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Online help-seeking prior to diagnosis: Can web-based resources reduce the duration of untreated mood disorders in young people?

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Abstract

Objective—Mood and anxiety disorders typically begin in adolescence or early adulthood, but those at the age of highest risk are among those least likely to access mental health services. However, they may be more likely than other demographic groups to seek help online. The goal of the present study was to investigate the online help- and information-seeking activity of young people newly diagnosed with mood and anxiety disorders in order to better understand how digital resources might serve this population.

Method—Participants, aged 15 to 35, with a diagnosis of a mood or anxiety disorder were eligible if they had received their first mental health diagnosis within 24 months. Participants were interviewed with the Pathways to Care Questionnaire, which inquires about online activity prior to one's first interaction with mental healthcare providers.

Results—Forty people participated (depression $n=30$, bipolar disorder $n=5$, generalized anxiety disorder $n=5$); average age 21 years ($SD=3.2$), 60% female. Eighty-one percent reported seeking help and/or information about their symptoms online. The gap between symptom onset and in-person help seeking was 91.90 weeks ($SD=133.7$). Most participants (85%) reported they would be open to communicating with a mental health professional online.

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Institutional Review Board

The study was approved by the Institutional Review Board (IRB) of Northwell Health (the coordinating institution) as well as local IRBs at participating sites.

Conclusion—A majority of young people experiencing clinically-significant symptoms seek help online. However, the gap between symptom onset and treatment initiation remains unacceptably long. Better strategies are needed to translate young people's interest in online resources into meaningful care, whether through web-based services or facilitated pathways to traditional treatment.

Many people with mood disorders will be symptomatic for months, or even years, before receiving an accurate diagnosis and appropriate treatment (Altamura, 2010; Drancourt et al., 2013; Kisely, Scott, Denney, & Simon, 2006; Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994; Perlis et al., 2004; Wang, 2007; Wang et al., 2005). Unfortunately, lack of treatment for mood disorders can lead to significant consequences; evidence suggests that individuals who do not receive treatment for their mood disorder are likely to have worse outcomes and a more difficult trajectory over time (Altamura, Dell'Osso, Mundo, & Dell'Osso, 2007; Drancourt et al., 2013; Ghio, Gotelli, Marcenaro, Amore, & Natta, 2014). Risk for suicide is also significant in this population – particularly among those who are symptomatic and not receiving adequate treatment (Garlow et al., 2008; Goldstein et al., 2012; Hauser, Galling, & Correll, 2013; Matlin, Molock, & Tebes, 2011; Tuisku et al., 2014).

Several factors can contribute to a delay in diagnosis and treatment, but age often plays a role; the most common age of onset for mood disorders is adolescence (Kessler et al., 2005), but common symptoms of mood disorders overlap with behavior of typically-developing youth. For example, withdrawal from one's family, sleep disturbances, and substance use can be developmentally-appropriate, but may also be indicative of mood pathology. Caregivers, or adolescents themselves, may not know when symptoms warrant professional attention. When a caregiver has concerns about an adolescent's health or when the youth is worried about their mental state, the Internet is a logical place to seek information. Research suggests that nearly 85% of adults look online for health information – with a majority seeking information about issues they have yet to discuss with a clinician (Powell, 2011) – health information-seeking online is even more prevalent among adolescents (Rideout & Fox, 2018). Sites like WebMD and Psychology Today offer clearly-worded, if simplistic, information about a variety of mental health problems that may be appealing to the general public. Related, many individuals share their own mental health experiences online through blogs, YouTube, or other social media sites, which may offer some comfort through shared experience. Information can also be gleaned from many sites promoting research evidence, the rigor of which varies widely.

In addition to ease of access and wealth of information, seeking help online may have other benefits. Mental illness is associated with significant stigma (Hartman et al., 2013; Heflinger & Hinshaw, 2010) and among adolescents, any perceived difference between them and their peers is likely to be seen as a source of embarrassment or shame (Pescosolido, Perry, Martin, McLeod & Jensen, 2007; Hartman et al., 2013; Hinshaw, 2005; Meeks, 2011; Pescosolido, 2007). For youth from cultures that tend to have a negative perception of the mental health profession, the barriers to treatment can be even higher (Stewart, Simmons, & Habibpour, 2012). Information can be accessed anonymously online, thus reducing fears of being stigmatized by others, and adolescents may find comfort in communicating with peers who

disclose their own mental health problems online (Fox, 2014). Another factor is independence; adolescents report that they prefer handling their problems without adult input (Gould et al., 2004) and may appreciate being able to learn about their symptoms online without parental participation.

