WITHDRAWN: Examining Substance Use Services and Treatment Barriers and Needs among People with Lived Experience (PWLE) in Ontario, Canada.

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EDITORIAL NOTE:

The full text of this preprint has been withdrawn by the authors while they make corrections to the work. Therefore, the authors do not wish this work to be cited as a reference. Questions should be directed to the corresponding author.

Abstract

Introduction: Substance use is a complex issue, with rates of illicit and licit substances varying across Canada, and in Ontario, specifically. Services and treatment options for problematic substance use remain vital. Recent initiatives to increase the effectiveness of services have been implemented, however, a disconnect remains between the availability and accessibility of these programs and the real-world experiences and needs of people with lived experience (PWLE). There is a lack of knowledge regarding barriers to accessing services and service needs, yet PWLE are best suited to identify these factors. As such, this study critically examined these issues among a cohort of PWLE in Ontario, Canada.

Methods: Semi-structured, one-on-one interviews with n=50 adult PWLE participants were conducted. Participants were recruited from substance use services across Ontario, based on ConnexOntario's directory of all provincial addiction services, as well as by word-of-mouth. Questions focused on participants' experiences and perspectives on substance use services. All data were transcribed and underwent an inductive thematic analysis based on key themes that emerged.

Results: Beneficial services identified varied based on participant experiences and needs. A variety of barriers to service access were acknowledged, primarily related to system-level issues such as an overall lack of services, a lack of service capacity, and a severe lack of service coordination and gaps in service delivery. Recommendations revolved around the need for low-barrier, affordable, seamless services run by non-judgemental staff, including fellow PWLE.

Conclusions: This study identified needs and barriers to substance use care among PWLE in Ontario, and highlighted important areas for policy change and program planning and implementation. Concrete recommendations include the development of a government-funded, low-barrier, comprehensive and integrated model of substance use services that includes PWLE as collaborators and program facilitators to ensure that services are as successful and meaningful as possible. Results from this study will work towards the improvement of substance use treatment and service provision across the province.

1. Introduction

Substance use is a complex issue, with rates of use and misuse varying depending on the substance. In Canada, use rates of select illicit and licit substances have been increasing over the past few years, while others have remained relatively stable. For instance, in 2019, a quarter of Canadians surveyed reported past year cannabis use, an increase from 22% the year prior; approximately one fifth (18%) of those used cannabis daily [1]. Nearly 4 out 5 Canadians reported using alcohol in the past year in 2017, while 2% reported using cocaine, which was an increase from 1% in 2015 [2]. In Ontario, specifically, past-year cannabis use increased from 16% to nearly 20% between 2016 and 2017, while lifetime cocaine use remained stable at around 2.5% [3]. Further, opioid use has been particularly problematic, with 12% of Canadians reporting any use in past year, and nearly 3% of Ontario adults reporting non-medical prescription opioid use in 2017 [2, 3]. The rising use and misuse of opioids and associated adverse health outcomes have contributed to nearly 20,000 hospitalizations and over 14,000 opioid overdose deaths between 2016 and 2019 in Canada, and nearly 1500 opioid-related mortalities in Ontario alone in 2018 [4, 5].

In response to the rise in problematic substance use and associated harms, and in particular, those related to opioids, the Canadian Federal and Provincial Governments have adopted a number of initiatives, including amendments to the federal drug strategy to increase access to harm reduction services and expanding public awareness campaigns to address stigma [6, 7]. Additionally, in recognizing treatment as a key component of a comprehensive public health response to the opioid crisis, in 2018, the Federal Government provided emergency funds to the provinces and territories to improve access to evidence-based treatment services [6, 8]. Despite these recent initiatives, rates of opioid-related harms continue to rise [9]. This is in part due to policy approaches that continuously fail to balance regulatory sanctions with public health needs. It is further compounded by a lack of consensus on the 'best' approach to addressing substance use issues since individual experiences and needs are subjective, and substances used vary.

One approach that has shown promise is 'harm reduction', which incorporates a spectrum of various strategies that aim to meet users' individual and specific substance use goals, including providing important referral pathways and connections to treatment and other vital healthcare services [10, 11]. Harm reduction is often the first step for many looking to reduce their use or ultimately seek treatment, and evidence has shown that accessing these services can lead to improved public health outcomes [12-15] such as decreasing the risk of infectious disease transmission (e.g., Hepatitis C, HIV, etc.) and substance use related overdoses [16-20]. However, 'harm reduction' models are controversial, and in Ontario, recent policy directives have introduced legislative restrictions that have stymied these initiatives [21].

With select substance use rates on the rise, no consensus on the best approach to address these issues, and equivocal support for evidence-based policies, it is clear that treatments and services for substance use remain inadequate. There is a severe disconnect between the availability and accessibility of such programs and the real-world needs, experiences, and reality of those who utilize these services, such as people who have lived experience with substance use (PWLE).

Policy decisions around substance use program planning and development often exclude the perspectives' of PWLE [22, 23]. Current literature highlights that community-based participatory research that engages PWLE throughout the process can result in beneficial public health outcomes such as reduced relapse rates, increased treatment retention, improved relationships with treatment providers and social supports, and increased satisfaction with treatment experiences [24-26]. Fortunately, governments and organizations are increasingly recognizing the need for community driven interventions to be informed by the people that use them and for whom they directly affect (i.e., PWLE) [27-29]. Specifically, scientific research funders have acknowledged the importance of community-based participatory and PWLE-involved research, while researchers in both Canada and abroad have developed recommendations to support the meaningful inclusion of PWLE in research, and have established research cohorts and longstanding partnerships with the local community to ensure research aligns with the needs of communities [27, 30-41]. Engagement of PWLE has thus been progressively supported as a best practice approach when developing research priorities and related programs and policies.

Therefore, it is evident that PWLE are best suited to identify potential issues and barriers in service and treatment provision, and to suggest appropriate responses that will meet their specific needs [42]. However, there is a general lack of knowledge regarding the needs, priorities and potential barriers to accessing substance use services among PWLE, including an absence of first-hand knowledge of these issues derived from primary research and conducted in meaningful collaboration with this population. In order to develop a deeper understanding of the complex issues that PWLE experience when accessing services and treatment for substance use, and to allow for significant engagement as partners and stakeholders, this study critically examined these issues among a cohort of PWLE in the Canadian province of Ontario. Results from this study contribute towards the improvement of substance use treatment and service provision across the province.

2. Methodology

2.1 Aims and Objectives:

This qualitative study had two main objectives: 1) to assess gaps and barriers in substance use service provision, availability, and accessibility in Ontario; and 2) to examine the service needs of PWLE including type and design considerations. The overall aim of the project was to synthesize this information towards providing concrete service design and implementation recommendations for substance use service provision in Ontario.

