Patient Engagement with an Internet Support Group Affects Mental Health Outcomes: Post Hoc Analyses from a Randomized Controlled Trial

Authors:
Emily M Rosenberger¹, MD PhD; Bea Herbeck Belnap²,³, Dr Biol Hum; Kaleab Z Abebe¹, PhD; Scott D Rothenberger¹, PhD; Armando J Rotondi, PhD⁴, Bruce L Rollman², MD MPH

¹ Division of General Internal Medicine, University of Pittsburgh Medical Center, Pittsburgh, PA, USA
² Center for Behavioral Health and Smart Technology, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA
³ Department of Psychosomatic Medicine and Psychotherapy, University of Göttingen Medical Center, Göttingen, Germany
⁴ VA Pittsburgh Healthcare System, Pittsburgh, PA, USA

Corresponding Author:
Bruce L Rollman, MD, MPH
230 McKee Place, Suite 600, Pittsburgh, PA 15213
Phone: 412-692-265
Fax: 412-692-4838
Email: rollmanbl@upmc.edu

Keywords: internet support group; patient engagement; anxiety; depression
Abstract

Background: The “1% Rule” posits that 1% of participants in online communities generate the majority of user-created content. We recently reported that depressed and anxious primary care patients randomized to a moderated Internet support group (ISG) plus computerized cognitive behavioral therapy (CCBT) did not experience improvements in depression and anxiety over CCBT alone at 6-month follow-up.

Objective: The aims of this study were to apply the 1% Rule to categorize patient engagement with our ISG and identify whether any patient subgroups benefitted from ISG use.

Methods: We categorized the 302 patients randomized to our ISG as: superusers (1%, N=3), top contributors (10%, N=30), contributors (36%, N=108), observers (29%, N=87) and those who never logged-in (24%, N=74), and applied linear mixed models to examine associations between engagement and 6-month changes in health-related quality of life (HRQoL; SF-12 MCS) and depression and anxiety symptoms (PROMIS).

Results: At baseline, participants’ mean age was 42.6 years, 81% were female, and mean PHQ-9, GAD-7 and SF-12 MCS scores were 13.4, 12.6 and 31.7, respectively. Of the 76% who logged-in, 62% created ≥1 post (median: 1 [IQR 0,5]); superusers created 40% of posts (median: 246 [IQR 78,306]), top contributors 38% (median: 11 [IQR 10,18]), and contributors 22% (median: 3 [IQR 1,5]). Compared to participants who never logged-in, the combined superuser + top contributor subgroup (N=33) reported 6-month improvements in anxiety (PROMIS: -11.6 vs. -7.8; p=.04) and HRQoL (SF-12 MCS: 16.1 vs. 10.1; p=.01) but not depression; no other subgroup reported significant symptom improvements.

Conclusions: Patient engagement with our ISG approximated the 1% Rule. Those with the highest engagement levels reported significant improvements in anxiety and HRQoL.

Trial Registration: ClinicalTrials.gov NCT01482806.
Introduction

Background
Internet support groups (ISGs) are specialized social media websites that connect individuals with common health conditions and provide a forum for peers to exchange information, resources and support [1, 2]. While ISGs for mental health conditions have become increasingly common [3], randomized trials [4, 5] and systematic reviews [6-8] find they have mixed benefits at reducing psychologic distress. In a recent randomized controlled trial, we reported that providing depressed and anxious primary care patients with access to a moderated ISG in addition to a computerized cognitive behavioral therapy (CCBT) program provided no additional intent-to-treat benefit in patients’ health-related quality of life (HRQoL) or mood and anxiety symptoms over the CCBT program alone at 6-month follow-up, although CCBT was more effective than primary care physicians’ (PCPs) usual care [9] (ClinicalTrials.gov NCT01482806). These null findings raise questions about whether any subgroups of ISG members may have benefitted differentially from our ISG based on their level of engagement.

