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Characterizing Self-Reports of Self-Identified Patient Experiences with Methadone Maintenance Treatment on an Online Community during COVID-19

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Abstract

Background: The coronavirus disease (COVID-19) pandemic has impacted patients receiving methadone maintenance treatment (MMT) through opioid treatment programs (OTPs), especially because of the unique challenges of the care delivery model. Previously, documentation of patient experiences during emergencies often comes years after the fact, in part because there is a substantial data void in real-time.

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Methods: We extracted 308 posts that mention COVID-19 keywords on r/methadone, an online community for patients receiving MMT to share information, on Reddit occurring between January 31, 2020 and September 30, 2020. 215 of these posts self-report an impact to their MMT. Using qualitative content analysis, we characterized the impacts described in these posts and identified four emergent themes describing patients' experience of impacts to MMT during COVID-19.

Results: The themes included (1) 54.4% of posts reporting impediments accessing their methadone, (2) 28.4% reporting impediments to accessing OTPs, (3) 19.5% reporting having to self-manage their care, and (4) 4.7% reporting impediments to accessing OTP providers and staff.

Conclusions: Patients described unanticipated consequences to one-size-fits-all policies that are unevenly applied resulting in suboptimal dosing, increased perceived risk of acquiring COVID-19 at OTPs, and reduced interaction with OTP providers and staff. While preliminary, these results are formative for follow-up surveillance metrics for patients of OTPs as well as digitally-mediated resource needs for this online community. This study serves as a model of how social media can be employed during and after emergencies to hear the lived experiences of patients for informed emergency preparedness and response.

Keywords

medication for opioid use disorder (MOUD); emergency management; disaster management; emergency preparedness; online communities; infoveillance; patient experience

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has exacerbated the opioid overdose crisis.[1–10] Medications for opioid use disorder (OUD) - methadone, buprenorphine and naltrexone - are the first-line, evidence-based treatments for OUD.[11] In the United States, methadone maintenance treatment (MMT) can only be administered for treatment of OUD at one of the approximately 1,800 certified opioid treatment programs (OTPs)[12] which provides care for approximately 383,000 patients.[13] Patients on MMT are required to visit their OTP daily for supervised dosing with the exception of some patients that are granted take-home doses (e.g., two take-home doses per a week). A missed dose of methadone can lead to withdrawal and an increased risk of drug use or overdose.

There are several reasons to expect that the COVID-19 pandemic could lead to lapses in care of OTP patients. First, past emergencies (e.g., 9/11, Hurricane Katrina) led to lapses in care.[14–18] Second, the societal fallout resulting from COVID-19 increased demand for MMT because of disruptions in illegal drug supplies and increased isolation of the public.[4,5,7,9,10,19–21] Third, existing barriers to treatment were exacerbated during the COVID-19 pandemic given that many patients already experience social instability (housing, economic, transport).[5,7] Third, the unique delivery model of supervised, in-person, daily dosing increased the risk of exposure and transmission of COVID-19 to a population at increased risk for COVID-19.[4,7] Finally, OTPs provide essential psychosocial treatment

along with pharmacological treatment and the COVID-19 pandemic challenged the ability to ensure continued delivery of the psychosocial component to treatment.

To mitigate the potential impact of COVID-19 to both patients and OTP staff, federal regulations for OTPs were relaxed. On March 19, 2020, the Substance Abuse and Mental Health Services Administration (SAMHSA) relaxed policies for take-home doses of methadone to extend take-home doses to up to 28 days for stable patients and 14 days for less stable patients,[22] up from 1 to 28 days (previously dependent on how long the patient had been in treatment).[23] Telehealth is now permitted for continued care of existing patients in MMT although new patients still require an in-person evaluation and all patients must pick up their medication in-person. However, similar to previous emergencies, these policies are implemented at the discretion of each OTP and provider.