2.2 Study Design:

The study was designed based on extensive consultation with researchers from the Ontario Node of the Canadian Research Initiative in Substance Misuse (CRISM) membership group, and a steering committee including members from Addictions and Mental Health Ontario (AMHO; a provincial organization representing over 220 addiction and mental health organizations in Ontario). In addition, the research team engaged with PWLE regarding study design, development of materials (interview guide), implementation of procedures (recruitment and outreach support), and results interpretation and finalization.

The study utilized qualitative data collection and analysis methods. We conducted semi-structured, one-on-one interviews with adult PWLE participants. The interview guide focused on participants' experiences and perspectives on substance use services in Ontario, including relevant probes related to services utilized, questions regarding how they were connected with services, what services they found beneficial, any barriers to service access, as well as suggestions towards service needs and priorities. Interviews were approximately 30 minutes to 1 hour in length and were conducted in person or over the telephone by a trained member of the research team. All interviews were confidential and all personal information were de-identified. Participants received a $30.00 gift card honorarium as compensation for their time, effort and involvement in the study.

The study protocol and all procedures were approved by the Centre for Addiction and Mental Health Research Ethics Board (REB# 064/2019).

2.3 Eligibility Criteria:

In order to be eligible to participate in the study, individuals were required to: 1) be 18 years of age or older, 2) reside in Ontario, 3) be fluent in English, and 4) identify has having 'lived' or 'living' experience with substance use (i.e., past and/or current use of any licit or illicit psychoactive substance(s) including alcohol, cannabis, opiates, stimulants, hallucinogens and/or polysubstance use, but not tobacco on its own).

2.4 Recruitment

An excel database of all adult-based substance use related services and organizations in Ontario was created using the ConnexOntario directory, resulting in a total of *n*=237 organizations to be contacted. The final ConnexOntario service list included organizations that provided a number of different services such as opioid agonist treatment, residential treatment, withdrawal management, harm reduction/drop-in services, psychiatric assistance, etc.

A member from the research team then contacted (or attempted to contact) every organization listed via telephone, where they identified a key contact at the organization who was willing to assist with the recruitment of potential participants who access their services. The study team then sent each interested organization an email containing further details about the purpose of the study and copies of the digital recruitment materials (i.e., a recruitment poster and brief study write-up). These were to be posted and distributed onsite at each location (including on social media platforms, where applicable) and were provided to potential participants.

Study participants were therefore recruited via a convenience sampling technique, and learned about the study either through a substance use-related organization they utilized, direct referral from a service provider, word-of-mouth, peer and social networks, or more generally through the recruitment materials. Potential participants then expressed interest in participating by either contacting the toll-free study line or the study email address provided on the recruitment materials.

2.5 Study Procedures

Interested participants contacted the study line or email address and were screened for eligibility. Eligible participants were then scheduled for an interview. Prior to commencing the interview, a trained research staff acquired informed consent from each participant. Interviews were audio recorded for transcription and analysis purposes. All interviews were conducted between October 2019 and February 2020.

2.6 Data Collection and Analysis

In order to maintain confidentiality and anonymity, participants were provided with a unique code, and all personal identifiers were kept separately and removed from the data.

Audio-recorded qualitative data were transcribed verbatim and imported in qualitative data management software (NVivo, version 12) [43, 44]. Interview transcripts underwent an inductive thematic analysis whereby key themes were identified and subsequently coded into categories. Initial themes were developed based on our research questions, and a coding scheme and codebook was created. All transcripts were initially coded by a research team member (CR). A second independent coder (FN) randomly selected 20% of the transcript files and conducted a quality check to ensure inter-coder reliability, as based on a calculation of Cohen's kappa coefficient, as well as percent agreeance [45]. The final weighted average Kappa score was 0.79; inter-coder percent agreeance was 98.95%. Based on these statistics, we were satisfied that the coding was reliable. For the codes in which the kappa scores were lower than 0.60, discrepancies were discussed and agreed upon.

In order to ensure the results were adequately represented and interpreted, an iterative feedback process was undertaken and all preliminary themes were shared with our PWLE advisory group. In addition, PWLE were given the opportunity to review the final research findings prior to publication. This is in line with current best practices when conducting community-based participatory research and/or including PWLE in research [34, 37, 46].

Major themes (i.e., commonly expressed ideas) were included in the results. From these, select illustrative samples were chosen to narratively represent these themes.

3. Results

A total of *n*=78 potential participants across Ontario expressed interest in participating. Of those, *n*=28 either subsequently declined to participate, or were unable to be reached for their scheduled interview, and were therefore excluded, leaving a total of *n*=50 participants who completed an interview.

Participants ranged in age from 22 to 63, with a mean age of 38.6 years. The majority (60%) were men. Most (70%) of the participants indicated polysubstance use, while specific substances of choice varied. The majority (72%) of participants indicated some form (either poly or mono) cocaine or crack-cocaine use, and 44% reported using opiates. Of note, in terms of licit substances, while 34% of participants reported polyalcohol use, only n=3 participants indicated alcohol as their sole drug of choice; no participants reported mono-cannabis use (see *Table 1*).

Table 1: Sociodemographic Characteristics and Substances Used among Participants

Characteristic	*n* (%)
Gender	
Men	30 (60%)
Women	20 (40%)
Mean age	38.6
Substances used*	
Cocaine/Crack-Cocaine	36 (72%)
Opiates	22 (44%)
Hallucinogens	4 (8%)
Amphetamines	7 (14%)
Cannabis	13 (26%)
Alcohol	17 (34%)
Benzodiazepines	4 (8%)
Polysubstance use	35 (70%)

*Substances used were not mutually exclusive.

In terms of regional distribution of participants, these have been categorized based on Ontario's new interim transitional Local Health Integration Network (LHIN) regions (see *Table 2*) [47].

Table 2: Ontario Regional Distribution of Participants based on LHIN Regions

Interim Local Health Integration Network (LHIN)	Participant n (%)
North LHIN	14 (28%)
East LHIN	12 (24%)
Central LHIN	17 (34%)
West LHIN	4 (8%)
Toronto LHIN	3 (6%)

All participants either had a history of engagement, or were currently engaged in services for their substance use. Level of engagement and services used varied across participants and specific communities. Most participants had learned about or were connected to services in their community through word-of-mouth via their peers, family members and/or their broader social networks. Many participants were referred to services such as aftercare or outpatient counseling upon completion of treatment or rehabilitation. In a few instances, participants were mandated to go to treatment or other services either through the court system or through their workplace.

While all participants had experiences with services for substance use, perceptions of whether those services were helpful varied considerably, and were dependent on factors such as substance(s) of choice, substance use experiences, life experiences and social trajectories, as well as stages of substance use (e.g., active use, reduced or managed use, abstinent, recovery, etc.). See Table 3 for breakdown of services that participants reported as beneficial.