One approach to classify engagement with an online community is the “1% Rule” [10, 11]. Adapted from the digital marketing literature, the 1% Rule posits that 1% of online community members create the vast majority of user-generated content (“superusers”), while approximately 10% create most of the remaining content (“contributors”) and 90% rarely contribute but mainly observe activity (“observers”). A recent observational study replicated the 1% Rule in four large ISGs for individuals with addiction and mood disorders [12] and found that participants’ demographic and disease-specific characteristics were not associated with their level of engagement with these online communities [13].

Goal of This Study
Little is known about the relationship between level of ISG engagement and clinical outcomes for treating depression and anxiety in primary care or any other mental health condition [5, 14]. Therefore, to classify the patients randomly assigned to our trial’s ISG arm by their level of engagement, we applied the 1% Rule based on the number of posts they created on the ISG. We then conducted post hoc analyses to compare these engagement level subgroups with patients randomly assigned to our ISG who never logged in to examine whether any patient subgroup benefitted from participating in our online community.

Methods

Study Setting, Patient Eligibility, and Randomization and Experimental Conditions
The protocol for the Online Treatment for Mood and Anxiety Disorders Trial was approved by the University of Pittsburgh’s Institutional Review Board and detailed in the trial’s primary outcomes report [9]. Briefly, PCPs in 26 southwestern Pennsylvania practices referred patients with a Generalized Anxiety Disorder scale (GAD-7) [15] or Patient Health Questionnaire (PHQ-9) [16] score ≥ 10, indicating moderately severe anxiety or depression symptoms, between August 2012 and September 2014. We randomized 704 protocol-
eligible participants to either: (1) care manager-guided access to the 8-session “Beating the Blues” CCBT program designed to provide users with basic cognitive behavioral therapy skills [17] (CCBT-only; N=301); (2) CCBT plus additional access to our password-protected and moderated ISG (ISG+CCBT; N=302); or (3) their PCP’s usual care (N=101). All study arms had similar baseline sociodemographic and clinical characteristics [9]. Analyses in this report focus solely on the 302 participants assigned to the ISG+CCBT arm.

Care Manager Support
Following randomization, the care manager exclusively assigned to the ISG+CCBT arm contacted each participant via telephone to provide basic psychoeducation and encourage them to start the CCBT program and log in to our ISG. Later, he contacted participants via email, text and telephone to promote adherence with the CCBT program and treatment recommendations, including suggestions to access various resources on our ISG (see Internet Support Group). The care manager presented each participant’s progress to the study PCP, psychiatrist and psychologist at a weekly case review meeting [18].

Internet Support Group
We used WordPress software to create our password-protected ISG that was accessible via computer or smartphone (Figure 1). In addition to discussion boards created by the care manager-ISG moderator and study participants, the ISG curated links to external resources including local $4 generic pharmacy programs; “find-a-therapist”; crisis hotlines; brief YouTube videos on insomnia, nutrition, exercise and other topics; our electronic medical record system’s patient portal; and the CCBT program (Multimedia Appendix 1).

Figure 1. Screenshot of our Internet support group homepage.
To preserve confidentiality, we assigned members’ usernames and regularly reminded them not to post any self-identifying information or photographs. Additionally, a study investigator logged in to the ISG daily to review new posts for suicidal thoughts and other potentially inappropriate content, and participants could flag comments for review by the ISG moderator and possible removal.

**Engagement with the ISG**

We provided participants with password-protected access to our ISG approximately 3 months after the start of subject enrollment and once the first 25 patients were randomized to the ISG arm so as to promote user-generated activity. Afterwards, we provided participants with ISG access shortly after randomization.

Participants created content on our ISG discussion boards by either initiating a new discussion thread or commenting on an ongoing thread (“posts”). On most weeks, the care manager-ISG moderator also initiated new discussion threads on such topics as coping with mental health symptoms, talking about depression and anxiety with friends, stressors (e.g., holidays, work-life balance) and lifestyle challenges (e.g., healthy diet, losing weight, exercise).

