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Authors

Garett, Renee
Cumberland, William
Chakravarthy, Bharath
et al.

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A Qualitative Exploration of the Potential Role of Using Online Social Media Support Communities to Increase Initiation of Medications for Opioid Use Disorder (MOUD)

Renee Garett, MSW, LCSW[a], **William G. Cumberland, PhD**[b], **Bharath Chakravarthy, MD, MPH**[a], **Sandra Springer, MD**[c], **Sean D. Young, PhD, MS**[d,e]

[a]ElevateU, Irvine, CA, USA

[b]Department of Biostatistics, University of California, Los Angeles, Los Angeles, USA

[c]Department of Internal Medicine, Section of Infectious Diseases, Yale School of Medicine, Yale University, New Haven, USA

[d]Department of Emergency Medicine, University of California, Irvine, Irvine, USA

[e]University of California Institute for Prediction Technology, Department of Informatics, University of California, Irvine, Irvine, USA

Abstract

Objectives: This study sought to explore the potential role of peer-led online communities to increase use of medications for opioid use disorder.

Methods: From January through March 2020, participants with opioid use disorder and their family members/friends were recruited from paid Facebook ads; public health key stakeholders were recruited from referrals from the study team and opioid experts. Thirty participants from California were interviewed; 23 persons reporting opioid misuse, 3 family members/friends of persons misusing opioids, and 4 public health key stakeholders. We conducted semi-structured interviews asking about preferences, barriers and facilitators of treatment options for opioid use disorder, and perspectives around the use of digital/online communities. The categories of participants interviewed were each asked slightly different questions depending upon their role.

Results: Results suggest that participants who misuse opioids (1) may prefer to engage in online communities rather than in-person meetings to discuss their opioid use, (2) generally prefer to receive opioid-related information from other patients with opioid use disorder and/or those in recovery rather than from health providers or other individuals, and (3) thought that an online community could be beneficial for helping address their opioid use.

Conclusion: Results suggest an openness and interest in a peer-led online community to discuss opioid use and treatment among people who misuse opioids.

*corresponding author: Sean D. Young, PhD, MS, University of California Institute for Prediction Technology, Department of Informatics, University of California, Irvine, 6091 Bren Hall, Irvine, CA 92617, syoung5@hs.uci.edu.

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Keywords

Opioid use disorder; Medication for opioid use disorder; Peer models; Social media; Digital tools

1. Introduction

Stigma is a pervasive barrier to access and retention in treatment programs for medications for opioid use disorder (MOUD) for both patients and providers. A review by Van Boekel et al. (van Boekel et al., 2013) found that, generally, healthcare providers had a negative attitude towards this population, in particular for those who used illicit drugs. For some providers, this attitude translated to poorer treatment outcomes such as shorter visits and task-oriented approach (van Boekel et al., 2013), obstructed patient-provider collaborative relationship (Tsai et al., 2019; van Boekel et al., 2013), punitive care terminations, and rigid dosage or duration caps (Tsai et al., 2019). On the patient side, patients who felt discriminated against tended to discontinue their treatment (Tsai et al., 2019; van Boekel et al., 2013). The role of stigma was more pronounced in rural areas or smaller communities due to potential violations of privacy and confidentiality (Tsai et al., 2019). Because stigma is so prevalent among opioid-using populations, there is a potential opportunity for peer-led interventions to reduce stigma around getting support with OUD and to increase engagement in treatment programs.

New technologies, such as online communities and digital intervention tools, might help to improve rates of initiation of MOUDs. Digital interventions have been used to achieve behavior change related to sexual health (Starosta et al., 2016; Young et al., 2015), smoking (Muñoz et al., 2016), physical activity (Robroek et al., 2010; Schwarzer et al., 2018), and weight loss (An et al., 2017). A randomized clinical trial by Young et al. (Young et al., 2020) used a social media peer-led intervention to increase engagement in discussing risk reduction strategies and decrease anxiety among chronic pain patients on opioid therapy. They used social media to discuss experiences with pain, prescription opioid use, coping strategies, and treatment seeking behaviors (Young et al., 2020, 2018). Other research has also studied the use of online communities among opioid users (Chancellor et al., 2019; Liang et al., 2021).

This study sought to explore, through qualitative interviews, the potential of a social media peer-led online community designed to engage people who use opioids about their opioid use, preferences about program features, and potential barriers and facilitators of using MOUD's.

