


Online Support Groups for Depression: Benefits and Barriers

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Abstract

This mixed-methods study aimed to explore the initial process of engagement with an online support group (OSG) for depression. Fifteen British National Health Service patients experiencing depression who had not previously used an OSG for depression were offered facilitated access to an existing peer-to-peer OSG for 10 weeks. Pre- and post-measures of depression, social support, and self-stigma were taken in addition to a weekly measure of OSG usage. A follow-up qualitative interview was conducted with a subsample of nine participants. Depression and self-stigma reduced over the 10-week period, but perceived social support did not change. There was no evidence of adverse outcomes. Perceived benefits of OSG participation included connection to others, normalization of depression, and stigma reduction. However, engagement with the OSG was generally low. Barriers included concerns over causing harm to others or being harmed oneself, feeling different from others in the group, and fears of being judged by others. OSGs may potentially reduce depressive symptoms and perceived self-stigma. However, considerable barriers may hinder people with depression from engaging with OSGs. Further work is needed to determine who will benefit most from participating in OSGs for depression and how best to facilitate engagement.

Keywords

online support group, Internet support group, social support, depression, stigma

Depression is one of the most common mental health problems, with a review of European studies estimating the 1-year prevalence of major depression as 5.7% (Wittchen et al., 2011). However, treatment may be hard to obtain or may not be sought (Meltzer et al., 2000). One potential additional source of help for people with depression is online support groups (OSGs), which have many users worldwide (Griffiths, Calear, Banfield, & Tam, 2009).

Although some people use depression OSGs even when they are experiencing severe depression (Houston, Cooper, & Ford, 2002; Powell, McCarthy, & Eysenbach, 2003), some aspects of depression, particularly negative thinking styles and low motivation, may make engagement with depression OSGs difficult. Professionals wanting to refer their clients to a depression OSG may not know how best to proceed. The only empirical evidence comes from Van Voorhees et al.'s (2013) randomized trial, which found that an induction procedure emphasizing internal motivation led to greater engagement than one emphasizing external motivation.

The present mixed-methods study aimed to explore the initial process of engagement with a depression OSG by examining the experiences of British National Health Service patients encountering such a group for the first time.

Method

Participants

British National Health Service patients who experienced depression were recruited. Adults on psychological therapy waiting lists in three London boroughs were invited to participate by their therapist; in addition, patients registered with general practitioners in these boroughs were able to self-refer in response to a study website or to information in community venues. The inclusion criteria were as follows: (a) self-identified as experiencing depression, (b) Internet access (either at home or in a public venue), (c) no previous experience of OSGs for depression, and (d) above 18 and fluent in English. The study was approved by the Local Research Ethics Committee.

Thirty-five eligible people (21, 60%, men) expressed interest. Of these, 15 (43%) went on to take part (6, 40%, women; 9, 60%, men). Their mean age was 43 (range =

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Table 1. Demographic Characteristics of Interviewed Participants.

Participant	Age	Gender	Ethnicity	Employment status	Previous episodes of depression	PHQ score pre-OSG	PHQ score post-OSG	Number of posts
1	40s	Male	Asian	Unemployed because of poor health	2 or more	17****	6**	2
2	20s	Male	Asian	Student	2 or more	22*****	22*****	9
3	50s	Male	White British	Unemployed because of poor health	None	24*****	21*****	2
4	50s	Male	White British	Unemployed because of poor health	None	23*****	15*****	0
5	40s	Male	White British	Unemployed because of poor health	2 or more	23*****	22*****	0
6	40s	Female	White British	Looking after home/family	2 or more	17****	14***	1
7	60s	Male	Asian	In full-time employment	2 or more	11***	11***	0
8	30s	Female	White British	Student	2 or more	17****	15*****	10
9	20s	Male	Asian	Student	2 or more	13***	3*	5

Note. PHQ = Patient Health Questionnaire; OSG = online support group.