Overlooked in informing strategies and policies are the perspectives and experiences of OTP patients during the COVID-19 pandemic.[24] In part, because clinics do not have the resources to engage in research and their patient population is difficult to otherwise include in ongoing surveillance (e.g., surveys). To address this knowledge gap, we turned to Reddit, a social media platform with more than 2 million online communities called subreddits that focus on a particular topic. Reddit is the seventh most popular website in the US[25] and rivals Twitter with 430 million active monthly users.[26] Reddit experienced statistically significant growth in usage between 2019 and 2021 with 11% and 18% of the US population using the platform, respectively.[27] Unlike other popular social media platforms (Facebook, Instagram, Twitter), Reddit is pseudo-anonymous, not socially networked, and without detailed profile information (e.g., location, user descriptions, profile pictures) making it an ideal platform for people seeking information on stigmatized health issues and has been used as a platform for research about stigmatized health issues including OUD.[28–31] In this study, we qualitatively examine self-reported impacts to the delivery of MMT by self-identified patients in the subreddit r/methadone, which allows people to “share [their] own experiences with methadone, clinics, treatment programs and more.” The subreddit r/methadone has nearly 10,000 subscribers (albeit substantially more viewers) with 3,429 unique usernames posting 7,900 posts since its inception (as of September 30, 2020).

Methods

Data Collection

Using the publicly available Pushshift Reddit dataset,[32] we extracted all posts on r/methadone that contained COVID-19-related keywords (“covid”, “covid-19”, “covid19”, “corona”, and “coronavirus”) occurring between the US declaration of a public health emergency on January 31, 2020 and September 30, 2020 resulting in a total of 308 posts.

Analysis

Using this dataset of 308 posts, first, we asked “Does this post discuss a perceived or enacted impact(s) to the poster’s OTP program?” If yes, the post was retained for further analysis resulting in 215 retained posts from 179 unique usernames. Second, we conducted an inductive thematic analysis[33] of the retained posts with the goal of discovering emergent

themes of self-reported impacts to the delivery of the patient's MMT. One author reviewed and openly coded posts until reaching thematic saturation, which occurred after reviewing 50 posts. In discussion (via email and online meetings) with the research team of public health experts, a sociologist, addiction psychiatrist, and a OTP physician, these codes were organized into larger thematic categories and incorporated into a codebook. We used Dedoose to organize and apply the codebook to the retained posts. Themes were not mutually exclusive to each post; each post could contain multiple excerpts containing a code or theme. To establish the reliability of the thematic categories,[34] a second co-author independently coded 25% (n = 60) (25% is the suggested upper threshold of overlap to calculate inter-coder reliability)[35] of the excerpts. Inter-coder reliability (Cohen's kappa (κ)) was calculated for each category and pooled using Dedoose. We then used Dedoose to produce frequency tables for the number of posts that contained each code and thematic categories.

Ethical Considerations

This study was deemed exempt from ethical review by the human research protections program at the University of California, San Diego. Although the posts in our study are public, to prevent re-identification outside of a post's intended audience, we adhere to data protections[36] including providing sample quotes that are composites to reduce reverse identification.[37] We only include modified excerpts to contextualize our results.

Results

During the study period (January 31, 2020 through September 30, 2020), there were 3,077 posts from 1,456 unique usernames. For context, that is a 41.5% increase from the number of posts in 2019 (there were 2,175 posts from 1,092 usernames in 2019). Of the 308 posts (10.0% of all posts during the study time period) that mention a COVID-19-related keyword, 215 posts (7.0% of all posts during the study time period) from 179 unique usernames discussed an impact on their MMT and were retained for further analysis. The 93 posts that were not retained mentioned COVID-19, but were not related to an impact to their MMT. For example, "*Hope you all are hanging in there with this COVID stuff!*"

We identified four themes in the posts: (1) access to medication (117 [54.4%] posts), (2) access to the physical OTP (61 [28.4%] posts), (3) self-management of care (42 [19.5%] posts), and (4) access to OTP providers and staff (10 [4.7%] posts). We achieved an inter-coder reliability (Cohen's κ) of 0.87 for access to medication, 0.92 for access to the physical OTP, 0.94 for self-management of care, and 1.0 for access to OTP providers and staff, and a pooled Cohen's κ of 0.91. Below we describe each of these themes with Table 1 providing supporting excerpts.

