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Digital Trajectories to Care in First-Episode Psychosis

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Abstract

Objective: The emphasis on reducing the duration of untreated psychosis (DUP) has highlighted complex barriers to accessing appropriate services. Internet and social media use by individuals with first-episode psychosis (FEP) was examined to explore how these platforms might be used to facilitate treatment initiation.

Methods: Participants ages 15–35 were interviewed with the Pathways to Care for Psychosis Questionnaire, an 81-item instrument designed to explore online activity during symptom emergence.

Results: Of 112 participants, 90% used the Internet and social media daily. The Internet was listed as the most used resource (62%) for information while symptoms were emerging. A minority (19%) shared concerns via social media, and 76% responded favorably to the possibility of receiving online mental health support.

Conclusions: The Internet and social media were part of daily life for participants with FEP. Activity continued throughout the DUP, offering the prospect of earlier intervention. Participants expressed positive attitudes toward Internet-based outreach and engagement efforts.

The consequences of untreated psychosis can be devastating. Despite efforts to improve access to effective services, there remains a substantial delay between onset of psychotic experiences and treatment initiation. The emphasis on reducing the duration of untreated psychosis (DUP) has highlighted the complex barriers to expeditious access to appropriate care.

Determinants that have been associated with deleterious pathways to care include systemic factors, such as poorly defined trajectories to care, inappropriate referral processes, poor detection, and provider concerns and referral delays, and demographic characteristics, such as earlier age at illness onset, male sex, race, and lower socioeconomic status (1). Qualitative studies have additionally identified subjective barriers to treatment initiation, including lack of education about the symptoms of psychosis, uncertainty about appropriate response to symptoms, stigma, and mistrust of the mental health system (2). This situation highlights the fact that there is no simple mechanism to completely address this public health challenge, because it involves a unique constellation of factors. Novel, innovative, and focused strategies are necessary in order to accomplish this goal.

The Internet and social media may prove to be critical resources for expediting help seeking and facilitating treatment initiation among prospective patients with first-episode psychosis (FEP). These technologies provide opportunities to diminish barriers to accessing services by reaching individuals earlier in the course of illness and promoting engagement with treatments that meet their needs. Google has been consistently ranked as the world's most popular search engine, with over 660 million daily visitors. Over 80% of Internet users search online for health-related information (3). Online search engines have become a primary resource for individuals seeking mental health information. This is especially true for stigmatized illnesses, such as schizophrenia, because the Internet provides a comfortable and anonymous setting to gather information(4). Importantly, many individuals using online mental health resources have not yet connected with treatment.(5). In addition, social media sites, including Facebook and Twitter, have drastically changed the way youths communicate and share information. Over 90% of U.S. adolescents use social media daily and disclose considerably more about themselves online than offline, including information related to mental health (6).

Despite the popularity of the Internet and social media, limited efforts have explored their role in pathways to care for individuals with psychotic disorders. Early published pilot data suggested that adolescents with psychosis were more likely to search online for information while symptoms were emerging, as opposed to or prior to discussing these symptoms with others (7). Internet searches appear to represent one of the first proactive steps toward treatment initiation and may affect a person's decision to seek professional care (8).

Given that many individuals with psychosis are online prior to presenting clinically, this project intended to expand on our initial findings in larger samples and to gather results that could inform future research exploring innovative Internet-based means of outreach and engagement. We hypothesized that most individuals with psychosis would report use of social media and the Internet throughout the DUP and that these platforms could play an important role in refining pathways to care.

METHODS

Participants ages 15–35 were recruited from Northwell Health’s inpatient and outpatient psychiatric departments. Youths with psychotic disorders were recruited between March 2013 and September 2017 from the Early Treatment Program, Northwell Health’s early psychosis intervention clinic, as well as from eight collaborating early psychosis programs located in Alabama, Alberta, California, Florida, Georgia, Missouri, Ontario, and Oregon. Eligibility criteria included an FEP, a nonpsychotic mood or anxiety disorder, or attenuated psychotic symptoms identified within the past 24 months, along with a suspected IQ >70. Healthy individuals were also recruited as a control group. Given our focus on DUP reduction, here we present data pertaining to participants with early psychosis, and we plan on presenting data from other cohorts in subsequent publications. The study was approved by Northwell Health’s Institutional Review Board and locally at participating sites. Consent was obtained from adults and from legal guardians of minors. Assent was obtained from minors.

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 early psychosis. The PCP-Q consists of 81 open-ended and multiple-choice questions designed to retrospectively explore trajectories to care emphasizing online resources used to obtain information about emerging symptoms and inform the decision to seek care. [A copy of the PCP-Q is available in an online supplement to this report.] In addition, questions adapted from items on the Topography of Psychotic Episode (9) were included to extract DUP and mode of symptom onset (acute versus insidious). All interviews were conducted by three members of the coordinating institution (authors MLB, AFR, and KF), either in person or via two-way video.

