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Internet use by patients with bipolar disorder

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

Rita Bauer^{a1}, Jörn Conell^{a1}, Tasha Glenn^b, Martin Alda^c, Raffaella Ardu^d, Bernhard T Baune^e, Michael Berk^{f,g,h,i,j}, Yuly Bersudsky^k, Amy Bilderbeck^l, Alberto Bocchetta^m, Letizia Bossiniⁿ, Angela M Paredes Castro^{f,g}, Eric YW Cheung^o, Caterina Chillotti^d, Sabine Choppin^p, Maria Del Zompo^m, Rodrigo Dias^q, Seetal Dodd^{f,g,h}, Anne Duffy^r, Bruno Etain^s, Andrea Fagioliniⁿ, Miryam Fernández Hernandez^t, Julie Garnham^c, John Geddes^l, Jonas Gildebro^u, Ana Gonzalez-Pinto^t, Guy M Goodwin^l, Paul Grof^{v,w}, Hirohiko Harima^x, Stefanie Hassel^y, Chantal Henry^{s,z}, Diego Hidalgo-Mazzei^{aa}, Vaisnvy Kapur^{ab}, Girish Kunigiri^{ac}, Beny Lafer^d, Erik R Larsen^u, Ute Lewitzka^a, Rasmus W Licht^{ad,ae}, Anne Hvenegaard Lund^u, Blazej Misiak^{af}, Scott Monteith^{ag}, Rodrigo Munoz^{ah}, Takako Nakanotani^{ai}, René E Nielsen^{ad}, Claire O'Donovan^c, Yasushi Okamura^x, Yamima Osher^k, Andreas Reif^{aj}, Philipp Ritter^a, Janusz K Rybakowski^{ak}, Kemal Sagduyu^{al}, Brett Sawchuk^r, Elon Schwartz^{am}, Ángela M Scippa^{an}, Claire Slaney^c, Ahmad H Sulaiman^{ao}, Kirsi Suominen^{ap}, Aleksandra Suwalska^{ak}, Peter Tam^{aq}, Yoshitaka Tatebayashi^{ai}, Leonardo Tondo^{ar,as}, Eduard Vieta^{aa}, Maj Vinberg^{at}, Biju Viswanath^{au}, Julia Volkert^{aj}, Mark Zetin^{av}, Peter C Whybrow^{aw}, Michael Bauer^{ax} (corresponding author)

Corresponding author: Michael Bauer, MD, PhD; michael.bauer@uniklinikum-dresden.de)

¹equal contribution

^aDepartment of Psychiatry and Psychotherapy, Universitätsklinikum Carl Gustav Carus, Technische Universität Dresden, Germany

^bChronoRecord Association, Fullerton, CA, USA

^cDepartment of Psychiatry, Dalhousie University, Halifax, Nova Scotia, Canada

^dUnit of Clinical Pharmacology, University Hospital of Cagliari, Cagliari, Italy

^eDiscipline of Psychiatry, School of Medicine, University of Adelaide, Adelaide, SA, Australia

^fIMPACT Strategic Research Centre, School of Medicine, Deakin University, Geelong, VIC, Australia

^gUniversity Hospital Geelong, Barwon Health, Geelong VIC, Australia

^hDepartment of Psychiatry, The University of Melbourne, Parkville, VIC, Australia

ⁱFlorey Institute of Neuroscience and Mental Health, Parkville, VIC, Australia

^jOrygen Youth Health Research Centre, Parkville, VIC, Australia

^kDepartment of Psychiatry, Faculty of Health Sciences, Ben Gurion University of the Negev; Beer Sheva Mental Health Center, Beer Sheva, Israel

^lDepartment of Psychiatry, University of Oxford, Warneford Hospital, Oxford, UK

^mSection of Neurosciences and Clinical Pharmacology, Department of Biomedical Sciences, University of Cagliari, Sardinia, Italy

