"All they ever see is the addict.": Lived Experience of Opioid Use in Timiskaming

Services de santé du TIMISKAMING Health Unit

Many thanks and acknowledgement to the fifteen people who stepped forward to share their experiences, insights, and wisdom. It was an honour and a privilege to meet you and to hear your stories. We are deeply grateful for your support of this research.

"Some of us just want to live our life and be happy just like everybody else wants to be right? We just have more obstacles."

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Timiskaming Health Unit

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Executive Summary

Purpose

The aim was to empower individuals who use opioids to share their experiences and to provide them with an opportunity to influence local priorities and program planning.

Research Question

What is the lived experience of individuals using opioids in Timiskaming? What are the health and medical needs of individuals who use opioids in Timiskaming?

Context

The Ontario Public Health Standards outline the requirements for health units to conduct public health interventions based on local needs. The Substance Use Prevention and Harm Reduction Guideline (2018) specifies that boards of health shall assess risk and protective factors for substance use, consult and collaborate with local stakeholders, and assess existing programs and services to build on community assets and minimize duplication. The information gathered through the interviews will be used to inform the opioid situational assessment to contextualize the surveillance data gathered, to identify priorities and gaps, and to inform program planning. The situational assessment is a systematic process to gather, analyze, synthesize and communicate data to inform planning decisions specific to opioid use in the Timiskaming Health Unit (THU) catchment area.

Moreover, the Harm Reduction Program Enhancement launched in 2017 further directs boards of health to build on existing harm reduction programs and services and to improve local opioid response capacity and initiatives. A component of the scope of work for this program is the completion of a situational assessment that meaningfully engages individuals with lived experience. The harm reduction program at Timiskaming Health Unit has seen a significant recent increase in demand and in the years of providing harm reduction services, there has been minimal client input.

Formal efforts to understand the perspective of individuals who use opioids in rural northern Ontario, specifically Timiskaming, have not been conducted. Individuals living in rural northern Ontario may cope with a wide range of unique challenges that can influence their lived experience such as: geographic isolation, transportation challenges, stigma and lack of anonymity, and lack of access to health care/specialized health care services such as addictions services. There is a need to understand the perspective of individuals with lived experience to deepen our understanding of the local needs of this population.

Methods

After receiving ethical approval from the Public Health Ontario Research Ethics Board, individuals who currently use opioids (prescription or illicit use) or have used opioids in the past two years self-identified when presenting to the harm reduction program at Timiskaming Health Unit. From December 2018 to May 2019, these individuals were provided an information package and the contact information of the lead investigator. They were also encouraged to engage in snowball sampling with others who met the inclusion criteria. Interviews were only available in English; therefore, any interested participants who did not speak English or who had not used opioids in the past two years were not eligible to participate in this project. Participants (n=15) were compensated for roundtrip travel expenses in the form of their choosing: either bus tickets or taxi vouchers. Participants received $50 for their participation in the research project.

The lead investigator began the interviews by collecting basic demographic information and then engaged participants in a discussion that encouraged them to share their lived experience using opioids. Individuals were guided to share their narrative through semi-structured interviews with open-ended questions, prompts, and probes. Participant interviews were recorded and transcribed for thematic analysis. Interviews ranged from 12 to 90 minutes with the average length of the interviews being 40 minutes. All interviews took place in a health unit office or in a private space at a local library.

Data Analysis

After each interview was transcribed by support staff, interviews were reviewed for accuracy and identifying and confidential information was redacted from the transcript by the lead investigator. Content analysis was used to systematically and objectively quantify the phenomena of the experience of opioid use in Timiskaming. The lead investigator and the project supervisor separately read the interviews several times to establish familiarity with the data. The data was then organized by making notes and writing the units of analysis in the margins separately. After the open coding process, groupings, categories, and abstractions were created. After which, the lead investigator and the project supervisor met to discuss and agree upon shared themes identified before finalizing the analysis.

Results

Although the sample was diverse, including individuals with a variety of backgrounds, methods of use, and source of opioids, many strong themes arose when participants were asked to share their lived experience of opioid use in Timiskaming. Participants were asked to share their history of opioid use, how they currently or did use opioids, and how opioids affect their daily life. In addition to eliciting themes, the interviews also provided rich information on the specifics of using opioids in Timiskaming including the routes and costs of use and how participants initiated their opioid use. The themes that arose from the interviews were: quality of life, interpersonal impacts of opioid use, stigma, managing addiction, and facilitators and barriers to accessing health care services.