Table 3: Services Participants Reported as Beneficial or Most Helpful

Beneficial Service(s)*	Participant *n* (%)
Counseling	27 (54%)
Treatment	24 (48%)
Other or a Combination of Services	20 (40%)
Self-Help Groups	13 (26%)
Harm Reduction	7 (14%)
Opioid Agonist Treatment	5 (10%)

*Beneficial services were not mutually exclusive. 'Other' services included addiction-related or community drop-in services (e.g., rapid access addition medicine clinics), shelter/housing services, mental health specific services (e.g., concurrent disorders programs), family services, parenting programs, aftercare. 'Combination of services' included those who indicated it was a combination of multiple services and resources that they found the most helpful.

Despite reporting a variety of beneficial services, participants also indicated encountering major barriers to accessing services. The most commonly reported barriers included a general lack of services, a lack of awareness, a lack of personal motivation, stigmatization, and a variety of structural barriers. These barriers significantly hindered the ability of services to be effective, as well as reduced the capacity for participants to successfully engage in them. These barriers and related issues are discussed below.

3.1 Barriers to accessing services

3.1.1 Lack of Services

Service availability varied greatly by community. While the majority of participants felt 'supported' by the services offered in their community, many indicated an overall lack of community-based services, as well as a lack of services tailored to meet their specific needs. This was particularly true for smaller or more rural communities. For example, one participant explained: *"In our community, there's no detox, there's no safe use site, no safe injection site, no rehab, there's no inpatient treatment centre…there's nowhere to go" (Participant 02).* When asked what services they had used in their community, another participant similarly alluded to a lack of community-based services:

"I'm on methadone now, so I use the OATC [methadone clinic]…but there is nothing else, there's no safe injection site or nothing like that in [community name] that you can go use. There's next to nothing in [community name] for anyone who's an addict. There's no treatment centres, there's nothing around here…there just isn't anything" (Participant 09).

Participants expressed frustration with not having enough support or services in their community, and indicated that because of this, they either had to travel outside their community for certain services, or simply did not receive the needed support.

3.1.2 Lack of Awareness

Whether or not services were reportedly available was likely influenced by the participant's knowledge and awareness (or lack thereof) of the services in their community. A number of participants indicated that they were not sure what services existed because they were either not actively looking for them, or were simply unaware. As an example, one participant explained: "*Well you gotta really look for them right? If you're not looking for them you're not gonna find them." (Participant 31).*

In addition to an overall lack of awareness on what services existed in their community, some participants stated that they had a lack of knowledge on how to initially seek assistance, as well as how to navigate the substance use service system more generally. For instance, one participant explained:

"I think even too is just having where to start. I think a lot of people don't have a starting ground on where to start. I know there are a lot of numbers and there is a lot of help but there's no one place to start and kind of direct. Just navigating the mental health system. I think there's a lot of great resources, but how to get started" (Participant 12).

Further, some participants specified that their lack of knowledge related to services was in part due to the isolation and stigma that they experience during active substance use, and how it can cause them to withdraw and not reach out for assistance:

"I think it's finding those resources. A lot of people don't know that those resources exist…most of the time, our disease, addiction, causes us to isolate so we don't ask for help, we don't let people know, we don't go seeking help from anybody, which means we don't really know where to go or how to look for any of those things" (Participant 04).

3.1.3 Lack of Motivation

Irrespective of whether or not services were available, or participants knew where and how to seek services, one of the most salient barriers to accessing substance use services was a lack of personal motivation. Although all participants interviewed had sought help at some point for their substance use, they indicated that when they were actively using substances, they often had no desire to reduce their substance use or abstain. In order for any of the services to be helpful, they explained that they must be in a state of personal 'readiness', where they felt personally motivated to seek the help they need. For instance, when asked about which services are the most helpful, one participant explained: "*Whichever you attend. When you're ready to do something it's a lot easier. I think when I went to [treatment] I wasn't ready to do anything. When you're in active use, you don't want to stop using" (Participant 29).*

Many participants expressed that when they had initially sought treatment, it was often driven and encouraged by someone else, such as a loved one or friend, or they were court mandated. As such, it took multiple attempts at seeking help and a number of relapse experiences before they became motivated and

committed to reaching their substance use goals. This underscored the ineffectiveness of 'forced treatment'. For example, one participant detailed the importance of personal motivation to reach their goals:

"I tried years ago to stop using… and like every person, if you're not willing to put the work in your gonna go right back to what you knew before. It was also part of my court conditions…once that was over obviously I went back to doing what I normally do which was use drugs. This time when I got clean, I needed to do that for myself so I wasn't there to impress anybody or jump through any hoops. I actually needed the help so I accepted it" (Participant 04).

3.1.4 Stigmatization

Another factor that played a substantial role in whether or not participants would seek treatment was stigmatization. However, feelings of stigmatization varied based on substances used (e.g., those who used licit substances such as alcohol or cannabis did not experience the same feelings of stigmatization as those who used illicit substances, and in particular, opiates). For these participants, many discussed experiencing stigmatization – including social stigmatization, structural stigmatization, and self-stigmatization – for their substance use, and explained how a fear of experiencing these different forms of stigma was a significant barrier to seeking treatment. For instance, one participant succinctly described the way that self-stigma affected their motivation to seek help this when they stated:

"Um, you know what, outside of stigma, guilt and shame, no there is no real barrier. There is a shame attached to the stigma of being an addict and asking for help because so many people, they're still out there, oh you have a choice, why don't you make better choices?" (Participant 04).

Participants often indicated that they had encountered structural stigmatization via judgmental staff members at different service organizations, and detailed a variety of negative experiences, many of which discouraged them from seeking further help. For example, one participant expressed this concern:

"There just isn't anything. Nowhere where you don't feel like you're being judged. And that's probably the main cause of a lot of people not going to get help. That's a big reason why I didn't get help for years. I've been into places where I went once and never went back because you could tell you were being judged. As soon as you admit you're an addict you're stereotyped" (Participant 09).

Others discussed social stigma, and reported being embarrassed or ashamed to seek help, and explained how no one in their community was willing to openly discuss substance use and related issues. Participants explained that this lack of open discussion contributed to feelings of internal shame and self-stigmatization, which in turn led them to hide their substance use from their friends and families, and in some cases, use in riskier ways.

3.1.5 Structural Barriers

Lastly, participants described a variety of structural barriers that impeded their ability to effectively access and utilize services. These have been categorized below under the following sub-headings: *Service gaps and lack of service coordination; service capacity; affordability; administrative; transportation and geographic location*.

3.1.5.1 Service Gaps and Lack of Service Coordination

One of the most commonly reported structural barriers was related to gaps in service delivery. Participants detailed accounts of a glaring lack of service coordination, and commonly discussed the overall fragmented nature of the system. Many participants indicated that transitions between services were not seamless, which was especially problematic. Examples included a lack of referral or being referred to the wrong or unhelpful services, a lack of follow-up, and having to go to multiple different services to find assistance. In many instances, frustration with not being properly connected to the services they needed had contributed to the continuation or acceleration of their substance use.

