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An Evaluation of the User Experience and Privacy Concerns of Individuals Misusing Opioids Using a Location Tracking Mobile Application

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Abstract

Opioid use disorder is a growing public health concern in the United States, causing economic burden and hindered by stigma. New forms of data, including location data, may improve the effectiveness of interventions for preventing and treating opioid use disorder and/or misuse, increase access to treatment and address racial and ethnic disparities. This qualitative study aimed to identify factors that contribute to users' experience with a publicly available location-tracking mobile app - and investigate their privacy and ethical concerns. The study was conducted through two 15-minute interviews within a 48-hour time frame. Participants were recruited from a pool of past research participants, Facebook ads, and referrals, and had to meet certain inclusion criteria related to opioid use disorder and/or misuse. The study had a final sample of 30 participants, 15 male and 15 female. The study suggests that a simple onboarding process and convenient experience can enhance participant adherence to the study app and other similar location-based research apps. However, the study also found that participants had concerns about privacy and transparency about locational privacy when sharing their location data. To improve the app, researchers suggest incorporating user behavior earlier in the app development stage. The study also highlights the importance of addressing ethical and privacy concerns such as limiting the types of collected data, incorporating data encryption and retention strategies, giving access to research staff only, and not sharing the data with third-party companies or law enforcement agencies to increase user satisfaction.

Keywords

Opioid use disorder; Opioid misuse; Qualitative study; Location tracking; Mobile app; Privacy and ethics; User experience

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Declaration of Interest:

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Introduction

Opioid use disorder is a growing public health concern in the United States (Seth et al., 2018). In a recent report by the National Survey on Drug Use and Health, 9.5 million people—3.4% of the population—misused opioids in 2019 in the United States (2020 National Survey of Drug Use and Health (NSDUH) Releases, 2020). Opioid use disorder causes a lot of economic burden on the community and individuals (Florence et al., 2021), and stigma inhibits the prevention and treatment of opioid misuse (Corrigan & Nieweglowski, 2018; Garrett & Young, 2022; McCradden et al., 2019). This growing concern calls for new interventions.

New forms of data, including location data, may help develop interventions based on opioid users' mobility patterns (i.e., aggregate location over time) or enhance the effectiveness of current interventions for preventing and treating opioid use disorder and/or misuse. This may enhance public health surveillance, resource deployment, and medication access for vulnerable communities (Dodson et al., 2018; Joudrey et al., 2022). There have been studies about the potential of using location data in opioid-related research. For example, location data collected from Twitter posts have been used for monitoring opioid misuse (Sarker et al., 2019). Locations of opioid users also offer insights to improve access to the treatment and users' utilization behavior. Location data can also be used to identify racial and ethnic disparities and address the spatial access issues for developing new interventions (McCarty et al., 1999; Mitchell et al., 2022; Nkemjika et al., 2022). Some studies have suggested that mobile apps' engaging user experience makes them better tools for collecting location data, compared to more conventional methods like wristbands that do not allow for an interactive user experience (Wasil et al., 2020). Mobile apps may also be better candidates to collect location data compared to smartwatches because of better lifestyle compatibility—charging it more constantly and carrying it everywhere—and they produce less missing data (Habibovi et al., 2020). Additionally, secure data storage, automatic location tracking, and eliminating manual data entry burdens may make mobile apps more feasible and effective for research (Geyer et al., 2019; Krebs & Duncan, 2015).

However, location data from mobile apps have prompted potential ethical concerns. Automated tolling (i.e., transponders for collecting tolls on roads, bridges, and tunnels, such as FasTrak), location-based search, and credit card usage trace individuals with no or limited consent (Blumberg & Eckersley, 2009). There have been multiple instances of “dataveillance” by collecting and using location data from mobile phones by tech companies or third-party data vendors (Baker-White, n.d.; Tau, 2021). Repurposing data outside the scope of a study exacerbates the ethical concerns and inherent risks in location-based data collection (Gasser et al., 2020). The combination of location data with personal information threatens individuals' sense of privacy (Wang & Loui, 2009). In a study conducted shortly after the onset of the COVID-19 pandemic, 72% of participants were willing to share their location data via a general health app (Romero & Young, 2022).