Introduction

Background

In 2017, the Ontario Ministry of Health and Long-Term Care launched a new initiative entitled the Harm Reduction Program Enhancement (HRPE) to support the implementation of the harm reduction pillar of the Ontario Opioid Strategy. Funding was provided to boards of health to build on existing harm reduction programs and services and to improve local opioid response capacity and initiatives. A component of the scope of work for this program is the completion of a situational assessment that meaningfully engages individuals with the lived experience.

The situational assessment is a systematic process to gather, analyze, synthesize and communicate data to inform planning decisions specific to opioid use in the Timiskaming Health Unit (THU) catchment area. The THU catchment area, hereafter referred to as Timiskaming, includes the District of Timiskaming except for the townships of Childerhose, Douglas, Doyle, Fripp, Geikie, Hillary, McArthur, McKeown, Musgrove, Pharand and Reynolds. The THU catchment area also includes the municipality of Temagami and the following townships: Ben Nevis, Bisley, Clifford, Pontiac, Clement and Scholes.

The Ontario Public Health Standards outlines the requirements for health units to conduct public health interventions based on local needs. The Substance Use Prevention and Harm Reduction Guideline (2018) specifies that boards of health shall assess risk and protective factors for substance use, consult and collaborate with local stakeholders, and assess existing programs and services to build on community assets and minimize duplication. The information gathered through the research project interviews will be used to inform the opioid situational assessment to contextualize the surveillance data gathered, to identify priorities and gaps, and to inform program planning.

The THU harm reduction program which distributes needles/syringes and other drug use supplies has seen a significant recent increase in demand. Over the last three years, a 60% increase in the number of needles distributed has been observed. More than 300 visits occur every year and those clients have developed strong rapport with the nurses who provide harm reduction services. The HRPE directives strongly encourage health units to seek the perspectives of individuals with lived experience and THU recognizes that in the years of providing harm reduction services, there has been minimal client input. There is a strong need to understand the perspective of individuals with the lived experience to deepen our understanding of the local needs of this population.

Research in this domain has been varied with many investigators exploring social context and perspectives of individuals using opioids in specific urban areas (Lindgren et al., 2015; Macneil & Pauly, 2011; Mars et al., 2014; Paquette et al., 2018; Yedinak et al., 2016), thus the findings may not be transferable to a rural and northern perspective. Formal efforts to understand the perspective of individuals who use opioids in rural northern Ontario, specifically Timiskaming, have not been conducted. Individuals living in rural northern Ontario may cope with a wide range of unique challenges that can influence their lived experience such as: geographic isolation, transportation challenges, stigma and lack of anonymity, and lack of access to health care/specialized health care services such as addictions services.

The purpose of this project is to gain perspective on the lived experience of individuals who use opioids in the THU catchment area and to deepen the understanding of this population's health and medical needs. We aimed to empower individuals who use opioids to share their experiences and provide them with an opportunity to influence local priorities and program planning. Providing those who use opioids the opportunity to share their lived experience empowers those whose voices may rarely be heard (Brooks et al., 2015).

Opioid Use in Timiskaming

Opioids are a highly addictive family of drugs that are prescribed to treat moderate to severe pain, including cancer related pain. In 2017, a total of 5,200 Timiskaming residents were dispensed an opioid to treat pain; equivalent to 16% of the population. Despite the slight decrease (0.5%) from 2016, the rate of opioids dispensed in Timiskaming in 2017 was still higher than Ontario's rate at 152.6 versus 110.2 per 1,000 population (Ontario Drug Policy Research Network, 2018). This is consistent with previous findings, where rural areas had more individuals dispensed an opioid to treat pain compared to urban areas (Gomes et al., 2017). *Figure 1* indicates that opioid use increases with age. Across all age groups the rate of THU was higher than the province with the exception of the youngest age group. The greatest variance is found in the 45-64 age group.