Although we encouraged participants to log in and post on the ISG throughout their 6-month intervention phase, we did not require them to do so. Still, we took several measures to encourage participants to log in and post by featuring status indicators on their profiles and posts (e.g., stars and “likes”), emailing notifications of new ISG activities and posts, highlighting new posts on their homepage based on their past ISG activity, inviting participants to serve as guest moderators, and holding various contests that promoted logging in and posting.

**Assessments**

Following confirmation of protocol eligibility and consent, a study assessor collected sociodemographic and clinical information from our study practices’ electronic medical record system and from the participant, and then administered the PRIME-MD Anxiety and Mood Modules to establish a psychiatric diagnosis [19], the 12-Item Short Form Health Survey Mental Components Score (SF-12 MCS) to measure HRQoL [20], and the PROMIS Depression and Anxiety short forms to measure depression and anxiety symptom levels, respectively [21]. Later, an assessor who was blinded to participants’ randomization assignment telephoned participants to re-administer the PROMIS and SF-12 MCS at 3 months and at the 6-month primary outcome timepoint.

We obtained counts of unique patient logins and posts from the logs of the server that hosted our ISG. We defined a post as an entry that initiated a new discussion thread or added an entry to an existing discussion thread, and we summarized the number of posts each participant made to arrive at a total.

**Classification of ISG Engagement**

Using the 1% Rule as our starting point, we classified participants into subgroups by level of engagement as measured by the total number of posts each created during the first 6
months after randomization (top 1% of posters, next 9% and remaining 90%) [10, 11].
Given our interest in identifying the gradient of participant engagement, we further
classified participants into the following subgroups: superusers (top 1%), top contributors
(next 9%), contributors (made at least one post), observers (logged in at least once but
never posted), and those who never logged in. Since several participants between the 9\textsuperscript{th}
and 11\textsuperscript{th} percentiles made the same number of posts, we re-classified our “top contributors”
as the next highest 10% of posters after superusers, rather than the next 9%.

**Statistical Analysis**
We calculated the baseline sociodemographic and clinical characteristics across the 5 ISG
engagement groups using percentages, means and standard deviations (SD), and medians
and interquartile ranges (IQR), and we made group comparisons using analysis of variance
and chi-square tests. As we had only 3 superusers, we grouped them with the 30 top
contributors for all analyses to conduct more meaningful comparisons.

We used linear mixed models for each of the clinical outcomes (SF-12 MCS, PROMIS
Depression, PROMIS Anxiety) that included fixed effects for engagement subgroup, time,
group-by-time interaction, education, race, gender and random effects for participants. We
also compared the 6-month change in HRQoL and depression and anxiety symptoms
between participants who were assigned to the ISG arm (ISG+CCBT) but never logged in
and participants in our combined superuser + top contributor subgroup. All analyses were
conducted using SAS version 9.4 (SAS Institute, Cary, NC, USA).

**Results**

**Baseline Sociodemographic and Clinical Characteristics**
At baseline (Table 1), the 302 participants randomized to the ISG+CCBT arm had a mean
age of 42.6 years, 81% (245 out of 302) were female, 48% (144 out of 302) had at least a
college education, and they reported moderately severe depression (mean PHQ-9: 13.4 [SD
4.7]) and anxiety symptoms (GAD-7: 12.6 [4.5]) and a low HRQoL (SF-12 MCS: 31.7 [9.4]).

While each engagement subgroup was predominately female, white and had comorbid
depression and anxiety, reflecting the overall composition of our study cohort, women,
whites and those with a college education or higher were more likely to be in the superuser
+ top contributor subgroup (e.g., ≥ 4-year college education: 70% [23 out of 33] superuser
+ top contributor vs. 36% [27 out of 74] of the never logins) (Table 1).