2. Methods

We asked participants about the potential of a peer-led online community that would be broadly based on the theory of behavior change discussed in the book Stick with It (Young, 2017), as well as in a theoretical paper from our team on digital behavioral interventions (Young, 2020). Our qualitative approach for interviewing participants was based on previous interviews and a structure we had used in adapting the HOPE intervention for chronic pain patients on opioids, which involved understanding the role of stigma in opioid use and how

online communities might help provide support to address stigma and treatment (Young & Heinzerling, 2017). In brief, the HOPE study uses peer leaders to engage with intervention participants in a private social media group (Jaganath et al., 2012; Young et al., 2020, 2013; Young and Heinzerling, 2017a).

2.1 Recruitment

2.1.1 Participants reporting opioid misuse, including their family/friends—

Paid advertisements on Facebook were used to recruit persons who reported misusing opioids and family/friends of persons who misuse opioids between January and March 2020, and targeted adults 18 years old and older living in California. Interested potential participants who clicked on the advertisements were directed to an online interest form. The interest form included questions about state of residency, confirmed that they were 18 years old or over, contact information, (for persons who misuse opioids) if they misused opioids in the last 90 days (e.g., not according to a prescription, to get high, or any heroin use) and (for family/friends) if they have someone in their life who is struggling with misusing opioids. The last page of the form also included the study information sheet which provided participant information about the study procedures, compensation, investigator information, and served as their informed consent.

Research staff reached out to potential participants to verify their information and request an interview time. Of six family members/friends who completed the online interest form, three were eligible and participated in the study. Of the 21 potential participants who completed the online interest form, ten were eligible and participated in the study. Participants were also referred from a concurrent study recruiting for individuals with OUD. Recruitment, eligibility criteria, and screening process for the study were similar to the current study. A total of 13 participants were referred from the other study. Additional questions were asked from persons who use opioids about their opioid use during the phone screening. These individuals were referred to as participants with OUD. All but three participants were interviewed via Zoom individually. The other three were interviewed via phone due to technical issues. A Zoom meeting link was sent to participants for the interview. All Zoom interviews were conducted with audio only.

2.1.2 Key stakeholders—

Key stakeholders were identified based on referrals from study team investigators. Inclusion criteria for key stakeholders were: 18 years of age and older and working as a health provider on opioid-related issues in a California organization for at least three months.

2.2 Interview

Qualitative interviews were conducted with a total of 30 individuals across the different roles. Prior to the interviews, all interviewees were reminded that the interview was being recorded and once the recording was transcribed, the recordings would be deleted. Participants were assured that no personal identifying information would be kept in the transcript. All interviews were conducted between January 23, 2020, and March 4, 2020. Interviews used a semi-structured approach with open-ended questions to guide the interview. Additional probative questions were asked participants to further clarify their

answers. At the beginning of the interview, all those interviewed were reminded that their responses would be used to tailor an online social media community for persons who use opioid. Questions asked during the interview were similar to those from a previous study investigators conducted with patients receiving chronic opioid therapy (Young & Heinzerling, 2017). Participants who reported misusing opioids were asked about their current opioid use, engagement in social media, comfort in discussing their substance use in online communities, social media influencers, educational topics that would be of interest and prompt engagement, and role of social environment in opioid addiction. Investigators also inquired about preference in group composition (urban vs. rural, prescribed opioids vs illicit drugs) and peer leader attributes.

Family members/friends were asked similar questions as participants who misused opioids, but were asked from the perspective of their family member/friend (e.g., “what type of stigma and other treatment barriers do you think are experienced by your family member/friend and others with OUD).” Both family/friends and key stakeholders were asked about barriers to treatment, sustainability of an online social media community to increase uptake of medication treatment for OUD, maximizing response of target population. Key stakeholders, as well as the first participant and family/friend were interviewed by a research associate and principal investigator, both of whom had prior experience with semi-structured interviews. The rest of the participants and family/friends were interviewed by the research associate only. Based on prior experience with previous studies, we had a goal of interviewing between 23–25 participants, 3–5 family/friends, and 5 key stakeholders. We stopped recruiting when we reached topic saturation. Interview recordings were transcribed.

