



Social Media and Early Psychosis Intervention: A Comprehensive Review of the Literature

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Abstract

Purpose of Review Early intervention (EI) is now seen as the most evidence-based approach to improving outcome for youth with first episode psychosis and youth at clinical high risk for psychosis. However, despite the established benefits of EI, several challenges persist, including lengthy and convoluted pathways to care, poor engagement in services, and high rates of relapse. There is hope that the use of technology, and specifically social media, can address some of these challenges. This review article provides a comprehensive overview of the existing literature on social media use and its implications for EI in youth experiencing early psychosis.

Recent Findings Several studies have identified the potential roles that social media can play in early psychosis intervention including (1) as a source of objective and clinically meaningful digital information, (2) as a means to improve access to care, and (3) as a tool to enhance treatment delivery.

Summary Despite risks, social media holds promise in enhancing early psychosis intervention though more research is needed. We outline its potential clinical applications and consider next steps for integrating social media data and use into clinical practice, aiming to maximize the benefits of social media use while minimizing associated risks.

Introduction

Schizophrenia spectrum disorders often emerge during the formative years of adolescent and young adult development. The onset, termed first episode psychosis (FEP), typically involves symptoms such as hallucinations, delusions, and thought disorder, which can disrupt the attainment and maintenance of healthy developmental milestones [1]. Even at the earliest stage of symptom emergence, youth at clinical high risk (CHR) for psychosis experience deficits in quality of life and functioning consistent with other psychiatric disorders [2]. Early intervention (EI) is now seen as the most evidence-based approach to improving outcomes and increasing the likelihood of achieving a full functional and symptomatic recovery [3–7]. However, despite the established benefits of EI, several challenges persist, including lengthy and convoluted pathways to care, poor engagement in services, and high rates of relapse [8, 9]. There is hope that the use of technology, and specifically social media, can address some of these challenges.

The internet has become central to modern society. Currently, there are 5.3 billion internet users worldwide, which accounts for 65.7% of the global population. Furthermore, over 4.59 billion people (56.9% of global population) regularly engage in social media, marking a significant increase from the 2.7 billion recorded in 2017 [10]. Social media, defined as any online platform that allows users to create and share digital content with others [11], has dramatically transformed the way we communicate and interact. This is especially true for adolescents and young adults, who are the greatest users of social media and are also at greatest risk for the emergence of a psychotic disorder [12]. In the USA, 97% of all adolescents ages 13–17 use social media (i.e., YouTube, TikTok, and Instagram) daily and spend on average 4.8 h per day online [13, 14]. Furthermore, 35% report using social media “almost constantly” [13, 14]. Among young adults

ages 18–29, rates are similar with 84% stating that they use at least one social media site regularly [14]. Rates among the general population are comparable to those of youth with early psychosis, with studies ranging from 68% [15] up to 90% [16] of youth with FEP using social media regularly and spending nearly 2 h per day online [16].

Although several studies have concluded that social media use may be detrimental to youth mental health [17–22], considerable research has also demonstrated important benefits critical to healthy development, including finding and developing a sense of community and belonging, providing and receiving emotional and social support, connecting with others who share similar experiences, and identifying and engaging healthy role models [23–30]. From a mental health perspective, social media may also offer novel opportunities to access health information, share personal narratives about living with mental illness, and connect with providers [17, 31, 32].

Harnessing the popularity of social media, researchers have been exploring the role that social media can play in enhancing mental health services [33]. For instance, therapeutic interventions and treatment groups have been deployed over Facebook, effectively extending treatment options beyond traditional treatment settings and modalities [34, 35]. Furthermore, social media use itself has demonstrated therapeutic benefit to youth by enriching relationships, enhancing communication, reducing loneliness, and strengthening social connections [36–38]. Other research groups have developed their own social media-like digital platforms, leveraging the features that make social media appealing, such as peer-to-peer social networking, offering new opportunities to enhance and deliver mental health services [39]. These studies have demonstrated high acceptability and user engagement, as well as high user perceptions of usefulness and

safety [39]. Social media data is also being studied as a source of objective digital information about an individual's thoughts and behaviors [40]. This line of research predominantly aims to use computational techniques such as machine learning (ML) and natural language processing (NLP) to help inform diagnostic procedures and symptom identification and management [41–43]. Studies have found that data shared on social media can be used to predict a variety of clinically meaningful outcomes with high degrees of accuracy based on changes in language and online behaviors [44–48]; see Chancellor and De Choudhury for a systematic review of this area [49].