**Distribution of Engagement**
Seventy-five percent of participants (228 out of 302) logged in to the ISG at least once
during their 6-month intervention phase, for a total of 2,041 logins. Of those, the median
number of logins per participant was 4 (IQR 2, 9.5; range 1-214). Participants created 1,488
posts over the 6-month intervention phase, and 62% (141 out of 228) made at least one
post (median posts per participant: 1 [IQR 0, 5]).
Table 1. Baseline sociodemographic and psychiatric characteristics by engagement level.

|                        | Overall | Superusers + Top Contributors 10.9% | Contributors 35.8% | Observers 28.8% | Never Login 24.5% | P<
|------------------------|---------|-------------------------------------|-------------------|-----------------|-----------------|------
| N=302                  | N=33    | N=108                               | N=87              | N=74            |                 |      
| Age, mean (SD)         | 42.6 (14.4) | 40.9 (13.3)                          | 41.9 (14.4)       | 43.0 (14.0)     | 43.9 (15.5)     | .72  
| Female, N (%)          | 245 (81%) | 31 (94%)                             | 88 (82%)          | 63 (72%)        | 63 (85%)        | .04b 
| White race, N (%)      | 242 (80%) | 29 (88%)                             | 94 (87%)          | 65 (75%)        | 54 (73%)        | .04b 
| ≥ 4-year college degree, N (%) | 144 (48%) | 23 (70%)                             | 54 (50%)          | 40 (46%)        | 27 (36%)        | .02  
| Married or living with partner, N (%) | 120 (40%) | 18 (55%)                             | 42 (39%)          | 36 (41%)        | 24 (32%)        | .38  
| Employed, N (%)        | 204 (68%) | 22 (67%)                             | 75 (69%)          | 62 (71%)        | 45 (61%)        | .52  
| Psychiatric diagnosis, N (%) |          |                                      |                   |                 |                 | .75b 
| Major depression only  | 63 (22%) | 8 (24%)                              | 21 (19%)          | 21 (24%)        | 13 (18%)        |      
| Generalized anxiety disorder only | 22 (7%)   | 3 (9%)                               | 4 (9%)            | 4 (8%)          | 4 (9%)          |      
| Both depression and anxiety | 207 (71%) | 22 (67%)                             | 78 (72%)          | 57 (66%)        | 50 (68%)        |      
| PHQ-9, mean (SD)d      | 13.4 (4.7) | 12.3 (5.5)                           | 14.0 (4.4)        | 13.2 (4.6)      | 13.3 (4.7)      | .27  
| GAD-7, mean (SD)d      | 12.6 (4.5) | 13.3 (4.8)                           | 12.8 (4.6)        | 12.6 (4.7)      | 12.1 (3.8)      | .62  
| PROMIS Depression T-score, mean (SD) | 62.0 (6.3) | 61.8 (6.7)                           | 62.4 (6.1)        | 62.0 (6.5)      | 61.5 (6.1)      | .79  
| PROMIS Anxiety T-score, mean (SD) | 65.8 (6.2) | 66.9 (6.7)                           | 66.0 (6.5)        | 65.6 (5.4)      | 65.2 (6.2)      | .57  
| SF-12 MCS, mean (SD)   | 31.7 (9.4) | 31.4 (8.9)                           | 30.9 (9.2)        | 31.2 (8.5)      | 33.6 (10.9)     | .25  
| Depression/anxiety medication use in past year, N (%) | 236 (78%) | 26 (79%)                             | 87 (81%)          | 68 (78%)        | 55 (74%)        | .66d 
| Mental health therapist visit in past year, N (%) | 59 (20%)   | 10 (30%)                             | 18 (17%)          | 19 (22%)        | 12 (16%)        | .35  

a P value represents comparison of the 4 engagement level groups
b P value from Fisher's Exact test
c 10 participants did not meet diagnostic criteria for depression or anxiety on the PRIME-MD; these participants were not included in the denominator when calculating the percentage with each diagnosis
d n=30 in Superusers and Top Contributors group

Abbreviations: SD, standard deviation; PHQ-9, Patient Health Questionnaire; GAD-7, Generalized Anxiety Disorder scale; SF-12 MCS, Short Form Health Survey Mental Components Score

As expected, the mean number of logins and posts differed widely across engagement subgroups (p<.001, Table 2). However, the distribution of posts in our sample was less skewed than predicted by the 1% Rule, with superusers making 40% of posts (median [IQR]: 246 [78, 306]), top contributors 38% (median: 11 [10, 18]) and contributors 22% (median: 3 [1, 5]). Moreover, 29% (87 out of 302) of participants in our ISG were classified as observers, i.e., they logged in to the site at least once but never posted.
Table 2. 6-month Internet support group logins, posts and process measures by engagement level.