This issue was particularly apparent for the linkage between detoxification and residential treatment. Participants explained that once admitted into detox, they could only stay a limited amount of time, after which they were expected to transition into residential treatment. However, they were often unable to be admitted directly into residential treatment, typically due to capacity issues and/or a waiting period. This resulted in participants being released from detox and often returning to substance-conducive living situations, which led to feelings of discouragement, fear, and frustration. On many occasions, they would relapse and have to start the entire process over again. To highlight this issue, and the 'revolving door' nature of detox, one participant explained:

"Um, I had gotten into a couple detoxes and then I was trying to get into rehabs but it made no sense because once I went to detox I had to wait months sometimes to get into a place" (Participant 14).

Other illustrations included limitations on the number of days allowed at certain services or ageing out of youth-oriented services, which often left participants in a treatment 'void'. As such, many participants felt as though they had 'fallen through the cracks' of the service system, and they expressed their frustration with the fragmented nature of services. One participant accurately described this feeling when they provided this anecdote:

"I had a friend who overdosed and died 6 months ago. He had to get to the detox, they sent him to the hospital…he had problems getting into detox and had to wait a week. So the whole process isn't seamless. The system kind of fell through for him. There's a fundamental hole in the system. Especially when it comes to opiates, they need everything to happen seamlessly. It's just one referral system to another and people get lost in the system" (Participant 12).

3.1.5.2 Service Capacity

Another major structural barrier to accessing services was service capacity. Participants indicated that many services were often at full capacity and could not take on any more clients. This was particularly the case for detoxification/withdrawal services where participants detailed numerous accounts of failed

attempts to get into detox facilities, while many complained about the amount of time and energy they expended calling multiple times a day to see if a detox bed had become available:

"I know detox isn't good though…It's busy, but then they don't even answer the phones. People there are strung out, overdosing on drugs, and then they call there and nobody answers the phone and they don't know what to do. Like what would you do? How do things get better when you pick up the phone and call someone to get better and then they don't answer the phone…you could die too or kill yourself" (Participant 25).

This was a common issue, especially when detox facilities were also being utilized as substitute for shelters or other temporary housing centres. Participants explained that they would use or seek out detox services when shelters had also reached capacity or they simply did not exist in the community:

"They say call [detox] every hour. I normally call every 30 minutes. Like I understand that there's situations that other people are already there, but a lot of people use them as shelters too right. I know [community name] detox, they hold beds there for people as a shelter. But then you call and they say they don't have a bed. It's not fair to people who are trying to change their life and not use anymore" (Participant 31).

As an additional related compounding problem, a lack of capacity became particularly problematic when detox facilities were used as a substitute for shelter, yet had certain admission requirements that precluded participants from being admitted unless they met them, such as being acutely intoxicated. This essentially encouraged participants to actively use substances in order to be able to have a place to sleep for the night. As a prime example of this issue, one participant expressed:

"It was literally a place to sleep. The shelters were full and the detox wouldn't take you unless you're intoxicated. So I made sure I was intoxicated so I could stay somewhere overnight. When the shelters get too full it's kind of scary. I literally got turned down from a detox because I was sober. So I said here, wait a couple hours, I'll be back" (Participant 39).

Beyond these issues, another common complaint was the inflexible nature of service provision and limited hours of operation. Participants explained that many places close early in the evening, and are not open on the weekends, and that services are often duplicated, with multiple organizations offering the same type of service, but all within the same nine-to-five work hours. Furthermore, many do not have the capacity to provide enough resources as needed (e.g., safe supplies, safe consumption booths, etc.), or take on more than a few clients at a time. For example, when asked about the barriers to accessing services, one participant described these issues in relation to a supervised consumption site in their community:

"Just the hours of operation. There's only one injection site open from 8:00-12:00, there's four injection sites. You need to have at least two open for the same amount of time. That becomes a big barrier when there's only one spot open and four booths and ten people waiting" (Participant 07).

Additionally, as a specific service capacity issue, wait lists were the most commonly reported service barrier. Participants described numerous accounts of having to wait to receive support at virtually every service. This had a detrimental effect and led to overwhelming feelings of discouragement. For example, when asked if there were any barriers to services in their community, one participant indicated: *"Well of course there's waiting lists, that's a big issue. You know sometimes people are waiting four to six months to get in somewhere…a lot of people get discouraged and don't wait and don't follow through" (Participant 01).*

One of the main reasons that wait lists were so detrimental was due to the difficulties participants experienced mustering the motivation to seek help, overcoming their fear of stigmatization, and then the exasperation they felt when they were not able to get the help they needed once they had made the effort to do so. As such, their motivation was often fleeting, and the window of opportunity to seek and accept support was time sensitive. As a key example, one participant explained:

"Cuz being a drug addict, in a sense, when you wanna stop and you wanna quit…that's the time to nab somebody and get it dealt with. Cuz if you give them any time again, it's just a circle, it's a loop… because once something clicks in your head when you use drugs, and you wanna quit, you gotta run with that. You can't just sit there because the addict mind will kick over and say where you going? No, no, go back to the street, go grab again, get high again" (Participant 14).

The importance of being able to receive immediate support when motivated to do so was further stressed by many participants. In some cases, participants gave accounts of how wait-times for services or treatment could be the difference between life and death:

"Especially for getting into treatment centres and stuff, and when you need help right away. I feel like people are dying out there…people just need to get into a place where they can detox. They just need that date. I've known many people that have died…I OD'd before I went to treatment this time. You just never know, that week could make a difference" (Participant 40).

3.1.5.3 Affordability

Beyond a lack of capacity, another commonly reported barrier was the lack of affordability of services, especially professional counseling and residential treatment. Many participants indicated that when they did try to seek help, they were unable to afford services and necessities, which hindered their ability to reach their substance use goals. In particular, participants indicated that residential treatment was generally unaffordable, and in particular, issues related to high admission costs of private for-profit treatment centres were commonly raised: *"I wish I found like a rehab program that you didn't have to pay 30 grand for. I was looking around for something like that before I got into the trouble and I didn't have much luck, they were all pay-for" (Participant 22).*

3.1.5.4 Administrative

Other barriers included burdensome administrative processes, such as difficulties in completing paperwork and medical examinations and securing identification. As a key example, one participant explained:

"You know, you have to fill out these medicals and all these things…I couldn't get it done. I could barely call in every two weeks because I was so messed up. How am I supposed to go for a TB [tuberculosis] test, and do this, and do that, and go back and get it checked and do all this other paper work? You know they expect you to do all this stuff and it's like you can't even pick up the phone, all you're thinking of is your dope" (Participant 40).

Moreover, some participants detailed their frustration and anger with having to re-tell their personal histories and traumatic experiences to multiple different workers and redo administrative intake forms and interviews every time they attempted to access a service or there was a staff turnover, which often re-traumatized them on a repeated basis.