*****severe depression. ****moderately severe depression. ***moderate depression. **mild depression. *no depression.

24-60). Nine (60%) were White British, 4 (27%) Asian, 1 (7%) Black British, and 1 (7%) Greek Cypriot. Ten (67%) were university graduates. Nine (60%) were self-referrals and 6 (40%) were recruited via clinical teams. Eight (56%) were currently taking anti-depressant medication. All participants were also invited to be interviewed, 9 (2, 22%, women; 7, 78% men) accepted. Their mean age was 43.5 (range = 24-60). Five (56%) of the interview participants were White British and 4 (44%) were Asian. Eight (89%) were university graduates. (See Table 1 for individual participant characteristics.)

OSG

The OSG selected for this study was PsychCentral.com. This was a U.S.-based peer-to-peer OSG which was “stand-alone,” that is, not linked to another intervention. It was chosen because it was a high-traffic website that had a constructive atmosphere and was moderated by a team supervised by a clinical psychologist. Permission was granted by the website’s owner for this research to take place.

Design and Procedure

This was a mixed-methods study, with quantitative measures taken before, during, and after the intervention, in addition to post-intervention qualitative interviews.

Participants were emailed an information sheet. If they consented to take part, they were emailed a link to the online questionnaire, on completion of which they were directed to the PsychCentral depression forum and given guidance on how to register. They were encouraged to write a post to introduce themselves to the group, and asked to engage with the site as they wished over the next 10 weeks. At the end of each week, they were emailed a link to the OSG Usage Report. At the end of the 10 weeks, they were emailed a link to the final questionnaire and were invited to participate in a

face-to-face interview. Participants were encouraged to contact the researcher by phone or email if they had difficulties using the OSG or if they wished to discuss their experiences.

Participants whose responses to the initial questionnaires suggested that they were severely depressed or a risk to themselves or others, i.e., scores >0.3 on the risk scale of the Clinical Outcomes in Routine Evaluation [CORE] or >1 on Item 9 of the *Patient Health Questionnaire* [PHQ-9] (“Thoughts that you would be better off dead, or of hurting yourself in some way”) were emailed with the suggestion that they seek additional help, in line with the study risk protocol. This procedure was followed for five participants.

Measures

Pre-post measures. The following pre-post measures were used: CORE—Outcome Measure (CORE-OM; Evans et al., 2000), a 34-item questionnaire assessing general psychological distress; PHQ-9 (Kroenke, Spitzer, & Williams, 2001), a nine-item depression scale; the Medical Outcomes Study Social Support Survey (MOSSSS; Sherbourne & Stewart, 1991), a 19-item social support measure; and Depression Self-Stigma Scale (DSSS; Kanter, Rusch, & Brondino, 2008), two subscales of which were used: “General Self-Stigma” and “Treatment Stigma.”

Measures taken at end only. OSG Questionnaire (OSGQ; Chang, Yeh, & Krumboltz, 2001) is a nine-item scale measuring overall satisfaction with an OSG. *Overall usage:* Postings made to the group were identified by searching for participants’ usernames. Each participant’s total number of posts over the 10-week study period was recorded.

Measure taken weekly throughout the 10-week period. OSG Usage Report, designed for the current study, asked how often participants had logged on to the group during the

Table 2. Outcome After 10 Weeks.

	Baseline <i>M</i> (<i>SD</i>)	10 weeks <i>M</i> (<i>SD</i>)	<i>t</i> (14)	<i>p</i>	Cohen's <i>d</i>
CORE-OM	62.7 (26.6)	59.3 (25.2)	0.88	.198	0.13
PHQ-9	14.6 (7.2)	12.3 (6.8)	2.22	.021*	0.33
MOSSSS	50.3 (18.6)	49.1 (20.5)	0.42	.343	0.06
DSSS	48.6 (15.9)	43.2 (17.4)	2.13	.025*	0.33

Note. CORE-OM = Clinical Outcomes in Routine Evaluation—Outcome Measure (Evans et al., 2000); PHQ = Patient Health Questionnaire (Kroenke, Spitzer, & Williams, 2001); MOSSSS = The Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991); DSSS = Depression Self-Stigma Scale (General Self-Stigma and Treatment subscales; Kanter et al., 2008).

**p* < .05. (one-tailed)

week, how long they had used it for, and how many times they had posted. It also had an open-ended question about experiences of the group during that week.

