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Feasibility of a Social Media/Online Community Support Group Intervention among Chronic Pain Patients on Opioid Therapy

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Abstract

Aims—Assess whether a Harnessing Online Peer Education (HOPE) social media-based support group can engage patients on opioids at risk for misuse/overdose to discuss risk reduction strategies.

Methods—Fifty-one patients on chronic opioid therapy and risk factors for aberrant medication-taking behaviors were randomized to a HOPE intervention or control (Facebook) group.

Results—Compared to control group participants, intervention participants had almost ten times higher posting engagement (n=411 posts versus 45; 73% versus 52% of participants). Participants discussed coping, pain, non-medication treatments, and other topics.

Discussion—Results suggest that a HOPE online community might serve as an effective behavioral intervention tool among chronic pain patients on opioid therapy.

Keywords

social media; opioids; online community

INTRODUCTION

Between 1996 and 2010, both prescriptions for opioids and deaths attributed to opioids nearly tripled. By 2016, the death toll in the U.S. from opioid overdose was higher than guns, car crashes and HIV/AIDS combined in a single year (1). Prescription opioid misuse (e.g., misuse of opioids to self-medicate co-morbid psychological conditions, addiction to prescription opioids, etc.) is particularly important to address to prevent overdose (2). Novel, low-cost behavioral interventions to reduce prescription opioid misuse are therefore urgently

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needed. However, only 5 behavioral interventions have been conducted on this topic to date (3).

Online behavior change communities for patients on chronic opioid therapy might be particularly effective as a behavioral intervention tool to reduce opioid-related complications (4,5). These technology-based platforms have the potential to more comprehensively support patients struggling with opioid addiction and ultimately augment harm reduction strategies, address opioid use risk factors and reduce the rate of addiction and opioid overdose.

For example, the Harnessing Online Peer Education (HOPE) intervention is a peer-led online behavior change intervention that has already been successfully applied among stigmatized groups, such as HIV and substance use populations (7,8). HOPE is a social media-based intervention rooted in a version of diffusion of innovations and social normative theory modified for online use. Patients on chronic opioid therapy, who also experience stigma in discussing their pain/mental health issues and in seeking help to reduce opioid-related complications, have already expressed interest and need in integrating an online behavior change intervention such as HOPE into their clinical and behavioral care (9). However, no research has explored whether and how patients with chronic pain and opioid use might use a HOPE community to discuss their chronic pain and opioid-related issues.

This study assesses the feasibility of a 12-week HOPE online support intervention to reduce risk of opioid misuse and overdose among patients on chronic opioid therapy for chronic non-cancer pain.

METHODS

Ethics Statement

The Institutional Review Board of the University of California Los Angeles (UCLA) approved the study. Participants consented for the study online.

Peer Leaders

Eight potential peer leaders were recruited for the intervention group. Peer leaders were selected on the basis of being: 1) UCLA patients; 2) 18 or older; 3) on chronic opioid therapy; and 4) recommended by a board-certified addiction medicine primary care physician as being sociable and having successfully dealt with problematic prescription opioid use in the past. Peer leaders were invited to attend two in-person training sessions at UCLA on chronic pain, how to use social media to build communities, and opioid-related safe behavior change, each lasting four hours. The role of peer leaders was to create a supportive and engaging community whereby patients would be more willing to discuss their chronic pain and opioid-related issues. The study team provided ongoing support and supervision to the peer leaders each week to guide them on topics to discuss with patients. Peer leaders were incrementally paid in online gift cards for completing these tracking sheets every week (Weeks 1-4: \$30, Weeks 4-8: \$40 and Weeks 8-12: \$50).

Participants

From July to October of 2016, 51 UCLA health system patients receiving chronic opioid therapy for non-cancer pain and at-risk for prescription opioid misuse/overdose were recruited and enrolled using the patient registry. Inclusion criteria were as follows: a Current Opioid Misuse Measure (COMM, 17 items) questionnaire score ≥ 9 (COMM score assesses self-reported aberrant drug-related behavior (e.g., early prescription refills), which has been found to be a predictor of actual aberrant medication taking behaviors among patients currently on opioid therapy) (10) and/or self-reported concomitant use of opioids and benzodiazepines (used to define high risk); 18 years of age or older; completed a baseline questionnaire on risk factors and pain.