The amount of mental health information adolescents and caregivers can access now is unprecedented, which creates both a problem and an opportunity. The quality of the information available ranges from cutting-edge research published on PubMed to potentially harmful recommendations from people without qualifications. For the average person, discerning between the two can be difficult or impossible (Kitchens, Harle, & Li, 2014). For professionals with beneficial information to offer, it is important to know where people are looking for mental health resources and for what information they are looking. With this insight, it would be possible to create a campaign to disseminate evidence-based information that would have a high likelihood of reaching its intended audience and could potentially help individuals with mood symptoms access good care.

Beyond psychoeducation, there are a growing number of web-based resources for clinicians and patients with mood disorders, including mood monitoring tools (Daus, Kislicyn, Heuer, & Backenstrass, 2018; Dogan, Sander, Wagner, Hegerl, & Kohls, 2017) and interventions (Dowling & Rickwood, 2013; Gliddon, Barnes, Murray, & Michalak, 2017; Santesteban-Echarri et al., 2017). These resources have the potential to reach many more people than services that require in-person visits, and may especially appeal to young people who are at high risk for the onset of mental health disorders, but may be hesitant to seek professional help (Heflinger & Hinshaw, 2010; McGorry, Bates, & Birchwood, 2013). Additionally, online interventions cost a tiny fraction of what most in-person care would cost and, in some cases, may be free. This is likely to hold significant appeal for young people who may have limited resources and/or may want to seek care without their caregiver's involvement. However, these resources can only benefit those who access them; determining the pattern of help-seeking behavior for young people with mood symptoms is essential to best serving this population. It is also important to investigate whether the appeal of these tools varies by demographic group, in order to better understand how to reach those interested in help online.

The goals of the present study were to (1) determine where participants sought information or help prior to receiving in-person treatment, (2) describe what information was sought, (3) establish whether participants disclosed their mental health concerns to others, and (4) evaluate differences in help-seeking related to demographic characteristics.

Method

Participants, aged 15 to 35, with a clinical chart diagnosis of a non-psychotic mood or anxiety disorder were recruited from the inpatient and outpatient psychiatric departments at nine institutions across North America as part of a larger study investigating how people experiencing mental health problems access information and treatment for their conditions. The study was approved by the Institutional Review Board (IRB) of Northwell Health (the coordinating institution) as well as local IRBs at participating sites. Written informed

consent was obtained from all participants over 18 and from the legal guardian from any participant under 18. Assent was obtained from those under 18. Exclusion criteria were minimal, participants were eligible if they had received their first mental health diagnosis within 24-months of enrolling in the study. This criterion was used in order to increase the reliability of the data; participants were asked to report about their behaviors during the period between symptom onset and diagnosis, by limiting the time period, we hoped to limit biases inherent to retrospective recall. Participants were compensated \$30 for their time.

Participants were interviewed with the Pathways to Care Questionnaire (PCQ; Birnbaum, Rizvi, Correll, Kane, & Confino, 2017; Birnbaum et al., 2018), which consists of 92 open-ended questions that assess how participants obtained information related to their mental health symptoms and how this information informed their decision to seek professional help. No other assessments were administered.

Analytic Plan

The analyses for this study were primarily descriptive, consistent with the goal of describing the ways in which people experiencing mood or anxiety symptoms for the first time seek information and decide to pursue treatment. In addition to calculating counts (for categorical variables) and means and standard deviations (for continuous variables), we also used correlations, chi square, and t-tests to determine whether there were differences in information or help-seeking behavior based on diagnosis, age, sex, or race.

Results

Forty people with mood spectrum diagnoses participated (depression $n=30$, bipolar disorder $n=5$, generalized anxiety disorder $n=5$). On average, they were 21 years old ($SD=3.2$; range 15–32), 60% were female. The majority of participants were white (66%); there were six black and five Asian individuals.

Where do young people seek mental health-related information?

The majority of participants reported seeking help and/or information in conjunction with the onset of their symptoms¹; 81% did so on the Internet. Of those who looked online for information or support, the majority (58%) conducted searches related to the symptoms they were experiencing, more than a third (35%) reported looking for information about suicide; only 19% reported seeking information about treatment. The Internet was, by far, the most popular resource; followed by medical professionals (28%) and family members (25%). Of those who indicated a “most helpful” resource, 39% ($n=11$) indicated the Internet, but many also reported that they found the Internet to be the “least helpful” resource ($n=6$). There was no difference in where people looked for help or what they found helpful based on diagnosis, sex, age or race.

When asked where they would *prefer* to get information about their symptoms, 43% of participants expressed a preference for getting information about their symptoms from a healthcare professional, 41% said they preferred the Internet, followed by peers/friends

¹Eight people did not answer this question, consequently, these figures are based on an n of 32.

($n=3$), and family/church ($n=2$). Similarly, a majority of participants expressed a preference for getting help with their symptoms from a healthcare professional (53%), followed by the Internet (20%), family/church (15%), or peers (10%). These responses were consistent across demographic groups.

