

# Credible, centralized, safe, and stigma-free: What youth with bipolar disorder want when seeking health information online

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## Abstract

**Objective** The Bipolar Youth Action Project (BYAP) is a two-year, youth-driven study. Our research explored: 1) bipolar disorder (BD) self-management strategies that are effective for Vancouver Island youth with BD; and 2) methods preferred by youth participants for sharing these strategies with their communities and support circles.

**Methods** The study employed a group of seven Youth Action Group members with BD who worked with the research team in a Community-Based Participatory Research (CBPR) framework. In collaboration, we designed and executed two Vancouver Island-based Research Forums, inviting youth with BD from the wider community to share their knowledge on self-management. Qualitative (focus group), consultation (World Café), and arts-based (graphic recording) methods were utilized. Qualitative findings underwent thematic analysis within a CBPR orientation.

**Results** Twenty-nine youth participants with BD were recruited to the two forums. Focus group findings identified five overarching themes, including ‘sources of self-management strategies.’ Half of the focus group participants described using online sources to either learn more about self-management or to strengthen their social support networks. World Café consultations indicated that, while participants primarily used online sources for mental health information, they experienced barriers, namely stigma and difficulty finding credible, safe, and evidence-informed information.

**Conclusion** Youth engagement in BD research and knowledge exchange is feasible. Moreover, youth with BD have constructive and important insights to share which, if harnessed, will help the research community to develop appropriate, effective, and safe online mental health spaces for future generations.

## Introduction

With the exponential rise in internet use, people are increasingly searching for health-related information online.<sup>1</sup> The internet may be a particularly valuable health communication and education tool for populations affected by stigmatized illnesses.<sup>2,3</sup>

Seeking mental health information online may be particularly attractive to people experiencing bipolar disorder (BD).<sup>4</sup> BD, a mood disorder characterized by episodes of depression and/or mania/hypomania, affects around half a million Canadians<sup>5</sup> and is often accompanied by diminished social support, stigma, and reduced quality of life (QoL).<sup>6-8</sup> Onset of BD typically occurs in young adulthood. Recent research has shown that, unlike in multiple episode or ‘late stage’ BD, QoL remains relatively well preserved early in the course of the condition,<sup>5,9</sup> suggesting that there is a critical window of opportunity for early intervention and support. To our knowledge, however, no research has yet explored how best to help youth with BD access online mental health information.

Youth are clearly heavy users of the internet, with 93% online regularly.<sup>10</sup> Developing online mental health information targeted toward youth makes sense due to commonly cited barriers to help-seeking, such as low mental health literacy, concerns regarding stigma, and preferences for self-reliance.<sup>11</sup> Yet, to our knowledge, no research

has yet explored online mental health information specifically for youth living with BD.

This article presents findings from the Bipolar Youth Action Project (BYAP), which was designed to explore: 1) self-management strategies that are effective for youth on Vancouver Island who live with BD; and 2) the best methods for sharing these strategies with other youth, their families, and the wider community. Specifically, this paper shares knowledge from the BYAP project about: 1) how BYAP youth participants currently seek mental health information online, and 2) youth preferences and desires for future developments in the arena of online mental health information provision.

## Materials and methods

### Community-based participatory research

Acknowledging the complexities of BD research and limited multidisciplinary work in this area, we established the Collaborative REsearch Team to study psychosocial issues in BD (CREST.BD) at the University of British Columbia in 2007.<sup>12</sup> CREST.BD includes academic researchers, healthcare providers, and community members who are dedicated to developing knowledge about psychosocial factors in BD through a Community-Based Participatory Research (CBPR) orientation.<sup>12</sup>

CBPR engages with community members with lived experience of an issue or health condition (in this instance, people living with BD and their supporters), with aims of building research capacity and influencing social change.<sup>13</sup> CBPR is based on the premise that collaborating with those with direct involvement and knowledge about an issue under investigation yields findings of relevance to the

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community. Substantial community input is sought throughout the research process.