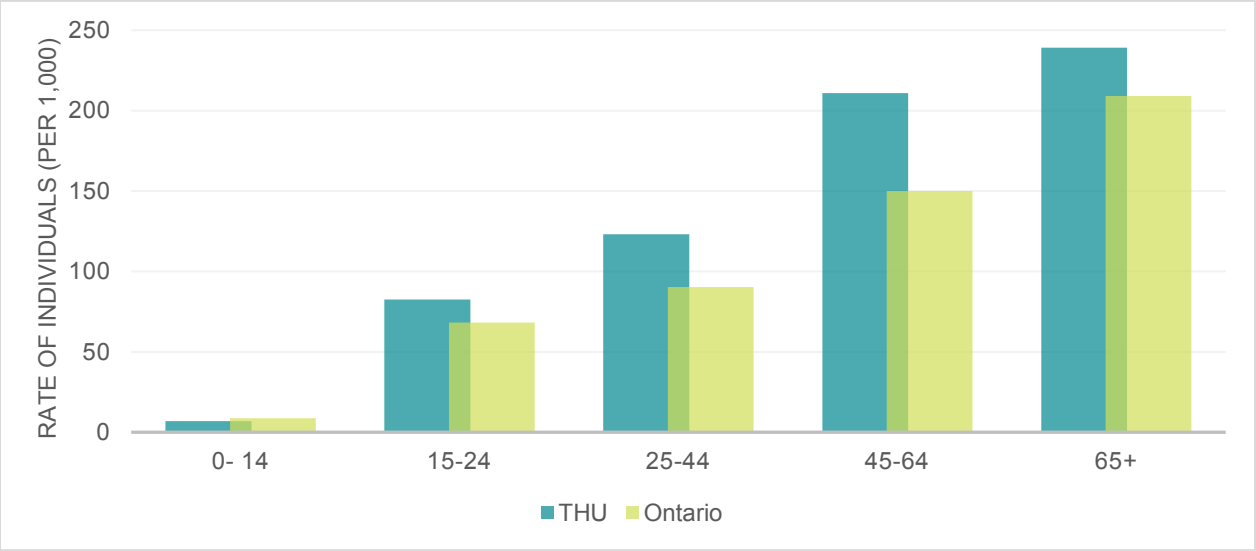

FIGURE 1: Rate of Opioid use per 1,000 individuals comparing Timiskaming Health Unit and Ontario by age group in 2017.

Methods

Research Questions

The objectives of this project were to identify: What is the lived experience of individuals using opioids in Timiskaming? What are the health and medical needs of individuals who use opioids in Timiskaming? The research questions under consideration were developed in response to the research gap identified in the situational assessment conducted by THU on the local opioid situation.

Recruitment Method

After ethical approval was received from the Public Health Ontario Research Ethics Board, posters were displayed in all health unit offices and nurses providing harm reduction services began recruiting participants. Convenience sampling was conducted through the harm reduction distribution program at Timiskaming Health Unit offices. Clients participate in harm reduction services sporadically; therefore, each client was provided information about the project each time they met with nursing staff working in the harm reduction distribution program. Nursing staff provided a leaflet (Appendix A) to individuals who identified as using opioids. The leaflet described the research initiative and the contact information of the lead investigator.

Participants were encouraged to assist in snowball sampling by providing the lead investigator's contact information to other individuals that met the inclusion criteria. Participants were also able to contact the lead investigator to withdraw from the study, to obtain a completed copy of the research project, or to report any other concerns. All interviews took place in a health unit office or in a private space at a local library. A saturation point of ten participants was initially selected but was increased to fifteen participants with ethical approval due to unanticipated success with the recruitment method. This sample size mirrors the saturation point set in similar studies (Mars et al., 2014; Lindgren et al., 2015; Paquette et al., 2018; Yedinak et al., 2016).

Participant eligibility criteria included: individuals who currently use opioids (prescription or illicit use) or have used opioids in the past two years. Interviews were only available in English; therefore, any interested participants who did not speak English or who had not used opioids in the past two years were not eligible to participate in this project. This timeframe was selected to align with the October 2016 Ministry of Health and Long-Term Care announcement of the release of a comprehensive strategy to prevent opioid addiction and overdose which included enhanced data collection and surveillance and the modernization of prescribing practices.