3.1.5.5 Transportation and geographic location

A final component of structural barriers identified by the study participants was transportation. Many participants specified that they do not drive or own a vehicle, and their ability to access services depended on factors beyond their control such as weather conditions and access to different means of transportation (e.g., bike, buses, and ride-share). Additionally, participants indicated that they often did not have the financial means to purchase a bus pass and that public transportation was unreliable. In instances where individuals received government assistance for a bus pass, it was often spent on substances or other necessities (including housing and food) instead. For instance, when asked about barriers to accessing services, one participant explained:

"A big one is transportation. You have to have a medical reason to get a bus pass and if you don't have that then you can't have a bus pass. So especially in the winter time, there's no way to actually get around because most people that are using have either spent all their money on drugs and don't have money for the bus, or just really can't afford it" (Participant 06).

Relatedly, due in part to the lack of overall services and limited capacity of existing services, some participants indicated that based on their geographic location and/or the rurality of where they reside, they would have to travel outside their own community in order to access services. Participants highlighted that they often did not have the means to afford long-distance bus tickets and/or did not have family or peers to give them a ride or support them in traveling and re-locating to a new community. Reasons for seeking treatment in a different community often included a lack of services in their community, stigma and/or privacy concerns.

3.2 Services and supports needed

Taking these access barriers into consideration, participants provided suggestions and recommendations for substance use services and supports that need to be available in their communities. While responses varied, most participants indicated that there is no 'one' specific service that is the most helpful, nor a specific trajectory or sequence they must follow in order to meet their substance use goals. They indicated that a 'one-size-fits-all' approach to treatment or services is not ideal since everyone has different experiences, needs and goals. As such, many indicated that the most important factor that needs to be considered and recognized by every service and service provider is personal agency; substance use care should be person-centered, and the needs of the individual must be heard and prioritized. Although this was a common thread throughout responses, participants further identified select and specific services that they considered helpful, and put forth concrete suggestions for services needed in their community. These have been categorized below under the following subheadings: *Harm reduction services; Self-help groups; Counseling; Treatment; and Transitional housing.*

3.2.1 Harm Reduction Services

Harm reduction services such as needle exchanges, naloxone distribution programs, supervised consumption services (where available), and low barrier community and addiction-related drop-in centres, such as rapid access addiction medicine (RAAM) clinics, were reported as both beneficial and needed by a number of participants. In particular, mobile services or street outreach programs were commonly suggested. This specific modality was reported as helpful because it came to wherever participants were and provided them with safe supplies, collected used ones, and offered a range of additional health and social services, on an anonymous basis, removing many of the barriers encountered when accessing services. Outreach was thus seen as a necessary service in the sense that it not only met them physically, by coming to them wherever they were and addressing a range of needs, but also in terms of prioritizing them in their treatment plans, as well as in terms of their substance use and goals. For example, one participant stated: *"Yeah, I'd like to see more outreach workers handing out kits, because there's not enough of that" (Participant 07).* Another participant also stressed this need when they discussed the merits of the mobile outreach needle exchange program in their community:

"Needle exchange is really good because you can just call them you don't have to give them your name, nothing, and just tell them where you are, anywhere, and they'll come meet you…they give you literally everything to keep it clean and safe right? Because they don't want people sharing needles right? And so, it's actually one really good thing" (Participant 14).

Beyond mobile outreach, more needle exchange services and overdose prevention sites and/or permanent supervised consumption sites, with multiple booths that allow for consumption of a variety of substances and routes of administration (i.e., smoking as well as injecting) were also requested. For instance, one participant who had assisted in establishing a number of grassroots, PWLE-led, overdose prevention sites outlined the necessity of these programs to allow for a range of consumption options:

"I've always smoked my drugs, so when we set up the supervised consumption sites I always ensure there's a place for people to smoke their drugs. But in Ontario, there's a lot of super strict smoking laws. People went from smoking their drugs to shooting it because they weren't allowed to smoke in the safe injection site, and it wasn't super harm reduction" (Participant 11).

Similar low-barrier harm reduction-based suggestions included drop-in services that can assist people with a range of needs, all in one centralized building. Examples of services that could be offered there included supervised consumption services, needle exchanges, counseling, access to opioid agonist treatment (including safe supply programs), connections to detox as well as short- and long-term treatment, access to doctors and other medical professionals, as well as the provision of food, shelter and housing supports. Ideally, participants indicated that these should be offered without burdensome application and administrative requirements (e.g., needing to fill out paperwork or requiring identification). This was highlighted when one participant suggested:

"I think they should do a community centre…where there's doctors that are there. You can go see a doctor and get prescriptions, whatever you need, with no ID. Yeah because at the community centre they can put a safe injection site right?" (Participant 09).

Another participant expressed the benefits of being able to access such a low-barrier harm reduction service in their community: "*I love to go to the community health care centres, especially the low-barrier ones. They've hooked me up with a psychiatrist and I'm able to really talk to them about safe supply. The community centre has a lot of resources" (Participant 11).*

Other specific suggestions included greater naloxone training and availability, particularly for merchants and storefronts located near highly concentrated drug use areas, as well as carried by all emergency responders. Additionally, preventative measures such as drug checking, and/or warning systems sent out through social media indicating new and dangerous drugs when the drug supply in the community was toxic were suggested.

Participants further indicated that harm reduction services are a great place to initiate substance use support because they not only recognize that every individual has different goals in terms of their substance use (e.g. abstinence is not everyone's goal), they take these goals into consideration when offering a range of services. For example, one participant expressed how harm reduction services are ideal for someone initially seeking help: *"For someone who is starting, the idea of harm reduction is a good starting point…not only is relapse common, but it's likely" (Participant 36).*

However, some participants indicated that while they understood the idea of harm reduction, and how it might be helpful for some, it was not something that was useful or worked for them as they were not able to use substances in less harmful ways. These participants were more likely to be those with 'lived' experience (i.e., past use), as opposed to 'living' (i.e., current use), with abstinence maintenance as their ultimate goal. For these participants, their substance use was all-or-nothing, and they required abstinence-based recovery supports and services. For example, one participant explained how harm reduction would not work for them:

"Yeah, so when I started to try and get clean I was doing the outpatient group…but it's a harm reduction [based program], so it's not necessarily like an abstinent program. After going to treatment I'm learning a lot more about addiction, like that that won't work for me. I needed to stop" (Participant 42).

The discrepancies between those who preferred harm reduction over abstinence-based programs underscores the necessity to take each client's individual needs and goals into account and to work with them on addressing and meeting them.

3.2.2 Self-Help Groups

To further highlight the individual needs and requirements of clients, many participants who had 'lived' experience (i.e., were currently abstinent from all substances) were actively engaged in self-help groups (such as Alcoholics Anonymous (AA), Narcotics Anonymous (NA), Self Management and Recovery Training (SMART) programs, or similar). These programs typically view abstinence as the ultimate substance use goal, and reward participants for extended periods of sobriety. These participants expressed that these types of programs had assisted them in reaching their goals, and that it was the recovery-oriented ongoing support provided through these programs that they found most beneficial. Developing social connections at meetings (including securing a sponsor) was highly regarded as it reinforced accountability and sobriety maintenance, as well as led to overall feelings of support through participation in a social 'community' For example, one participant elaborated on the ways in which self-help groups were helpful for them:

"Because of the relationships that you make in those recovery programs, that's what's keeping me sober. The connections, accountability and participation in a community that cares. I think a lot of alcoholics and addicts don't have anyone they can trust and so another sober person helping another is quite huge" (Participant 13).