A clear rationale can be made for the potential benefits of youth engagement in research and evaluation.<sup>14</sup> Indeed, participatory approaches have been used successfully in various areas of youth mental health research.<sup>15,16</sup> Recognizing a gap in the application of CBPR approaches to BD research in youth, we secured funding from the Vancouver Foundation for a two-year CBPR project to build knowledge on effective self-management in youth with BD. Integral to this process was the establishment, at study inception, of a Youth Action Group (YAG) consisting of twelve Vancouver Island-based peer researchers (aged 20 to 25) living with BD (type I, II, or not otherwise specified (NOS)), two of whom acted as co-leads of the YAG. In addition to the YAG, the project team consisted of: two lead researcher team members (EM and AP), a youth engagement expert from London, ON (EC), a graduate student trainee with experience in qualitative methods (KN), and a research coordinator (NE).

The YAG members collaborated with the wider team to design, implement, and evaluate the findings from two research forums held in Victoria, BC on July 12th and November 15th, 2015.

### Forum participants

Forum participants were required to have a (self-reported) diagnosis of BD (type I, II, or NOS), be between 16 and 25 years, and reside primarily on Vancouver Island. Forum II participants included some of the same participants from Forum I, but participants were not required to attend both forums. Ethics approval for BYAP was granted by the University of British Columbia Behavioural Research Ethics Board (H14-00063) and the Island Health Research Ethics Board. Participants aged 19 and over provided written consent; participants aged 16 to 18 provided both their written assent and the written consent of a legal guardian. Both the YAG members and the Forum participants received honoraria for their participation.

**Table 1** | Summary of Forum I demographic and clinical characteristics

Total N	21
<b>Gender</b>	<b>N (%)</b>
Male	6 (28.6%)
Female	14 (66.7%)
Other	1 (4.8%)
<b>Ethnicity</b>	<b>N (%)</b>
Caucasian	14 (66.7%)
Other (Ethiopian-Canadian, Polish-Canadian, Portu- guese-Canadian, Canadian)	5 (24.0%)
Missing	2 (9.5%)
<b>Age M (SD)</b>	21.2 (3.1)
<b>Age of diagnosis M (SD)</b>	17.3 (3.8)
<b>Diagnosis</b>	<b>N (%)</b>
BDI	5 (23.8%)
BDII	6 (28.6%)
BD NOS	7 (33.3%)
Unsure	3 (14.3%)
<b>Employment</b>	<b>N (%)</b>
Student	12 (57.1%)
Employed	4 (19.0%)
Long-term Disability	1 (4.8%)
Unemployed	3 (14.2%)
Other	1 (4.8%)

**Table 2** | Summary of Forum II demographic and clinical characteristics

Total N	8
<b>Gender</b>	<b>N (%)</b>
Male	0 (0.0%)
Female	7 (87.5%)
Other	1 (12.5%)
<b>Ethnicity</b>	<b>N (%)</b>
Caucasian	4 (50.0%)
Other (Filipino-Canadian)	2 (25.0%)
Missing	2 (25.0%)
<b>Age M (SD)</b>	19.9 (1.9)
<b>Age of diagnosis M (SD)</b>	16.6 (1.5)
<b>Diagnosis</b>	<b>N (%)</b>
BDI	0 (0.0%)
BDII	4 (50.0%)
BD NOS	3 (37.5%)
Unsure	1 (12.5%)
<b>Employment</b>	<b>N (%)</b>
Student	5 (62.5%)
Employed	0 (0.0%)
Long-term Disability	1 (12.5%)
Unemployed	1 (12.5%)
Other	1 (12.5%)

M = Mean  
SD = Standard Deviation

**Table 3** | Forum 1 focus group questions

1.	Are there self-management strategies that you have found are helpful for living well with BD?
1a.	Are there strategies that you have found work particularly well for when you're depressed?
1b.	Are there strategies that you have found work particularly well for when you're hypomanic or manic?
2.	In your opinion/experience, are there any strategies that are particularly important or useful for younger people living with BD?
3.	How did you learn about these self-management strategies?
4.	What suggestions for effective self-management would you give to a young person who has been diagnosed with BD? Probe: are there any messages you would want them to know?

