



Adaptation of a peer based online emotional support program as an adjunct to treatment for people with schizophrenia-spectrum disorders



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ABSTRACT

The aim of this study was to describe the adaptation of a program designed to leverage 7 Cups of Tea (7Cups), an available online platform that provides volunteer (i.e., listener) based emotional support, to complement ongoing treatment for people with schizophrenia-spectrum disorders. The adaptation of the program was based on two stages: First, following platform demonstration, six clinicians specializing in the treatment of schizophrenia completed a survey examining attitudes towards the program and suggested modifications. In response to clinicians' feedback, a computerized training program that provides information for listeners supporting people with schizophrenia was developed, and one hundred and sixty eight listeners completed an online knowledge test. In the second stage, 10 outpatients with schizophrenia-spectrum disorders were recruited to chat with listeners, provided post-session open-ended comments as well as usability and usefulness ratings assessed on a five point Likert scale. The additional training significantly increased listeners' knowledge and confidence ($0.38 \leq \text{Cohen's } d \leq 1.14, p < .024$). Patients' attitudes towards the listeners were positive and they expected the platform will be usable and helpful. Most patients expected a positive gain by having the opportunity to receive an outlet for emotions and socialize. The authors conclude that the use of an available digital platform resulted in a feasible intervention in terms of cost and availability, which is now ready for evaluation in real-world settings.

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1. Introduction

Social and emotional support are considered to be important factors in determining the coping process, feelings of competence and well-being of people with schizophrenia-spectrum disorders (Bengtsson-Tops and Hansson, 2001; Buchanan, 1995; Eack et al., 2007; Erickson et al., 1998; Ritsner et al., 2000; Yanos et al., 2001). The importance of psychosocial interventions aimed at providing such support is sustained by studies showing that pharmacological treatment alone may not suffice for illness management (Buchanan et al., 2010; Kane, 1995). However, lack of trained staff or limited funding limit the availability of these interventions (Drake et al., 2009). This notion provides a call for programs to introduce additional resources of social and emotional support for people with schizophrenia-spectrum disorders, which are both cost effective and easy to implement in real-world conditions.

One way to overcome barriers of cost and lack of trained staff is to develop programs that leverage inexpensive human resources, such as

non-professional-assisted interventions (Kazdin and Blase, 2011; Kazdin and Rabbitt, 2013). While studies have shown positive outcomes from the use of peer support programs (Ahmed et al., 2012; Chinman et al., 2014; Davidson et al., 2006) and family psychoeducation for people with schizophrenia (Dixon et al., 2000; Randolph et al., 1994), their effect is still limited by the need to develop and implement practical methods to engage, screen, train, and refer non-professionals to promote service assimilation and reach.

Technology-based interventions for people with schizophrenia have already demonstrated promising outcomes in reducing accessibility barriers, promoting service utilization (Ben-Zeev, 2012; Ben-Zeev et al., 2014), successfully engaging people with family supporters (Rotondi et al., 2010) and providing a social network of peers (Alvarez-Jimenez et al., 2013). It seems that technology could also introduce feasible solutions to screening, training, and connecting non-professionals with those in need of just in time support.

7 Cups of Tea (7Cups) was chosen for this study since it offers such a solution. The 7cups platform trains volunteers (i.e., listeners) to provide free online emotional support, and then engages them with interested users. A previous study focusing on 7Cups users demonstrated high user satisfaction with 84.6% of users positively perceiving the listener they had chatted with. The study also showed that, on average, users

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who indicated previous experience with psychotherapy evaluated their listeners' emotional support to be as helpful as psychotherapy (Baumel, 2015). While these findings may imply positive outcomes from the utilization of volunteer-based emotional support they represent subjective opinions of people who already enjoy that service. It is not certain, thus, how a clinically diagnosed population being referred to this kind of support will perceive the service, whether they will find it useful, and under which circumstances.

In this paper we describe the development process of SUPPORT, a program to provide online volunteer-based emotional support based on 7Cups platform as an adjunct to treatment for people diagnosed with schizophrenia-spectrum disorders. This program aims to respond both to costs and implementation barriers mentioned above by leveraging an available platform, inexpensive human resource, and scalable methods to train and engage non professionals with those in need of their support.

2. Methods and results

The development and evaluation of SUPPORT was based on two stages that followed an overview of 7Cups and adaptation of safety practices for vulnerable populations (Sharkey et al., 2011). In the first stage, we gathered clinicians' feedback and examined the efficacy of an additional computerized training program for listeners developed in response to this feedback. In the second stage, we referred patients to chat with a trained listener and examined platform usability and attitudes towards the program and the listeners. Study procedures for both stages were approved by the Feinstein Institute Review Board.

