2015

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The Role of Social Media and the Internet in Pathways to Care for Adolescents and Young Adults with Psychotic Disorders and Non-Psychotic Mood Disorders

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Background and Objectives

The emphasis on reducing the duration of untreated psychosis (DUP) in early phase psychotic disorders has illuminated the complex and convoluted trajectories by which patients and their families access appropriate behavioral health care. Gaining an understanding of the factors that influence pathways to care for individuals with psychotic disorders is crucial to achieving the key objectives of early symptom identification and service engagement. Research to date has explored pathways to care by focusing primarily on identifying the initial professional and non professional contacts,[1,2,3] determining the number of contacts prior to receiving appropriate psychiatric intervention,[4,5] outlining the many referral sources, as well as ascertaining relevant contributors to referral delays.[6,7,8] The period of time prior to making the first contact has been a notable and neglected area of pathways to care research. The events leading up to, and informing, help seeking behavior undoubtedly impact pathways to care and DUP.

A critical development in recent years has been the enormous growth of internet and social media use, particularly among young people. Social media and the internet have transformed the way youth interact, learn, communicate and share information. According to a recent survey, 90% of all United States teens have used social media placing it ahead of texting (87%), email (77%) and instant messaging (63%). Three-quarters of teens have their own personal social networking site, and nearly one in three teens visits their social networking profile several times a day or more.[9] Additionally, more than 93% of both teens and young adults in the United States use the internet on a regular basis.[10] Young people in particular are increasingly using the internet as a source for obtaining physical as well as behavioral health related information.[11,12] Although the onset of psychotic symptoms is likely to occur during adolescence for many individuals,[13] there has been remarkably little research on how

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the internet and social media impact pathways to care and help seeking behaviors in youth. Limited previous reports have suggested that online information and communication technologies, including social networking sites are utilized and well received by young people, including those with psychosis. Additionally many young people demonstrate positive attitudes toward internet based psychiatric interventions including online peer-support groups, online family interventions, and psychoeducation.[14]

Given that millions of adolescents and young adults in the United States are online and share ideas on social networking sites every day, we set out to explore help seeking behaviors and pathways to care in youth with a psychotic-spectrum disorders (PSD) and non-psychotic mood disorders (NPMD), emphasizing how online resources are being used in response to emerging symptoms. The aim of this study was to gather results that could inform future research projects exploring innovative internet-based means of outreach and engagement targeting DUP reduction and improving pathways to care. We hypothesized that an overwhelming majority of youth with early phase PSD and NPMD would utilize social media and the internet before and during symptom onset, seek information about mental health and be open to being approached via social media by early outreach and intervention teams.

Methods

Participants between the ages of 12 to 21 years old were recruited from The Zucker Hillside Hospital's adolescent and adult inpatient units as well as outpatient departments. All participants had either a primary psychotic disorder or a non-psychotic major depressive or bipolar disorder diagnosed within the last 24 months.

Participants were interviewed with The Pathways to Care for Psychosis Questionnaire (PCP-Q). This questionnaire was developed by three of the authors (MLB, CUC and JMK), with additional input from experts in the areas of prodromal and first episode psychosis. The interview was designed to retrospectively explore trajectories to care emphasizing resources used to obtain information about symptoms and inform the decision to seek care. The PCP-Q consists of approximately 70 open ended and multiple choice questions.

Sample questions include:

- When did you first notice changes in your thoughts, feelings, behaviors or sense of self?

- Which experiences were most distressing?

- What did you think was contributing to these changes?

- Where did you go to find answers? Which were helpful?

- Did your social media habits change? In what ways?

- Did you ever discuss your concerns/changes online?

- Did you ever receive any advice online?

- How would you feel if we (the Early Treatment Program) used the internet or social media to reach out to you directly to initiate a conversation?