Participants were compensated for roundtrip travel expenses in the form of their choosing: either bus tickets or taxi vouchers. Participants received $50 for their participation in the research project. This amount was determined based on minimum wage, the length of the interviews and travel time to the interview location, and the risk to the participant. The amount of incentive acknowledges the value of the participants' lived experience where all too often no value, or negative value, are assigned. By participating in this research initiative participants were making themselves vulnerable to a health care provider, exposing potentially illicit use, and sharing highly sensitive material. By providing a cash sum, the researchers were able to

give participants agency to choose how they utilized the compensation. Bardwell et al. identified that “stipends were an important incentive in promoting engagement within drug user organizations and a significant symbolic representation of the value of the time, skill, experiential knowledge and labour of people who use drugs.” (Bardwell et al., 2018).

In similar qualitative studies with individuals who utilized substances the research participants were provided compensation ranging from no compensation to $60 per interview (Bardwell et al., 2018; Darker et al., 2016; Lancaster et al., 2014; Mars et al., 2014; 2016; Paquette et al., 2018; Rance et al., 2017; Yednik et al.).

Interview Technique

Narrative inquiry is a form of qualitative research that uses a collection of stories as its source of data (Duffy, 2012). Narrative research is a form of inquiry that aims to gather stories and represent them to readers and stakeholders (Riessman, 2007) and amplifies voices that may have remained silent (Wang & Geale, 2015). Narratives reveal the meanings, conventions, dominant beliefs, and values of a time and place in which a person lives (Duffy, 2012). These narratives express our ways of knowing, communicating and understanding a given topic or experience. Narratives not only communicate the experience but also engage others at a deeper level beyond the data and provide a human perspective on the experience.

The lead investigator began the interviews by collecting basic demographic information (Table 1) with the purpose of describing the participant sample. Participants were engaged in a discussion that encouraged them to share their lived experience using opioids as per the interview guide (Appendix B). An individual’s lived experience and narrative provides a reflection on psychological, emotional, social, and physical aspects of opioid use. Individuals were guided to share their narrative through semi-structured interviews with open-ended questions, prompts, and probes. The interview questions also assessed the health and medical needs of participants and identified barriers and facilitators to access and areas for improved service provision for this population.

Participant interviews were recorded and transcribed for thematic analysis. Interviews ranged from 12 minutes to 90 minutes with the average length of the interviews being 40 minutes. Due to the targeted demographic and confidential nature of the study, participants were not contacted for transparency or validation.

Data Analysis

After each interview was transcribed by support staff, interviews were reviewed for accuracy and identifying and confidential information was redacted from the transcript by the lead investigator. Content analysis was used to systematically and objectively quantify the phenomena of the experience of opioid use in Timiskaming. Elo and Kyngas (2007) describe content analysis as a research method which makes replicable and valid inferences from data to their content with the purpose of providing knowledge, new insights, representations of facts, and a practical guide to action.

Content analysis seeks to observe patterns in a manner that collects several different types of data: written, verbal, or visual communication. This method is used in qualitative research as a

means for researchers to make inferences about characteristics of text, causes of the message, and the effects of communication (Cole, 1988). Content analysis enables researchers with the ability to decode a sampling of messages and collect themes based on the codes found in the data. These themes arise from patterns found in the messages the researcher collects.

The inductive content analysis as described in Elo and Kyngas (2007) begins with preparation: selecting the unit of analysis with a word or a theme. During the preparation phase, the lead investigator and the project supervisor separately read the interviews several times to establish familiarity with the data. After this stage, the data was organized by making notes and writing the units of analysis in the margins separately. After the open coding process, groupings, categories, and abstractions were created. After which, the lead investigator and the project supervisor met to discuss and agree upon shared themes identified before finalizing the analysis (Elo & Kyngas, 2007).

Thematic Analysis

Although the sample was diverse, including individuals with a variety of backgrounds, methods of use, and source of opioids, many strong themes arose when participants were asked to share their lived experience of opioid use in Timiskaming. Participants were asked to share their history of opioid use, how they currently or did use opioids, and how opioids affect their daily life. In addition to eliciting themes, the interviews also provided rich information on the specifics of using opioids in Timiskaming including the routes and costs of use and how participants initiated their opioid use. The themes that arose from the interviews were: quality of life, interpersonal impacts of opioid use, stigma, managing addiction, and facilitators and barriers to accessing health care services.

Results

Demographics

The demographic variables collected (Table 1) were age, gender, highest educational level attained, types of opiate used or currently using, and number of years using opiates. Five participants reported their ages as between 15 and 29 years of age, seven reported their age as between 30 and 49 and three identified as fifty years of age or older. Eight participants were male and seven were female. Additionally, the educational level attained was identified as being less than grade twelve by seven individuals, six had graduated post-secondary (college and/or university) and two had graduated grade twelve.

