the variables in this study that are most associated with increasing the odds (younger age, more years of education) or decreasing the odds (age gap) of Internet use are consistent with those reported previously for international samples. Most of the patients in this study who do not use the Internet either do not know how, or do not have access. Although gender did not affect the odds of using the Internet in this study, the International Telecommunications Union (ITU) reports an 11% gender gap in technology use globally, based on a 2% gap in developed countries and 16% gap in developing countries (ITU, 2013).

Of the 81% who used the Internet in this study, 78% searched for information about bipolar disorder online. Similarly, about 70–80% of Internet users in seven European countries, Japan and the US, searched for health information on the Internet (Andreassen et al., 2007; Harris Interactive, 2002; Pew Research, 2013; Rock Health, 2015). In this study, any participation in patient support groups and educational classes increased the odds of using the Internet as an information source. Prior research has noted the importance of peer-to-peer access to those who seek health information on the Internet (Ziebland and Wyke, 2012). Many view the possibility of learning from lay people as well as professionals, reading first-person accounts, and making contact with peers as key benefits of seeking health information online. A majority of the US public who look online for health information prefer to turn to lay people on the Internet rather than to professionals for emotional support in dealing with an illness (Pew Research, 2013). Another finding of the current study was that feeling very confident in the ability to manage living with bipolar disorder decreased the odds of searching the Internet for information. Among Internet users, age did not significantly change the odds of searching for information on bipolar disorder.

In this study, the patients who used the Internet were well educated, similar to previous findings that educational achievement in patients with bipolar disorder was higher than in the general public (Kogan et al., 2004; Mitchell et al., 2009). Notably, as the ratio of years of education increased in relation to the country mean years of education, the odds of seeking information on bipolar disorder online decreased. One issue for very educated patients may be that materials presented on websites for the general public are too basic. For example, much information available on MedlinePlus is written at a 5th to 8th grade level (MedlinePlus, 2015). Other issues may be concerns about information accuracy (Barnes et al., 2009; Monteith et al., 2013; Prusti et al., 2012), or about privacy due to routine leakage of personal data to unregulated commercial enterprises (Huesch, 2013; Libert, 2015). The primary reason given by Internet users who did not seek information online about bipolar disorder was that they prefer to rely on information from a doctor. This implies that these patients have a strong trust in their psychiatrist, are able to communicate effectively, and highly regard individualized treatment advice.

Overall, in this study, 63% of the patients searched for information on bipolar disorder on the Internet. Bipolar disorder may be associated with exceptional baseline intellectual ability (Gale et al., 2013; MacCabe et al., 2010) and creativity (Kyaga et al., 2011), or with cognitive dysfunction (Goswami et al., 2006; Martínez-Arán et al., 2004) and impairment of social skills (Grande et al., 2016; Martini et al., 2013; Samanez et al., 2012). The Internet cannot be thought of as a one-size-fits-all medium for distributing information to such a diverse group of patients. The design of websites about bipolar disorder should be tailored to a target audience, including the readability, visual appeal, ease of use and accessibility (CDC, 2012), with an understanding of the readership consequences of the selected approach.

The Internet offers a unique opportunity to educate at many levels, from basic to scientific. However, the Internet is just one of multiple sources used by patients to learn about bipolar disorder. This use of multiple sources of health information is consistent with findings from the general public (Paek and Hove, 2014; Rains and Ruppel, 2013) including college students (Percheski and Hargittai, 2011). In the current study, all patients consulted a physician. The 63% of the patients who used the Internet consulted more additional sources of information on bipolar disorder. This suggests that online access enables people to find new sources of information, and complements but does not replace other sources (Percheski and Hargittai, 2011). Other information sources remain important. It would be optimal for clinicians to provide patients with a list of trusted information sources on bipolar disorder for a variety of media.

4.1. Limitations

All data were self-reported, and there was no opportunity to discuss responses to individual questions. The survey was collected as a convenience sample which may bias the results since the survey participants do not reflect the demographic compositions of the countries. Due to recruitment of many patients at academic medical centers, there may also be a selection bias related to gender and education levels. There is no data on how many patients were approached and refused to participate, which may have uncovered bias. This study did not include patients with bipolar disorder who do not seek professional help, who may be less educated or have a less stable living situation. Patient dissatisfaction is associated with increased online searching for health information (Tustin, 2010). However, this survey was administered by the treating psychiatrist so questions on patient
satisfaction were omitted. This survey cannot be used to establish causality. This survey does not provide details on patient preferences for other information sources. The use of technology is changing rapidly and estimates should be repeated in a few years.

5. Conclusion

In conclusion, the percentage of patients with bipolar disorder who use the Internet, and of Internet users who search for health information is similar to the general public. Overall, 63% of the patients used the Internet to search for information on bipolar disorder. Patients use multiple sources to obtain information about bipolar disorder, including physicians, the Internet, other patients, printed media and television. The Internet may increase exposure to information sources on bipolar disorder, as patients who use the Internet consult more sources. While the Internet offers unique opportunities to reach patients with bipolar disorder, trusted sources of information are still needed on a variety of media.

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