This qualitative study explores the experience of individuals with opioid use disorder and/or misuse on a publicly available location-tracking app for research purposes, through semi-structured interviews. We want to learn which factors contribute to users' experience with

the app, while sharing constant location with researchers and identify technical issues over 48 hours of interacting with the app. We also investigate users' privacy and ethical concerns about sharing their location and assess how their concerns may negatively affect their experience. The research outcomes may result in an improved version of the study app and provide insights for similar mobile apps, specifically in the public health domain.

Methods

Study Design:

We conducted a qualitative study consisting of two 15-minute interviews with prospective participants between June 30, 2022, and August 11, 2022, over Zoom. The focus of these interviews was to explore their experience and privacy concerns related to the utilization of the UCIPT (University of California Institute of Prediction Technology) Mobility app—a location-tracking app for research purposes. These interviews were conducted within a 48-hour time frame so that we could evaluate the user experience right at the beginning (during onboarding) and after 48 hours of having the study app on their device and interacting with it. We intended to incorporate the feedback received from the participants to improve the study app iteratively. These data could provide insights to other mobility researchers. This study was exempted by the University of California, Irvine Institutional Review Board.

Recruitment and Participants:

Study participants (N=40) were recruited from three different sources: a participant pool (n=32), Facebook ads (n=4), and referrals from other participants (n=4). The eligibility of the participants was measured against the following inclusion criteria based on the screening questions (Appendix 1 - Screening Questions) confirmed over a phone call: 1) The participant should be over 18 years of age, 2) can install the study app on a personal mobile phone, and 3) self-reports being diagnosed with opioid use disorder by a primary care doctor, having used heroin in the past 90 days, or having misused prescribed opioids (higher dosage or not as prescribed) for recreational purposes in the past 90 days.

Eligible participants received an email containing the Study Information Sheet (SIS) (Appendix 2 – Study Information Sheet) with details about the study. Participants were informed through SIS that the audio-only interviews would be over Zoom and the audio would be recorded, de-identified, and transcribed for study purposes. They were told they could refrain from answering questions during the interviews. They were also informed that the transcripts would be kept confidential within the research team for future research use.

Eligible participants were asked to schedule two 15-minute interviews within 48 hours of each other. Initial scheduling and reminders of the interviews were done through phone calls over Skype and text messages on the EZ Texting Platform.

Of the 40 eligible participants with whom we scheduled two interviews within 48 hours of each other, five eligible participants did not join either of the interviews and five other participants missed the second interview session. Therefore, we had a final sample of 30 participants who completed both interviews, 28 of which joined interviews within approximately 48 hours of each other, and two of the participants did both interviews at once

because of having strong opinions against the purpose of the study app and refrained from having the app on their phone for the next 48 hours.

Participants who completed both interviews (or had both interviews at once) were each compensated with a total of \$20 Amazon gift cards.

Data Collection:

We conducted two semi-structured interviews within 48 hours of each other, lasting 15 minutes each on average. At the beginning of each audio-only interview conducted over Zoom, participants were informed and consented that the audio was being recorded to be deidentified and transcribed for further data analysis. Initial interviews were conducted by SY and observed by MH, and the remaining interviews were led by MH, utilizing the patterns identified during the initial ones.

In the first interview, the interviewer guided the participants to install the study app from AppStore or Google Play depending on their device. Following installation, the interviewer asked a set of questions (Appendix 3 - First Interview Questions) about different topics such as onboarding experience, perception of the app, good-to-have features and information, and their location-sharing preference. They were also probed about potential issues with running the app in the background and sharing location over the 48 hours until the second interview. Participants confirmed having the location permission set to the highest access level for the study app (“Always Allow” on Android devices and “Allow While Using” on iPhone devices).