Variable (n)	Count	(%)
Age (15)		
15-29	5	33%
30-49	7	47%
50+	3	20%
Gender (15)		
Male	8	53%
Female	7	47%
Highest education attained (15)		
Less than Gr. 12	7	47%
Grade 12	2	13%
Post-secondary	6	40%
What type of opioids did/do you consume? (15) Total # responses - 41		
Opioid combination (Percocet, Tylenol #3, Fiorinal with codeine #3)	9	60%
Morphine	8	53%
Oxycodone (OxyContin, Oxyneo)	8	53%
Opioid Agonist Therapy (Methadone, Suboxone)	5	33%
Fentanyl	5	33%
Hydromorphone (Dilaudid)	4	26%
Purple heroin (purp, purple H)	1	6%
Whatever is available	1	6%
Years using opiates (15)		
0-5	2	13%
6-10	3	20%
11-15	4	27%
16-20	3	20%
21+	3	20%

TABLE 1: Participant Demographics

Participants were able to identify any opioids they currently consume or have consumed, which elicited 41 responses. Nine participants have used or are currently using an opioid combination pill such as Tylenol #3 or Percocet. Eight participants have used or are currently using morphine and/or oxycodone. Opioid agonist therapy and fentanyl use were each identified by five individuals, four participants reported using hydromorphone, and one participant used or currently uses purple heroin. Lastly, one individual reported that they will use whatever opiate is available.

The lead investigator also inquired about the years participants had been using opiates with two reporting five years or less, three reporting having used between six to ten years, four identified using for eleven to fifteen years, and three shared that they had used opiates for 16 to 20 years. Three individuals had used opiates for more than 21 years.

Starting on Opioids

Participants in the research report identified two methods of initial exposure to opioids: through prescription access or illicit access. Of the fifteen participants, seven participants identified starting on opioids illicitly; eight participants described starting on opioids through prescription use.

Prescription Opioids

Prescription opioids include morphine, oxycodone, fentanyl, Percocet, Vicodin, and codeine. Prescription opioids can be taken by a variety of methods: by mouth, intravenously, or absorbed through the skin via a patch. Opioids may be consumed at a higher than recommended dose because, in addition to relieving pain, they can cause a euphoric feeling which can lead to dependence. Research participants shared that their initial access to prescription opioids often occurred after being injured or undergoing a surgical procedure. Participants described receiving prescriptions to manage the pain from injuries, surgeries, motor vehicle accidents, growing pains, and chronic pain.

Many participants received prescriptions exceeding seven days, which, according to Health Quality Ontario (2018), renders them much more likely to become physically dependent and to experience withdrawal symptoms. Figure 2 demonstrates that the percentage of new starts for more than seven days in the North East Local Health Integration Network was higher than the provincial average. Family doctors accounted for nearly half of all of the prescriptions in the region (47.3%).

> *"I was injured and I was prescribed OxyContin and that's what started it basically. I was prescribed three months' worth while I was recovering and then it was dropped…down, dosage down but it was already too late. And I just continued using off and on since then, basically."*