<table>
<thead>
<tr>
<th></th>
<th>Superusers</th>
<th>Top Contributors</th>
<th>Contributors</th>
<th>Observers</th>
<th>Never Login</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1%</td>
<td>9.9%</td>
<td>35.8%</td>
<td>28.8%</td>
<td>24.5%</td>
</tr>
<tr>
<td></td>
<td>N=3</td>
<td>N=30</td>
<td>N=108</td>
<td>N=87</td>
<td>N=74</td>
</tr>
<tr>
<td># ISG logins</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>119.0 (84.3)</td>
<td>22.5 (16.5)</td>
<td>7.3 (6.6)</td>
<td>2.5 (2.1)</td>
<td>---</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>90 (53, 214)</td>
<td>18 (13, 27)</td>
<td>5.5 (3, 9)</td>
<td>2 (1, 3)</td>
<td>---</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>31.2 (38.5)</td>
<td>7.3 (6.6)</td>
<td>2.5 (2.1)</td>
<td>---</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>20 (13, 31)</td>
<td>5.5 (3, 9)</td>
<td>2 (1, 3)</td>
<td>---</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td># ISG posts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>210.0 (118.2)</td>
<td>17.2 (13.3)</td>
<td>3.2 (2.1)</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>246 (78, 306)</td>
<td>11 (10, 18)</td>
<td>3 (1, 5)</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>34.7 (64.8)</td>
<td>3.2 (2.1)</td>
<td>---</td>
<td>---</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>12 (10, 14)</td>
<td>3 (1, 5)</td>
<td>---</td>
<td>---</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td># CCBT sessions completed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>8.0 (0.0)</td>
<td>7.4 (1.4)</td>
<td>5.8 (2.6)</td>
<td>4.2 (3.0)</td>
<td>1.9 (2.7)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>7.4 (1.3)</td>
<td>5.8 (2.6)</td>
<td>4.2 (3.0)</td>
<td>1.9 (2.7)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td># Care manager contacts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>36.0 (11.8)</td>
<td>19.4 (5.6)</td>
<td>18.4 (6.4)</td>
<td>15.7 (5.0)</td>
<td>13.1 (4.7)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>20.9 (7.8)</td>
<td>18.4 (6.4)</td>
<td>15.7 (5.0)</td>
<td>13.1 (4.7)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

* P value from Kruskal-Wallis test
Abbreviations: ISG, internet support group; CCBT, computerized cognitive behavioral therapy; SD, standard deviation; IQR, interquartile range

Process Measures of Care
Overall, the mean number of CCBT sessions completed was 5.5 (SD 2.7), and 36% (108 out of 302) of our study cohort completed all 8 CCBT sessions. Across engagement subgroups, participants who created more posts also completed more CCBT sessions (p<.001) and had more care manager contacts (p<.001) (Table 2).

Mental Health Outcomes at 6 Months
After adjusting for gender, race and education level, all engagement subgroups reported similar improvements in symptoms at 6-month follow-up regardless of level of engagement with our ISG (Table 3). Furthermore, compared to participants who never logged in to our ISG, the combined superusers + top contributors subgroup reported a greater improvement in HRQoL (mean Δ SF-12 MCS: 16.1 [SE 1.9] vs. 10.1 [1.3], p=.01) and anxiety symptoms (mean Δ PROMIS T-score: -11.6 [1.5] vs. -7.8 [1.0], p=.04); we did not observe a similar improvement in depression symptoms.
Table 3. Mental health outcomes by engagement level.a