The second interview was conducted after having participants interact with the app for 48 hours to attain more in-depth insight. The interviewer asked a series of free-response questions (Appendix 4 - Second Interview Questions) about demographics, their experience interacting with the app, location-sharing preference with commercial apps (e.g., Google, Facebook, Life360) versus research apps (e.g., PEG LOG, UCIPT Mobility app), and privacy concerns (if any). The interviewer also probed participants to evaluate their willingness in sharing their location with the study app knowing the following privacy-related statements:

- No other types of data except location data, IP address, and Mobile Advertising ID (MAID) would be collected by the app
- Data would be encrypted and could not be traced back to the participant
- Data would not be sold to third-party companies as this is a common practice among companies such as Google and Facebook

Finally, participants were asked about their interest in a year-long study by sharing location data using the study app with the research team, what might persuade or prevent them, and their preferred method of compensation. They were also asked about their willingness in referring this type of long-term app-based study to other potentially eligible individuals.

Interviews were initially transcribed using the Zoom program and subsequently validated by MH to ensure accuracy and correct any discrepancies.

Data Analysis:

The researchers employed thematic analysis to analyze the interviews, aiming to investigate priori themes and uncover emerging themes associated with participants' experiences using the location tracking app, as well as technical issues and ethical concerns. Initially, MH reviewed a set of transcripts to identify common themes. After the initial review, the identified themes were presented to the team, and reviewed, modified, and confirmed by SY. To ensure a comprehensive and rigorous analysis, the team engaged in frequent discussions as they progressed. As all transcripts were coded, new themes were introduced, or existing ones were redefined. This iterative process of redefining and adding themes was carefully reviewed, modified, and confirmed by SY.

Results

Demographics of the Participants:

We conducted qualitative interviews with the final sample of 30 individuals, 15 male, and 15 female participants. The average age of the participants who completed the interviews was 41.7 years old (22 to 65), and three participants did not share their ages with the interviewer.

Many of the participants (n=19) self-identified as non-Hispanic White, the rest of the participants self-identified themselves as non-Hispanic Native American (n=3), non-Hispanic African American (n=2), Hispanic (n=2) (no race reported), and four participants did not share their race and ethnicity with the interviewer.

We asked participants about their use of opioids and 17 participants mentioned they started using opioids as prescribed by doctors for pain management but ended up using higher than the prescribed dosage and for recreational purposes. 10 participants stated they have started using opioids as recreational drugs and three participants did not disclose information about their opioid use. Participants had 14 years of opioid use experience on average.

Device and Perceived Technology Literacy:

Most participants owned an Android phone (n=23) and installed the corresponding version of the study app from the Google Play store and the rest (n=7) installed the iOS version from the AppStore. Most participants (n=27) had proper digital literacy (evaluated by the interviewer), and only three participants needed extra help for the installation and onboarding process. Participants installed the study app (version 1.0) from the app markets. There is a more recent version of the app available with the incorporated feedback and bug fixes, at the time of writing this article. Next, we get into more detail about the main themes arising from the interviews.

Emergent Themes:

The seven main themes arising from the interviews were:

1) An easy and Straightforward Onboarding Process—Most participants (n=27) identified their onboarding experience and enrolling in the study as a very easy, straightforward, and simple process. For example, **P#6** mentioned:

“It was fine and easy to use, easy to navigate, and enroll in the study.”

P#28 stated: *“It was easy and self-explanatory”*

The interviewer walked the few people (n=3) who struggled with the onboarding process up to the point they enrolled in the active study.

P#2 shared: *“Onboarding was a little bit frustrating but probably on my end because since I am old school. I want it quick, and I am a bit impatient, but it was not too bad, everything was pretty simple”*

P#12 stated: *“I couldn’t have done it without you, but it was easy”*

2) Lack of Visibility about the Purpose of the App—The interviewer asked participants about their perception of the app’s purpose and their expectations after enrolling in an active study. All participants confirmed setting location permission at the highest access level (“Always Allow” on Android devices and “Allow While Using” on iPhone devices) and went through the page where the purpose of the app was stated (“Participate by sharing your location and helping science”) during the onboarding process. However, only three participants could correctly identify the purpose of the app (location tracking). The interviewer explained the purpose of the app to the rest of the participants (n=27).

