

Safety and Privacy Outcomes From a Moderated Online Social Therapy for Young People With First-Episode Psychosis

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Objective: Internet-based treatments for early psychosis offer considerable promise, but safety and security need to be established. This study pilot tested Horyzons, a novel online treatment application that integrates purpose-built moderated social networking with psychoeducation for recovery from early psychosis. **Methods:** Safety, privacy, and security were evaluated during a one-month single-group trial with 20 young consumers recovering from early psychosis who were recruited in Melbourne, Australia. Known clinical risk factors informed the safety protocol. Safety, privacy, and security were evaluated with respect to relapse and self-harm, users' perceptions of safety and privacy, and activity using Horyzons. **Results:** No clinical or security problems with use of Horyzons were noted. Participants described feeling safe and trusting Horyzons. **Conclusions:** Private moderated online social networking

combined with psychoeducation was a safe and secure therapeutic environment for consumers recovering from a first episode of psychosis. Testing the intervention in a randomized controlled trial is warranted. (*Psychiatric Services* 65:546–550, 2014; doi: 10.1176/appi.ps.201300078)

Acute first-episode psychosis typically responds to several months of treatment. However, effective interventions that promote the longer-term process of recovery are urgently required. Specialist psychosocial programs for individuals recovering from early psychosis are effective, but treatment effects may not be sustained when early intervention ceases (1). Furthermore, the cost of intensive psychosocial interventions can limit their broad dissemination, and stigma can jeopardize engagement. Information and communication technology has the potential to deliver nonstigmatizing, constantly available interventions, but online therapies have not been used with individuals recovering from early psychosis.

Young consumers recovering from early psychosis could be engaged in long-term treatment via online social networks that could also provide social benefits for consumers and reinforce psychoeducational content. Consequently, we pioneered “moderated online social therapy” (MOST)—

a new model of online therapies that integrate interactive psychoeducation and therapeutic online social networking, with the involvement of online moderators. We have applied the MOST concept to an application called Horyzons that is designed to assist young consumers in their recovery from a first episode of psychosis (2).

Implementation of Horyzons raised important safety and privacy considerations. First, online social networking requires adequate levels of protection and oversight. Second, individuals recovering from early psychosis may have personality traits that jeopardize safety within a social network. Third, symptoms such as suspiciousness may be exacerbated in an online environment (3). Fourth, the privacy issues facing youths with psychosis are especially salient given their degree of vulnerability.

Our safety strategy systematically addressed both “static” and “dynamic” factors that could predictably jeopardize consumer safety (4). Static factors entail long-standing or trait variables, whereas dynamic risk factors are subject to change—for example, fluctuations in mental state. Our principal research question was: Can moderated online social networking be delivered safely over a one-month period for young people recovering from early psychosis?

Methods

Horyzons was developed as an adjunctive intervention for consumers

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receiving specialist early psychosis care. Its development has been described elsewhere (2). The application integrates online therapy modules (“road map” menu) and moderated social networking functions (“cafe” menu). Interactive modules address psychoeducation, early warning signs of relapse, stigma and social anxiety, depression and stress, and identification and use of personal strengths. [Screen shots showing various pages of the intervention are included in an online supplement to this report.] The cafe functions include a personal profile page, a network (similar to “friends” function), group problem solving, discussion threads linked to the modules, and a “job zone” that provides vocational information.

A separate moderator interface was developed to enable monitoring of all posts and activity within the system. The interface also facilitates communication between moderators regarding any risks, enables moderators to suspend specific user accounts in the event of inappropriate use of the system, and allows the site to be shut down in an emergency. A “report button” enables participants to send an alert to moderators regarding any concerning posts. An automated keyword system becomes activated if a participant posts a contribution containing content that is included in our self-harm dictionary. A message on each page provides emergency guidelines for users.

Participants can temporarily hide their Horyzons profile and all of their online communications at any time if they develop heightened concerns about their activity within the system.