- ⁿDepartment of Molecular Medicine and Department of Mental Health (DAI) and University of Siena and University of Siena Medical Center (AOUS), Siena, Italy
- ^oDepartment of General Adult Psychiatry, Castle Peak Hospital, Hong Kong
- ^pAP–HP, Hôpitaux Universitaires Henri-Mondor, Créteil, France
- ^qBipolar Disorder Research Program, Department of Psychiatry, University of São Paulo Medical School, São Paulo, Brazil
- ^rDepartment of Psychiatry, University of Calgary, Calgary, Canada
- ^sAP–HP, Hôpitaux Universitaires Henri-Mondor, INSERM U955 (IMRB), Université Paris Est, Créteil, France
- ^tDepartment of Psychiatry, University Hospital of Alava, University of the Basque Country, CIBERSAM, Vitoria, Spain
- ^uDepartment of Affective Disorders, Q, Mood Disorders Research Unit, Aarhus University Hospital, Denmark
- ^vMood Disorders Center of Ottawa, Ottawa, Canada
- ^wDepartment of Psychiatry, University of Toronto, Ontario, Canada
- ^xDepartment of Psychiatry, Tokyo Metropolitan Matsuzawa Hospital, Setagaya, Tokyo, Japan
- ^yDepartment of Psychology & Aston Brain Centre, Aston University, Birmingham, UK
- ^zInstitut Pasteur, Unité Perception et Mémoire, F-75015 Paris, France
- ^{aa}Bipolar Disorders Program, Hospital Clinic, University of Barcelona, IDIBAPS, CIBERSAM, Barcelona, Catalonia, Spain
- ^{ab}Department of Clinical Psychology, NIMHANS, Bangalore-560029, India
- ^{ac}Leicestershire Partnership NHS Trust, Leicester, UK
- ^{ad}Aalborg University Hospital, Psychiatry, Aalborg, Denmark
- ^{ae}Department of Clinical Medicine, Aalborg University, Aalborg, Denmark
- ^{af}Department of Psychiatry, Wroclaw Medical University, Wroclaw, Poland
- ^{ag}Michigan State University College of Human Medicine, Traverse City Campus, Traverse City, MI, USA
- ^{ah}Department of Psychiatry, University of California San Diego, San Diego, CA USA
- ^{ai}Affective Disorders Research Project, Tokyo Metropolitan Institute of Medical Science, Setagaya, Tokyo, Japan
- ^{aj}Department of Psychiatry, Psychosomatic Medicine and Psychotherapy, University Hospital Frankfurt, Goethe-University Frankfurt am Main, Germany
- ^{ak}Department of Adult Psychiatry, Poznan University of Medical Sciences, Poznan, Poland
- ^{al}Department of Psychiatry, University of Missouri Kansas City School of Medicine, Kansas City, MO, USA
- ^{am}Croton on Hudson, NY, USA
- ^{an}Department of Neuroscience and Mental Health, Federal University of Bahia, Salvador, Brazil
- ^{ao}Department of Psychological Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia
- ^{ap}City of Helsinki, Department of Social Services and Health Care, Psychiatry, Helsinki, Finland
- ^{aq}Department of Psychiatry, Department of Medicine, University of Hong Kong, Hong Kong

^{ar}Harvard Medical School–McLean Hospital, Boston, MA, USA

^{as}Lucio Bini Center, Cagliari e Roma, Italy

^{at}Psychiatric Center Copenhagen, Copenhagen, Denmark

^{au}Department of Psychiatry, NIMHANS, Bangalore-560029, India

^{av}Department of Psychology, Chapman University, Orange, CA, USA

^{aw}Department of Psychiatry and Biobehavioral Sciences, Semel Institute for Neuroscience and Human Behavior University of California Los Angeles (UCLA), Los Angeles, CA, USA

Corresponding author:

Michael Bauer, MD, PhD, Department of Psychiatry and Psychotherapy,

Universitätsklinikum Carl Gustav Carus, Technische Universität Dresden, Germany

Fetscherstr. 74, 01307 Dresden, Germany. Phone: +49–351– 458-0, Fax: +49-30-450-

51 79 62; michael.bauer@uniklinikum-dresden.de

Abstract

There is considerable international interest in online education of patients with bipolar disorder, yet little understanding of how patients use the Internet and other sources to seek information. 1171 patients with bipolar disorder diagnosis in 17 countries completed a paper-based, anonymous survey. 81% of the patients used the Internet, a percentage similar to the general public. Older age, less education, and challenges in country telecommunications infrastructure and demographics decreased the odds of using the Internet. About 78% of the Internet users looked online for information on bipolar disorder or 63% of the total sample. More years of education in relation to the country mean, and feeling very confident about managing life decreased the odds of seeking information on bipolar disorder online, while having attended support groups increased the odds. Patients who looked online for information on bipolar disorder consulted medical professionals plus a mean of 2.3 other information sources such as books, physician handouts, and others with bipolar disorder. Patients not using the Internet consulted medical professionals plus a mean of 1.6 other information sources. The percentage of patients with bipolar disorder who use the Internet is about the same as the general public. Other information sources remain important.

Key words: bipolar disorder, internet, world wide web, information source

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; Hidalgo-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 (Borzekowski et al., 2009; Carras et al., 2014; Record et al., 2015; 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 undeveloped 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 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 increase the odds of using of the Internet by 27%, while a one year increase in age will decrease the odds of using of the Internet by 10%. A one unit increase in the age gap will decrease the odds of using of the 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%).