Interview

The semi-structured interview schedule covered three main areas: (a) depression and face-to-face social support, (b) engaging with the OSG, and (c) view of, and interactions with, others in the group. Interviews lasted about an hour and were digitally recorded. Participants were offered £10 plus expenses.

The data were analyzed using thematic analysis (Braun & Clarke, 2006). For each transcript, units of meaning were identified and collated into a tentative set of themes. Themes were compared across all the transcripts and organized into general themes and sub-themes, which were checked against the original transcripts and modified accordingly. During the process of analysis, the two authors discussed the emerging thematic structure and attempted to resolve any areas of uncertainty. The interview data were also triangulated with week-by-week written feedback from the OSG usage report.

Researchers' Perspective

Qualitative research guidelines (e.g., Barker & Pistrang, 2005) recommend that researchers disclose relevant background. The first author was a female clinical psychology graduate student with a positive but limited experience of using an OSG in a personal capacity. Her initial assumptions were that OSGs can potentially be helpful, but that there might be barriers to engagement. The second author was a male clinical psychologist who had conducted research on support interventions. The researchers attempted to "bracket" their assumptions during the course of the study to be aware of how they might influence their interpretations of the data.

Results

Outcome, Usage, and Satisfaction

Eleven of the 15 participants completed all pre- and post-measures. Missing data were handled on an intent-to-treat basis using last-observation-carried-forward.

Depression and self-stigma reduced over the 10 weeks (Table 2). In terms of reliable change (Jacobson & Truax, 1991), three people improved, 12 showed no change, and no one deteriorated. There was no change in perceived social support or the total CORE-OM.

Usage was generally low. The median percentage of weeks in which participants logged in was 30% (range = 0-80%). The median number of posts over the 10 weeks was 2 (range = 0-13). Eight (55%) participants completed the OSGQ; their mean score was 27.4 (*SD* = 10.7, range = 11-39), indicating a moderate level of satisfaction.

Qualitative Interviews

Context. Most participants interviewed described experiencing severe recurrent depression, which had affected their ability to work and had in several cases led to suicide attempts. Only one was experiencing a first episode. Several also experienced other mental health problems such as anxiety, post-traumatic stress disorder (PTSD), and trichotillomania. None had had any experience of OSGs for depression. One described a positive experience with an OSG for trichotillomania, and others had used non-mental health online communities. About half had been hopeful about what the OSG might offer them, for instance, looking forward to sharing ideas with others and finding people with similar experiences. The rest were less optimistic, reporting that they had not expected to benefit from the OSG; they appeared to be motivated by curiosity or a desire to further psychological research.

Thematic analysis. The themes generated from the qualitative interviews and weekly feedback were grouped into two domains (see Table 3): perceived benefits and barriers to engagement.

Benefits

I'm not alone in this. Participants valued the opportunity to make contact with others with experience of depression. Five said that they felt less socially isolated as a result of using the OSG and felt an emotional connection with other users, promoted by others' openness about their experiences of depression. Three felt that the site had helped to make depression

Table 3. Themes and Subthemes.

