

Internet-Based Interventions for Psychosis: A Sneak-Peek into the Future

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KEYWORDS

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KEY POINTS

- People suffering from psychosis use the Internet regularly and online-based interventions have been well-received by people with psychosis and their carers.
- The use of the Internet in psychosis treatment has been neglected and is overdue.
- Online-based interventions for psychosis should be designed to supplement existing models of care and augment social inclusion, rather than replacing available resources.
- Innovative and flexible interventions that integrate different technologies, evidence-based therapy, and peer and professional support are likely to be more acceptable and effective.
- Internet-based interventions may begin to overcome major challenges in the field of early intervention including engagement with specialised services and maintenance of treatment effects.

INTRODUCTION

Psychotic disorders are among the most costly mental health disorders in terms of human suffering and societal expenditure.¹ Their onset, typically in the critical development period of adolescence and early adulthood, has severe effects on individuals, families, and society.² Although advances in antipsychotic medication have led to a better prognosis in relation to psychotic symptoms,³ this has not translated into

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improved functional or social outcomes.⁴ Compared with the general population, people with psychosis are disproportionately undereducated, unemployed, living in unstable accommodation, or homeless.⁵ People living with psychosis experience extreme social isolation, with most experiencing difficulties in maintaining close relationships, and more than half reporting significant unmet needs in relation to their treatment.⁵

Psychosis continues to be one of the most stigmatized conditions, with nearly half of patients experiencing frequent discrimination or victimisation.⁶ The diagnosis of psychosis is commonly associated with a perception of a catastrophic loss of social status that often results in self-stigma, shame, and social avoidance.⁷ Many medical treatments exacerbate this by disempowering people with psychotic illness, for example through the use of compulsory treatment orders or compulsory commitment to inpatient treatment.⁸ Stigma further diminishes self-esteem and self-efficacy⁹ and adversely affects help seeking and treatment engagement among many patients.⁸

Family members are as much victims of psychosis as the patients themselves.¹⁰ Caring for a young person with psychosis is demanding, often isolating, and leads to high levels of distress and burden.¹¹ Moreover, the stigma associated with having a family member with psychosis often leads to social isolation, avoidance, and shame, causing many families to lose their own support network.¹¹

The Development and Challenges of Psychosocial Interventions for Psychosis

In recent decades, there has been a growing interest in the development and evaluation of psychosocial interventions focused on improving functional and social outcomes in psychosis. Novel interventions such as cognitive behavioral therapy,^{3,12,13} vocational support,¹⁴ peer-support services,¹⁵ psychoeducation,¹⁶ and family interventions^{17,18} have been shown to be effective in improving clinical symptoms, relapse rates, vocational outcomes, and quality of life, and reducing the burden of carers. However, despite mounting evidence supporting their effectiveness, studies uniformly point to unacceptably low penetration rates, with less than 10% of patients having access to evidence-based psychosocial interventions.^{19,20} Reasons for poor accessibility include costly delivery and dissemination of specialized interventions, geographic barriers and transportation costs, and the stigma associated with mental health treatment, which limits help seeking and treatment attendance among people with severe mental disorders.⁸

The previous decade has witnessed the increasing use of the Internet, which has become more than a simple information and communication tool.²¹ With increasing access to novel information and communication technologies in developed countries, a growing number of users resort to the Internet for information on, and support for, mental health disorders.²² A wide array of different resources exists, ranging from psychoeducation and peer-to-peer support forums to e-counseling and self-help therapy.²³ Given the acceptability and accessibility of novel information and communication technologies, Internet-based interventions have the potential to overcome existing barriers by providing cost-effective, nonstigmatizing, and ongoing support to people with psychosis. However, although research has investigated the use of Web-based and mobile-based applications to support depression^{24,25} and anxiety,²⁶ such approaches have rarely been applied to the treatment of psychotic disorders.