Social media will likely have an increasingly important role in the clinical care of youth with mental illnesses including early psychosis. In this review article, we summarize the existing literature regarding social media use (see Table 1) and its implications for early intervention in adolescents and young adults (collectively termed “youth”) with both FEP (defined as psychotic symptom onset within the past 5 years) and at CHR (defined as having attenuated psychotic symptoms). We highlight risks, benefits, and gaps in the literature, as well as discuss strategies for implementation in the treatment of youth with early psychosis.

Social media data as a form of objective and clinically meaningful digital information

Psychiatry relies nearly entirely on clinical assessment and patient self-report, which is limited by recall bias. Social media offers easily accessible and objective information that can potentially be used to complement current standards and facilitate more informed treatment decisions. Studies have found unique objective alterations in the ways in which youth with early psychosis engage with others online. As such, there is hope that social media data can one day be used to inform the diagnostic process, symptom management, and relapse prediction in youth with early psychosis [48, 50–52].

Beginning with self-report, studies have found that FEP participants may use social media differently than their peers. For instance, among 59 youth ages 18–35, “active” posting on social media, defined as commenting and/or contributing content at minimum weekly was significantly lower ($p < 0.01$) in those with a psychotic disorder (5%, 1/21) compared to non-psychotic controls (27%, 4/15) and those at CHR (43%, 10/23) [53••]. Similarly, among 112 FEP youth, 74% (77/104) stated that they noticed changes in their social media habits during symptom emergence, including the timing and frequency of use, and 24% (27/112) reported that others noticed changes in their activity as well [16].

Computational approaches, such as ML and NLP, have accelerated efforts to identify objective signs of psychotic disorders in social media data [54••, 55–60]. For instance, using Instagram data, researchers found that FEP youth ($N = 34$) were more likely to post images with significantly lower saturation ($p = 0.03$) and lower number of faces ($p < 0.001$) compared to healthy volunteers [61••]. While not statistically significant, FEP youth also tended to upload images with less color [61••]. Furthermore, FEP youth exhibited a significantly lower ratio of followers to followees compared to healthy volunteers ($p = 0.03$) [61••]. Similarly, using Facebook data, Birnbaum et al. collected 52,815 status updates across 51 FEP youth and used ML to predict psychotic relapse with 88% accuracy. Significant differences were found in

Table 1. Summary of studies exploring the role of social media in early psychosis intervention

Roles	Summary	Studies
Social media data as a form of objective and clinically meaningful digital information	<p>Individuals with early psychosis may exhibit unique and measurable alterations in how they engage with others online</p> <p>Computational approaches may help inform the diagnostic process, symptom identification, and relapse prediction in youth with early psychosis</p>	<p>Feldman et al. 2021; Fonseka et al. 2022; Bjornestad et al. 2018; Birnbaum et al. 2019; Franco et al. 2022, Birnbaum et al. 2018; Bae 2021; Hswen 2018, Kim 2020; Mitchell 2015; Lejeune et al. 2022; McManus et al. 2015; Birnbaum et al. 2017; Hansel et al. 2021; Birnbaum et al. 202</p>
Social media as a tool to improve access to care	<p>Social media platforms may offer novel opportunities to connect youth with early psychosis (and their caregivers) to care</p> <p>Social media platforms may help enhance delivery and dissemination of high-quality information about early psychosis and treatment options to support help-seeking behaviors</p>	<p>Birnbaum et al. 2018; Lal. et al. 2015; Bonet et al. 2018; Buck 2021; Birnbaum et al. 2022; Amsalem et al. 2023</p>
Social media as a tool to enhance treatment delivery	<p>Social media-like digital platforms (i.e., Horyzons, MOMENTUM, and EMBRACE) have been tested in early psychosis populations in Australia, the USA, and Canada both during and post coordinated specialty care (CSC) with promising results</p>	<p>Biaganti et al. 2018; Santesteban-Echarri et al. 2018, Alvarez-Jimenez et al. 2014; Alvarez-Jimenez et al. 2013; Alvarez-Jimenez et al. 2021; Engel et al. 2023; O'Sullivan et al. 2022; O'Sullivan et al. 2023; Lal. et al. 2020; Ludwig et al. 2021; Pokowitz et al. 2023; Alvarez-Jimenez et al. 2018; McEnery et al. 2021; Schlosser et al. 2016; Schlosser et al. 2018</p>