### Data collection

#### Forum I Focus Groups

Forum I explored the question of “what self-management strategies are effective for youth on Vancouver Island who live with BD?” Qualitative focus groups were selected as the primary data collection method with the goal of fostering group dialogue in a safe atmosphere. An arts-based approach (graphic recording) was also incorporated. Focus groups (n=5) were semi-structured (see Table 3 for details of focus group questions), 90 minutes in length, and facilitated by an (adult) team member with experience in qualitative methods and a YAG member taking notes. Focus group proceedings were audio recorded and then transcribed verbatim by YAG co-lead LL.

#### Forum II World Café

Forum II explored the question of “what are the best methods for sharing information on self-management strategies with other youth, their families, and the wider community?” The event began with YAG members sharing the knowledge gained in Forum I through presentations, group activities, and arts-based methods. A World Café approach was selected as the primary data collection method for Forum II. World Café involves inviting participants to circulate among several tables, each table with its own host who facilitates a different discussion topic. Participants bring questions or thoughts from previous tables to new ones, allowing for cross-pollination of ideas from which themes may emerge.<sup>17</sup> Forum II World Café tables (n=4) were each devoted to a different medium for sharing self-management information: 1) written, 2) in-person, 3) visual, and 4) social media. Questions posed for each table were: “What media appeal to you?”, “What is and isn't effective about those?”, and “How would you use those to effectively target youth with BD?” Forum participants moved between tables for 20 minute discussions hosted by a research team member with experience in group facilitation. YAG members also participated in the World Café. World Café discussions were recorded and analyzed by LL and research coordinator NE.

#### Forum I analysis

Focus group findings were analyzed using thematic analysis.<sup>18</sup> LL initially reviewed the transcripts for pattern and structure before inductively coding them.<sup>19</sup> The inductive codes were organized into categories, forming the initial coding framework. LL then re-analyzed 25% of the data. LL and KL regularly discussed the coding framework (e.g. during uncertainty around the definition or organization of a code), leading to ongoing refinement of the framework and subsequent themes. As the framework evolved, LL co-analyzed a total of 50% of the data to

ensure internal consistency and analytic validity. The findings presented in this paper are supported by direct quotes from participants to enable readers to evaluate the interpretations. All identifiers have been removed or changed to ensure confidentiality.

### Forum II analysis

World Café group discussions were audio recorded and subsequently analyzed by LL and NE. Concrete ways of information sharing discussed by each group were extracted and organized according to the World Café questions posed: 1) written Media, 2) in-person methods, 3) visual media, 4) social media.

## Results

### Participant characteristics

Forum I recruited 21 participants: fourteen who identified as female, six as male, and one as gender neutral. All participants self-reported as having a diagnosis of BD I, II, or NOS. 3 participants reported having received a diagnosis of BD, though were unsure of their specific diagnostic category. Forum II recruited eight participants; all identified as female except one individual who identified as gender neutral. Diagnostic breakdown by gender for both forums was BD I: 4 females, 2 males; BD II: 1 other gender, 9 females, 0 males; NOS: 6 females, 3 males; unsure of specific BD diagnosis: 3 females, 1 male. All participants from both Forums, except three individuals, resided in Victoria. Full demographic and clinical characteristics of participants are provided in Tables 1 and 2.

### Forum I focus group results

Thematic analysis identified five primary themes: 1) healthy lifestyles help regulate mood in youth with BD; 2) in-the-moment strategies to manage depressive and manic mood states; 3) support networks are helpful; 4) sources of self-management strategies; and 5) key messages we want to share.