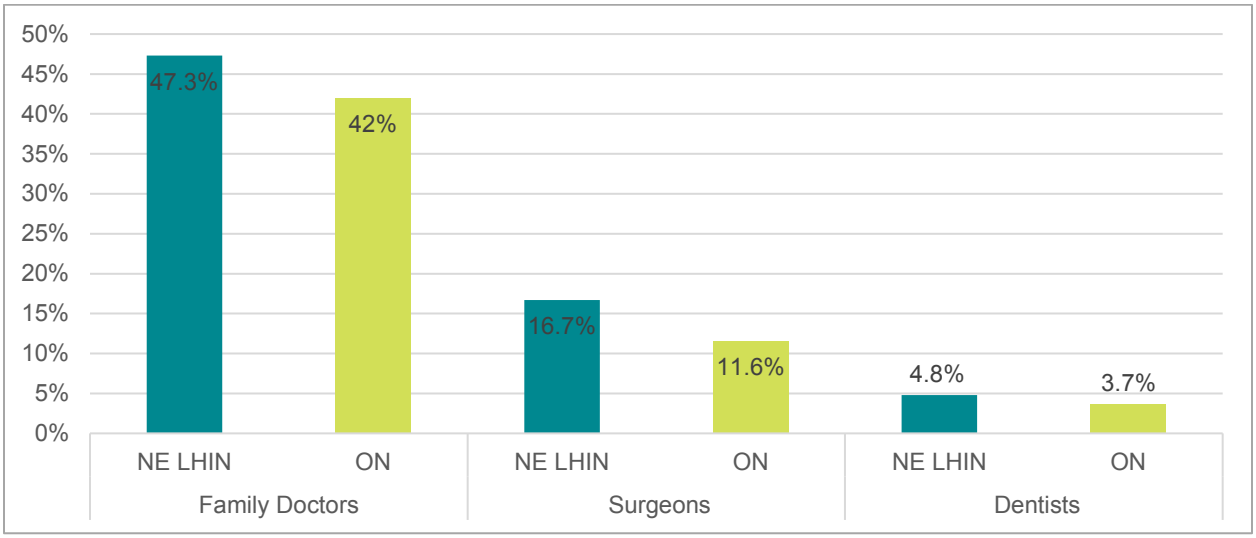

FIGURE 2: Percentage of new opioid prescriptions when days of supply is greater than 7 days by prescriber and region, in 2016.

Illicit Use

Illicit opioids can include diverted prescription medications, counterfeit pharmaceuticals, or opioids mixed with other illicit substances. Fentanyl is a synthetic opioid used to treat severe pain and it has been found in counterfeit prescription pills which are made to look like opioid prescription pain relievers. It has also been cut into other street drugs, such as cocaine and heroin. It has no taste, colour, or smell, making it difficult to detect.

Without a prescription, opioids can be accessed through the illicit market or from other people who have been dispensed opioids. More than one-quarter of the Canadians who reported using opioids in a survey said that they have leftover opioids stored in the home (Statistics Canada, 2018). The most common reason (75%) for keeping them was for personal future use (Statistics Canada, 2018).

Stored medications can end up in the hands of other individuals. In northern Ontario, approximately 1 in 10 students (Grades 7 to 10) reported using opioid pain relievers for non-medical purposes without a doctor's prescription in the past year (Boak, Hamilton, Adlaf, & Mann, 2017). Many research participants using illicit opioids identified that they access these from family or friends. One individual recalled stealing pills from a friend's parents when they were young: *"When I was 11 or 12 years old is what I remember when it started, my friend stealing pills from his parents and we would take them."*

Route of Use

Participants described a variety of methods for consuming opioids such as: oral, snorting, smoking, and injection. Oral consumption, also known as eating, describes taking a pill by mouth. Some participants also described sucking on fentanyl patches. Intranasal use refers to users sniffing or snorting crushed pills with a rolled bill or straw. Inhalation, or smoking, can be

implemented by cutting a fentanyl patch and putting it on tinfoil over heat. The plastic part separates and the medication will stay on the tinfoil to be smoked or injected. Intravenous use was described as the crushing of pills into fine powder, dissolving it and heating it in a spoon, then putting it through a filter to inject it.

Interviewees identified using opioids in a combination of methods depending on the amount and strength of the opioid they had available to use: *"If I only have a little amount is when I will use it intravenously because you get better results out of it but if I have a decent amount I usually like to either eat it or snort it or whatever…if you eat it, it lasts a little bit longer but it takes a while to take effect. If you snort it, it gets into your system right away but if you use it intravenously it goes right into the blood so it's a faster effect."*

Many participants also reported receiving Methadone and Buprenorphine/Naloxone (Suboxone), which are opioid agonist therapies used to treat opioid dependence. These medications prevent withdrawal and reduce cravings. Treatment usually lasts at least a year but may continue for longer, sometimes for many years (Herie, Godden, Shenfeld, & Kelly, 2010). In 2018, Timiskaming had 260 opioid agonist users, of which 60 individuals were new users (Ontario Drug Policy Research Network, 2018). Over the past five years the number of individuals utilizing Methadone in the Timiskaming area has stayed relatively stagnant with 176 users in 2013 and 191 users in 2018 (Ontario Drug Policy Research Network, 2018). Conversely, Suboxone has had a steady increase from 15 users in 2013 to 87 users in 2018 (Ontario Drug Policy Research Network, 2018).