Domain and theme (Ns)	Illustrative quotation
Benefits	
1. <i>I'm not alone in this</i>	
1.1. Feeling connected to others (5)	<i>There were some people who I could really empathize with. I felt like they were in exactly the same situation. I think on one occasion I actually posted something saying that I empathize to that effect . . . (P2)</i>
1.2. The site normalized depression (3)	<i>[Using the site] has just reminded me that this is a . . . very common thing, and the people of the world who experience this . . . that kind of normalizes it a bit. (P8)</i>
2. <i>The value of talking to strangers online</i>	
2.1. Site feels safe and non-judgmental (4)	<i>The thing about an illness like depression is I think the criticism you get from outside is quite harsh, painful, and people who have experienced it or have some understanding of it are, are not like that, it's safe. (P7)</i>
2.2. Anonymity makes it easier to self-disclose (3)	<i>It was a bit easier [online] because I knew that I was anonymous. I wouldn't necessarily have to face those people again. (P8)</i>
2.3. Others here have no preconceptions of me (2)	<i>But usually when you're speaking to your friends, they already have an image about you . . . in the group you're being addressed on what you actually say. (P9)</i>
3. <i>Supporting others and being supported</i>	
3.1. I have the group to fall back on (3)	<i>There is just this surplus of people in my life to help me that give me this assurance that I'm going to be okay, and that I'm never going to go into isolation again . . . If nothing else works out, I have the group to fall back on, and as for my problems, and I know that I'll have someone to speak to me. (P9)</i>
3.2. I wanted to help others (2)	<i>If they have been positively affected [by my post], then I would consider it like you know, a pat on my back, like okay, so I've done a good job, I've done something good for the day that has affected somebody's life. And that's why I would want to do it. (P9)</i>
3.3. Reading about others' experiences helped me (2)	<i>It's quite easy to get some support from reading the other people's experiences . . . Somebody's had something then they say what happened that made it better which helps because you think "yeah, I can do that." (P7)</i>
4. <i>Could be useful for others or for me at a different time</i>	
4.1. It could be useful for me if I were more/less depressed (4)	<i>I remain open-minded about it. It could be that at a different stage of the illness it would have been differently useful. (P4)</i>
4.2. It seems helpful for other people (4)	<i>I'm sure it's a really good site for a lot of people because there's a lot of people using it and some of them have been on there like 11 years and I'm sure they get a great deal out of it. (P3)</i>
Barriers	
5. <i>Fear of negative impact on others</i>	
5.1. I would not be able to help others (3)	<i>I don't think [posting] contributed anything. I didn't think it did anything for me, I didn't think it did, or would do, anything for anyone else. (P4)</i>
5.2. I might make others feel worse (5)	<i>So I kind of worry that I'll go on and there'll be some, probably some quite young person in their teens or whatever, just coming to terms with this, and if I come along and say "Well, here I am after 20 years and it hasn't got any better" then that's not going to be very encouraging for them so I'd rather not say anything at all. (P8)</i>
5.3. I might cause trouble (3)	<i>People tend to say the same things. After a while a certain sort of house style starts to apply. People all say the same stuff and I thought if I do say something it's going to be radically different from what a lot of other people have said and it might cause trouble. (P5)</i>
6. <i>Fear of negative impact on self</i>	
6.1. There's nothing helpful that anyone can say (3)	<i>I just didn't find the things, their replies, were particularly comforting or useful so I didn't post again for a while. (P2)</i>
6.2. It might make me feel worse (5)	<i>"I'd been there, I hated it, I don't want to remember" was one of them; the "no no you're going to do yourself damage if you do that" is another one; the "no you just don't understand" or at least "you don't understand where I've been." (P4)</i>
6.3. Fear of being judged by others in the group (2)	<i>I felt like all my sort of social anxiety that I feel about going into a physical room full of people it was also there, even in this totally anonymous online group. It still felt as though I was walking into a big party and didn't know anyone, it was strange. (P8)</i>

(continued)

Table 3. (continued)

Domain and theme (Ns)	Illustrative quotation
<i>7. Not my kind of people</i>	
7.1. People were too different from me (5)	<i>There was almost a feeling of "If you're well enough to be on here, relating like this, writing coherently and reading stuff, then you and I are not in the same place." (P4)</i>
7.2. It was hard to tell whether people were genuine (3)	<i>It wasn't like I was reading things from real people, I was reading things from people's online versions of themselves which put me off a bit. (P5)</i>
7.3. Discussion was not serious enough (3)	<i>I know they mean well the people but it's all that patting on the back and "there, there, there." It just seemed like it was more of a social gathering than a help group. (P3)</i>
<i>8. It was hard to talk (to strangers) online</i>	
8.1. It was hard to share things about myself (4)	<i>What I wanted to offload to someone was all the specific thoughts and worries I was having, and I didn't feel I could put them down because they were . . . because I didn't know these people, they wouldn't really know what I was talking about, or it would be too personal . . . (P8)</i>
8.2. Having too much time to think made it difficult to write (2)	<i>I found it harder online because you've got to think about what to put down. You can't like . . . When I talk, things come out totally different. (P3)</i>
8.3. The value of people who really know me (4)	<i>People on the site didn't really know me or my history at all and they couldn't be expected to. But that makes a difference because people might just come up with, you know, a kind person might make a suggestion of something that was good for them but it might be totally inappropriate for me, but anyone who really knew me wouldn't have suggested that. (P8)</i>

seem like a common, universal experience, which they found reassuring. This was linked to the size and the international nature of the OSG.