2.3 Data analysis

Data were analyzed using a directed content analysis approach for participants with OUD (Hsieh and Shannon, 2005). Three themes were used to review the transcript based on previous research (Young & Heinzerling, 2017). The three themes were: (1) peer leader attributes, (2) benefits of an online community, and (3) community discussion topics. Upon review of the transcript, a research associate identified codes and categories. After perusing the transcript for codes, broad categories were created and assigned a color scheme. The transcripts were then reviewed again and color-coded to highlight categories.

All participants were provided a $20 gift code to an online retailer after their interviews. This study was approved by the university Institutional Review Board.

3. Results

A total of 30 participants were interviewed, including n=23 individuals who self-reported using heroin or opioids outside of a prescription [13 males, 10 females]; n=3 family/friends of individuals who use opioids [1 male, 2 females]; and n=4 male public health key stakeholders). Of the 23 participants reporting opioid misuses, 10 stated that they were initially prescribed opioids for pain management before they began to misuse opioids. Among the rest of the participants, 12 stated they began using opioids recreationally, and one did not specify how they began using opioids. Of the 12 participants who started using recreationally, three were prescribed opioids for pain management after their initial use, and

one participant's family member provided buprenorphine without a prescription before they initiated recreational use.

3.1 Participants

Regarding participants, data were organized into themes, broad categories, and codes. Table 1 displays the themes, categories, codes, and description of codes. Table 2 shows participant preferences for a social media online community.

3.1.1 Peer Leader attributes—Regardless of the reason that participants reported as to why they first used opioids (e.g., pain management or recreational use), most (n=21) agreed that they would be more likely to trust information from someone with OUD than without OUD (i.e., a peer rather than a health researcher or health provider). Participants who reported opioid misuse (n=8) valued empathy over other attributes as important in a peer leader's ability to engage with and gain the trust of members of an online community. They expressed believing that only people experienced with addiction, stigma, and physical symptoms of withdrawal would be able to truly understand them and interact with them free of judgement. For example, Participant 9 said,

> Somebody who has been through it themselves, somebody who people can relate to. Someone who has good leadership skills, but the big thing is mainly someone who people can relate to because I see recovery pages and recovery communities where the people who are running it weren't addicts themselves and I feel that really makes people push away…Having somebody they can relate to is huge.

Although most of those interviewed preferred peer leaders who have experience with opioid misuse (n=21) and are in recovery (n=8) to provide information regarding treatment of OUD, a small number of participants (n=4) stated that someone with a medical background or a licensed therapist would work well in addition to a peer leader in moderating the online community and engaging participants in discussion.

3.1.2 Benefits of an online community—Participants who reported opioid use had mixed feelings about in-person meetings but had a positive response to an online community. Several of these participants stated that they had attended in-person meetings such as Alcoholics Anonymous and Narcotics Anonymous in the past (n=11), with some stating that they had neutral feelings about them or they were somewhat beneficial (n=5) while others had negative experiences or the format did not work out for them (n=6). However, participants overall expressed great interest in having an online community to address their opioid use and related needs. Factors that participants found especially appealing about an online community included ease of speaking with others online versus in person (n=10), a sense of anonymity (n=8), and convenience and easy access (n=4). For some participants, an online forum was a welcome change instead of in-person venues, because of logistical issues, such as having to drive to attend a meeting (n=2). Some of the participants stated that persons who used opioids, especially those who felt stigmatized, might better engage with others about their addiction online than in person (n=3). For example, Participant 11 reported,

> I'm good at talking to people, but I'm also kind of an introvert. It's easier for people to open up over a computer. It's easier for people to open up online in Facebook than it is to open up in person.

3.1.3 Online community discussion topics—When asked about educational content of the online community, participants agreed that information regarding treatment and where to get treatment was a topic that should be discussed (n=11). Participants were open to receiving information from trained peer leaders about treatment options as well as counseling and therapy. In response to the question of type of educational topics they would like presented in an online community,

In addition to treatment options, participants suggested presenting information on other topics such as mental health (n=7), alternatives to opioid use for pain (n=5), and factors that influence misuse (n=4). Some participants (n=3) mentioned the mental aspect of addiction such as depression and anxiety and the need to help those struggling with opioids on how to deal with these issues.

For example, participant 9, said, "…another topic is how to overcome social anxiety because it's really hard to talk to somebody, and you know, even doctors, because you can talk to nobody... And depression, talking about depression."