What are young people with mood disorders seeking online?

When asked about their online activity, the majority of participants reported seeking help (63%; e.g., someone to talk to, validation that their symptoms were real) or information (25%; e.g., to learn more about depression, to understand why they were feeling a certain way). A quarter of the participants ($n=7$) reported that they did not seek help or information for their psychiatric symptoms online. There were no differences in what people sought based on their demographics.

Do young people discuss their mental health symptoms?

Thirty-eight percent of participants reported that they posted on social media about the symptoms they were experiencing. Facebook was the site participants most frequently posted on (60%), followed by Tumblr and Yahoo Answers (20% each). In contrast, 79% of participants reported seeking input from someone in person. In most cases, the person they reached out to was a friend (60%), or relative (33%). Very few reported reaching out to a mental health professional ($n=2$). When asked to describe initial conversations about their symptoms, participants reported that they were encouraged to seek professional help in most instances (50%); other responses included advice on self-care (e.g., try yoga, talk to friends) or general support. When asked about what ultimately led them to seek professional help, 60% reported that they decided on their own. The remaining 40% said they went because someone else told them to, typically a family member (75%), although some were mandated ($n=2$) or referred by another unrelated person ($n=2$).

Some participants expressed reservations about having a clinician reach out to them unsolicited online (40%), but the majority said it would be OK with them if a clinician used the Internet or social media to reach out to them directly to initiate a conversation about their experiences before they ever came in for treatment. Additionally, 85% of participants said it would be OK with them if a professional offered them help/advice/suggestions via the Internet or social media. These responses did not vary based on participant demographics.

Discussion

The results of our study suggest that young people with mood spectrum disorders often seek information or help online prior to speaking with someone about their symptoms or seeking professional help. There is often a long delay between when a person first becomes symptomatic and when s/he receives a diagnosis and appropriate treatment, which contributes significantly to poor outcomes (Berk et al., 2010; Conus, Macneil, & McGorry, 2014; Conus & McGorry, 2002; Elanjithara, Frangou, & McGuire, 2011). The delay to treatment has remained consistently long (10 years, on average (Drancourt et al., 2013; Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994) over recent decades – the Internet may offer a way to reach people and encourage help-seeking earlier in the illness course.

There is no doubt that the majority of people at the age of highest risk for developing a mood spectrum illness (i.e., late adolescence, early adulthood) are very active online; 95% have access to a smartphone and 45% report being online “almost constantly” (Pew Research Center, 2018). Additionally, they tend to conduct much of their lives online – socializing, shopping, even completing academic work – and report a high comfort level with the idea of seeking and receiving healthcare online. Our results indicate that over 80% of people who would later be diagnosed with a mood spectrum disorder sought information and/or help online, and on average, they went online before they talked to anyone in person about the difficulties they were experiencing. This is consistent with what was found in a national poll of adolescents and young adults (aged 14–22; Rideout & Fox, 2018); among those with elevated symptoms of depression (based on the PHQ-8), 90% said they had gone online for information related to mental health (compared with 48% of those without symptom of depression), more than half reported seeking peers with similar lived experience, and 32% reported connecting with a health professional online. It is clear that young people seek information and help online; however, our results suggest that satisfaction with online resources is mixed, and in most cases, our participants reported that it was a conversation with another person – rather than something online – that eventually led them to seek treatment. It is also important to note that the average wait before seeking in-person treatment was sought was nearly two years – a period during which substantial harm could accumulate from lack of intervention. Current online resources have the potential to serve a valuable role, but are not as effective as we would hope at facilitating access to treatment.

When asked about their preferences for receiving information or help, most participants indicated that a healthcare professional would be best. However, this would not have to be in an office; 94% indicated that it would be OK with them if a mental health professional offered help, advice or suggestions online (fewer – but still a majority – were also open to the idea of having a professional contact them online to talk about their symptoms). Furthermore, young people may be more comfortable receiving mental health services online than in person (MacDonell & Prinz, 2016) and might respond positively to mental health professional being easily accessible online. Technology makes this possible; when we browse the Internet, we see advertisements related to a search we recently conducted or specific to a location where we recently booked a trip. The same algorithms make it possible to target information or services to people who are conducting searches related to specific symptoms or services. This type of approach is already being used to try to prevent suicide; Google and Facebook post information for suicide hotlines and encourage help-seeking when users search suicide-related content (Buchwald, 2018; Franco-Martín et al., 2018; Pourmand et al.). A similar approach has been used to try to reach individuals with first episode psychosis (Birnbaum et al., 2017). The challenge is to make the resources engaging enough that adolescents and young adults spend enough time with the resource for it to be impactful (Van Meter & Cosgrove, in press). Additionally, it is important to consider the ethical implications of engaging with someone in psychological distress whose identity and location may be unknown. When mental health professionals meet with patients, they can assess safety and recommend more intensive services (i.e., hospitalization) or follow-up with the patient frequently to assess his/her mental health. If a clinician in New York is speaking online to someone in California who conducted a Google search related to depression and