<table>
<thead>
<tr>
<th></th>
<th>Superusers + Top Contributors</th>
<th>Contributors</th>
<th>Observers</th>
<th>Never Login</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10.9%</td>
<td>35.8%</td>
<td>28.8%</td>
<td>24.5%</td>
</tr>
<tr>
<td>N</td>
<td>33</td>
<td>108</td>
<td>87</td>
<td>74</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>SF-12 MCS, estimated mean (SE)b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>31.2 (1.9)</td>
</tr>
<tr>
<td>6 months</td>
<td>47.2 (2.0)</td>
</tr>
<tr>
<td>Δ 6 months</td>
<td>16.1 (1.9)</td>
</tr>
<tr>
<td>Δ 6 months, Superusers + Top Contributors vs. Never Login</td>
<td>16.1 (1.9) -- -- 10.1 (1.3) .01</td>
</tr>
<tr>
<td>Δ 6 months, Login vs. Never Loginc</td>
<td>12.6 (0.7) 10.1 (1.3) 0.11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>PROMIS Depression T-score, estimated mean (SE)d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>62.0 (1.5)</td>
</tr>
<tr>
<td>6 months</td>
<td>51.7 (1.5)</td>
</tr>
<tr>
<td>Δ 6 months</td>
<td>-10.3 (1.3)</td>
</tr>
<tr>
<td>Δ 6 months, Superusers + Top Contributors vs. Never Login</td>
<td>-10.3 (1.3) -- -- -7.6 (0.9) .09</td>
</tr>
<tr>
<td>Δ 6 months, Login vs. NeverLoginc</td>
<td>-8.7 (0.5) -7.6 (0.9) .31</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>PROMIS Anxiety T-score, estimated mean (SE)e</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>67.2 (1.5)</td>
</tr>
<tr>
<td>6 months</td>
<td>55.7 (1.5)</td>
</tr>
<tr>
<td>Δ 6 months</td>
<td>-11.6 (1.5)</td>
</tr>
<tr>
<td>Δ 6 months, Superusers + Top Contributors vs. Never Login</td>
<td>-11.6 (1.5) -- -- -7.8 (1.0) .04</td>
</tr>
<tr>
<td>Δ 6 months, Login vs. Never Login</td>
<td>-9.3 (0.6) -7.8 (1.0) .20</td>
</tr>
</tbody>
</table>

a All models are adjusted for gender, race and education; n=259 (25 participants were missed at the 6-month assessment, 9 participants withdrew from the study)
b Range, 0-100; higher scores indicate better health-related quality of life
c Compares Superusers, Top Contributors, Contributors and Observers vs. Never Logins
d T-score range, 37.1-81.1; lower scores indicate less severe symptoms
e T-score range, 36.3-82.7; lower scores indicate less severe symptoms
Discussion

Principal Findings
To the best of our knowledge, this is the first report to demonstrate that high levels of patient engagement with a moderated ISG, compared to no engagement with the ISG, are associated with improved anxiety symptoms and HRQoL in primary care. Our findings also provide further empirical evidence to support the extreme level of participation inequality suggested by the 1% Rule.

Our work confirms that depressed and anxious primary care patients are willing to engage in an ISG even when not required by study protocol to do so. Indeed, the sizable majority of our study subjects logged in to the ISG at least once, which is consistent with login rates reported in other studies of ISGs for depression [4, 22]. Furthermore, among those who logged in to our ISG, we observed a broader distribution of posting than posited by the 1% Rule, as our top 1% and 10% of posters together generated 78% of all user-created content on our site, not 99% as the 1% Rule predicts. Still, challenges remain in developing even more equitably engaged online communities to improve health and HRQoL.

Prior work on the impact of ISG engagement has been limited largely to comparing psychosocial outcomes between posters (defined as individuals who made at least one post) and observers in ISGs for women with breast cancer [23, 24]. Findings from this work are mixed: while a moderate sized cross-sectional study showed more benefits in perceived social support in posters than observers [23], a large prospective study showed higher perceived functional well-being and fewer mood symptoms in observers than posters at 3-month follow-up [24]. To our knowledge, the only other study to explore the impact of engagement on mood symptoms in ISGs for mental health measured engagement by time spent on the ISG, showing that members who spent more than 5 hours on the ISG over a 2-week period were more likely to have resolution of depression at 6 months than members who spent less time [4].