Access to Medication

Seventy-three posts discussed changes to take-home protocols for the poster's OTP and inquired about changes in other OTPs' take-home protocols to make comparisons (excerpt 1). They often described benefits or new challenges with an increased quantity of take-homes ranging from increased flexibility in their day-to-day routines to an unease over

their ability to adhere to their prescribed dosing to problems with poorly-sealed liquid medications spilling during transport home.

Fifteen posts discussed difficulty adhering to the prescribed dosing regimen, often describing that they had run out of their take-home doses and, as a result, described that they had to locate other sources of opioids (primarily illegal opioids) or were experiencing withdrawal. Many of these posts were hesitant to reveal this to the poster's OTP for fear of losing their new take-home privileges (excerpt 2), but two of these posts had contacted poster's OTP and were told that the only option was to dose at an emergency department. Ten posts discussed faulty seals on their liquid take-homes, which resulted in part or all of their doses being spilled during transport home. Many of these posts reiterated that they contacted the OTP, but the staff did not believe them and were now looking for strategies to self-manage withdrawals until they picked up more take-home doses (excerpt 3).

Other topics discussed within this theme included interest in expanding or reducing the number of take-home doses (n = 6 posts) (excerpt 4), disruption to medically supervised tapering or increases of methadone dosing (n = 2 posts) (excerpt 5), the impact of callbacks (i.e., the requirement for the patient to bring take-home doses into the OTP for inspection) or drug testing associated with take-home doses (n = 3 posts) (excerpt 6), sharing experiences of successful adherence to take-home dosage (n = 5 posts) (excerpt 7), concerns about potential disruptions to the supply of methadone (n = 3 posts) (excerpt 8), and discussions about how take-home policies may change after COVID-19 (n = 2 posts) (excerpt 9).

Access to the Physical OTP

Twenty-four posts described the types of safety protocols in place at the poster'sOTP. Sixteen of these posts described a lack of program preparation of or adherence to safety protocols to prevent the transmission of COVID-19 (excerpt 10, excerpt 11). While only two of these posts expressed that the new safety protocols at the poster's OTP made them feel safer (excerpt 12).

Twenty-two posts described a lack of anticipatory guidance about what would happen to OTP operations during an emergency. These posts expressed clear confusion over what to do in an emergency including if OTPs were closed or hours were reduced and where they could go for their medication if needed. Often these excerpts indicated their location to compare information with others in similar locations (excerpt 13).

Nine posts discussed uncertainty of protocols for patients who have been exposed to or had acquired COVID-19 (excerpt 14) with one post describing even showing up at the poster's OTP after a positive test result (excerpt 15).

Other topics discussed within this theme included changes to group therapy for psychosocial support (n = 6 posts) including continuation of in-person group meetings (n = 1) (excerpt 16), cancellation of group meetings (n = 2 posts) (excerpt 17), and transition to group meetings via phone (n = 3 posts) (excerpt 18); changes to intake policies (n = 2 posts) (excerpt 19); the potential for exposure to COVID-19 at OTPs (n = 6 posts) (excerpt 20); a reduction to the operating hours of the poster's OTP (n = 6 posts) (excerpt 21); and a change

in health insurance status either because of a lost job or COVID-related delays (n = 2 posts) (excerpt 22).

Self-Management of Medication Self-Taper and Inadequate Dosing or Loss of Medications

Thirty-two posts described using this time period of increased take-home doses and reduced work responsibilities for a self-administered taper of methadone. These posts ranged from mentioning their interest in self-tapering to inquiring about dosing for a self-taper to announcing a successful taper (excerpt 23, 24). Ten posts focused on impending withdrawals, mostly from not adhering to their prescribed dosing regime (i.e., running out of their take-homes) or spilled dosages, and strategies to mitigate withdrawals (excerpt 25, 26).

Access to OTP Providers and Staff

In comparison to the other themes, fewer posts (n = 10) described an interruption to access to OTP providers and staff. Nine of these posts focused on how the new take-home protocol now limited in-person access to OTP providers and staff, especially if they would like to either taper or increase their dosage (excerpt 27, 28). Notably, no posts mentioned the use or availability of telehealth to facilitate interactions between patients and providers or staff.