posts in the month before hospitalization including increased words related to anger ($p < 0.001$) and death ($p < 0.0001$) and decreased words related to friends ($p < 0.0001$) [48]. There was also an increase in co-tagging ($p < 0.001$) and friending behaviors ($p < 0.0001$) in the month preceding a relapse hospitalization [48]. In another study exploring both languages extracted from Instant Messages (personal private messages between users) and images uploaded as profile pictures on Facebook, significant differences were found in FEP participants' use of words related to perception ($p < 0.01$), swear words ($p < 0.01$), and use of negative emotion words ($p < 0.01$) compared to youth with mood disorders and healthy volunteers. Further photos uploaded were significantly smaller in height and width ($p < 0.01$). Many of these differences were apparent over a year in advance of the first psychiatric hospitalization and differences grew larger as symptoms escalated [47].

Social media as a tool to improve access to care

The time between symptom onset and receiving care can be lengthy, resulting in worse outcomes [62–64]. Global efforts to expedite treatment initiation have catalyzed unprecedented demand for innovative healthcare solutions aimed at increasing access to available and effective treatment options [65–70]. There is promise that social media can be leveraged to help advance help-seeking and improve trajectories to care as exemplified by the studies described below.

Several studies have demonstrated that FEP youth use social media both prior to and after connecting with care. For example, Birnbaum et al. found that among 112 youth with FEP, 90% ($N = 101$) reported regular social media use, characterized by checking social media 9.0 times daily and spending on average 1.9 h per day online [16]. Additionally, individuals reported searching online (62%, $N = 53$) for information before initiating treatment over seeking help from medical professionals (42%, $N = 36$), family (24%, $N = 21$), and friends (12%, $N = 10$) [16]. Similarly, Buck et al. found that 97.4% (75/77) of FEP youth searched online for information, 84.4% (65/77) went online to seek individuals with similar health concerns, and 53.2% (41/77) connected to health providers online [71]. Lal et al. found that 85% (57/67) of FEP youth reported utilizing YouTube to access mental health information and hypothesized that information obtained online could impact treatment-related decisions [72]. Similarly, Bonet et al. found that compared to patients with established schizophrenia spectrum disorders ($N = 40$), FEP youth ($N = 105$) were more likely to use the internet to seek health information ($p = 0.04$) [73]. This line of research suggests that social media could be used to help connect youth with early psychosis to providers earlier in the course of illness development.

In 2021, an 18-month digital media campaign aiming to expedite treatment initiation for youth and their caregivers was launched in New York State (NYS) [74]. The campaign utilized targeted digital advertisements over social media and the internet to proactively identify and engage participants online. Once an advertisement was clicked, participants were brought to a landing page offering opportunities to learn about early psychosis, complete a

symptom screener, and engage with a peer mentor or mental health clinician over text or two-way video. Throughout the campaign, 34,341 individuals visited the website and 364 (1.1%) advanced to remote clinical assessment (median age = 24.4), including 53 allies and 318 youth. Of those assessed, 53 individuals (14.5%) reported psychotic experiences (62.2% female, mean age 20.7 years) including 26 (7.1%) reporting symptoms consistent with CHR and 13 (3.6%) reporting symptoms consistent with FEP [74••]. Although the campaign failed to reduce the duration of untreated psychosis in NYS, their data suggest that digital media campaigns may be beneficial to enhance early identification and engagement efforts for youth with early psychosis online. They hypothesized that the leap between information gathering and care initiation may be too large to overcome with a digital media campaign alone and are currently studying the impact of novel automated digital prompts aiming to advance help-seeking beyond information gathering [74••].