Once enrolled, participants were randomized to a HOPE peer-led intervention or control (no peer leaders), closed, secret group on Facebook for 12 weeks. Participation in the online community was voluntary. Participants were paid in online gift cards to complete research assessments at baseline (\$30) and 12-week follow-up (\$40).

Facebook Community Groups

Participants in the control group enrolled in the Facebook Community Group without peer role models. Intervention group participants were enrolled in the Facebook Community Group with peer role models. For both groups, we recorded the number of participants who were engaged in the Facebook community group over the 12-week period. Engaged participants were defined as those that posted, commented or reacted at least once. Among the engaged participants, we recorded an “engagement score,” defined as the summation of posts, comments, and reactions. Posts and comments were categorized into the following topics: Physical health status, mental health status, pain, non-medication treatment, medication treatment, substance use disorder, coping, social support, and other topics.

Data Analysis

Grytics software was used to automatically collect and aggregate online community discussions for both the intervention and control groups. The software provided data on number and rates of engagement in each group, as well as most popular topics. One researcher hand-coded the topics for each 4-week period of the 12-week intervention using a modified grounded theory. Another researcher assessed reliability in coding the conversation topics by analyzing a subset of topics. Once all disagreements were resolved, the first researcher continued hand-coding the remaining topics. Data on total number of conversations by topics were aggregated and presented into descriptive tables. Engaged participants were defined as participants who posted, commented, or reacted at least once. The mean engagement score was defined as the summation of posts, comments, and reactions. In reporting engagement metrics such as number of posts, we excluded peer leader engagement frequencies in order to create equivalent metrics between the control (no peer leaders) and intervention (including peer leaders) groups. For examination of group differences in the demographics, number of engaged participants, and the mean engagement score, chi-square test of independence was used for categorical variables (demographic characteristics, number of engaged participants) and two-sample t test was used to compare differences in continuous variables (age, engagement score).

RESULTS

Among the 51 participants who consented to enroll in the Facebook community groups, 25 were randomized to be in the group without the peer role models (control group), and 26 were randomized to be in the group with the peer role models (intervention group). There were no significant demographic differences across the two groups.

Tables 1–2 highlights the number of engaged participants and engagement score by intervention status over 12 weeks. For each study period, a higher number of participants in the intervention group were engaged compared to those in the control group. This difference was statistically significant during the first wave of the study period (weeks 1-4). However, the number of engaged participants declined in both groups over time. Among those engaged participants, those enrolled in the intervention group had a significantly higher engagement score across all time periods, compared to those enrolled in the control group.

Over the 12-week period, 13 out of 25 participants (52%) in the control group provided a total of 45 posts or comments. In contrast, 19 out of 26 participants (73%) in the intervention group provided a total of 411 posts or comments (Table 3). Those in the intervention group posted about the following topics over the 12-week period: Coping (33%), physical health status (32%), medication treatment (27%), pain (26%), non-medication treatment (24%), mental health status (21%), and social support (19%). Intervention group participants broadly discussed a large number of chronic pain and opioid-related topics, such as describing personal experiences with their pain, treatments they tried, as well as comments about their enjoyment in being able to participate in the group and being able to meet other patients with similar experiences. By contrast, control group participants primarily focused on their personal clinical experiences. Out of the 45 posts and comments posted by the control group, more than half were attributed to the following topics: Physical health status (56%) and medication treatment (53%). Topic frequencies were highest during the first wave of the study period (1-4 weeks).

DISCUSSION

Results suggest that a HOPE peer-led social media community may serve as an effective online tool to engage participants with chronic non-cancer pain on opioid therapy. Compared to the control group who made a total of 45 posts over the 12-week study period, those in the HOPE intervention group posted an almost ten-fold higher number (n=411). In addition, increased levels of engagement in the intervention group was further supported by higher engagement score (summation of posts, comments, and reactions), compared to those in the control group (5-fold higher engagement score during 1-4 weeks and 9-fold higher engagement score during 5-8 weeks). Moreover, this feasibility study demonstrated that online community groups with peer role models, such as HOPE, can facilitate online discussions (via posts and comments) pertaining to various prevention-related topics including physical health status, mental health status, coping, pain management, and social support. Our study underscores the importance of utilizing peer role models to manage and facilitate online communities.