Discussion

This is the first study to examine how COVID-19 has impacted those receiving MMT in OTPs by analyzing patient perspectives of unmet needs and unintended consequences posted to an online community. Our results are formative highlighting the need for additional research to inform more robust emergency management as well as strategies to interact with this online community as many patients in this community had avoidable problems including inconsistent take-home policies, inconsistent implementation of safety protocols, concerns about access to clinical staff, and a need to self-manage their care as a result.

Informing strategies in response to patient experiences

Patients in this community sought comparisons among their online peers to better understand what may happen in their own OTP. While federal regulations for take-homes were relaxed in anticipation of COVID-19-related impacts, these guidelines were left to the discretion of each OTP. A lack of uniformity in these policy rollouts may have resulted in the confusion of what options were available for continuity of MMT in a patient's OTP. With a greater central oversight of OTP responses to emergencies, including the pandemic, across the country, targeted and active information campaigns could be deployed in these online communities to help inform patients of options for uninterrupted continuation of their psychosocial and pharmacological treatment.

Patients in this community also sought peer help to strategize self-care including managing withdrawal symptoms and self-tapers as a result of the changes to take-home policies, reduced potential to interact with clinical providers to manage treatment, or additional downtime. Experts anticipated telehealth could help bridge the gap to in-person care,[3] however, this community of patients indicated that telehealth (specifically telephones and conference calls) was used to transition mandatory psychosocial support groups away from

physical in-person meetings and did not mention telehealth facilitating interaction with OTP providers or staff.

With regard to take-home doses, the main issue patients in this community reported was feeling that they could not adhere to the prescribed dosing regime (i.e., taking the doses early or often) without the consistency of supervised dosing. We did not observe patients in this community mentioning any novel dispensing and supervision methods, like modified directly observed therapy, such as using video to record taking their methadone medication daily and submitting the video through a smartphone app,[38] to help them manage their dosing.

Patients in this community expressed frustration that the poster's OTPs were not implementing adequate safety precautions including distancing, wearing a mask, or providing products like hand sanitizer. Patients in this community described being left in the dark on how to handle their care should they be exposed to or tested positive for COVID-19 despite the fact that the US DEA has authorized alternate delivery methods for methadone (e.g., doorstep delivery) for quarantined patients.[39] Although OTP patients are at increased risk of COVID-19 and expressed concerns over inadequate safety precautions at OTPs, they were not considered to be a priority during the early stages of the vaccination effort.

Harnessing data to learn from and respond patients

Taken together, the insights from this community indicate that despite significant disruptions to OTPs in the wake of previous emergencies, OTPs may remain in need of additional resources and continue to be underprepared for emergencies[16] to address the distinct needs that patients may face.[40] Beyond the previous recommendations such as establishing a central patient registry, methodologically, these insights also suggest that opportunities for rapid digital surveillance and support could be implemented as part of emergency response. Researchers can extend our digital surveillance to include real-time surveillance of unmet needs and consequences voiced by social media users. For example, experts may not have anticipated that OTPs would refer patients to emergency departments for dosing in the midst of emergency departments transitioning to higher priority COVID-19 patients where they may proverbially fall through the cracks. In addition, researchers might follow up on the findings from this research to do qualitative interviews of patients and clinical staff in OTPs to do deeper exploration of the issues raised, especially across socio-demographic characteristics, and to compare how these issues are managed in non-emergency times.