This article provides a critical review of the potential for Internet-based applications to improve clinical and psychosocial outcomes in people with psychosis. Current evidence on Internet-based interventions, potential benefits or harms, and current challenges are reviewed and recommendations are proposed for future interventions for psychosis using these technologies.

IS INTERNET-BASED SUPPORT ACCEPTABLE TO PEOPLE WITH PSYCHOSIS?

The extant research indicates that the Internet is a powerful source of information and support for patients with psychosis, with the potential to significantly influence health-related behaviors and decisions as well as the clinician-patient relationship.²⁷ Although more studies are needed, preliminary evidence suggests that the use of the Internet by people with psychosis resembles that of individuals not affected by mental illness.²⁷ In addition to the general advantages such as accessibility and the capacity to access a wide array of resources,²⁸ people with psychosis resort to the Internet because of the anonymity and absence of a hierarchy on the Web and its potential to assist in overcoming difficulties with social interaction.²⁷ A reported advantage of Internet-based support is the disinhibiting effect of online communication as well as the potential for such communication to overcome the fear of stigma by removing the face-to-face aspect.²⁹ In the context of online therapy, disinhibition can encourage therapeutic expression and self-reflection, helping patients to be more open about their illness.^{30,31} In this sense, some online therapists report anecdotally that relating through text-based self-disclosure can induce a high degree of intimacy and honesty from early in the therapy process.³²

Information and communication technologies can be particularly useful for young people, including those with psychosis. Individuals less than 25 years of age are the greatest users of Internet resources³³ and the adolescent population is particularly comfortable interacting within the computer environment.²⁹ Recent surveys have shown that young people are more likely than their older counterparts to trust mental health information Web sites and perceive them as likely to be helpful.²¹ In addition, some young people, particularly teenagers, would sometimes rather interact with a computer than talk to a therapist.³⁴ Parental attitudes toward the Internet, belief in help seeking, and greater willingness to relate with peers with mental disorders seem to predict whether young people consider the Internet to be helpful in dealing with mental illness.²¹ Although there is little evidence on the acceptability and feasibility of online interventions for young people with psychosis, preliminary qualitative research suggests that this population shows positive attitudes toward Internet-based interventions and, in particular, toward online social networking.²⁹

WHAT TYPE OF INTERNET-BASED INTERVENTIONS ARE EFFECTIVE IN THE TREATMENT OF PSYCHOSIS?

Until recently, despite their clinical and social potential, online interventions had not been used and tested for the treatment of psychosis. Only a few recent studies have investigated the effectiveness of Internet-based interventions such as online peer-support groups,³⁰ family interventions,^{35,36} psychoeducation,³⁷ and mobile interventions³⁸ in the treatment of psychosis, with no studies specifically focused on patients with first-episode psychosis (FEP). However, taken together, the preliminary research provides useful insights into the potential, challenges, and future directions of such interventions.

Online Peer-Support Groups

The development of peer support or user-led services for people with mental disorders has rapidly increased worldwide. The enthusiasm for these services is based on solid theory as well as promising research findings.¹⁵ Peer support rests on the assumption that people who have overcome adversity can provide valuable support, guidance, and hope to others facing similar difficulties.¹⁵ Moreover, consistent with the helper-therapy principle,³⁹ being able to be of assistance to others can improve

self-esteem and reduce experiences of self-stigma.⁴⁰ Research on user-led services has found robust associations between peer support, empowerment, and recovery in people with psychosis.⁴⁰ Likewise, interactions with peers in settings that respect empowerment and self-determination have been postulated to reduce self-stigma through enhancing group identification and, in turn, increasing self-esteem and self-efficacy.⁴¹ In addition to these benefits, the potential of peer support to enhance social support networks and improve quality of life is widely recognized.³⁰

With the widespread use and access to the Internet, online peer-support groups have proliferated, many of which are specifically mental health support groups.³⁰ However, despite their prevalence and likely benefits, little is known about the effectiveness or risks of such groups in people with psychosis.