Social media is also being studied as a platform to disseminate high-quality education about signs and symptoms of psychosis, as well as treatment options, aiming to reduce stigma and encourage help-seeking. For example, Amsalem et al. demonstrated that young adults ($N = 606$) who viewed brief educational videos about psychosis reported increased willingness to seek help and decreased stigma compared to controls ($p < 0.001$) [75••]. The team hypothesized that deploying these videos to social media could improve treatment-seeking behaviors [75••].

Social media as a tool to enhance treatment delivery

Another focus has been on developing interventions that incorporate the unique and engaging features of social media, such as 24/7 accessibility and innovative modalities for social interactions [76]. These studies have trialed initiatives involving platforms designed to function like social media [77, 78].

For instance, Horyzons was designed to extend and enhance the clinical and psychosocial benefits of early psychosis intervention. The platform integrates tailored, strengths-based, and interactive digital modules; peer-to-peer social networking; and live support from a clinician, an education and employment specialist, and a peer advocate [79]. Results from an 18-month clinical trial found that those receiving Horyzons ($N = 86$) were significantly more likely to find and/or remain employed or in school ($p = 0.04$) and had decreased usage of emergency services ($p = 0.03$) compared to treatment as usual ($N = 84$) [80••]. Horyzons was cost-saving and cost-effective leading to a 24% reduction in healthcare costs compared with treatment as usual post-discharge from early intervention services, with evidence of a dose-response effect (i.e., when youth engaged more with the platform, costs decreased, and outcomes improved). Secondary analyses showed that those with maintained use showed significant improvements in social functioning, negative symptoms, and overall symptom severity compared to those with lower usage [81••, 82]. Interestingly, an analysis using multiple convergent cross mapping showed that the online social network component was a key driver of long-term engagement with the Horyzons intervention and fostered engagement

with key therapeutic components and ingredients of the intervention. This suggests that online social networks can be leveraged to engage youth with psychosis with therapeutic content, leading to sustained clinical benefits [83]. Horyzons has since been studied in FEP populations in Canada and the USA with promising results [84, 85••, 86••].

Building off Horyzons, Alvarez-Jimenez et al. developed a similar platform, called MOMENTUM, for youth at CHR. In its pilot study ($N=14$), engagement was high, with 72% ($N=10$) reporting at least 7 logins during the study and 57% ($N=8$) reporting at least 28 posts or comments. One hundred percent (100%, $N=14$) reported an overall positive experience, and 93% ($N=13$) reported helpfulness. Additionally, participants reported significant improvements in social functioning, measured by the Global Functioning: social scale ($p<0.001$) and self-reported well-being ($p=0.03$) at follow-up [87]. EMBRACE, a third platform, has been implemented to treat comorbid social anxiety in FEP youth. Results from a pilot study ($N=10$) found significant improvement in social anxiety as measured by the Social Interaction Anxiety Scale ($p=0.0005$) and Liebowitz Social Anxiety Scale ($p=0.002$) [88••].

Lastly, PRIME, another social media-like mobile application developed for FEP youth, incorporates text message-based coaching and social networking through peer-to-peer messaging and a community newsfeed [89]. Compared to youth randomized to receive the “waitlist,” defined as TAU for 12 weeks followed by prime ($N=21$), participants receiving PRIME ($N=22$) demonstrated significant improvements in self-reported depression ($p=0.03$), defeatist beliefs ($p=0.03$), self-efficacy ($p=0.02$), and motivation ($p=0.03$) post-trial, with maintenance of gains 3 months after [90].