Results

We interviewed a total of 80 youth (mean age=18.3±2.2, range=12–21, 48.8% male). 40 participants (50.0%) had a psychotic-spectrum disorder (PSD) and 40 (50.0%) had a non-psychotic mood disorder (NPMD). Sample characteristics are displayed in Table 1. The overall mean duration of untreated illness was 6.11±6.69 months (PSD= 6.68±7.79, NPMD= 5.47±5.24, p=0.44).

97.5% of participants reported regularly using social media on average for the past 5.07±2.5 years (Table 2). Participants spent approximately 2.6±2.5 hours per day online, checking social media sites 12.7±20.2 times per day. Facebook was by far the most common social media site used by both groups (93.7%), followed by Instagram (61.2%) and Twitter (45.0%). Patients with PSD were significantly less likely to use Tumblr (22.5% vs. 50.0% p=0.01) and Youtube (27.5% vs. 50.0%, p=0.04) compared to participants with NPMD.

First symptoms noted in the PSD group were low mood (25.0%) and hallucinations (25.0%) followed by paranoia (17.5%). NPMD participants first noted low mood (77.5%) followed by change in sleep patterns (30.0%) and anhedonia (30.0). 31.2% of our sample attributed early symptoms to stress (30.0% PSD, 32.5% NPMD, p=0.80). Significantly more participants with PSD reported uncertainty about the worst possible outcome (32.5% vs. 7.5%, p=0.005), while significantly more patients with NPMD feared that killing themselves could be the worst outcome (30.0% vs. 7.5%, p=0.009). 60.0% (60.0% PSD, 60.0% NPMD, p=1.0) believed that symptoms would go away on their own if left untreated. 22.4% of our sample (19.4% PSD, 25.0% NPMD, p=0.56) reported waiting to reach out for help because they thought symptoms would disappear. Participants reported waiting on average 12.3±24.8 weeks (12.89±31.74 PSD, 11.85±16.57 NPMD, p=0.86) before reaching out for help either in person or online. 32.5% of our sample (35% PSD, 30% NPMD, p=0.63) used the internet as their primary source for obtaining mental health related information. 76.5% of subjects (67.5% PSD, 85.0% NPMD, p=0.06) noticed changes in their social media habits during symptom emergence. 27.5% reported spending more time on social media (15.0% PSD, 40.0% NPMD, p=0.01) and 45.0% reported spending less time on social media (47.5% PSD, 42.5% NPMD, p=0.60). 30.0% of participants reported discussing their symptoms on social media (22.5% PSD, 37.5% NPMD, p=0.14). Participants with NPMD were non-significantly more likely to consult with a health care provider compared to PSD participants (22.5% vs. 10.0%, p=0.13).

Participants with NPMD were primarily interested in obtaining information on how to stop symptoms (40.0% vs. 13.5%, p=0.01), while youth with PSD were more commonly interested in what caused their symptoms (21.6% vs. 15.0%, p=0.45). Numerically more patients with PSD (42.9% vs. 25.0%, p=0.10) stated that they would prefer receiving mental health information via the internet. Altogether, 63.6% of participants (64.9% PSD, 62.5% NPMD, p=0.83) were amenable to a mental health clinician proactively reaching out to them via social media during symptom emergence prior to initiating psychiatric care. 74.3% of

participants (78.4% PSD, 70.0% NPMD, p=0.40) liked the idea of obtaining help/advise from a professional via social media.

Discussion

Despite the severity and chronicity of severe psychotic disorders, DUP continues to be alarmingly high[15] and pathways to care remain suboptimal in clinical practice.[16] The internet and social media provide an unprecedented opportunity to supplement and potentially transform early intervention services, especially for adolescents and young adults who are both the highest utilizers of social media and the internet and at the greatest risk for the emergence of a psychotic disorder. This is the first study to explore the impact and potential utility of social media in pathways to care for youth with psychotic spectrum disorders. Our data suggest that online resources, such as Google, Facebook and Twitter, are intricately intertwined with the daily lives of young people experiencing the early stages of a psychotic or non-psychotic mood disorder. Additionally, our findings indicate that information gathered from these resources by youth impacted by mental illness plays an important role in the initiation of help seeking by influencing an individual's understanding of symptoms and informing their decisions to seek care. Finally, our data suggest that outreach and engagement efforts initiated by mental health clinicians via social media would be an acceptable and well-received, novel approach to connect with youth experiencing early phase illness.