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 univariate models, gender was not significant, but some country telecommunications, education and survey responses were significant. The best fitting model for the use of the Internet to find out about bipolar disorder is shown in Table 3, and includes education ratio, attending a support group, and confidence in managing living with bipolar disorder. The estimated coefficients suggested that a one year increase in education ratio will decrease odds of using of the Internet to find out about bipolar disorder by 46%. Ever

having attended a support group or class will increase the odds of using the Internet to find out about bipolar disorder by 42%, and being very confident in the ability to manage living with bipolar disorder will decrease the odds by 31%. In a follow-up question of the Internet users who did not look online for information about bipolar disorder, the reasons were: they prefer to rely on information from their doctor (143, 72.6%), they distrust the information (42, 21.3%), there is too much information (32, 16.2%), it is too hard to concentrate (12, 6.1%), they have privacy concerns (10, 5.1%), there is nothing of interest (8, 4.1%), they do not know how to search (7, 3.6%) and other reasons (47, 23.9%).

There was internal consistency between responses to the questions about the using the Internet to find about bipolar disorder. The response to the general question on information sources was 62.4% while the calculated percent from the specific questions was 63.0% ($63.0\% = 81.1\% * 77.7\%$).

4. Discussion

With 81% of this study population using the Internet, the percentage of people with bipolar disorder who are Internet users is 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., 2015; Martini et al., 2013; Samamé 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 was 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. 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.

4.2 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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Table 1. Patient demographics (N=1171)

Variable	Value	N*	%
Diagnosis			
BP I		728	63.2
BP II		372	32.3
BP NOS		52	4.5
Gender			
Female		726	62.2
Male		441	37.8
Area of residence			
Urban		699	60.0
Suburban		286	24.5
Rural		180	15.5
Employment status			
Full-time		321	27.9
Part-time		135	11.7
Student		85	7.4
Unemployed		146	12.7
Receives disability		198	17.2
Retired		169	14.7
Not in work force		96	8.3
Marital status			
Single		404	34.8
Married		432	37.2
Living with partner		139	12.0
Divorced		126	10.9
Separated		25	2.2
Widowed		35	3.0
Income group			
Upper income		79	6.8
Middle income		578	49.9
Lower income		501	43.3
Live alone			
Yes		293	25.2
No		868	74.8
Mood in last six months			
Mostly normal		555	47.8
Mostly depressed		299	25.7
Mostly manic		41	3.5
Mostly manic and depressed		267	23.0
BP interfered with regular activities			
Frequently		391	33.6
Sometimes		342	29.4
Rarely		229	19.7

Never	203	17.4
Confident managing living		
Very confident	441	38.0
Somewhat confident	567	48.9
Not confident at all	152	13.1
Confident when to see doctor		
Very confident	677	58.1
Somewhat confident	426	36.6
Not confident at all	62	5.3
	N*	Mean (SD)
Age	1166	44.4 (13.9)
Years of education	1152	14.0 (3.2)
Age of onset	1153	27.1 (10.8)

* Missing values not included.

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

Survey question: Do you use the Internet?

Data		
Categorical Data	N	%
Do you use the Internet?		
Yes	922	81.0
No	216	19.0
Continuous Data	N	Mean (SD)
Age	1138	44.4 (13.8)
Years of education	1138	14.0 (3.2)
Age gap**	1138	1.3 (0.2)

* Missing values not included.

** Ratio of youth (15-24) to overall Internet users.

Estimated Model***

Parameter	Significance	OR	95% CI
Age	< 0.001	0.904	0.887, 0.922
Years of education	< 0.001	1.271	1.187, 1.360
Age gap	< 0.001	0.036	0.013, 0.098

*** Model estimated using GEE with binomial distribution, a logit link function and an independent working correlation matrix.

Table 3. Model of seeking information on bipolar disorder by Internet users (N=833)*

Survey question: Do you use the Internet to find out about bipolar disorder?

Data

Categorical Data	N	%
Do you use the Internet to find out about bipolar disorder?		
Yes	641	77.0
No	192	23.0
Ever attended any patient support groups?		
Yes	483	58.0
No	350	42.0
Very confident about managing living with BP?**		
Yes	312	37.5
No	521	62.5
Continuous Data	N	Mean (SD)
Education ratio***	833	1.3 (0.4)

* Only includes responses if the patient used the Internet.

** Very confident as compared to somewhat confident or not confident at all.

*** Ratio of patient years of education to the mean country years of education.

Estimated Model***

Parameter	Significance	OR	95% CI
Education ratio	0.024	0.536	0.312, 0.923
Attend support group	0.027	1.419	1.040, 1.937
Confident managing BP	0.001	0.686	0.547, 0.859

*** Model estimated using GEE with binomial distribution, a logit link function and an independent working correlation matrix

Highlights

- Paper-based survey on Internet usage of 1171 patients with BP from 17 countries
- The percentage of Internet users is similar to that of the general public (81%).
- 78% of Internet users searched for information about BP, or 63% of total sample.
- All patients used multiple sources of information about BP.
- Web sites about BP are valuable, but other information sources remain important.