P#4 who identified the purpose of the app correctly stated: *“It is for research, and I assume that it is collecting your location data to improve society.”*

On the other hand, **P#14** described the perceived purpose of the app: *“To help people look for studies to participate in, and showing a pop up to ask for information like name and so on”*

Participants were asked what could help with identifying the correct purpose of the app,

P#3 suggested: *“Just more informative where you select to allow location data. More specific wording”*

P#11 shared: *“Information of the app purpose before downloading, and a disclaimer when you download it”*

P#16 stated: *“Transparent information before installing the app that it is what we want and some sort of reassurance that it is only for research.”*

P#23 mentioned design strategies for better visibility: *“Need study information of what it is that you are contributing to and making a difference, some kind of insight, a bolder font and color, a better and encouraging and more inviting sentence”*

3) Features to be added to the App for a Better User Experience—In the first interview, participants were asked to go through the features available on the study app, such as the “Geo Data” page which displays participants’ locations on a map, or the “Contact Us” page, where they can contact the research team.

The interviewer asked free-response questions during the interviews about potential features participants would like to see on the study app that is not currently available.

Two participants requested accessibility accommodations given their use of larger font sizes and the current version was not equipped for supporting that at the time of the interviews.

There were a lot of requests from participants to include more information, e.g., an FAQ page.

P#23 mentioned: *“A section where participants can reread what was presented at the beginning or after they have downloaded the app at any point, a FAQ on what is happening with my personal data”*

P#21 shared: *“Showing the results of previous studies to give people an idea of the goal of the study”*

There were some technical features requested as well.

P#28 shared: *“Notification when the app is closed to remind for opening saying “you are missing your bitcoin, click here and restart the app”, and remind them with that something is at stake”*

4) Mobile Using Habits that can Change the Quality and Quantity of the Collected Data—We wanted participants to open the app, log in and keep it running in the background for the duration of the study (48 hours) since we could only collect location data when the app was open and running in the background. As a result, swiping the app closed or running out of battery would stop data collection. To identify the technical challenges that could impact the data collection, we asked them open-ended questions about their device usage, the frequency of swiping stacked open apps closed, and running out of battery regularly. There were mixed responses to these questions.

P#6 mentioned: *“I have a tendency to close my apps for battery life and I do not even realize it “*

P#18 mentioned her phone should be on all the time due to her work needs and shared: *“I close everything and do not have any open apps because of battery”*

P#19 shared: *“No, I hardly ever swipe apps, I charge my phone throughout the day, so it dies very seldom”*

And **P#30** stated: *“It shouldn’t be hard, I leave apps open forever, and generally doesn’t run out of battery”*

Overall, battery usage was a recurring concern raised by participants, but fewer people reported swiping their apps closed regularly.

5) Privacy Concerns around Sharing Location—We have privacy concerns of study participants about sharing their location with the study app under three main categories:

5.1) No Privacy Concerns (n=15): Half of the participants (15/30) expressed having no privacy concerns about sharing their location with researchers because they trusted in research practices, their previous experience collaborating with researchers, and the good that might result from their location sharing with researchers for the individuals dealing with opioid misuse. The following statements highlight this point of view:

P#23 mentioned: *“Knowing this is a research app definitely put me at ease of mind to keep it running in the background”*

P#9 stated: *“I trust because you are using my personal information for a purpose to either create something or do something, to better complete your research or come up with ideas you haven’t thought of”*

Some participants stated they have no concerns about sharing their location, not only with researchers but also with companies, as it is a common practice already.