For many participants, both with PSD and NPMD, the internet was the first and primary resource used in order to obtain mental health related information during the emergence of their symptoms. While the desired and sought out information differed significantly between both groups, the online environment is clearly a powerful resource regularly used by the vast majority of youth during prolonged periods of untreated illness. Perceived and experienced stigma is known to impact a high percentage of patients with psychotic spectrum disorders, including patients with early phase illness.[17] Fears related to the consequences of seeking information and asking for help in person likely keep some prospective patients from discussing early symptoms with family, friends and health care providers. The internet however, provides a platform for exploring topics without disclosing personal details and likely represents a less threatening and stigmatizing option for seeking mental health related information.

In our sample insufficient information or incorrect appraisals in both groups, such as the belief that symptoms would go away on their own (60.0% PSD, 60.0% NPMD, p=1.0), likely contributed to preventable treatment delays. While each group differed significantly in their understanding of the worst possible outcome at the time of symptom onset, participants might have sought care sooner had they known that deterioration and hospitalization could have been avoided through early and appropriate psychiatric intervention. We have learned from our previous work[18] that the online environment can unfortunately be quite misleading and stigmatizing, therefore, supporting pre-existing misconceptions about mental health and psychiatric treatment options and potentially contributing to treatment avoidance.

Social media provides a unique opportunity for mental health clinicians to engage and meaningfully interact with struggling youth at the earliest phases of illness potentially altering the trajectory to care. Social media sites like Facebook and Twitter allow users to interact with each other, and share and receive online information in real time. Nearly all youth in our sample were actively engaged in online resources including social media prior to and during the time of symptom onset (100.0% PSD, 95.0% NPMD, p=0.15). Additionally, a subsection of our sample (22.5% PSD, 37.5% NPMD, p=0.14) shared their experience of their emerging psychotic and mood symptoms via social media. These findings suggest that not only are youth accessible through social media platforms, several of them are actively reaching out to others via online resources before receiving professional care. Furthermore, the vast majority of participants in both groups who were actively engaged in social media liked the idea of obtaining help/advise/suggestions from mental health clinicians via social media (78.4% PSD, 70.0% NPMD, p=0.40). Interestingly, the NPMD cohort was significantly more likely to increase their time on social media while becoming ill than the PSD group (40.0% vs.15.0%, p=0.01) suggesting that the former might be a particularly rich target for the utilization of social media as a means to identify and/or engage such individuals. Mental health clinicians however, are unfortunately not taking full advantage of this platform. A recent report suggested that 50% of mental health professionals surveyed used social media for personal reasons only, 10% reported using social media for business only, and 40% reported using social media for both business and personal reasons. It is unclear how many mental health clinicians, if any, use it to interact with existing or potential patients.[19]

Limitations

The results of this study need to be interpreted within its limitations. First, the sample size with 40 patients in each group was modest, which may have limited our ability to detect statistically significant group differences. Second, the NPMD group was heterogeneous. Since patients with major depressive disorder and bipolar disorder may differ in their social media habits and since the mood polarity may also play a role, it may be preferable in future studies to choose a more homogeneous control group. Third, the retrospective design of this study may have introduced a recall bias. While we attempted to minimize this effect by limiting the duration of symptoms and thereby recall to no more than 2 years, some participants may have had difficulty remembering exactly how they engaged, interacted and responded to online material during symptom onset. Finally, we did not include collateral input. Although collateral information would have been valuable to support participants` reporting of events, informants may lack accurate knowledge about the nature and details of internet and social media use. Despite these limitations, this is the first study to assess internet and social media use in relationship to emerging psychotic or non-psychotic mood disorders and pathways to care.