2.1. Overview of 7Cups

7Cups is a web- or app-based messaging system that provides volunteer-based emotional support (7 Cups of Tea website, 2015). Listeners are required to complete a computerized training course on active listening (Rogers and Farson, 1957) before being able to respond to chat requests (see Fig. 1 for main screenshots of user/listener interaction).

Upon logging into the platform, users can choose who they would like to chat with from a list of available listeners (see Fig. 1). Users who wish to chat with the same listener can do so by agreeing on a mutual time to chat, or by leaving the listener a message that she or he can later respond to through the platform's internal mailing system. Users can also view listeners' page in order to receive some information about the listener including the listener's country, age group they listen to, preferred topics for chats (e.g., parenting), and experience on the platform (e.g., number of chats conducted). Users can additionally see the listener's average rating scores on 1 to 5 point scale covering several domains (e.g., Helpfulness, Professionalism), based on ratings provided by users who chatted with the listener in the past.

2.1.1. Safety practices

SUPPORT follows recommended safety practices for internet based intervention research that involves vulnerable populations (Sharkey et al., 2011) and relates to system security, online and clinical safety (see Table 1 for finalized safety features). Online safety is managed with accordance to U.S. Department of Health & Human Services guidelines and 7Cups system security was reviewed and approved by the IT risk management team of Feinstein Institute for Medical Research, part of NS-LIJ health system.

7Cups is anonymously based and users have to confirm that they are not in crisis before beginning the chat. A banner is presented on screen with help lines available for crisis situations, and listeners are directed to refer users to more intense programs or other resources in cases of need (Baumel, 2015). Based on previous work done within The Zucker Hillside Hospital, a large mental health center in New York, and in accordance with internet based intervention studies that relate to safety

concerns for people with history of psychosis (Alvarez-Jimenez et al., 2013; Gleeson et al., 2014) it was decided that the following populations will be excluded from participation: (a) patients with suicidal or homicidal intent, and (b) patients that did not achieve remission from acute psychosis.

2.2. Stage 1: Adjusting 7Cups to supplement the treatment for people with schizophrenia-spectrum disorders

2.2.1. Clinician feedback

The lead author met separately with 6 clinicians specialized in the treatment and rehabilitation process of people with schizophrenia-spectrum disorders (4 psychiatrists, 2 clinical psychologists). The aim of these meetings was to gather feedback regarding ways that volunteer-based, online emotional support could be used as an adjunct to other treatments for patients with schizophrenia-spectrum disorders. At the beginning of the meeting, the lead author demonstrated the 7Cups platform, explained the listeners' training, how members engage listeners, and encouraged the clinicians to ask any clarifying question. At the end of the demonstration, the clinicians were asked to answer a survey containing close-ended questions regarding the use potential of SUPPORT using a 5 items Likert scale ranging from strongly disagree (1) to strongly agree (5). The survey also consisted of open-ended questions regarding the way this service could complement ongoing treatment, specific populations who might greatly benefit from utilizing this program, and further recommendations for program modification. Clinicians were instructed that this input was part of a larger research program to refer patients to use this service as an adjunct to other ongoing treatments.

2.2.1.1. Clinicians' responses. Clinicians' responses to close ended questions are presented in Table 2. All clinicians reported expecting a positive gain from referring people with schizophrenia-spectrum disorders to receive volunteer-based online emotional support. They stated that this program has the potential to support patients in between clinical meetings, improve patient outcomes, and also help patients engage in therapeutic activities. Some clinicians were neutral regarding the ability of this kind of platform to make it easier for people with schizophrenia to socially engage with other people.

All clinicians stated that online emotional support could be helpful by providing a resource for contacting other people and socializing ("patients without a network of connections will be able to talk about their difficulties with people different from clinicians"; "This is essentially people from the community. it fosters the idea that people care for one another") and some suggested it might be a step forward in reducing social isolation by providing some training before socializing within their community ("It may really help facilitate engagement and help them eventually go back into the community"; "If they practice socialization online, hopefully they will be able to use these skills to socialize in their real world"). Respondents also stated that this support might provide patients with an outlet for emotions, which many of them are lacking within the outpatient setting ("Most patients meet with the psychiatrist and don't receive ongoing emotional support. This is an opportunity for patients to highlight things that are meaningful for them and have people respond and communicate about them specifically").

Clinicians thought that people with first episode psychosis will be able to benefit from this program, as they are mostly young and accustomed to this kind of medium. They suggested that people with cognitive impairment who may not naturally use Smartphones or computers, or who may not be able to type will not benefit from this program. Another identified group who might not benefit from this program included people who have a strong net of social support.

Clinicians recommended providing listeners with information about schizophrenia, how to provide support while refraining from providing reinforcement for false beliefs, and how to avoid escalating the situation if they feel misinterpreted. Finally, some clinicians reported the

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