A range of security measures are designed to prevent unauthorized access. Privacy and online safety are managed in accordance with published Australian online social networking guidelines (5). Unusual patterns of activity in the system are used as indicators of potential hacking of the site.

We mapped three levels of risk via Horyzons, including clinical safety, online safety, and system and privacy protection. The evidence for clinical risk factors, derived from clinical practice and research, is presented in Table 1, along with examples of potential risks posed by these static (6–8) and dynamic (3,7,9–12) factors. The corresponding

risk management strategies employed in the study are also outlined in Table 1. Privacy and confidentiality risks were also foreseeable—for example, hacking of the system. The safety protocol was developed in consultation with clinical, information technology, and legal experts.

We conducted a single-group follow-up pilot study with 20 young people enrolled in a specialist early psychosis program. All participants had full access to their usual treatments. Horyzons was considered to be safe if all participants reported feeling supported by moderators, two or fewer participants experienced a psychotic relapse during the study, no participant engaged in deliberate self-harm, and no unlawful entries into Horyzons were made. We selected conservative criteria because of the unconventional nature of Horyzons. The safety criteria were assessed without reference to any causes of safety outcomes to prevent the risk of post hoc confirmation bias.

The study participants were recruited from the Early Psychosis Prevention and Intervention Centre (EPPIC), a comprehensive early psychosis program for youths in Melbourne, Australia (www.epic.org.au). The study was approved by Melbourne Health Human Research Ethics Committee. Participation was voluntary, and all participants provided written informed consent. Inclusion criteria for the study were a first episode of a *DSM-IV* psychotic disorder or mood disorder with psychotic features, six or fewer months of antipsychotic treatment before registration with EPPIC, and age from 15 to 25 years. Exclusion criteria were intellectual disability as estimated by case managers, inability to converse in or read English, or a *DSM-IV* diagnosis of either antisocial personality disorder or borderline personality disorder.

Baseline measures, completed in face-to-face interviews, included demographic characteristics, the Structured Clinical Interview for DSM-IV (SCID) mood and psychotic disorders, and the 24-item Brief Psychiatric Rating Scale (BPRS). At the conclusion of the one-month trial the research assistant conducted an in-person, audio-recorded, semistructured interview with each participant. The interview included

questions regarding perceived safety, confidentiality, helpfulness, and patterns of use in Horyzons. Events such as user logins, posts, and Horyzons page reads were recorded in the system’s database. System use was tracked for each participant. The following adverse events were tracked throughout the study: psychotic relapse, deliberate self-harm, and unauthorized access of Horyzons. Exposure of users to hostility in the social networking environment was monitored by moderators.

The research assistant, who did not participate in the treatment of any participant, administered the SCID and the BPRS at baseline. The research assistant oriented participants in person to Horyzons and the terms of use and described potential consequences of inappropriate online communication. Participants were coached in all Horyzons functions and management of personal privacy on the site and were told what to expect from online moderators. Participants could access Horyzons at their convenience, 24 hours per day, via the Internet, over a period of one month.

Quantitative variables from online posts and follow-up interviews were aggregated into simple descriptive statistics. The qualitative data were transcribed and coded and summarized into themes for analysis. We used accepted qualitative methods (13,14), which recommend multiple parses of the data with different levels of coding, and we also developed theoretical notes and memos as we progressively worked through the data. Using the audio-recorded material, three coding cycles were undertaken as suggested in accepted coding approaches, and the data were marked up using the software NVivo, version 9. The open and axial coding cycles were used to induce propositional statements (14). [Details of the coding process are available in the online supplement.]