Most questions were closed ended, asking participants to pick one response from a list of available options, to provide a date (month/year), or to provide a number (quantity/frequency). Participants were occasionally encouraged to choose multiple responses from a list of available options (for example, “rank top 5 social media sites used”). Some questions offered the opportunity to elaborate by listing an “other” option. Responses to open-ended questions (for example, “Which changes did you first notice?”) were initially assigned to one of several categories (e.g., preoccupations, perceptual disturbances, or sleep dysfunction) by two of the authors separately and again together to achieve consensus. Results are presented as descriptive statistics. Frequencies and percentages are reported for categorical variables. Means and SDs are used for normally distributed continuous variables; medians and interquartile ranges are used for nonnormally distributed variables. Histograms, q-q plots, and the Shapiro-Wilk test were used to determine whether the continuous variables were normally distributed. Differences in sex, age, and race-ethnicity were examined by using chi-square analysis for categorical variables and independent-samples analysis of variance (ANOVA) or Kruskal-Wallis test (nonparametric ANOVA) for continuous variables. No significant differences were found in sex, age, and race-ethnicity except for greater duration of social media use in the older cohort.

RESULTS

Altogether, 190 patients and 79 control group participants were interviewed. Of these, 112 had a diagnosis of a primary psychotic disorder (Table 1). The mean±SD age of the 112 patients was 22.5, and 68% were male. All participants reported either current or past social media use. Ninety percent of patients reported current regular use, and they reported checking social media 9.0 times daily and spending an average of 1.8 hours daily online. The 112 participants reported using social media on average for the past 7.6 years, predating diagnosis by approximately five years. Facebook was listed as the most popular site (86%), followed by Instagram (62%). The most common reasons cited for social media use (N=109) included communication with others (N=89, 82%), followed by sharing information (N=32, 29%) and gathering information (N=29, 27%).

Participants reported first noticing preoccupations and delusions (76%), followed by changes in sleep patterns (55%). Stress was the most frequently reported perceived contributor to emerging symptoms (39%), followed by illicit drug or alcohol use (32%). Most participants (66%) believed that early symptoms would resolve on their own without intervention, whereas 36% considered that changes might get worse. Participants reported waiting a mean of 36.6±102.4 weeks before disclosing their symptoms to anyone.

The Internet was the most widely used resource for participants seeking mental health information. Approximately 62% reported using online search engines to understand early changes. This was followed by seeking information from medical professionals (42%), family (24%), and friends (12%). Although the Internet was listed among the most helpful resources by some participants (N=22, 20%), it was also listed among the least helpful resources by others (N=9, 8%). Participants (N=104) were most interested in understanding reasons for early changes (N=50, 48%), followed by how to manage symptoms (N=35, 34%).

Altogether, 74% of participants reported noticing changes in their social media habits while symptoms were emerging. Approximately 24% (N=27) of the entire sample reported that others expressed concern or noticed changes in their social media activity. A minority of participants (19%) explicitly shared their experiences with others via social media. Only 6% (N=7) stated that social media activity affected their trajectory to care.

Most participants reported a desire to obtain digital resources and online interventions. Fifty-nine percent stated that they would have felt comfortable if they had been proactively identified and engaged by a mental health professional via the Internet or social media while symptoms were emerging. Seventy-six percent responded favorably to the possibility of receiving online mental health help or support via the Internet. Eighty-one percent reported a willingness to share their online activity data with researchers.

DISCUSSION

The Internet and social media may offer opportunities to improve pathways to care through innovative identification, outreach, and engagement strategies. Our data reinforced several relevant findings. Online resources, including Google, Facebook, and Twitter, were an

important part of daily life for participants with early psychosis. Online activity often predated illness onset and continued throughout the DUP, which offers the prospect of earlier intervention. Importantly, participants with early psychosis expressed positive attitudes toward Internet- and social media–based intervention efforts.

Online search engines have become a primary source of mental health information for the general population (10). For many participants, results of online search queries represented a primary source of information during symptom emergence. However, despite the ease and popularity of search engines as a vehicle for exploring early experiences, some participants described the Internet as being among the least helpful resources owing to the vast amount of misinformation available. Most participants attributed early changes to increased levels of stress, and some incorrectly anticipated resolution of symptoms without intervention, possibly contributing to treatment delay. The impact of inaccurate information gathered online supporting participants' misconceptions about mental illness remains to be fully appreciated.

Some participants chose to obtain information or support via social media by self-disclosing symptoms to their social network. This finding is in line with existing work suggesting that social media is increasingly being used in the general population as an opportunity to share personal health information, including mental health–related information (11). Although social media is not an anonymous setting, it is transforming the ways by which people communicate and can offer opportunities to seek social support and feedback from individuals online through a personalized and selective social platform. Despite the popularity of social media, few participants reported that social media activity affected their pathway to care, suggesting that the unique potential of this channel has yet to be fully developed.