Our finding that the participants who were highly engaged with the ISG reported improved anxiety symptoms and HRQoL at 6 months compared to individuals who never logged in identifies a subgroup that may benefit from participating in an ISG. Interestingly, this group did not report similar benefit for depression symptoms compared to the group that never logged in. On average, this highly engaged subgroup posted 5.8 times per month, which averaged to approximately one post per login. Demographically, this subgroup had higher proportions of women, whites and college educated individuals than the group that never logged in, but both groups had similar levels of baseline depression and anxiety. This finding offers encouragement about the potential for ISGs to improve clinical outcomes in individuals who engage highly with an ISG. Still, more work is needed to confirm our findings in a randomized trial and identify the critical threshold of engagement needed to demonstrate clinically meaningful improvements in health.
Our work motivates further study into how to most accurately measure engagement with an ISG. We quantified engagement using the relatively simple metric of number of posts, and we assigned each post an equivalent weight. However, other quantitative metrics such as time spent on the ISG and number of pages viewed may offer a different perspective. Moreover, qualitative metrics that analyze post content may also be an important dimension of engagement, particularly considering evidence from breast cancer ISGs suggesting that a subset of members derive psychological benefit from creating posts that provide “insightful disclosure” [25].

Limitations
Our study has several limitations. First, our finding that high levels of engagement improved clinical outcomes reflects a post hoc analysis that we undertook to identify a subgroup that may have benefitted from our ISG. Second, the limited size of our ISG precluded further subgroup analyses and required us to combine the superuser and top contributor groups for all outcome analyses. Third, we quantified engagement using a simple measure of post counts, and we used this measure to stratify the sample into engagement levels based on the 1% Rule rather than statistical methods that avoid specifying an a priori hypothesis about engagement distribution. Finally, since all participants had access to the CCBT program, we cannot exclude that the overall improvements we observed could be attributed to the CCBT program given its demonstrated efficacy [9].

Conclusions
In summary, we demonstrated that patient engagement with our moderated ISG for depressed and anxious primary care patients approximated the 1% Rule. Although engagement levels based on the 1% Rule were not associated with clinical outcomes, we showed that ISG members who engaged most with our ISG benefitted from doing so. Future work is needed to confirm our findings in mental health and other conditions and determine the threshold of patient engagement needed to benefit from an ISG.

Acknowledgements
This work was supported by grant R01 MH093501 from the National Institute of Mental Health and grant TL1 TR000145 from the National Center for Advancing Translational Sciences of the National Institutes of Health.

Author Contributions
ER, BHB, KA and BR designed the study. KA and SR analyzed the data. ER, BHB, KA, SR, AR and BR drafted the manuscript. All authors critically revised and edited the draft and approved of the final version. ER, BHB, KA, SR, AR and BR had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Conflicts of Interest
None declared.

Abbreviations
CCBT: computerized cognitive behavioral therapy
GAD-7: Generalized Anxiety Disorder scale
HRQoL: health-related quality of life
IQR: interquartile range
ISG: Internet support group
PCP: primary care physician
PHQ-9: Patient Health Questionnaire
SD: standard deviation
SF-12 MCS: Short Form Health Survey Mental Components Score

**Multimedia Appendix 1**
Slide 1: Screenshot of the smartphone version of our Internet support group homepage.

![Screenshot of the smartphone version of our Internet support group homepage.](image1)

Slide 2: Screenshot of our Internet support group discussion boards.

![Screenshot of our Internet support group discussion boards.](image2)
Acknowledgements
This work was supported by grant R01 MH093501 from the National Institute of Mental Health and TL1 TR000145 from the National Center for Advancing Translational Sciences of the National Institutes of Health.

References