The limited existing research suggests that online mental health groups for depression can improve depressive symptoms and increase the use of health services as a result of the information accessed through the Internet.⁴² In addition, some people prefer online peer support rather than face-to-face interventions because of the stigma associated with mental illness,³¹ making online interventions a valid alternative for those unlikely to engage in traditional treatment.

Research on the effects of these groups for people with psychosis is even more sparse. A recent study that involved patients with depression and psychotic disorders found that participation in an unmoderated, unstructured peer-support group was not associated with clinical or psychological benefits.³⁰ This finding is in contrast with previous studies examining structured or moderated support groups,^{31,43} suggesting that group facilitation and the structure in which peer support occurs may be important elements to bringing about positive results.³⁰ It has been argued that the lack of moderation and structure may adversely affect the group's ability to attain a sense of community, a pivotal element of peer support.³⁰ An alternative is that unmoderated and unstructured forums may lead to an excess of expressions of fear and anxiety, which have been associated with increased levels of depression and lower quality of life.⁴⁴ In addition, although participants may feel positive about helping others, the absence of formal supervision or guidance may generate higher levels of distress in some peer supporters.

Online Family Interventions

Family intervention is a recommended and evidence-based treatment in schizophrenia.⁴⁵ The effectiveness of family interventions in reducing relapse rates and hospital admissions, and improving compliance with medication in schizophrenia, is well documented.⁴⁶ Family interventions have shown effectiveness in improving the experience of caregiving and reducing the burden of the caring role.¹⁸ However, despite their widely recognized benefits, only a small proportion of those caring for a family member with schizophrenia have access to such interventions,^{19,20} mainly because of high dissemination costs. Online interventions have the potential to overcome some of these barriers and, therefore, to improve the accessibility of evidence-based support for carers.

To date, only 2 studies have investigated the effectiveness of online family interventions in schizophrenia.^{35,36} Rotondi and colleagues³⁵ assessed the effectiveness of an online family psychoeducation program focused on promoting self-efficacy, self-management, and problem-solving strategies, in tandem with professionally moderated patient and carer discussion forums. This study showed a high level of engagement in and usage of the online intervention by patients with schizophrenia and their carers. In addition, the online intervention significantly improved positive psychotic symptoms and knowledge about schizophrenia in both patients and their supporters. However, the intervention showed no effect on other clinical or social

variables.³⁵ Glynn and colleagues³⁶ evaluated the effectiveness of an online multi-family intervention for relatives of people with schizophrenia. The intervention comprised a real-time, professionally moderated chat program for anonymous groups of 5 to 6 relatives, a discussion board, and educational material on behavioral family interventions. Consistent with the results of Rotondi and colleagues,³⁵ this study showed a good level of participation and engagement in the online groups, although the intervention did not have a significant effect on clinical status, relatives' distress, or perceived social support.³⁶

When taken together, these findings indicate that it may be necessary to involve patients in the online family intervention to realize positive clinical results.³⁶ In addition, real-time chats for relatives may not be required to obtain clinical benefits, with asynchronous interventions possibly being more acceptable and convenient for carers. In contrast with the study by Glynn and colleagues,³⁶ Rotondi and colleagues³⁵ provided an initial 4-hour workshop for participants, which may account for the increased intervention uptake seen in the latter study. Thus, it may be that social networking that is not anonymous fosters a sense of belonging to the virtual community and the motivation to participate in online forums.

Online Psychoeducation

Psychoeducational interventions for schizophrenia seek to enhance patients' knowledge of, and insight into, their illness to assist them in coping more effectively with their condition, thereby improving prognosis.¹⁶ A substantial body of research has provided evidence that psychoeducation improves medication compliance, reduces relapse rates, promotes social functioning, and increases satisfaction with mental health services.¹⁶ Preliminary research suggests that computer-based psychoeducation can be acceptable, as effective as face-to-face or paper-based methods, and preferred by some.^{37,47} Although more research is needed to ascertain their effectiveness, useful elements, type of content, and format, novel technologies are likely to provide a cost-effective and acceptable medium to deliver psychoeducation, which may appeal to younger patients and those more familiar with Internet-based technologies. In the meantime, online interventions that provide clear and engaging information and cater for cognitive deficits and levels of insight are likely to produce better outcomes.^{13,48,49}