Within the ‘sources of self-management strategies’ theme, many focus group participants described the process of identifying self-management information as being largely trial and error. Participants proactively expended significant time and energy searching for strategies that work for them. They described exploring diverse sources for BD information, including books, online resources, healthcare professionals, and peers. 10 of the 21 focus group participants (47%) described accessing online information about self-management of BD, specifically through Facebook, Reddit, YouTube and online videos, websites, apps, and Tumblr.

Participants described using online sources primarily to 1) learn more about self-management strategies for BD (Table 4-1) or to 2) strengthen social support networks (Table 4-2). Apps that monitored mood states and informed personalized self-care (DO-158), as well as apps designed to target mood symptoms (CB 239), were used to learn more about self-management strategies for BD. Strengthening social support networks was seen as valuable in particular by participants who had few, if any, peers with BD (EL D315-317). For example, participants cited using Reddit to find online “bipolar pen pals” (GD 334). Online sources were also used to improve off-line support networks.

Stigma and misinformation were also key points brought up by focus group participants. Many struggled with mental health stigma, feeling afraid to disclose their condition at school or to their friends, feeling shame about a new diagnosis, or feeling that their friends and family were misinformed about BD. Although most participants were judicious about disclosure, many indicated that directing members of

their support networks to credible online mental health information helped to spread understanding and awareness of mental illness within their social circles (MI B94) and to decrease stigma and misinformation in the context of their own lives. Importantly, some participants also cited that their ability to share online content with their networks and to interact with peers online not only improved their existing relationships (MI B34), but also gave them a feeling of increased empowerment and control over their lives (DS A223, MI B117-121).

### Forum II World Café results

Across all four World Café table discussions, participants cited the internet as the primary vehicle they used for accessing mental health information. When asked about what participants wanted from online health information, feedback centered on existing barriers to accessing information online. The main barriers described were stigma in online environments, negative or distressing content, and difficulty finding credible content.

Stigma was a significant barrier to accessing mental health information online. Participants described fears of being judged for what they posted, shared, or even viewed online, particularly with regards to Facebook. Many participants mentioned having contacts on Facebook who were not aware of their mental illness and felt dissuaded to share mental health information for fear of “outing” themselves as living with a mental health condition.

With regards to online platforms that allow for more anonymity (e.g. Reddit), participants expressed that the freedom of being “faceless” can itself create room for stigma and negative/distressing content. Interestingly, some participants reported negative content as a worse problem on user-driven platforms that include more discussion about mental health conditions, such as Reddit and Tumblr. Some participants described how Reddit members would distort the acceptance of mental illness to the extreme view of stigmatizing those without a mental illness. Participants expressed that holding people who live with mental health conditions in higher regard than people who do not promoted unproductive and even self-destructive behaviours online, rather than promoting safe coping techniques.

Finding credible, high-quality online content was also a significant barrier. Many participants expressed that they, and those in their support networks, had often resorted to “Doctor Google,” that is, relying on indiscriminate Google searches to find mental health self-management information. Participants noted that it was difficult for them to know where to look for such information; as such, they and their supports used information that they later found to be inaccurate. A desire for credible, centralized, safe, and stigma-free online content was the dominant request.

## Discussion

The emerging field of online mental health information provision for youth with BD offers both promise and potential pitfalls. In terms of promise, prior research suggests that many people with BD are attracted to the accessibility and anonymity of online spaces, which can foster peer-provision of emotional support on complex issues, such as stigma, isolation, disclosure, and interpersonal relationships.<sup>4,20,21</sup> Research has also highlighted the potential benefits of online sources for those recently diagnosed with BD, in an effort to support the development of self-management strategies, peer connections, and acceptance of BD.<sup>22</sup> In terms of pitfalls, however, existing online BD resources are heterogeneous in content quality, and privacy and security issues abound.<sup>23</sup> The sheer diversity of currently available online

resources and interventions for BD hampers drawing conclusions about their collective efficacy.<sup>20</sup> Clear gaps are also apparent, for example, few available BD online tools address QoL or recovery-focused orientations.<sup>24</sup>