P#20 shared: *“I am not really worried about it; it is just that everything tracks you nowadays”*

P#14 stated: *“I trust you and I kind of give my information to Google all the time, I am not hiding anything, so I trust giving it to you guys.”*

Participants identified that collecting different types of information is commonly used with or without their permission and while they have nothing to hide or escape from, being a research app makes data sharing more comfortable for them.

5.2) Concerned but more Information Helped with Trusting Researchers (n=12): Several participants had various concerns, they asked for more information about the app developers, the collected data, and the sharing practices with the public, law enforcement, healthcare providers, and pharmacies where they get their prescribed opioids. **P#3** questioned the custodial side of the data collection and security of the system regarding collecting and storing participants’ data and the chances of a data breach.

P#1 stated: *“I want to know where my information is going to be used and who is it being shared with; I do not want that information to be public”*

P#4 asked: *“We don’t know who the creator is. Why do you need my location? What is the purpose of knowing where I am? Are you just trying to steal my information? Because there a lot of people out there who are scammers, who make a fake app and steal information”*

P#28 mentioned: *“There is a lot of concern about all the tracking and tracing and what they will do with the information later, they are going to commercialize it”*

Some participants wondered if the collected data is limited to location data or it is going to collect more personal information from them such as calls, messages, and emails.

P#13 mentioned: *“I want to know if the location is the only thing they are tracking, or if they are looking at my phone calls or my texts. “*

In more extreme cases, participants asked for a guarantee that the data will not be shared with law enforcement and government agencies and ensuring that sharing location with the study app will not put them at risk in the future.

P#12 asked: *“My question would be, can you prove you won’t pass it to law enforcement?”*

P#16 shared her concern about the pharmacy cutting her opioids knowing her activity:

“Pharmacy says if she is going to the store four times a week or walks twice a week so she can do things and does not need opioids and cuts the opioids”

Although the interviewer answered the raised questions and participants were willing to share their location based on the received information, these questions were common and including them in the FAQ page of the study app would be valuable for future studies.

5.3) Unwilling because of Safety Concerns (n=3): Most participants were willing to share their location with researchers with no or limited concerns. However, there were a few participants (n=3) who were not willing to share their location with researchers because of safety measures corresponding to their unique situation.

P#6 was a mother who was concerned about her child’s safety, stating:

“I have a child and there are those child predators out there, I’d rather be safe than sorry”

In another case, **P#22** shared her experience with domestic violence as the underlying reason:

“I am afraid because I am also a survivor of domestic violence and afraid of them finding me through somehow tracking the phone, although he is in jail now.”

Domestic violence was raised in another interview as well, but the participant was fine with sharing her location.

Another participant (**P#10**) shared his unwillingness to share his location, not because of his privacy, but for the drug dealer’s privacy.

6) General Attitude towards Participating in a Year-Long Study, What can Persuade and Prevent them, and their Preferred Compensation Method—The interviewer asked participants whether they were interested in participating in a similar study that would last for a year, their preferred compensation method, and its value, and what could potentially persuade or prevent them from joining such a study.

Most participants (n=25) stated they would be interested in joining a year-long study of sharing their location with the research team using the study app.

P#12 was interested in joining the year-long study but had concerns about it as well: *“Yes, as long as I know you don’t give the data to cops”*

P#3 shared his interest in participating given his experience over the 48 hours of interacting with the app: *“Yes, I would be comfortable based on the fact that I didn’t really notice any performance issues while it was running”*

P#9 shared his interest but in a shorter-term study: *“I do not know what is happening in a year, but 3 months is good”*

Compensation and helping science were the most common reasons that would persuade participants to join a year-long study.

P#14 shared: *“The money and helping science and people with addiction to find a cure”*

Amazon gift cards, gas cards, and Visa gift cards were more popular among compensation methods, and most participants shared they were interested in monthly installments, to keep participating for a year in this research.