Mobile-Based Interventions

Mobile devices, including microcomputers, tablets, mobile phones, and smart phones, are developing at a rapid rate, and hold great promise for influencing and even transforming treatment delivery in psychosis.⁵⁰ Recent evidence shows that mobile technology is helping to bridge the gap between socioeconomic layers through far-reaching access to such devices in relation to computer-based Internet connection or home-serviced Internet packages.⁵⁰ With mobile phone subscriptions having reached almost 6 billion worldwide,⁵¹ emerging evidence shows that homeless and socially disadvantaged people use mobile phones regularly.^{50,52} US studies suggest that some minority groups such as African American and Latino people have become leading users of mobile Internet devices.⁵³ Coupled with their widespread accessibility, the portability, online connectivity, and ease of use of current mobile devices provide an unprecedented opportunity to deliver evidence-based interventions, enable real-time support, and gather ecologically valid information in psychosis treatment.

Preliminary evidence shows that mobile devices are both acceptable to, and efficiently used by, people with schizophrenia.^{38,50,54,55} In addition, preliminary research shows that mobile interventions can bring about improved outcomes in schizophrenia.

Spaniel and colleagues⁵⁶ conducted a 1-year open trial with patients with schizophrenia and their carers in which early warning signs of relapse were assessed weekly by a 10-item questionnaire delivered via a mobile phone. Responses were collected using SMS (short message service), and, if the total score exceeded a given threshold, an alert was declared and the treating psychiatrist notified by an e-mail message. Phone contact with the patient and prompt evaluation of the patient's current status was then recommended. Compared with the year before the intervention, there was a 60% reduction in the number of hospital admissions.⁵⁶

In contrast, Granholm and colleagues⁵⁵ recently used mobile devices to administer cognitive behavioral interventions in a therapeutic context. In their study, 55 participants with schizophrenia received 840 text messages over a 12 week-period targeting medication adherence, socialization, and auditory hallucinations. The text-messaging intervention incorporated principles of cognitive behavior therapy, with 4 types of messages sent for each outcome of interest: outcome and cognition assessment, pre-elicited thought-challenging messages, and personalized behavioral coping strategies. The intervention was acceptable to most users and was associated with a significant improvement in auditory hallucinations and number of social interactions.⁵⁵ Medication adherence improved for those living independently, suggesting that the intervention was effective in assisting participants with higher functioning and/or lower support in taking medications.⁵⁵ However, those with lower functioning and more negative symptoms were less likely to complete the intervention, although newer generations of smart, easier-to-use phones may enable mobile interventions to be effectively used in these patients.⁵⁵

Oorschot and colleagues⁵⁷ deployed an experienced sampling method (ESM)⁵⁸ to elucidate individual patterns of symptoms, social interaction, contextual factors, and their longitudinal interaction, with the purpose of delivering tailored psychoeducation. This innovative approach may augment face-to-face interventions by improving insight, promoting the therapeutic alliance between clinician and patient, and personalizing treatment strategies.⁵⁷

Internet and FEP

In the preceding 2 decades, early intervention for psychosis has emerged as a major international focus of clinical service delivery.⁵⁹ The enthusiasm for early intervention is bolstered by findings that treatment delay leads to symptomatic and psychosocial deterioration⁶⁰ and worse clinical response.⁶¹ In addition, the early course of psychosis is thought to be a critical period after which the level of disability sustained,⁶² or recovery attained,⁴ is likely to endure into the longer term.⁶³ As a result, it has been argued that there is a window of opportunity to minimize or even prevent disability in this group by providing prompt psychosocial interventions as part of their rehabilitation.¹⁴

Novel information and communication technologies provide an unprecedented opportunity for enhancing, and even revolutionizing, early intervention for psychosis. Given the general enthusiasm of young people for novel technologies, Internet-based interventions may be particularly effective for, and appealing to, patients with FEP. Innovative interventions using these technologies may play a pivotal role in addressing significant challenges, including access to and engagement with specialized early intervention services, and provision of extended support to maintain the clinical and functional gains of specialized early intervention services.