Importantly, most participants indicated that because self-help groups are so common in their communities, they often feel like there is always somewhere to go where they can get support:

"Because there's meetings every day, it's a little more intensive than [outpatient treatment] where you see your worker maybe once a week or something…it's just a lot of support…you start to form close bonds with everyone there because you see them like every day…I just feel like there's always somewhere to go no matter what" (Participant 03).

However, while participants indicated that there are usually meetings in most communities, they suggested the need for more meetings with flexible hours and accessible locations that target substance-specific groups. For instance, many participants did not feel as though what they learned at AA applied to their cocaine or narcotics use, but had a hard time finding these specific groups in their community. Additionally, some participants highlighted that many self-help groups tend to stigmatize people who are engaged in mixed harm reduction recovery models, but whom still get value from attending meetings. As an example, some participants expressed that being on opioid agonist treatment is viewed by some as continued substance use, which makes them feel uncomfortable and judged when they attend meetings. As such, they suggested there should be more self-help and support groups that also embrace a harm reduction lens, rather than absolute sobriety, which would provide the benefits of self-help meetings to those whose substance use goal is not abstention.

3.2.3 Counseling

Beyond harm reduction and self-help groups, participants indicated that counseling was a service that was commonly used and beneficial. Nearly all participants had experiences with counseling, including one-on-one and/or group formats, with many having experiences with both. The settings in which participants received counseling varied and was quite broad; participants reported receiving counseling from different types of professionals (psychiatrists/psychologists, counselors, therapists, addiction or social workers, peer-support specialists, etc.) and in a variety of locations (through low-barrier RAAM or drop-in clinics, hospitals, mental health and addiction clinics, residential or day treatment, private practice, etc.).

Most participants preferred one-on-one over group counselling, as they did not feel comfortable opening up and expressing themselves in group settings, and many found that group settings could be triggering, especially when people in the group were not at the same stage of recovery or did not have the same substance use goals. This was particularly the case for participants who were currently abstinent from substances and felt that the presence of others who were actively using substances was triggering: *"When I go to my support group, there's lots of drug users that are active and they're asking and trying to get us to use. So it's not really helpful because they're supposed to be encouraging the recovery, not the active use" (Participant 06).*

Whereas others actively sought out group therapies as they felt a better connection to people who had similar experiences, and this allowed them to open up and accept feedback from counselors and PWLE.

The format of the counseling was also important. In particular, trauma-informed counseling was considered the most beneficial as it emphasized the role of traumatic experiences in shaping peoples' substance use trajectories and enabled participants to address the underlying issues that they felt had led or contributed to their substance use or misuse. For instance, one participant expressed the benefits of receiving trauma-based counseling:

"[Counseling] is really helpful if you've got trauma from when you were a child. Like I've got trauma from when I was a child. They're helping me to overcome that and deal with the problem and make sure I don't get stuck with that. My counselor tells me if I keep that inside and don't talk about it, it builds up and you're gonna wanna use. For me, I find talking about it, I don't want to use again" (Participant 27).

Additionally, specific counselor characteristics were highly regarded as important determinants of participants' motivation and willingness to engage in counseling sessions. Specifically, counselors who were caring, empathetic, non-judgmental and/or had their own lived experience (i.e. PWLE) were preferred. PWLE counselors were often seen as the easiest type of counselor to open up to and trust, and participants valued and respected these counselors, mainly in comparison to those who were taught 'by the book' (i.e., did not have lived experience). For example, one participant succinctly explained this when they stated: *"They've lived it, they've been there, they understand it, they're not going by textbooks." (Participant 09).* Some participants indicated that utilizing PWLE would allow for meaningful engagement with those who are best suited to assist people, while increasing the number of counselors available and ensuring that counseling is provided in a non-stigmatizing and relatable manner. One participant expressed this when they said:

"The government needs to know that we need [PWLE] workers to help addicts with their issues…because it's somebody who understands because they've been through the same thing, right? They're not gonna be judgmental, right? People who haven't been in the addiction don't understand the addiction and think, 'oh you just wanna use drugs'. No, it doesn't work like that, it comes from a long line of trauma that led us to where we are today and we're trying our best with what we have" (Participant 07).

With this in mind, participants suggested that more counselling options need to be made available to people. Most participants indicated they simply wanted someone to talk to who understands their issues. Participants specified that they would like to have long-term, affordable or free counselors who offered trauma-informed services that addressed a variety of life domains and issues.

Specific counseling formats included suggestions of one-on-one as well as daily drop-in groups, as well as familial or grief counseling. Notably, in line with the harm reduction model, participants were clear that counselors (regardless of format or credentials), needed to actively listen to their needs and develop a functioning therapeutic relationship where they could work together towards reaching the participant's substance use goals.

3.2.4 Treatment

Another common service that was suggested as both beneficial and needed was 'treatment'. However, 'treatment' consisted of a variety of modalities and methods (e.g., individual, group, drop-in, long-term, etc.). Based on responses, it was operationalized under two preeminent sub-categories: 1) rehabilitation/residential treatment (where participants can go and live or stay for a period of time such as 21, 28, or 90 days); and 2) outpatient/day treatment and/or aftercare/drop-in programs (where participants can attend daily drop-in type programs as they desire or upon completion of residential treatment).

Rehabilitation/residential treatment was largely regarded as superior to outpatient/day treatment by most participants, and reasons for this preference varied. For many, it provided the break they needed from their current lifestyle and allowed them the ability to meet their substance use goals while healing from various traumas or issues in their lives. For example, when asked which service utilized was the most beneficial, one participant indicated: *"Probably actually going to rehab itself. Well there was 19 days, or almost 3 weeks of a safe environment where you're not gonna use. You don't have to worry about work or stress. That set me up for the best success" (Participant 12).*

Notably, participants expressed the importance of long-term residential treatment. They indicated that the longer length of stay would allow them the time to heal, adequately address and overcome their problems, and provide them the foundation needed to reach their substance use goals:

"There needs to be more money put into funding places that doesn't have an end date right? You're there to heal yourself. It [healing] doesn't happen in 90 days, 60 days, 30 days. It's something that you continue to work on. If the government could realize that and give a little bit more funding, you're gonna fix a lot of addiction. People are gonna be able to handle a lot better and go out and become active members of society and give back again" (Participant 35).

Specifically, participants desired to have long-term residential programs that were affordable or, ideally, free. For instance, one participant suggested that the provincial government should cover the cost of residential treatment:

"I would love to see a treatment centre that would take OHIP [Ontario Health Insurance Plan] patients. That would be amazing. It's just not realistic to expect people to be able to fork out 15 thousand dollars or however much it is to go to treatment. It would help so many people" (Participant 03).