Future directions

Future research projects should focus on understanding precisely how youth with emerging mental illness are interacting with the internet and social media to search for answers, reach out for help, share information and express themselves. One strategy that we have initiated

at The Zucker Hillside's Early Treatment Program is to extract participant's actual social media posts directly from their social media feeds, providing detailed and specific data on social media behavior and changing patterns and frequency of use before, during and after psychosis onset.

An interesting and key question is whether or not we can identify a psychosis specific signal in the online activity of youth, such as changing patterns of use, specific search terms, phrases, themes, as well as changes in grammar and syntax. The majority of our participants noted changes in social media utilization and patterns of use as symptoms developed (67.5% PSD, 85.0% NPMD, p=0.06). Discovering a psychosis specific signal would be a major step both in identifying youth in the early stages of illness and also possibly predicting relapse in individuals known to have an existing psychotic disorder. Using technology to assist in symptom and illness management in various psychiatric disorders has been previously explored with some success.[20,21] Innovative and novel strategies could be adapted to social media platforms enabling targeted and improved methods of outreach and engagement. Given that many participants were amenable to proactive outreach via the internet or social media during symptom emergence, future DUP reduction initiatives should explore the possibility and feasibility of selectively identifying those individuals who may benefit from psychiatric intervention and subsequently using social media to offer online consultations, education and support. Slight alterations in the online experience of youth in the early stages of illness might promote important reductions in duration of untreated symptoms and improve pathways to care.

Conclusions

Our study found that online information and social networking platforms have an important role in pathways to care. These findings suggest that as we continue to explore DUP reduction initiatives, mental health clinicians must consider transforming the online experience for struggling youth through innovative and novel strategies of early identification, engagement and treatment. Mental health clinicians must adapt to new technologies in order to positively impact duration of untreated psychosis and improve trajectories to care.

Acknowledgments

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Table1

Sample Characteristics

Characteristics	Total	PSD	NPMD	*P*
Mean Age	18.32	18.75	17.9	*0.08*
Sex:				
Male	39	26	13	*0.48*
Female	41	14	27	*0.51*
DUI Mean ± SD in Months	6.11 ± 6.69	6.68 ± 7.79	5.47 ± 5.24	*0.44*
Diagnosis n (%):				
Psychotic Disorder NOS	21 (26.25)	21 (26.25)	–	–
Bipolar Disorder with Psychotic Features	10 (12.5)	10 (12.5)	–	–
Schizophrenia	6 (7.5)	6 (7.5)	–	–
Schizoaffective Disorder	1 (1.25)	1 (1.25)	–	–
Brief Psychotic Disorder	1 (1.25)	1 (1.25)	–	–
Schizophreniform	1 (1.25)	1 (1.25)	–	–
Major Depressive Disorder	20 (25)	–	20 (25)	–
Mood Disorder NOS	9 (22.5)	–	9 (22.5)	–
Bipolar I Disorder	6 (7.5)	–	6 (7.5)	
Bipolar Disorder NOS	4 (5)	–	4 (5)	–
Bipolar II Disorder	1 (1.25)	–	1 (1.25)	–

Table 2

Social Media Usage and Frequencies

Social Media Characteristics	Total	PSD	NPMD	P
N (%) using any Social Media	78 (97.5)	40 (100)	38 (95)	0.15
Top Social Media sites Used:				
Facebook	75	39	36	0.16
Instagram	49	20	29	0.03*
Twitter	36	17	19	0.65
YouTube	31	11	20	0.04*
Tumblr	29	9	20	0.01*
Mean Years of Social Media Use	5.07	4.87	5.25	0.52
Mean Hours per Day on Social Media	2.62	2.04	3.15	0.05
Frequency of Checking Social Media Sites per Day	12.67	9.79	15.3	0.23

*=significant p<0.05