To our knowledge, despite their theoretic potential, no study has investigated the feasibility or effects of Internet-based interventions for patients with FEP. We therefore conducted a focus group with young people with psychosis with the aim of examining

their views on technology-based tools. Qualitative analysis showed that patients with FEP were enthusiastic about the use of Internet-based strategies as part of their treatment program. They preferred a system characterized by connectivity (ie, users should be able to contact peers, share personal experiences, support each other, and contact clinicians if required). In addition, the system should resemble regular social networking programs (ie, asynchronous, ongoing communication), but be separate from them, and expert moderators should guide, but not censor, the interaction to ensure a safe and supportive network. Patients also indicated that the system should provide useful and updated information relevant to their needs, and optional therapeutic interventions (ie, cognitive behavioral strategies).

In contrast, there was little enthusiasm for SMS-based systems, particularly if the messages were automated rather than of human origin. Concerns were also raised about the potential risks of Internet-based strategies when experiencing active psychotic symptoms (ie, acute phase). Patients were also negative about systems that required them to fill out numerous questionnaires, and, on the whole, about content that made them feel worse and focus negatively on their condition.

CHALLENGES, RISKS, AND ETHICAL ISSUES OF INTERNET-BASED INTERVENTIONS IN PSYCHOSIS

In addition to their potential to bring about significant clinical benefits, Internet-based interventions for psychosis pose both familiar and new clinical risks and ethical issues. Some of these challenges and suggested solutions are discussed later.

It has been argued that participation in Internet peer-support forums may cause harm by increasing participants' social isolation, exposing participants to harmful or misleading advice, or reducing engagement with health care providers.³⁰ Research specifically assessing the potential risk or harm of online forums for schizophrenia is limited, and the evidence coming from mental health forums and the general community is mixed. Initial research on the general community suggested that Internet use may increase social isolation and reduce well-being, indicating that online ties were displacing strong, face-to-face relationships.⁶⁴ In contrast, more recent evidence has challenged these earlier findings by showing an association between Internet usage, decreased loneliness and depression, and increased perceived social support, self-esteem, and well-being.^{65,66} There is also evidence that Internet use does not interfere with face-to-face relationships and may serve as a tool to create or augment relationships or enhance users' connection with the community.⁶⁷ These mixed results may be partly accounted for by user personal characteristics and social context, with more extroverted and socially connected users benefiting more from Internet usage.⁶⁶ It is also likely that Internet content mediates the relationship between Internet use, personal characteristics, and outcomes, with less socially connected users engaging in less beneficial or even harmful online activity. For example, excessive expressions of fear and anxiety have been shown to induce increased stress and reduce quality of life,⁴⁴ whereas Internet interventions focused on self-efficacy have produced improved clinical outcomes in patients with schizophrenia.³⁵

Concerns about misleading advice or reduced access to health care providers are not supported by the literature. Recent studies have shown that advice provided by peers is generally appropriate, and inaccurate advice is corrected by others in a timely manner.⁶⁸ Furthermore, participation in online peer-support groups has been shown to encourage members to seek professional advice⁶⁹ and to empower participants to become more involved in their own treatment,³¹ indicating that Internet-based support is unlikely to interfere with face-to-face mental health care.

In our view, Internet-based interventions for psychosis that are specifically designed to supplement existing mental health services and augment traditional relationships through online interaction (either enhancing existing relationships or encouraging new ones that carry over to the off-line world) are likely to be most beneficial. In addition, professionally moderated forums focused on positive constructs such as self-efficacy, problem solving, and social recovery may enhance their clinical effectiveness and minimize risks related to negative content or misuse of the online tool.