Results

The 20 participants were recruited in a three-week period, and no participants who were approached by the research assistant refused to participate. The mean age of the 20 participants was 20.3 ± 2.7 years, and ten (50%) were males. Ethnicity was self-reported: nine Australians, five Asians,

Table 1

Framework for design of Horizons risk management strategies

| Type of variable and attribute of prospective user | Potential adverse outcome and evidence | Risk management strategies |
|--|--|--|
| Static risk variable Age <18 years | Outcome: exposure of minors to inappropriate content through interactions with adults online. Evidence: no specific evidence in early psychosis, but children are known to be at higher risk on social networking sites of exposure to potentially harmful content (6) | Orientation of parents and minors to the application; orientation to conditions of use for all participants ^a ; moderator interface and safety protocol to enable timely response to inappropriate communication ^a |
| Antisocial personality disorder (ASPD) co-occurring with early psychosis | Outcome: exposure of users to interpersonal aggression. Evidence: premorbid forensic history predictive of aggression in early psychosis (7) | Exclusion of clients with moderate or higher levels of hostility or ASPD at baseline |
| Borderline personality disorder (BPD) co-occurring with early psychosis | Outcome: risk of impulsive behavior, anger outbursts, and behavior perceived as interpersonally manipulative. Evidence: patients with first-episode psychosis who have co-occurring BPD are at very high risk of interpersonal hostility and aggression (8). | Exclusion of clients with co-occurring BPD |
| Vulnerability to further psychosis after early psychosis | Outcome: exposure to hostile or critical interactions may increase the risk of psychotic relapse. Evidence: patients with a history of psychosis are vulnerable to psychotic relapse, especially when exposed to high levels of criticism and hostility. | Exclusion of clients with moderate or higher levels of hostility; regular communication with treating team regarding changes in psychotic symptoms ^c |
| Dynamic risk variable Moderate or higher levels of suicidality | Outcome: an online social environment may be harmful for users with moderate or high levels of suicidality and may cause distress to other users. Evidence: rates of self-harming behaviors are known to be high (12%) over the first 7 years of treatment for psychosis, and intensive interventions are indicated (9). Participation in online social networks may be associated with a downward depressive spiral among persons with depression (10). | Exclusion or withdrawal of participants with moderate or higher levels of suicidality ^b ; weekly communication with treating team regarding changes in suicidality; withdrawal of participant from program when indicated ^b ; automated keyword filter; moderator interface to monitor for evidence of deterioration in mental state |
| Acute phase of psychosis or mania | Outcome: online interaction may exacerbate paranoid delusions or the distress associated with psychotic symptoms. Published case reports suggest online social networking may exacerbate psychotic symptoms (3). Acute manic symptoms may lead to impulsive behavior online, which may distress others. Evidence: among consumers with early psychosis at first treatment contact, 40% present with aggression, which is predicted by manic symptoms (11). Online interactions in this phase of the disorder may result in subsequent shame and fear of stigma, which may trigger social anxiety disorder. Evidence: shame in early psychosis is predictive of social anxiety, which affects 1 of 3 patients (12). | Participants must have achieved remission from acute psychosis; moderator interface used to monitor for evidence of deterioration in mental state ^c ; system enabled all users to hide their profiles and all posts in the system |
| Interpersonal hostility | Outcome: exposure of other users to interpersonal hostility, which may increase the risk of depression and relapse. Evidence: aggression in early psychosis is predicted by level of hostility (7). | Exclusion of participants with moderate or higher levels of hostility; moderator interface to screen for evidence of deterioration in mental state ^b ; weekly communication with treating team |

^a Participants could be excluded from Horizons if they did not comply with terms of use. Moderators could remove offending material or deactivate user account.

^b Indications of increased clinical risk activated the Horizons safety protocol, which stipulated that the moderator would conduct a risk assessment on the basis of available information, inform the senior researchers, contact the emergency contact nominated by the participant, and contact appropriate clinicians when necessary.