At the time of symptom emergence, participants appeared to be mostly interested in obtaining information to understand the cause of their experiences. Few participants were searching for traditional referral information to begin psychiatric intervention. This finding is consistent with prior work suggesting that many who utilize the Internet as a mental health resource have yet to connect with treatment (5) and may have little, if any, desire to do so. This result highlights an important discrepancy in DUP reduction efforts. For prospective FEP patients, accessing care may not be a priority. Mental health clinicians may need to refocus efforts on providing digital tools that meet the needs of their target audience. These tools should be designed to facilitate a smooth transition to care once a prospective patient is ready to take that step. Unfortunately, utilization and engagement with existing digital mental health tools are poor (12), and new and innovative solutions need to be explored.

Harnessing social media and Internet-based technologies provides opportunities to improve the ways we identify, engage, and meaningfully interact with individuals experiencing emerging psychosis. Mental health clinicians have an opportunity to contribute to the online universe by developing effective mental health Web sites and social media pages. These resources must be designed to compete with the abundance of inappropriate, stigmatizing, and misleading Web sites. At the same time, there is a growing body of literature that describes use of personalized online digital data in search engines and social media

platforms to automatically identify individuals who may be experiencing mental illness (13,14). Advertisers mine online data to identify customers and tailor advertisements that have the highest likelihood of influencing behavior. Similar efforts to apply available technology to identify, engage, and facilitate treatment initiation have begun in psychiatry (15). Nearly all participants in our study were engaging in online and social media activity during symptom emergence, prior to receiving care, which offers the prospect of earlier detection and intervention online. As efforts to successfully identify and effectively interact with individuals with emerging psychosis improve, these tools may become increasingly relevant in targeted DUP reduction initiatives.

The study had noteworthy limitations. First, interviews were retrospective and limited to participant recall. Although participants had been given a diagnosis within the past 24 months, accurate recall of use of and response to online resources can be challenging. Furthermore, the degree of insight varied, and discrepancies were occasionally noted between recollected accounts from participants and medical records. In addition, at the time of the interview, all participants were receiving care, which may have affected their memory of events. Finally, differences may have existed in variables, including speed of symptom onset, first identified psychotic symptom, access to technology, education, and race-ethnicity, which may affect pathways to care and which need to be further delineated.

CONCLUSIONS

Information gathered online appears to play a role in help seeking and may represent one of the first proactive steps toward treatment initiation. As technology companies, including Facebook and Google, expand efforts to improve mental health resources for their users, clinicians must take an active role in studying and refining these tools. Mental health clinicians should focus on mapping out the precise digital trajectories from online search query to receipt of mental health services and explore points of potential intervention. Furthermore, clinicians need a better understanding of how individuals interact with and respond to online resources throughout the trajectory to care in order to develop successful interventions. Finally, stakeholders should focus on improving the array of online resources available to individuals with psychosis, providing them with the tools they seem to be most interested in obtaining at different stages of illness development. These tools should be designed to provide information and support as well as encourage and facilitate treatment initiation at the right time.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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TABLE 1.

Characteristics of 112 participants with first-episode psychosis interviewed with the Pathways to Care for Psychosis Questionnaire (PCP-Q)^a

Characteristic	N	%
Northwell Health site	57	51
Non-Northwell Health site	55	49
Sex		
Male	76	68
Female	36	32
Diagnosis		
Psychotic disorder not otherwise specified	36	32
Schizoaffective disorder	8	7
Schizophrenia	54	48
Schizophreniform disorder	12	11
Brief psychotic disorder	2	2
Current social media use	101	90
Top social media sites used (N=101)		
Facebook	86	85
Instagram	62	61
YouTube	49	49
Years of social media use (M±SD)	7.6±2.8	
Hours per day online (M±SD)	1.8±2.4	
Frequency of checking social media per day (M±SD)	9.0±17.2	
Selected PCP-Q questions		
Which changes did you first notice? (N=111)		
Preoccupations or delusions	84	76
Sleep changes	61	55
Perceptual disturbances	58	52
What did you think was causing or contributing to these changes? (N=112)		
Stress	44	39
Relationship problems	25	22
Traumatic event	12	11
Mental illness	8	7
Physical illness	6	5
Drugs or alcohol	36	32
Did you think changes would go away on their own? (N=107) ^b	71	66
Did you think changes would get worse? (N=108) ^b	39	36
Where did you go for answers? (N=86)		
Books	5	6
Internet	53	62
Magazines	0	–

Characteristic	N	%
Friends	10	12
Family	21	24
Medical health professional	36	42
Clergy	4	5
Other professional	2	2
Other	7	8
Did your social media habits change during symptom emergence? (N=104) ^b	77	74
Did you talk about your concerns on social media during symptom emergence? (N=102) ^b	19	19
Would you be OK with online proactive outreach from mental health professional? (N=105) ^b	62	59
Would you be OK receiving online help from mental health care professional? (N=109) ^b	83	76
Would you be comfortable sharing your online data with researchers? (N=109) ^b	88	81

^aMean±SD age=22.5±3.4;median (interquartile range) of duration of untreated psychosis, 31.5 (75.6) weeks

^bNs and percentages reflect those who answered yes.