Clinical providers and regulatory agencies could leverage social media for real-time digital support of patients to better understand patient-lived experiences. For example, after observing common need for COVID-19 related health information, health organizations could build a living knowledge base of factual information for online communities such as r/methadone that directly addresses their primary concerns in an easily accessible wiki (a Reddit convention that links factual information on the subreddit). Additionally, within the existing framework of Reddit, applicable experts (e.g., OTP providers) could work with moderators to implement "flair," to indicate that the poster is an expert. We observed posts by posters claiming affiliation with an OTP or SAMHSA; however, formalizing these affiliations would lend credence to the expert-provided information, much like the verified

mark on Twitter. Experts could host “Ask Me Anything” sessions, a Reddit convention where a poster announces they will be available to answer any questions within a specified time frame. Coordination of this type of dissemination could be supported by federal health agencies and professional societies. During the COVID-19 pandemic, #MedTwitter has become popular for sharing information with the public. However, unlike Twitter, Reddit is pseudo-anonymized and ideal for people discussing health issues, like MMT, that can be stigmatized in mainstream society. Additionally, recent research shows that conversations about MOUDs on Twitter primarily originate from people who do not use opioids, have OUD, or are engaged in treatment with MOUDs.[41] Finally, public health experts could partner with online moderators of these communities to establish a process that allows people participating in these online communities to submit their experiences in real-time either to their specific OTP, a network of OTPs, or at the regional or state-level. This real-time feedback could provide valuable information to the OTP potentially allowing for the OTP, region, or state to pivot policies to address their community in near real-time.

Limitations

First, our study is limited to an online community of OTP patients, which may not be representative of the general population of OTP patients, including persons with limited internet access. However, prior research has shown that the non-networked structure of Reddit provides a cloak of anonymity for those seeking help with stigmatized health issues, including substance use, representing untapped opportunity for intervention.[42,43] Second, due to the pseudo-anonymized nature of Reddit, we are unable to ascertain the descriptive characteristics of the posters’ identities, including socio-demographic characteristics like age, race, ethnicity, gender, literacy, language, and economic status. Research with OTP patients who may not use social media platforms such as Reddit will be needed to complement knowledge of COVID-19 patient experiences, especially across demographic characteristics. Additionally, previous research has indicated that 58% of people who inject substances in a large US city had routine internet access[44] and more than 70% of outpatient clients engaged in substance use disorder treatment programs had routine access to the internet.[45] Although this study is limited to a singular online community it is likely the largest self-organized group of OTP patients with 10,000 subscribers (and many more passive viewers) in one location. Third, our study did not examine perceived or enacted impacts to the poster’s OTP program over time. Future work should focus on examining how the public is responding to policies as they change over time, including shifts in policy after the COVID-19 pandemic resolves. Fourth, our study intentionally limited the dataset to posts that explicitly mention COVID-19. It is likely that other posts discuss COVID-19-related impacts to their treatment program, however, this approach ensures a precise dataset (i.e,. we ensure that the post indeed is discussing a COVID-19-related impact instead of inferring). Finally, our study may be limited by self-selection bias (e.g., our study may capture patients voicing more negative experiences).

Conclusions

The unique circumstance during COVID-19 contributes to an inevitable lack of “data and insights needed to make strategic planning and response decisions”[46] in part because

primary data collection for many studies has been suspended or at best delayed.[20] Surveilling social media communities of patients represents an opportunity to identify unmet needs that may be addressed in real time. Additionally, surveilling these communities can serve as formative work highlighting potential concerns to explore using more traditional research like surveys and focus groups. Together, these insights can help inform policies and interventions that are responsive to emergencies such as the COVID-19 pandemic. These interventions and rollouts of policies can often come in the form of a rapid public health response that meets people where they are, which these days is often on the internet.

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Subst Use Misuse. Author manuscript; available in PMC 2022 September 05.

Table 1:

Examples of Excerpts for the Themes.