suicide, the clinician will have little information about that person and no easy way to follow-up with them. However, national crisis intervention services (e.g., suicide hotlines) provide information and support to anonymous individuals and have methods for contacting local emergency services if necessary. A difference is that crisis intervention relies on people contacting them, whereas online it would be possible for a mental health professional to proactively reach out. This would make it possible to reach more people, but could also entail a higher level of risk. Our results suggest that this proactive help would be welcomed by many and could help to reduce the long period between symptom onset and treatment.

Online interventions are becoming increasingly available and may provide a valuable bridge to more traditional mental health services. Although mindfulness apps or mood tracking tools are not adequate replacements for psychotherapy or pharmacological treatment, these may help people who recognize there is a problem, but are not yet ready to initiate this level of care – whether because they don't have the resources to do so or because they are not yet convinced their symptoms warrant more intensive services. A positive experience with an app or an online supportive service, like Seven Cups of Tea, may help an individual gain comfort thinking and communicating about their symptoms (Baumel, Correll, & Birnbaum, 2016), making the step of calling their local mental health clinic less intimidating. Still, it is important – especially in cases of major depressive disorder or bipolar disorder – that the online resources act as a gateway to more intensive services, not a replacement.

Limitations

This study is one of the first to describe the online help-seeking behaviors of young people with mood spectrum disorders, and offers valuable insights for future work to better reach young people with mental health disorders online. However, our findings also have some limitations. Due to the nature of our recruitment strategy – through mental health clinics around the country – only individuals who eventually did seek treatment are represented. Learning more about those who seek help online and never initiate treatment (or do so much later) could be even more important for the development of new strategies for identifying and engaging people at risk through the Internet. Additionally, the retrospective nature of our data collection could introduce bias; recall of past events and experiences is influenced by current events and experiences (Means & Loftus, 1991; Safer, Levine, & Drapalski, 2002; Wilson, Meyers, & Gilbert, 2003), and being asked about help-seeking behaviors or having more recently gone online to look into something mental health-related could lead to inaccurate reporting.

Related, we were surprised to find that there were no differences, based on race, in patterns of help- and information-seeking. Youth from ethnic minority cultures are less likely to have access to in-person mental health services and may be more likely to be stigmatized within their communities for experiencing mental health problems (Chandra & Minkovitz, 2007; Gary, 2005). Consequently, we had expected that participants from racial minority groups might access online resources more frequently. This was not the case. However, the fact that all our

participants did eventually seek treatment means that the question of interest – are racial minority youth who do not have ready access to mental healthcare more likely to access

online resources – cannot really be addressed. Additionally, our sample is relatively small, mostly white, and the majority had a diagnosis of depression. The sample also covered a wide range of ages; although 78% fell within one standard deviation of the mean, there were people outside of this range (both young and older) who were more than a decade apart in age. It is possible that the patterns in help- and information-seeking that we observed vary at the tail ends of our age range where we had fewer individuals represented. For example, a 16-year-old experiencing depressed mood for the first time might handle it differently than a 30-year-old experiencing similar mood changes. Finally, although our work suggests similar help-seeking patterns among individuals with first episode psychosis (Birnbaum, Candan, Libby, Pascucci, & Kane, 2016; Birnbaum et al., 2018), individuals with bipolar disorder are under-represented in our sample. This is a notable gap, as people with bipolar disorder often have poor insight about their symptoms, particularly during manic episodes, and it is possible that this would make it more challenging to reach them through online means.

Conclusion

Mood disorders are most likely to begin during adolescence or young adulthood, but most people do not receive an accurate diagnosis and treatment for many years (Drancourt et al., 2013; Lish et al., 1994; Perlis et al., 2004), contributing significantly to the burden of these disorders on individuals and society. Our results, consistent with other reports (Pew Research Center, 2018; Rideout & Fox, 2018), suggest that young people experiencing symptoms for the first time, are highly engaged online and that they use the Internet as primary source to find help and information related to their symptoms. However, satisfaction with the resources online is mixed and accessing this information does not seem to translate into treatment-seeking as quickly as it should. The Internet has potential to reach young people at a time of need, but resources need to be more engaging in order to facilitate follow through and reduce the duration of untreated mood symptoms.

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Highlights

- The duration between mood symptom onset and treatment initiation is unacceptably long in most cases.
- Young people experiencing clinically-significant mood symptoms often seek help online before seeking in-person treatment.
- There is a need for online resources and services that facilitate effective interventions and reduce the duration of untreated mood symptoms.