**Table 4** | Forum 1 focus group quotes

1 Learning about self-management strategies
<p>“...[On Tumblr] people send master posts, of like, links... “If you’re feeling this, go to this website,” and it’ll... give you ideas of things to do. And, so... that’s where I... started to learn about [self-management].” (MI-B133/136)</p>
<p>“I know there’s some really good apps that you can download that... you know, it’ll remind you every hour, like, ‘how are you feeling right now’. And you can kind of track, like... maybe I noticed that, you know, I didn’t go to bed ‘til three last night, and so I had a really crappy day the next day, or something like that. And you can kinda start making connections and form your own self-care plan, and realize that, say I have to go to bed by ten every night, or whatever.” (DO-158)</p>
<p>“I go on Tumblr a lot, and there’s a lot of like posts, about like, self-care...” (MI-B133/136)</p>
<p>“There’s an app called ‘What’s Up’ that really helps me out. It’ll ask you, ‘...name five things you see,’ or ‘name five things you smell.’ And it actually snaps me out of my mood sometimes. There’s like, lots of little mini games on it and whatnot... I use it weekly. (CB-239)</p>
<p>“I watched a lot of videos on YouTube about [self-management]. And that helped.” (CB-C370)</p>
2 Strengthening social support networks
<p>“I find there are some pretty great forums... that you can, even if you’re not aware of many people around your area, that can give you support and share their perspective” (EL D315-317)</p>
<p>“I actually went out and found a couple of bipolar pen pals online... so I have more people to talk to. I found them through Reddit.”            “We love Reddit!” [laughter] (G-D334)</p>
<p>“Just connecting with other people... it really helps you feel like you’re not alone... ‘Cause I’m, like, someone newly diagnosed, I feel like, ‘Oh, this is... my life from now on.’ But then, seeing someone else [living well with BD], it’s like, ‘no, this is not how it’s gonna be every day... you’ll eventually figure it out, and... everything will make sense.’” (MI B117-121)</p>
<p>“When I’m depressed, I go into, like, hermit mode. I will just shut off from... everything. And so, even though it’s hard, I find like, reaching out to friends... on Facebook [is easy], ‘cause you’re not doing [it] face-to-face, you’re... a little bit detached. So it’s easy to say, you know, ‘Hey, I’m not feeling so well, you know, can you come over.’ ...Even if they just, like, message you [and say] ‘How are you, hi?’ That can... help brighten your day.” (MI B34)</p>
3 Challenging stigma
<p>“I think the education is such an important part. Like... I send links to my mom all the time.” (MI B94)</p>
<p>“I’ll just send her links, uh, pages, articles I see, and get her to read them. And she’s more... educated about it.”</p>
<p>“Yeah, I do that as well, and same with my friends. That’s how I educate them.” (MI B94)</p>
<p>“It was a really big thing for me to teach my mom... about my mental illness, so that she can better help me. And she’s willing to learn.” (ME B78)</p>
<p>“[Having respectful supporters gives] some level of control over my own life. [It’s important that I’m] Not... being treated like a child.” (DS A223)</p>

This project applied a CBPR approach to build knowledge on how youth with BD are currently using online self-management resources and their recommendations for future developments. Focus group findings from Forum I indicated that participants accessed online spaces primarily to learn more about self-management strategies and to strengthen their social support networks. Forum II consultations indicated that youth encountered significant barriers when accessing self-management information online, including stigmatizing attitudes, negative or distressing content, and difficulties finding credible content. These results reflect observations from the wider literature on the use of online health information by youth facing mental health challenges. For example, prior research has shown that youth commonly search online for information not just on symptoms and diagnoses, but also self-management strategies and interpersonal issues.<sup>25</sup> Approximately half of youth with mental health issues report using forums to connect with peers.<sup>25,26</sup>