The value of talking to strangers online. Some participants felt more comfortable talking about depression to strangers online than to their friends and family. They attributed the safe, non-judgmental nature of the OSG to the fact that users had personal experience of depression. Three felt that the anonymity enabled them to disclose more freely. Two spoke about the helpfulness of talking with people who did not have any preconceived ideas about them.

Supporting and being supported. Participants felt supported from being in contact with the group, even without any actual communication. Three said that knowing that it was there, even if they were not using it, was helpful. They appreciated being able to access the group immediately and at any time, and some contrasted this with their experience of waiting a considerable time for therapy. Two talked about wanting to help others as a result of reading their posts and the sense of reward that comes from offering help, and two others talked about the support they had got from reading about others' experiences. One felt that seeing other people going through cycles of low moods reminded her that she would once again come through her own current low patch, and another spoke about the way in which he had been inspired to try different ways of coping.

Could be useful for others or for me at a different time. Even if they had not found the site helpful, participants without

exception expressed the view that the site could potentially be a useful resource for people with depression, and commented that users appeared to be supporting each other and seemed to benefit. Four felt that they had been severely depressed at the time of the research: One spoke about finding it difficult to even motivate himself to log on. Two felt that the group may have been more useful to them if they were less depressed, although others said that they would be more likely to use the site if they were having a bad time.

Barriers

Fear of negative impact on others. Participants' concern for the other people involved with the group was striking, and some cited the potential negative consequences that their involvement could have for others as one of the reasons that they did not contribute more. In some cases, the concern that they would not be able to help others held participants back from seeking support, as they felt strongly that their relationship with the site should be reciprocal. Four participants said that they sensed that others in the group were vulnerable and worried that their contributions could make people feel worse: one said that hearing about her long history with depression might be discouraging for someone who was newly diagnosed. Three worried that they might get into conflict with others in the group and had held back from posting because they were afraid that they would express anger or criticism.

Fear of negative impact on self. Participants were concerned that spending time on the site might make their depression

worse, particularly if they were not feeling especially depressed. Three felt that others on the site could not help them, and one who posted messages did not find the replies helpful. One expressed the view that when people were depressed they were too withdrawn to interact and when they were well they were afraid of interacting with other depressed people for fear of being pulled back down into depression. Two participants described experiencing social anxiety in face-to-face situations, and worried about how they would come across in the group and whether others might be critical of them.

Not my kind of people. Participants mentioned various aspects of how others in the group communicated which discouraged them from becoming involved. The site being based in the United States made it hard for some participants to relate to the other users: they mentioned differences in language, social contexts, and medication names as barriers to understanding. Three felt that it was hard to gauge whether others were being genuine, making it difficult to feel comfortable sharing thoughts and feelings. Three said that the level of discussion on the site was too shallow and people's posts could be experienced as patronizing.

It was hard to talk (to strangers) online. Participants said that although they wanted to express themselves, it was difficult to do so in the OSG, because they felt embarrassed and vulnerable. Four spoke about the difficulty in establishing rapport online (sometimes attributed to factors such as the asynchronous nature of responses and the absence of body language and eye contact) which would have made them feel comfortable enough to reveal personal information. Two said that both having time to think about what they were about to say, and not having the pressure of having to produce something for a listener in front of them, were the inhibiting factors. Four felt that people who really knew them were in a much better position to help them through their depression than strangers online. In interactions with people who knew them well, these participants valued that they did not have to explain themselves and their history, that people could tell how they were feeling, and that they could remind them what they were like when they were not depressed, which instilled a sense of hope. Comments from strangers, although supportive, were experienced by some as "meaningless" whereas real friends' support had more impact.