P#5 shared: *“Amazon, you can do much with it, it is so convenient”*

P#23 stated: *“Amazon because you can personalize it, gas card because of recent gas price increment”*

P#1 who was not interested in joining a year-long study shared what prevents him from participating:

“It feels insecure and a negative feeling knowing I am always being tracked. The fact that I know I would be tracked 24/7 for a whole year and that my location is being shared constantly, that’s a lot of data, I mean you can basically figure out someone’s whole life by figuring out just where they go and what time.”

7) Willingness to Share the Year-Long Research Opportunity with other Individuals—Finally, participants were asked if this type of year-long study is something they would share with other individuals within the specific population. Responses to this question were mostly positive and they mentioned compensation as the reason behind their interest.

P#8 mentioned: *“Yes, simple study and get the reward to help researchers”*

P#25 shared: *“Yes, my friends, they can use the incentive and they have nothing better to do”*

However, there were a few neutral and opposing ideas.

P#1 shared: *“I would and then let them make their own informed decisions”*

P#16, a chronic patient misusing opioid declined: *“No, because that might require revealing a part of me to someone I don’t want to”*

Discussion

This study assessed users’ experience with a publicly available location-tracking app for research purposes among individuals with opioid use disorder and/or misuse. We sought to understand which factors, including technical issues and addressing privacy and ethical concerns, created a more comfortable experience for users. The research results will help to guide an improved version of the study app (for future research) and provide insights for similar mobile apps from other researchers, specifically in the public health domain.

Mobility and opioid use disorder apps need to offer a good user experience, including addressing privacy issues and having an easy-to-understand onboarding experience. Interview results suggested that participants enjoyed the easy and straightforward onboarding process and had a good experience interacting with the app in-between the two interviews. Participants shared their interest in participating in a longer-term study based on their pleasant 48-hour experience. These findings suggest that a simple onboarding process and a convenient experience can enhance participant adherence (willingness to join the study) to the study app and other location-based research apps. Our results also indicate the need for improved transparency about locational privacy when participants are asked for sharing their location data to access in-app services or to enroll in research studies. There should be clear statements describing the purpose of the app at enrollment time, specifically with participants from stigmatized populations as derived from this study. Our participants shared different underlying reasons for their privacy concerns, such as having a child to care for, being a victim of domestic violence, and being followed by law enforcement agents when selling and buying opioids and other recreational drugs. They also shared concerns about the privacy of their vendors.

User behavior, such as swiping the app closed or frequently running out of battery, may impact the constant location data tracking. To avoid this, it is important to strategize and incorporate user behavior earlier in the app development stage. Our analysis suggests that having pop-up notifications to inform users of opening the app (if closed) or enabling location sharing (if selected otherwise) may result in more consistent data collection. A toggle switch for location sharing within the app is also suggested by participants as a convenient alternative to doing the same from phone settings.

This study was limited by multiple factors. Participants were asked to run the study app for a limited time (48 hours), so their experience might be different given more time interacting with the app. The interviewer intervened and asked participants about their initial choice with location-sharing permissions and requested the highest access level (“Always Allow” on Android devices and “Allow While Using” on iPhone devices). The interviewer evaluated the participants’ level of digital literacy given their responses and interactions with the app and this might be subject to mistakes. The current status of opioid use was not explicitly collected from participants. This may have an impact on participants’ experience and vary among different subgroups. Our study can be subjected to social desirability bias as well

since participants might have avoided certain locations in-between interviews because they knew that they were being tracked.

Overall, the easy and straightforward onboarding process was effective in participants' interest in continuing with the study and using the study app. Participants were interested in enrolling for longer-term research studies with location tracking applications given information—e.g., the purpose of the app—early in the onboarding process. Ethical and privacy-aware decisions such as limiting the types of collected data, incorporating data encryption and retention strategies, giving access to research staff only, and not selling or sharing the collected data with third-party companies or law enforcement agencies may result in higher user satisfaction. Amazon gift cards, gas cards, and prepaid Visa cards were among the preferred compensation methods. Monthly compensations were preferred to one-time or less frequent payments (quarterly) in longer-term studies and might also result in better user retention. This may also increase the possibility of referrals to potentially eligible participants.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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