Of interest is our finding that BYAP project participants were often hesitant to use more public social media platforms, such as Facebook, for mental health support, describing fears of stigmatization. Prior research in this area yields mixed statistics. One survey, for example, reported 77% of youth were unlikely to use social media platforms to access mental health information,<sup>25</sup> whilst another survey on the use of specific social media platforms reported high rates of usage for more anonymous platforms, such as YouTube (85%), with less use of less private platforms, such as Facebook (58%), Skype (40%), and Twitter (39%).<sup>27</sup> Social media platforms that protect privacy and identity might, therefore, be preferable moving forward.

Our findings that youth who live with BD face barriers in sourcing credible health resources online and their desire for centralized sources of online health information are in line with findings from previous studies.<sup>25,27-29</sup> Prior research has identified that youth report feeling uncomfortable conducting online searches for mental health information, both in terms of their own abilities to perform internet searches, as well as the way health information is presented online.<sup>27</sup> Finally, previous studies have found that youth required a tailored mix of online and in-person mental health supports,<sup>30</sup> which is a finding echoed here.

In an effort to provide a ‘one stop shop’ for evidence-based information on self-management of BD, CREST.BD recently designed, developed, and piloted a sophisticated online ‘Bipolar Wellness Centre.’ A range of engagement strategies are embedded within the website, including webinars that speak to fourteen diverse areas of BD self-management, videos where a peer-researcher with BD illustrates concrete examples of self-management in action, and a ‘Living Library’ where users can ‘check out’ an expert with lived experience of BD via secure telehealth software to help tailor self-management resources to their specific context. Serving as a ‘gateway’ to the Bipolar Wellness Centre is an online QoL Tool measurement system, which empowers users to access tailored self-management evidence and resources based on their personal QoL profile. Many features of the Bipolar Wellness Centre compliment the priorities of youth for online health information, for example, it is credible, centralized, and built around messages of hope and recovery by prioritizing language and content that are empowering rather than stigmatizing. However, the website was designed initially for adult knowledge users; we look forward to incorporating the results from the BYAP project into the website moving forward and creating youth-friendly content.

There are potential limitations to our research that warrant consideration. First, our YAG had no visible minority members and only 14% (n=4) of total forum participants self-identified as visible minorities; consequently, discussions were not held on the topic of mental health and racial marginalization. Second, conversations around sexual orientation and the needs of LGBTQ youth were also missing from both forums. The lack of voices from these populations greatly impeded our ability to apply an intersectional lens to the provision of tailored, appropriate online mental health information. Third, with all but three participants residing in suburban areas, generalizability to both rural and urban populations is limited. Finally, it is important to note that none of our participants or YAG members self-identified as of First Nations descent, although our research was conducted on the traditional territories of the Songhees and Esquimalt First Nations.

Notwithstanding the above limitations, the results of our community-engaged project incrementally advance this nascent field of research.

## Conclusion

Our team applied a CBPR approach to develop knowledge on the self-management strategies deemed effective by Vancouver Island youth living with BD and their preferred methods for sharing information about these strategies with the wider community. Focus group findings spoke to five central themes: 1) healthy lifestyles help regulate mood in youth with BD; 2) in-the-moment strategies to manage depressive and manic mood states; 3) support networks are helpful; 4) sources of self-management strategies; and 5) key messages we want to share. While youth with BD primarily access online sources for mental health information, they often experienced significant barriers in this process, including stigma and difficulty finding credible, safe, and evidence-informed information. At a broad level, our results demonstrate that youth engagement in BD research and knowledge exchange is feasible. More significantly, they show that youth with BD have constructive and important insights to share which, if harnessed, will help us develop appropriate, effective, and safe online mental health spaces for future generations.

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