Internet-based interventions may expose vulnerable participants to hostile interactions or to others who may take advantage of them as a result of disclosing private information, because anonymity reduces accountability for one's actions.³⁰ One solution to this problem is to develop anonymous forums that ensure users' safety and reduce the risk of sensitive information being disclosed beyond the confines of the online group. However, anonymity may induce a lack of connection to other group members by reducing the sense of trust and, as a result, the likelihood of developing positive relationships, an essential element of peer support and online interventions. An alternative and potentially more cost-beneficial strategy may be to develop closed, secure online forums, in which users are clients of existing clinical services and/or identities are verified by the researchers.⁷⁰ Moreover, appropriate screening procedures, with exclusion of high-risk individuals (eg, participants with significant paranoid ideation or antisocial personality traits), regular moderation of online content, a report button for users, clear forum guidelines and usernames specific to the online group⁷⁰ (but identities possibly known to other users) may enhance the benefits of online interventions for patients with schizophrenia, the risk of participation being lessened.

In addition, patients with schizophrenia are at risk of experiencing a psychotic relapse, self-harm, and other psychiatric emergencies and Internet and mobile-based interventions typically include assessments of clinical symptoms that extend beyond the traditional model of care. Although around-the-clock monitoring provides a unique opportunity for relapse and suicide prevention, it also introduces significant practical and ethical dilemmas. To address this issue, rigorous protocols for safety need to be carefully devised. Although further work is warranted to optimize online safety in patients with psychosis, general recommendations include visible emergency guidelines and contact information for users,³⁶ regular monitoring of online interactions,⁷¹ computerized monitoring of self-harm-related terms,^{72,73} and a detailed emergency response protocol.³⁸

DEVELOPMENT OF INTERNET-BASED INTERVENTIONS FOR PSYCHOSIS: IMPLICATIONS FOR PRACTICE

Although the procedure for devising Internet-based interventions for psychosis is underinvestigated, a systematic and phased development is likely to increase the likelihood of acceptance and the effectiveness of such interventions.⁷⁰ To this end, several recommendations have been put forward, including careful analysis of users' needs and preferences before development,⁷⁰ active involvement of stakeholders throughout all phases of development,⁷⁰ and regular consultations with potential users in all aspects of the protocols (ie, emergency responding, therapy/psychoeducation content and wording, graphic design, and specific features).³⁸ In addition, the relevance of multimodal and carefully planned induction and training procedures and extensive pilot testing has been highlighted.³⁸

SUMMARY AND RECOMMENDATIONS FOR FUTURE RESEARCH

Preliminary research suggests that people with psychosis use the Internet in a similar manner to those not affected by mental illness. Likewise, Internet-based or

mobile-based interventions developed to support people with psychosis and their families have been consistently well received by users. Such interventions may be particularly acceptable to, and beneficial for, young people with early psychosis. However, despite their potential, the use of innovative Internet-based technologies in psychosis treatment has been neglected and is overdue.

In the meantime, future interventions for psychosis should be systematically developed in accordance with user needs and in regular consultation with stakeholders. Careful attention should be paid to ethical issues, clinical safety, and emergency procedures. Innovative and flexible interventions that integrate different technologies (eg, mobile phones, chat rooms), evidence-based therapy, and peer and professional support are likely to be both more acceptable and more effective. Online-based interventions should be designed to supplement existing models of care and augment social inclusion, rather than replacing available resources.

Internet-based interventions hold great promise to revolutionize psychosis treatment and early intervention through increasing the accessibility of evidence-based interventions, reducing the stigma and anxiety associated with face-to-face care, and providing around-the-clock peer and professional support to patients and their families. These novel interventions may begin to overcome some major challenges, including engagement with mental health services and maintenance of treatment effects. The Internet has the potential to foster global recovery in people with psychosis beyond what is possible in traditional interventions. Internet-based support can be empowering, enabling consumers to link up, and even shape the nature of the services, support, and care they are receiving in line with the main principles of the recovery framework.⁴⁰

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