Risks and challenges associated with social media use in early psychosis intervention

Studies have focused on identifying risks associated with social media use that may be unique to youth with early psychosis. For example, social media may be a source of misinformation, especially when it comes to misunderstood illnesses like schizophrenia. While some have suggested that mental health-related discourse over social media tends to contain more compassion compared to other news outlets, stigma certainly still exists [91]. In 2016, Birnbaum et al. rated the top 5 search results that populated in response to 18 psychosis-related search terms on Google, Facebook, and Twitter. They found that most results yielded information that was misleading, stigmatizing, and/or inaccurate [92]. Only 3/18 search terms on Twitter yielded results that were rated to be helpful, while 0/18 search terms on Facebook yielded educational material, encouraged consultation, or connected users to professional pages. On Google, only when searching very specific search terms, such as “Do I have schizophrenia?” did the team identify results that encouraged help-seeking [92].

Magaud et al. found that youth at CHR may be particularly prone to cyberbullying and online victimization and found that among 50 youth at CHR, 38% ($N=19$) experienced cyberbullying (Magaud 2013). Similarly,

Pelletier-Baldelli et al. found that youth at CHR ($N = 52$) exhibited significantly greater problematic internet use ($p = 0.002$), defined by higher total scores on the Internet Addiction Test (IAT) compared to healthy volunteers ($N = 46$). Youth at CHR also demonstrated significantly greater social withdrawal and unhealthy social behaviors ($p < 0.001$), resulting from internet use. These social problems were significantly correlated ($p = 0.02$) to poor emotional processing, which has been found to be impaired in some youth at CHR [93].

There is some evidence to suggest that social media use itself may exacerbate psychiatric symptoms in youth with early psychosis. For instance, Tran et al. studied self-reported social media habits in 25 patients at CHR and found that increased self-stigma experienced through social media was associated with significant increases in delusion severity ($p = 0.05$) and anxiety ($p = 0.004$) compared to healthy controls [94]. There are even some reports of social media use contributing to the development of psychotic symptoms. For instance, Baldwin et al.'s co-twin control study, which enrolled 7708 twins from birth to age 22, found that monozygotic twins exposed to greater cyber victimization self-reported more "psychotic experiences" (i.e., paranoid thoughts, hallucinations) on the Specific Psychotic Experiences Questionnaire (SPEQ) compared to their co-twins ($\beta = 0.30$) [95]. Similarly, Nitzan et al. reported on three youth who experienced "de novo" psychotic symptoms (e.g., tactile hallucinations, suspiciousness of strangers) after utilizing platforms like Facebook [96].

Implementation and future directions

While a growing body of research has demonstrated that social media technologies hold promise to enhance early psychosis intervention, several questions remain regarding how best to integrate social media data and use into clinical practice and, more importantly, how to maximize its benefits while minimizing risks.

At a minimum, all clinicians working with youth with early psychosis should ask directly about their social media habits early on in treatment. This includes the timing, frequency, duration of use, and the type of platform and features most frequently used [97•]. Moreover, clinicians should ask about the types of experiences (both positive and negative) youth encounter online and screen for signs of problematic social media use. Research shows that many young patients are already inclined to bring social media data to their clinical teams [98•]. This information will deepen clinicians' awareness of clinically relevant experiences such as the frequency and quality of social interactions and engagement with online peer support. Throughout treatment, this information should be reassessed routinely as social media activity fluctuates over time and online experiences (both positive and negative) can have important impacts on recovery [99•].