However, other participants expressed the benefit of outpatient/day treatment, with many indicating that upon completion of a residential treatment program, they relied on an outpatient/day program or an aftercare modality to maintain sobriety and/or meet their substance use goals. Therefore, residential treatment was largely conceptualized as necessary to build the foundation required to be able to be connected with outpatient care, and that it was the combination of both that was the most beneficial. One participant explained this when they said: *"The program I'm in now is [helpful] because I was able to go to a treatment centre first…after the treatment centre I was able to get right into this program, and it's gonna be able to give me a foundation" (Participant 40).*

Importantly, many residential treatment centres require participants to undergo a period of detoxification/withdrawal before they can enter treatment, which can be a major hurdle to accessing treatment. As such, participants suggested that treatment models need to be flexible, and that blended residential treatment models which are harm-reduction based and which help clients manage their risk in terms of their substance use are required. Therefore, as a specific service model, a number of participants recommended building a medical detox component, as well as wrap-around supports, directly into residential treatment facilities. Participants expressed that this would improve service coordination and enable seamless transition from detox into treatment and beyond. This model would also eliminate the waiting period and ensure that those who got into detox were connected to a treatment centre. As an example, one participant suggested:

"Even if like a big facility, rehab facility, where they can house over 100, 150 people. Have a detox built right into it. So you walk into the detox and you're already in the facility, so you just go from one room to the next. Yeah, all in one shot" (Participant 14).

In addition to suggestions related to service design, many participants indicated that increasing the number and availability of residential treatments in their community would also be helpful so that they would not have to travel outside their community to attend treatment and receive support.

3.2.5 Transitional Housing

As related to the necessity of wrap-around services, many participants identified housing as an important prerequisite to attaining their substance use goals. As such, participants indicated a need for more housing, including both short term and/or temporary shelters, as well as longer-term transitional housing such as recovery houses and/or sober living environments. In particular, participants articulated a desire for housing at two distinct and crucial time periods: 1) during the waiting period between detox and residential treatment, and 2) after the completion of residential treatment. To illustrate, one participant suggested:

"You know the detox will only house you for a few days and there's one spot for safe beds. So maybe a dedicated place that has safe beds for people that want to get into a treatment centre, and they'll keep you until your date where you leave to go to treatment. That would probably be really good" (Participant 46).

In terms of the provision of post-treatment housing, many participants indicated the need for affordable recovery houses, and that this was vital to ensuring that the healing process and 'foundation' built through treatment was not futile. For instance when asked what services or supports they needed in their community, one participant explained:

"Recovery houses, transitional housing. Once people get out of treatment and they're coming back to the city because that's where they're from, they're right back in the same environment that they got out of. It's just the same cycle again. We need to see more of those" (Participant 04).

Participants also expressed the importance of providing transitional housing in terms of cost-effectiveness, and highlighted the futility of paying to send someone to treatment, and then losing that financial investment by not providing them with a safe place to live and maintain their goals afterwards.

4. Discussion

This study examined barriers to accessing services and treatment for substance use, as well as supports needed among a sample of PWLE in Ontario, Canada. Importantly, the study meaningfully engaged with PWLE throughout the process, from study concept, to design, implementation and interpretation of results. The collaborative process enabled us to generate valuable data informed by end users' experiences that offer important insight for substance use policy and program initiatives in Ontario. Thus, this study highlights the importance of engaging PWLE in the development of the evidence base towards informing effective and client-oriented substance use policy and program interventions.

The present study extends our knowledge about access barriers and support needs of PWLE, and fills an important gap in current research by providing PWLE perspectives on substance use treatment and service issues. Specifically, our results confirm particular barriers to accessing treatment among PWLE, such as lack of information about available services, lack of motivation to seek support, discrimination and stigmatization, accessibility issues (including geographic and transportation), cost of treatment, service capacity and wait lists, among other structural barriers [48-55].

As our results highlighted, personal motivation to initiate and maintain engagement with substance use programs is a key component of a successful substance use service system. It is therefore pivotal that once PWLE have reached a state of readiness to seek and accept support, they are able to receive it without facing barriers that may derail the process and discourage consistent care and recovery seeking behaviour. As such, in conjunction with implementing concerted efforts to address tangible barriers to service access, substance use programs should adopt strategies to establish and maintain client engagement and support motivational interviewing techniques [56-60]. This can be achieved by creating opportunities for client engagement to allow their needs and

concerns to be heard by empathetic and enthusiastic service providers who can work with them towards reaching their goals, and who can assess the client's current state of readiness on an ongoing basis by providing frequent one-on-one needs assessments [61]. Such a patient-centered, collaborative approach would allow clients' voices and needs to be paramount in their treatment plan, which would increase willingness for recovery and ultimately the success of treatment [61-64]. Service providers should actively seek out, employ and collaborate with PWLE who are experientially qualified to help design and deliver client-centred substance use programs. Furthermore, offering PWLE program facilitators who can conduct motivational interviewing with clients, may serve as an example that meeting substance use goals is possible, which may lead to increased motivation to change among clients. It also has the potential to improve the relevance, quality and capacity of services to address client's diverse needs. Moreover, engaging PWLE in meaningful decision-making processes for service design and delivery has been found to reduce harms associated with substance use (e.g., reductions in HIV prevalence rates in injection drug use communities), increase access to social and material resources, and to improve equity in the distribution of services, in a cost-effective way [33, 65-67].

While many of the participants in our study indicated they have experienced stigmatization, those who used illicit substances - opiates in particular - more commonly reported experiencing this access barrier. In line with the literature, stigmatization can manifest differentially, depending on the substance(s) used, as well as the context of individual substance use, yet it often perpetuates marginalization regardless [68-70]. Employing and utilizing PWLE's unique knowledge and expertise holds the ability to further combat discrimination as services can be provided in a non-judgemental manner. This can counterbalance the stigma and isolation many clients may experience, and can instill a sense of empowerment, boost self-esteem, build trust, and ideally increase treatment and service uptake while reducing barriers to service access [65, 71-75]. It can further empower clients to overcome self-shaming thoughts, attitudes and negative evaluations [69]. Likewise, it provides a more visible point of contact between PWLE, health care professionals, and the general public, which can help increase health literacy, and thus, reduce stigmatizing beliefs [76].

While increasing motivation and PWLE engagement and addressing the potential for stigmatization is critical to ensuring program success, our results also underscore a systemic gap in service delivery, with unacceptable wait times and a severe lack of coordination between various substance use services available for PWLE. This impedes their ability to receive needed supports, and to progress and transition successfully through programs. While a service lapse was true for most services, it was particularly the case for the linkage between detoxification and residential treatment, where participants indicated an evident disjuncture. However, these issues are not novel [77]. Literature has highlighted that many patients do not successfully complete this transition for a variety of reasons, and face numerous barriers at the patient (e.g., motivation), program (e.g., wait times) and system (e.g., lack of coordination) levels while trying to navigate these services [78]. A lack of inter-program coordination and collaboration, and how this deters treatment completion and successful transitions, has specifically been noted within the Ontario context [79]. This lack of coordination contributes to the 'revolving door' nature of detox and related services, where participants do not receive timely and adequate support, and end up frequenting services in a cyclical manner. It is therefore imperative that participants are connected from detoxification to treatment in order to reduce unnecessary treatment readmissions and to relieve the substance use service system of any undue stress and expenditures.