Excerpt No.	Example Excerpt[a]	Topic[b]	No. (%) of Posts
Theme: Access to Medication			**117 (54.4)**
1	*I was getting two week takehomes, but when COVID happened, my clinic allowed us to have one month of takehomes. What is your clinic doing?*	Changes to other OTPs' take-home protocols	73 (34.0)
2	*I got two weeks of takehomes from my clinic and I wasn't ready for it. I took them all already and still have 4 days until my next refill. I'm scared they will kick me out if i say something. What should I do?*	Difficulty adhering to prescribed dosing regimen for take-homes	15 (7.0)
3	*Hey! What should I do? My clinic switched bottles and these new lids suck. After driving home, I opened the box and noticed that several of the bottles had leaked. I called the clinic, but they said they are not responsible for spilled bottles.*		
4	*So because of COVID, I got more takehomes. I'm an addict, of course I'm not ready for that. I wish I could go back to daily dosing. I feel more stable that way.*	Changing the number of take-home doses	6 (2.8)
5	*I was on a supervised taper, but because of the new takehome rules they will not fill my bottles with the tapered dosage. They said these are the new rules and I have to have the same dose for the entire takehome period. They say it's an updated policy. Has anyone else experienced this?*	Disruption to methadone dosing or tapering	2 (0.9)
6	*Does anyone know what they will do with the new corona takehomes if you do not pass a drug test?*	Callbacks and drug testing	2 (0.9)
7	*I'm really proud of myself because I haven't abused my increased takehomes despite tremendous anxiety and stress during coronavirus.*	Successful adherence to take-home dosage	5 (2.3)
8	*Could clinics run out of methadone because of supply issues?*	Disruptions to supply	3 (1.4)
9	*Are they just going to revert back to normal takehome quantities after all of this is over?*	Post-COVID-19 policy changes	2 (0.9)
Theme: Access to Physical OTP			**61 (28.4)**
10	*My clinic hasn't done anything to prepare for COVID. They've only put out hand wipes in the bathroom.*	Safety protocols	24 (11.2)
11	*One of the clinic staff yelled at me that a mask would not do me any good, so no point in wearing it.*		
12	*My clinic has enforced social distancing. They require everyone to line up outside. But I've heard of other clinics in town where this isn't required.*		
13	*Does anybody know what is going on in Florida? Have there been any closures? I'm worried what will happen if the clinic closes.*	Lack of anticipatory guidance for OTP operations during emergencies	22 (10.2)
14	*I asked if there was a protocol for if someone tested positive for COVID-19. They just said no.*	Protocols for patients that have been exposed to or acquired COVID-19	9 (4.2)
15	*I got a positive COVID test. I didn't know what to do, so I showed up at the clinic. They put me in a room by myself.*		
16	*Are they still making you go to groups at the clinic? My clinic is. How can I file a complaint?*	Changes to group therapy for psychosocial support	6 (2.8)
17	*My clinic doesn't do group meetings or therapy right now because of COVID. I need support.*		
18	*We moved to group meetings by conference calls on the phone.*		
19	*Are clinics still doing intakes?*	Changes to intake policies	2 (0.9)

Excerpt No.	Example Excerpt[a]	Topic[b]	No. (%) of Posts
20	*I live with high risk people. I'm afraid that going to the clinic puts them at risk, but my clinic refuses to follow SAMHSA guidelines.*	Potential for exposure to COVID-19 at OTP	6 (2.8)
21	*My clinic is only dosing for 2 hours. I live in a large city and it's hard for me to get there in time.*	Reduction in operating hours for OTP	6 (2.8)
22	*I lost my job because of COVID. I can't afford to keep going to the clinic. What should I do?*	Change to health insurance status	2 (0.9)
Theme: Self-Management of Care			**42 (19.5)**
23	*I'm going to use this down time from work to taper off methadone. I plan on tapering my takehomes and never returning to the clinic again.*	Self-administered taper of methadone	32 (14.9)
24	*I used COVID times to successfully taper myself off methadone. Ask me anything.*		
25	*My clinic doesn't believe that two of my bottles spilled so I need to make it through 2 more days. Any helper meds for withdrawals?*	Anticipated withdrawals	10 (4.7)
26	*I took my medicine too soon and ran out early. I have to go 4 days without methadone. I know I'm in for a ride. Is there anything I can do to help with withdrawals in between?*		
Theme: Access to OTP Providers and Staff			**10 (4.7)**
27	*Because of COVID, the doc wasn't there this morning. So there was nobody to answer my questions about my dosage.*	Interruption to access of OTP providers and staff	10 (4.7)
28	*With COVID and the takehomes, I haven't been able to talk to my counselor about changing my dose.*		

[a] All excerpts were slightly modified to avoid reverse identification of the original post.

[b] Topics embedded within themes.

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