^c Psychotic relapse and subsequent withdrawal from Horizons was defined either by ratings of 6 or 7 on any one of three Brief Psychiatric Rating Scale (BPRS) items—unusual thought content, hallucinations, and conceptual disorganization—with a duration criterion of one week or by a score of 5 on any of the three BPRS items plus a 2-point increase on one of the three items.

three Europeans, one African, and two of other racial-ethnic groups. Seven participants (35%) were unemployed, and none of the participants had ever married. *DSM IV-TR* diagnoses at baseline were as follows: schizophreniform disorder (N=4), schizophrenia (N=3), schizoaffective or bipolar disorder (N=3), major depressive disorder with psychotic features (N=4), and psychotic disorder not otherwise specified (N=6).

Data on usage of Horyzons showed that 14 participants (70%) logged in weekly, with a total of 275 log-ins during the trial. The social networking features were used by 19 participants (95%), with a total of 371 postings.

Analysis of qualitative data revealed the following four overarching themes: comments on individual site features, overall properties of the site, suggestions for future use, and statements about overall global user experience.

In relation to our a priori safety criteria, all participants agreed or strongly agreed with the statements that they always felt supported by moderators and that they considered Horyzons to be both safe and confidential. No concerns were expressed by any participant regarding safety or confidentiality. Furthermore, 18 participants (90%) specifically reported that moderation contributed to the safety of the system.

One participant was admitted to an inpatient unit after experiencing a psychotic relapse. The treating team believed the relapse was unrelated to use of Horyzons. The follow-up interviews indicated that there were no other relapses. According to reports from case managers, no participants deliberately harmed themselves during the study. There was no evidence of any unlawful entries into the system or privacy breaches. No inappropriate use of the system occurred, and the keyword function did not indicate any postings containing indications of potential self-harm. No users chose to hide their accounts during the course of the pilot study.

All participants expressed a belief that the site was confidential and private. Responses indicated that participants attributed the safety of the site to EPPIC or because the site was enclosed. A participant's remark illustrates

this theme: "It's a limited network of users. Not everyone can use it. And also it's like a study for you as well, so you will definitely keep it confidential and private." Furthermore, all participants expressed a view that the online social networking provided a safe and welcoming environment. As one participant said, "I always felt safe. No one was threatening, no one was mean. It was a supportive space."

In relation to safety, participants linked the sense of safety to the option to remain anonymous. One noted, "It was safe because it was no real names, and part of your name not your full name." Others linked safety to the privacy of the site and the input of moderators: "Because even though it was social networking, it was quite private—you didn't really have any information about yourself on the profile apart from your name—like say, a photo."

Finally, all participants endorsed the involvement of moderators in ensuring a welcoming and safe environment. As one said, "It didn't feel like someone was bossing you around. It was just guidance, like supervision, to make sure everything works fine and is going well for you."

Discussion

Our principal research question was: Can moderated online social therapy be safely delivered over a one-month period for young people recovering from early psychosis? Our pilot trial successfully met all of the a priori safety criteria. To the best of our knowledge this was the first study to evaluate moderated online social therapy, an integrated social networking and psychoeducation intervention for consumers with serious mental disorders. Our one-month pilot study indicated that we successfully managed risk. Therefore, it is possible with judicious consideration of potential risks and a comprehensive risk management framework to provide a safe and supportive social networking environment for young people recovering from early psychosis.

The safe outcomes and the users' trust in the system appeared to have been related to two aspects of the application. First, Horyzons included a private online social network available

only to registered EPPIC consumers. Second, the moderators provided a safe atmosphere and conducted close monitoring for any signs of deterioration. These results have significant implications for the enhancement of early psychosis services for the critical stage of recovery, because they offer the promise of extending the reach of specialized psychosocial interventions over time and geographical regions.

The duration of the study was necessarily limited to one month because of the pilot nature of this study, and it is possible that deleterious effects may have developed after more prolonged exposure to the intervention or after a delay. It is also possible that participants' qualitative feedback on the system was biased by the close links between the research team and the clinical team.

Conclusions

The MOST model can be managed safely, and future trials are warranted to test whether it provides an effective strategy for engaging young people in psychosocial interventions over the long term to reduce relapse rates and facilitate recovery.

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