Cost of Illicit Opioids

Participants described how the economic market of supply and demand directly affects the cost of opioids in our communities; as strength of the opioid increases, so does the street value. One participant described the cost of Hydromorphone (Figure 3) as: *"the blue ones go for about $10, the orange ones, the 12s go for anywhere from $15 to $25, and then the 18s go from $20 to $40 a pill."*

The availability of opioids also affects the pricing. The price increases based on the decrease of community availability: *"…if nobody in town can find anything and somebody has something, they are going to charge extra for it because they know that they can make the money because…people will pay extra because they can't find anything else and they may not find anything else for the rest of the day or they might not find anything for two days so you are going to pay whatever they ask for it. You are going to pay."*

Participants also described that diverted prescriptions provide the bulk of what is being sold in the local opioid market: *"…there's a lot of people that have prescriptions and then they end up selling their prescription. That's how a lot of it I think gets on the street."* The danger with drastically reducing the availability of prescriptions is that it will increase the cost of street-available prescription medications. This could increase the risk to individuals who may choose to purchase drugs such as purple heroin (a

FIGURE 3: Hydromorph Contin Hydromorphone Extended Release

combination of illicitly manufactured fentanyl and heroin). These drugs may cost less in relation to their strength, but they have an increased risk of overdose as they are laced with an unknown amount of opiates.

The current market value of fentanyl patches was consistently described by participants as between $700-800 per 100 mg patch: *"I would know the size of the Fentanyl piece I needed to smoke for the day and that'd be it for the day. And it got to the point because people knew they could charge what they wanted, it was ridiculous. At one point they were $700 for a 100 mg patch."* Fentanyl patches are highly valued as they can be cut into smaller quantities and sold individually and they provide a consistent amount of medication that can be smoked. The financial impact of opioid addiction was prevalent in many of the themes identified in the interviews.

Quality of Life

The impact of opioid use on the participants' quality of life was illuminated through many stories. The use of opioids affected participants' ability to access basic needs such as food, shelter, safety, and security. Many identified that basic needs had to be sacrificed to obtain the desired amount of opioids. For example: *"Sure I had money to get high but then I would have to choose between either eating that day or getting high that day which was really not much of a choice. When you are craving your fix, you are just craving it. There is nothing else you want more."*

Participants also reported the burden that seeking their next fix had on their ability to fully participate in society: *"You're not high all the time… a fraction of the time but most of the time [you're] hurting and searching for drugs. Like a small sliver is getting high and the rest is hurting and looking for it and trying to find money to buy it. Not a good quality of life. I don't think so."*

Moreover, several participants reported experiencing inadequate pain management, needing opioids to function, and requiring opioids first thing in the morning. One participant shared that *"…it gets to the point where your body needs it, you know. I couldn't get out of bed, it's not about using anymore it's just about needing it to get out of bed, need it to function…"* Another interviewee relayed that *"every morning you wake up and it's all you think about, it's all you care about is your next fix and it's affecting everything in my life."* Another shared that *"I get up and I go straight to my cash box, my safe, I pull my medication out because that's the first thing on my mind when I get up."*

Some participants also shared the extreme lengths that individuals will go to fund their addiction, such as prostitution, stealing, and dealing drugs: *"Every day like you have to go out and find it if you don't have the money or when you got your money you're paying off your debts. Like who you owe or who you fronted from, when you are going to look for it, you're stealing for it. People are sleeping with people for it. I've never had to resort to that. I'll beg, borrow or steal before I would do that but I know a lot of girls who have and who still do."*

Emotional numbing was a commonly reported effect, whether it was desired or not, of opiate use: *"I didn't feel pain anymore so it was great. No physical or emotional pain."; "I didn't want to think about missing my kids. Because I wanted to numb my pain…"*

Several participants described their opioid use as ruining their lives, causing them to lose everything, impeding their ability to work or finish school, and as having a significant impact on

their mental health, for example: *"it really swallows everything that you are. It was hard. I never really enjoyed my life being on it for sure. And I didn't enjoy what it made me become because I'm not that kind of person, usually I'm not."* Opioid use affects an individuals' ability to obtain goals, to integrate into society, and to feel connected to others.