Discussion

This mixed-methods study introduced a small sample of 15 people with depression, recruited through the British National Health Service, to a depression OSG and tracked their engagement with it. Most had moderate to severe levels

of depression at baseline. Over the 10-week period of the study there were modest reductions in depression and perceived stigma, with no change in perceived social support. Overall, there were low levels of engagement with the OSG.

The reduction in depression is consistent with the results of many other studies (Griffiths, Calear, & Banfield, 2009). However, in the absence of a control group, it is not possible to attribute a causal role to OSG participation, particularly because engagement was low.

The low levels of activity may reflect the way in which people naturally engage with OSGs, that is initially spending a long time viewing the site without posting ("lurking") before joining the discussion. Lieberman (2007) found that 74% of participants in breast cancer OSGs lurked before they posted, with half of these doing so for 2 to 8 weeks. To observe the engagement process as it naturally occurs, a longer study period would be needed.

Participants not only described several benefits of taking part in the OSG but also emphasized factors that had hindered their engagement. In contrast to previous studies that have recruited participants from among existing users of OSGs (who are likely to be at least reasonably satisfied with such groups), the present study recruited people who had never before used a depression OSG, tracking their engagement and allowing the voices of those who find such groups less helpful to be heard.

Participants showed a striking concern for the well-being of others in the group and wanted to help them, but several felt unable to do so, often because their own struggles left them without resources. Sometimes this inhibited participants from using the group, as they felt that their relationship with it should be reciprocal. This raises the question of what could be done to help users access support without feeling a pressure to reciprocate immediately.

The main barriers to participation were fears of having a negative impact on others in the group, or the group's having a negative impact on oneself. Participants also worried about their depression being made worse by their interaction with the group and reported avoiding reading posts with negative content. This may reflect a more general tendency toward emotional avoidance among participants which may have affected their low engagement with the group (Cameron et al., 2005). In addition, negative beliefs about seeking help (e.g., that it is a sign of weakness) may also have inhibited participation.

These concerns are understandable in the light of the well-documented "cognitive triad" of negative beliefs about the self, the world, and the future that characterizes depressive thinking (Beck, Rush, Shaw, & Emery, 1979). Levine and Moreland (2006) suggested that in general people try to join groups that are maximally rewarding and minimally costly. Depressive thinking may have led participants to

underestimate the rewards and overestimate the costs of joining the OSG. As they did not engage, there was no opportunity for them to gain evidence to disconfirm their negative preconceptions.

Limitations

This was a small-sample, mixed-methods study. The quantitative arm had low statistical power; the measures were included to give an indication of participants' overall outcomes. The sample was a convenience one, but it did have the advantages of having a range of ages and ethnic backgrounds, and of giving people access to an OSG for the first time.

Limiting participants' choice to a single OSG was problematic, as there is evidence that when people choose a group that "fits" them best, they are more likely to engage with it (Lieberman, 2004, 2007). Moreover, the choice of a predominantly North American group was with hindsight unfortunate, as cultural differences were often mentioned as a barrier to participation. Thus, it is unclear whether the low levels of engagement and barriers to participation found in this study reflect engagement with OSGs for depression in general or with this OSG in particular. When the study started, there was no comparable U.K.-based OSG in terms of moderation, positive group climate, and high volume of traffic.

Implications

There was no evidence of negative effects from the OSG, and some participants reported benefits, which suggested that clinicians need not be concerned by their clients' involvement with OSGs. It appears that prospective members who anticipate negative effects simply do not engage with such groups. Many of the barriers to participation relate to people's fears of what might happen were they to take part, rather than to actual experiences of participation. It is unclear to what extent these fears are related to cognitive aspects of depression. Depressed clients may benefit from some therapeutic work to help them test the accuracy of their negative predictions in the initial stages of engaging with such a group.

Some of the barriers identified in this study are related to the negative thinking style, withdrawal and lack of motivation characteristic of depression. It would be valuable to design an intervention to help participants overcome these initial barriers and evaluate if this had any impact on engagement. If barriers to active participation can be minimized, people with depression may then be able to derive more benefit from online support.

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