Clinicians need an effective and reliable method to measure and interpret social media activity [100•]. Some data, like usage data, is available directly through sites like Facebook and Instagram and may also be extractable from

the “setting” section of mobile devices. For example, the Screen Time feature on an iPhone can track time spent on social networking sites including a user’s longest session. Scales may be more useful, such as the IAT and the Social Media Use Integration Scale (SMUIS). However, most scales to date do not appreciate both the risks and benefits of social media use and future research is needed to develop comprehensive scales that more accurately capture social media use and its impact on health and wellness. For some patients, it may be beneficial to review social media data together. Collaborative manual review of social media activity can provide a more nuanced understanding of the data and allow for more personalized recommendations. However, manual review can be tedious and may thus limit the amount of data being examined.

Clinicians have a responsibility to provide psychoeducation about the potential dangers (as well as the potential benefits) of social media use. Clinicians can buffer problematic use by educating patients about cyberbullying and preparing youth for the likelihood of encountering stigma and misinformation online [101]. Furthermore, clinicians should provide guidance on how best to address these challenges such as setting daily time limits, blocking negative content, unfollowing certain users, and replacing negative content creators with healthier role models. Additionally, clinicians should emphasize the importance of reaching out to adult allies and/or professionals for guidance when encountering challenging situations online. Clinicians should support positive aspects of use as an alternative or complimentary tool to socializing, especially in situations where symptoms may be interfering with a person’s ability to socialize in person, and as a resource for additional peer support via online groups. Caregivers should be enlisted as resources to help monitor use and support social media–based interventions at home.

Researchers have already begun exploring how best to incorporate social media-like platforms such as Horyzons into clinical care, though challenges exist. For example, while many youths experience the benefits of social networks within the intervention including increased peer support, co-creating a social space and increased optimism, a subgroup experience increased burden [102]. This highlights the need to develop customizable and personalized treatment options that account for varying levels of social connection and psychological need that could otherwise interrupt young people’s usage of social media–based interventions [102]. Moreover, patients and clinicians will need to be educated on how to properly use these platforms, which may be a barrier for some with minimal prior experience. Clinicians and patients must also have a clear sense of where these platforms exist within the clinical workflow including when to initiate them and when, and how, to discontinue them [103•]. In addition, the cost involved in training and implementation may deter clinics from incorporating these technologies. Some studies have recommended incorporating human support alongside these interventions to support implementation [100•, 103•, 104] such as a digital navigator [104]. Of note, there are considerations related to security of these technologies and data protection [105] as well as ethical concerns that by promoting use of social media-like technologies, patients may become increasingly isolative and have less in-person engagement which may be a barrier to important outlets such as work and school. The success of implementation of social

media technologies into clinical care will ultimately be largely dependent on addressing these concerns.

Finally, in an era of rapid digital innovation, policies must adapt to allow for growth. Regulations must be flexible enough to support innovation but strict enough to protect patients [103•]. For instance, as ML algorithms become increasingly sophisticated and our ability to predict health information using social media data improves, stakeholders will need to develop standards to protect the confidentiality and the rights of patients while also ensuring that the enabled technologies are used in the service of positive outcomes [100•]. Interdisciplinary teams of researchers, clinicians, and patients must continue to work together on addressing challenges in ethics, privacy, consent, clinical responsibility, and data ownership. We anticipate that youth with early psychosis may one day be able to “donate” their social media data to inform their clinical care, much like the way that blood is drawn when a provider orders lab tests to inform treatment.

Conclusion

Research has demonstrated that social media technologies have the potential to enhance early psychosis intervention through serving as a source of objective information, as a way to improve access to care, and as a means to augment treatment delivery. More research is needed to explore how to best integrate social media into clinical care while mitigating risks. Future efforts should focus on developing effective ways to measure social media activity and its impact, optimizing integration of social media and social media-like platforms into clinical practice, and addressing challenges in policy, privacy, and ethics.

Author contributions

I.L., A.E., and M.L.B. conceptualized and wrote the main manuscript text and prepared Table 1. Revisions were completed by M.D.C., M.A., and M.L.B. All authors reviewed and approved the manuscript.

Declarations

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

Competing Interests

M.L.B. is a consultant for North Shore Therapeutics and holds equity. The other authors have no competing interest to declare.

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- Of importance
- Of major importance

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