In line with common suggestions towards services and supports needed from participants in our study, as well as with evidence examining these issues, there are a number of potential solutions, many of which have shown success. Examples include escorting patients from detox to treatment, providing incentives as well as direct transportation between services and/or covering transportation costs, providing ongoing discharge planning and case management between clients and service providers, and providing short-term transitional housing and recovery 'safe bed' options while clients wait to be accepted into treatment or other services [80-82]. Significantly, some of the highest transition rates have been found when detox and residential treatment were fully integrated (i.e., contained in the same setting), and single-setting systems have been found to provide seamless transition between all levels of substance use care [78, 83, 84].

However, in order for substance use services and treatments to be accessible, they must be affordable. To address affordability as a significant barrier, it is necessary that the Ontario Provincial Government – which is in charge of administering and funding provincial health care – increase overall funding and provide subsidy for long-term residential treatment and counseling options, while shifting services away from private for-profit, stand-alone services. This would allow for better standardization, accountability, integration into the health care system, while lending itself to a more comprehensive continuing care model. However, historically, publicly funded substance use services have been characterized by unacceptable wait times and are often restricted to basic amenities and less-than-desirable care [85]. Therefore, publicly-funded programs must also undergo reform to ensure that they offer the same service and care that private programs do.

As such, future substance use interventions in Ontario should focus on the integration of services into a government-funded, one-stop-shop model that can effectively address the range of issues identified, such as affordability, wait lists, as well as detrimental service gaps and interruptions. These should further include low-barrier harm reduction services and options such as mobile outreach and supervised consumption services, which have been proven cost-effective [86], as well as transitional housing support to ensure that efforts to connect and retain clients in treatment and care are not futile. As an example of such an integrated, collaborative model of substance use care, British Columbia has developed a tiered model of services and supports in line with these suggestions, as well as a Provincial 'standards for residential substance use treatment' document to help ensure quality of care and seamless linkage between services [87]. Additionally, service providers there have recognized the importance of clinical integration of services and have recently developed and implemented a dedicated care setting in which patients experiencing mental health and problematic substance use issues can access a one-stop-shop service that provides rapid clinical assessment, addiction care, transitional housing, supports and follow-up from an inclusive team of medical specialists, social workers and nurses [88]. Such a progressive and comprehensive program is required in Ontario.

Recognizing this need, the Ontario Provincial Government recently implemented a new mental health and addictions strategy that includes directed funding and the establishment of a Mental Health and Addictions Centre of Excellence. The centre will oversee the delivery and quality of substance use service provision with the aim of standardizing care, expanding service and access, reducing wait times, and helping clients navigate the system [89, 90]. Importantly, the strategy is committed to employing a collaborative approach to expanding harm reduction services and supports to meet clients' need throughout their

recovery journey. This is vital since the absence of PWLE voices and involvement in program design and delivery can be detrimental to effective service provision. As the end-users of substance use services, PWLE should be at the forefront of policy decisions as they are experientially qualified to identify important areas for policy change and program implementation.

While these efforts exist, our results indicate a lack of scale up for policy initiatives that aim to integrate services and develop a cohesive and client-oriented model. PWLE continue to face unsurmountable barriers to accessing substance use services in Ontario, and greater effort is needed, especially for PWLE who fall through the cracks due to system fragmentation and insufficient collaboration. Our results also indicate the need to increase the availability of services across communities in Ontario. Further, enhancing the coordination and collaboration between services towards a comprehensive and integrated system that is affordable, delivered seamlessly, has lower barriers to entry, and that incorporates PWLE as experts and program facilitators is imperative for services to be optimally effective.

4.1 Strengths and Limitations

The strength of the current study includes ongoing collaboration with PWLE throughout the entirety of the research project. Our sample included diverse participants from a variety of communities, backgrounds and experiences, enabling us to assess a wide range of issues related to substance use service provision in Ontario. However, the results should be interpreted with caution and limitations must be noted. The results may be susceptible to biases inherent in self-report data as our sample size (n=50) was small and based on convenience sampling. Our results may not represent the experiences and concerns of all PWLE in Ontario due to a lack of regional representation from certain communities. Also, the small sample size of mono-use of licit substances may indicate that our results cannot be generalized to this group. Even though substance use service involvement and experiences varied greatly, our data met criteria for qualitative data saturation, and we are confident that the themes discussed accurately reflect the experiences and desires of the participants.

Future research examining service and treatment needs and barriers of PWLE should include a larger representative sample. They should also explore PWLE-informed strategies for integrating services.

4.2 Conclusion

Substance use service provision in Ontario is severely fragmented and has major barriers to entry for PWLE. In order to address these issues, it is necessary that PWLE are meaningfully engaged as partners and stakeholders throughout policy decisions regarding service design and delivery. This study identified PWLE-informed needs and barriers to substance use care and highlighted important areas for policy change and program implementation.

Recommendations include the implementation of a government-funded, low-barrier integrated model of substance use service provision, based on collaboration with PWLE. Ontario is moving in the right direction to further incorporate PWLE in these decisions, and in recognizing the importance of harm reduction-based services in meeting client's diverse substance use goals. However, service gaps and barriers exist, and without the significant inclusion of PWLE, service provision will remain insufficient. The phrase "nothing about us, without us" succinctly captures the importance of including PWLE to ensure that services provided meet their needs and are effectual.

5. Declarations

Ethics Approval and Consent to Participate

The study protocol and all procedures were approved by the Centre for Addiction and Mental Health Research Ethics Board (REB# 064/2019).

Consent for Publication

Not Applicable

Availability of Data and Materials

The datasets generated and/or analysed during the current study are not publicly available due to the inclusion of personal identifying information, but a de-identified dataset can be made available from the corresponding author on reasonable request.

Competing Interests

The authors declare they have no competing interests.

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Authors' Contributions

CR contributed to data collection instruments, led and contributed to data collection procedures, data analysis, interpretation of results, and manuscript development, writing and editing.

FA conceived original project idea and designed the study, contributed and designed data collection instruments, contributed to interpretation of results as well as manuscript development, writing and editing.

FN contributed to data analyses, interpretation of results, and manuscript writing and editing.

SL contributed to development of data collection instruments, interpretation of results and manuscript writing and editing.

SI contributed to interpretation of results and manuscript writing and editing.

TEM conceived original project idea, designed the study, supervised findings of this work and contributed to manuscript writing and editing.

JR conceived original project idea, secured funding, designed the study, supervised the findings of this work, and contributed to interpretation of results and manuscript writing and editing.

All authors read and approved final manuscript.

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Authors' Information

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