Another topic that participants were also interested in was how to navigate relationships (n=7), with both people who provided support and those that served as a trigger for their addiction. Social support was deemed important for a variety of reasons, including a safety net for those in crisis and in the path to seeking treatment and sobriety.

3.2 Family/Friends of persons reporting opioid misuse

Family/friends echoed the sentiments of participants regarding the need for an online community for those struggling with opioids. All three stated that an online community would be a good platform for obtaining information or just a means to find social support. Similarly, family/friends noted that comfort level of speaking honestly in an online community would fare better than in person (n=2). In response to asking what they thought about an online community on social media, Participants 2 said,

> I think it's needed. I think it would be great, especially for people who are on social media. I have friends who go to NA and they're always on social media. So, if there's a platform, there's some people I know who just needs to talk to somebody, and chatting with people online to get information.

Aside from educational information, family/friends reported that the connection with others is what would draw and sustain the online community for those with OUD (n=2). For example, Participant 12 reported,

> People like people, and people love to connect with other people that are doing the same thing they are, whatever it is…And if it's some kind of online community or online forum where everybody's doing the same thing, then they can commiserate…and lean on each other.

3.3 Key Stakeholders

Key stakeholders came from various fields such as public health (n=2), medicine (n=1), and telemedicine (n=1).

3.3.1 Seeking treatment for opioid misuse—Key stakeholders provided insight into the factors that affect treatment options for OUD patients and suggestions for how online communities might help to reduce the stigma associated with OUD. They agreed that the type of MOUD prescribed for a patient should be based on the need of the patient given their life circumstances (n=4). In choosing the appropriate treatment, providers took into consideration the severity of the patient's OUD. Providers, through the use of motivational interviewing, can confer with patients what patients perceived as an appropriate treatment plan (n=2). However, they also acknowledged that there are biases among OUD patients about different forms of MOUD such as stigma associated with a specific type of treatment (n=2).

3.3.2 Peer models—Key stakeholders also appreciated the idea of peer-to-peer support as part of an intervention. They expressed that peers who are empathetic to those with OUD through shared experiences might be more effective in communicating information compared to those who are less empathetic. They expressed that the model of using peer counselors is already employed at various methods of engaging those struggling with substance use (n=3) and would be novel and needed if it could be adapted online.

4. Discussion

Our results suggest that persons who misuse opioids, their family and friends, as well as medical and public health experts, support the idea of a social media online community for those who are living with OUD or at risk for development of OUD. As social media use is extremely common, including among individuals with opioid use disorder, individuals might find these communities by conducting internet searches, browsing social media groups, through word of mouth from other group members, as well as from referrals from community organizations serving these populations.. The online community can provide a social environment that is a convenient way for members to find support and treatment resources they are seeking. It can serve as a replacement or supplement to an in-person meeting for those who are ambivalent about group meetings, have had negative experiences, or prefer a more secular space for support.

A key and surprising finding from this study was that most participants with opioid use disorder reported having greater trust in receiving information about opioids from other patients (people who have similar personal experience) compared to health providers. This has important implications for clinical and public health practice in learning how to both address rates of potential misinformation happening online that might occur in patient forums (Garett and Young, 2022, 2021), as well as identifying new and changing roles for medical experts. The perceived connection resulting from shared experience of drug use and the physical, mental, and psychological consequences was emphasized by OUD participants as important in building trust and rapport. In the same vein, word of mouth about resources or treatment option from their inner circle could have an impact in seeking treatment.

Both OUD participants and key stakeholders highlighted the role that stigma plays in the lives of those struggling with opioids. Perceived stigma felt by participants led to delays in seeking treatment. One participant noted the resistance to seek treatment due to family and friends' lack of support and stigmatization of drug use (data not included). This was supported by previous research citing stigma as a barrier to treatment (Browne et al., 2016; Cunningham et al., 1993; Paquette et al., 2018). Bias against current MOUD was noted by both participants (those reporting opioid misuse) and key stakeholders. A study by Moore et al. (Moore et al., 2014) found that youth stigmatized against methadone despite its success in treating opioid dependency. Schwartz et al. (Schwartz et al., 2008) found adults held negative views of methadone due to its short and long-term effects on the body. This negative perception is shared by health providers who believe that buprenorphine (DeFlavio et al., 2015) and naltrexone (Alanis-Hirsch et al., 2016) served as a replacement and not a proper treatment for opioid dependency.