Furthermore, online support communities allow researchers to track changes in conversation topics over time, providing information about the specific needs of patients with chronic opioid use. These conversation topics provide a qualitative measure on patient outcomes over time, which can be used to provide tailored support via social media.

Despite these promising results, the study also revealed challenges. Although engagement was higher in the intervention group, engagement among both groups declined over time. There are at least two potential causes for this effect. First, peer leader attrition was higher in this study (62.5%) compared to previous HOPE interventions (~10-15%), reducing peer leader involvement compared with previous HOPE studies. Second, other HOPE studies purposefully had a larger number of non health-related (e.g., friendly) conversations during the beginning of the study. In this study, peer leaders expressed a desire to immediately discuss pain-related topics. Approximately 50% of conversations in the first four weeks were therefore related to pain and health-related issues. This differs from our previous HOPE studies, where peer leaders discussed non-health related topics more frequently in the beginning. An additional limitation is that we do not know whether patients who were using both opioids and benzodiazepines were using benzodiazepines according to a prescription versus illicitly. Finally, the study was limited by small sample size and participation rate.

It is important to note that experiences of patients who have been prescribed chronic opioid therapy for chronic pain are different from other patient populations, making it unclear whether and how HOPE or other online behavior change interventions might need to be modified for patients on chronic opioid therapy.

As a next step, research should assess whether online behavior change communities positively impact patient outcomes. For example, an online support community for patients on opioids might improve outcomes including: reducing stress and anxiety, reducing the stigma around seeking help for opioid misuse, providing a forum for patients to express fears and gain knowledge around opioid use and addiction, as well as act as a tool for integrating with other chronic pain treatments. To address this question, we are currently examining whether our intervention impacted patients' opioid-related risk factors. Future research is also needed to assess long-term outcomes in a larger RCT, as well as studying whether and how to integrate an online behavior change community into routine behavioral healthcare. Another area for future research, involves gaining a better understanding of patient risk for aberrant drug-related behaviors at the time of prescribing. With a more personalized assessment of risk, it may be possible to tailor treatments and reduce some of the complications resulting from opioid therapy.

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Table 1.

Number of Engaged Participants by Intervention Status over 12 Weeks

Weeks	Control Group (n = 25)	Intervention Group (n = 26)	p-value*
1-4	14 (56%)	21 (81%)	0.05
5-8	11 (44%)	15 (58%)	0.33
9-12	9 (36%)	10 (39%)	0.86

Note: Engaged participants are participants (does not include peer leaders) that posted, commented, or reacted at least once.

* p-values are based on chi-square test of independence at each time period.

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Table 2.

Mean Engagement Score (SD) among Engaged Participants by Intervention Status over 12 Weeks

Weeks	Control Group (n = 25)	Intervention Group (n = 26)	p-value
1-4	2.04 (0.41)	11.79 (2.23)	<0.001
5-8	1.08 (0.22)	8.89 (1.68)	<0.001
9-12	0.64 (0.13)	3.93 (0.74)	<0.001
Average for 12 weeks	1.25 (0.25)	8.20 (1.55)	<0.001

Note: Engagement Score = posts + comments+ reactions.

* p-values are based on two-sample t-tests at each time period

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Table 3.

Topic Frequencies by Intervention Status over 12 weeks

Topics	Control Group (n = 13) Total number of posts and comments (n=45)	Intervention Group (n = 19) Total number of posts and comments (n=411)
Physical Health Status	25 (56%)	131 (32%)
Mental Health Status	3 (7%)	86 (21%)
Pain	17 (38%)	108 (26%)
Non-Medication Treatment	13 (29%)	99 (24%)
Medication Treatment	24 (53%)	110 (27%)
Substance Use Disorder	0 (0%)	14 (3%)
Coping	12 (27%)	134 (33%)
Social Support	18 (40%)	79 (19%)
Opioid	3 (7%)	45 (11%)
Addiction	0	40 (10%)
Benzo	0	3 (1%)
Narcotics	0	14 (3%)
Other	10 (22%)	100 (24%)

Note: Multiple categories could be assigned to a post. The relatively high percentage of social support posts in the control group is due to the fact that “welcome” posts fall into this category.