This study has limitations. Data may lack generalizability as most participants were recruited online through Facebook. Despite increasing internet use, certain communities continue to have lower access to broadband (Pew Research Center, 2021). This digital divide may have alienated potential participants who do not have access to Facebook and the study recruitment ads. Nonetheless, results are likely representative of a vast majority of people who use online social media.

4.1 Conclusion

This study demonstrated that there is a need and interest in a social media online community among those affected by the opioid crisis. As digital interventions have already had an impact in facilitating behavior change in a number of areas, including among chronic pain patients on opioids, researchers and public health advocates should consider the potential of these tools in increasing uptake of medications for opioid use disorder.

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7. Data availability statement

Due to the sensitive nature of the questions asked in this study, survey respondents were assured raw data would remain confidential and would not be shared.

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Table 1.

Description of codes.

Theme	Categories	Codes	Description
Peer Leader attributes	Opioid experience	Gone through/been through/experience	Mentions past experience of potential peer leaders with opioid use, seeking treatment, addiction
		Situation	Any mention of past struggle with opioid use
	Empathy	Listen	Discussion of peer leader's ability to listen without judgement
		Relate/sympathize	Any mention of potential peer leader's understanding of lived experience with opioid use, misuse
		Sensitive/compassion	Discussion about potential peer leader's ability to treat someone as equals and not look down on them
Benefits of an online community	Openness	Easier	Any mention of convenience in participating in online community instead of in person
		Comfortable/open up/be myself	Mentions feeling more comfortable sharing online instead of in person about misuse of opioids, honesty
	Judgement	Stigma/judgement	Discussion about avoiding stigma online compared to in person meetings, no one judging you
	Anonymity	Anonymous	Discussion about the benefits of no one knowing you personally and being anonymous
		Run into/in person/see/ face-to-face	Any mentions of seeing someone you know in real life, the pressure of in person interaction
Online community discussion topics	Resources	Treatment/clinics/ places	Mentions of medications, process of finding treatment, or where to go for treatment
		Mental health	Discussion about treating not just the physical aspect of opioid misuse but the psychological and mental component of misuse, the trauma associated with misuse. Any discussion about any mental health topics like anxiety, depression
		Resources/help	Mentions of any kind of information of where or how to get help, access to help outside of medication treatment, harm reduction
		Information	Discussion about information on side effects of treatment, pain management/tolerance, violence perpetuated against those misusing, legal information
		Programs/rehab/ recovery	Any mentions of life while in a recovery program
		Alternatives	Any mentions of alternative forms of treatment outside of prescribed medication
	Support	Social/relationships/ family	Discussion about maintaining relationships, including after treatment, safety net during crisis
		Support	Any mentions of support groups
		Faith	Any mention of religion or faith community helping with recovery process or spiritual guidance
	Daily living	Life/day-to-day	Discussion of how to get life back on track, how to get back on feet, skills essential for daily living, choosing healthier options
		Job/finances	Discussions of getting a job, job interview skills, addressing homelessness
	Factors affecting misuse	Triggers	Discussions on addressing people/friends who still use opioids
		Dependency/struggles	Any mentions of how to deal with struggles of misusing or root cause of dependency
		Motivation	Any mention of facilitators to quit using opioids

Table 2.

Preferences of participants who reported misusing opioids

Preferences	N=23 (%)
Peer Leader attributes	
Experience with opioid misuse	21(91.3%)
In recovery	8 (34.8%)
Professional[a] (i.e. counselor, medical expert)	4 (17.4%)
Benefits of an online community	
Easier to engage online than in person	10 (43.5%)
Anonymity/not face-to-face	8 (34.8%)
Convenience and easy access	4 (17.4%)
Free of judgement compared to in person	3 (13.0%)
Online community discussion topics	
Treatment sources	11 (47.8%)
Mental health	7 (30.4%)
Social support/relationships	7 (30.4%)
Alternatives to opioid use	5 21.7%)
Factors/influence of misuse	4 (17.4%)
Daily tasks/basic skills	4 (17.4%)
Mental side of addiction	3 (13.0%)
Faith	2 (8.7%)

[a]Participants preferred to have two leaders in a group, someone who has experience with opioid misuse and a professional.