Interpersonal Impacts of Opioid Use

The interpersonal impacts of opioid use were prevalent throughout the interviews, encompassing relationships with family, friends, other users, and children. Most participants identified opioid use as having an impact on their relationships with family and friends while using or when in recovery from addiction. Social isolation was a reported impact of opioid use with some sharing that having inadequately managed pain, experiencing withdrawal, and being high all negatively impacted their ability to maintain relationships and social commitments. Some participants also reported that the need to keep their addiction secret negatively impacted their relationship with family and friends.

Participants expressed awareness of the stress their opioid use causes their family and friends and many had guilt associated with that. One participant shared the impact of their opioid use on their mother: *"That hurts me a lot knowing that my mom overthinks a lot, that I can be in danger which maybe I am… It's just the fact that they are worried for me every day. That hurts a lot."* Another participant shared: *"My family started to notice…when I had meds and when I didn't."*

Many participants reported the support of their family and friends as being integral to their journey to recovery. Having an encouraging social network was associated with successful recovery journeys in the sample. However, relationships with family and friends also created challenges when individuals were in recovery with many reporting that they lost friends and social connections as they were no longer able to socialize with other individuals who use drugs:

> *"…you know it takes a lot of time and determination and willpower, motivation and staying away from the people, the crowds and the drugs and the scenes is what it is."*
>
> *"You have to…basically cut out everyone. Everyone, because if you don't it's kind of tempting because they are still going to be doing drugs around you or the people who sell drugs don't care that you are trying to stop…they will keep trying to give you things and keep trying to push it on you because they don't want to lose a customer."*
>
> *"I stayed clean for six months but then I went around the wrong people…when you are ready to get clean you have to watch where you are, who are you are with, and the things that you do."*
>
> *"You have to kind of step back from everything that you stepped forward to before. Because even for friends…if they use, you can't be their friend, you can't hang with them and coming from a small place like this…it's hard to find a so-called safe place because you have to realign your whole life."*

Others reported that despite it being a challenge to be around others who are using, their social networks remained unchanged and they supported their friends in supplying clean needles, carrying naloxone, and encouraging treatment.

Lastly, the negative impact of opioids on parenthood was a commonly shared phenomenon. Some participants reported their interactions with child welfare agencies and subsequent loss of custody of their children. However, despite these challenges, increasing permissions or custody privileges were a great source of motivation for those participants seeking or undergoing recovery: *"I can't wait to be a mom again."* Other participants who had custody of their children shared the financial implications of their addiction and the impact it had on their ability to provide for their child which compounded the guilt they expressed about using: *"I wanted to be clean for [them] so [we] would be able to go and do things or go away for a trip or something and not have to come back because I didn't have enough drugs or can't stay long because I didn't have drugs and I'm withdrawing."*

Stigma

Stigma is a well-documented global barrier to health-seeking behaviour, engagement in care, and adherence to treatment across a range of health conditions (Stangl et al., 2019). Mental health-related stigma is often grounded in stereotypes where anticipated and perceived stigma are common manifestations that have a profound influence on self-esteem and self-efficacy (Stangl et al., 2019). Most participants reported experiencing a form of stigma: individual perceived stigma, community stigma, and stigma in the health care system.

Individual stigma was expressed by many participants who internalized their shame and negative self-perception. This perceived stigma seemed to be a barrier for access to health care with some participants being hesitant to access health services, delaying their health care needs, or even turning to street substances rather than seeking prescriptions and experiencing stigmatizing behaviour from health care providers. One participant shared*: "I was just sick of being the way I was. Lying to people. Being an addict. Being ashamed of myself."* On delaying access to health services, one participant reported *"I didn't want to go at first to the Methadone clinic just because I guess to the stigma attached to the Methadone clinic…I didn't want to go there or be seen going in there. Even putting my car close to there. But I had to go. I had to go. So eventually we went to the clinic and asked for help."*

Community stigma was intertwined with the rurality of Timiskaming, with many participants sharing their frustrations with having a lack of anonymity, feeling like an outsider, and being unable to repair their reputation when in recovery. One participant shared *"Most people know everything because it's so small and people talk. The neighbours would notice things. Again, people's perception of me is kind of important to me… I wouldn't want people to think I'm a junkie."* Another emphasized the challenge of rehabilitating a reputation in a small community: *"Just like everywhere else in this town, all they ever see is the addict. I could be clean for 10 years and I will still be an addict."*

Some participants shared their experiences of perceived stigma when accessing health care services: *"he didn't treat me like a normal person. He treated me like I was a degenerate, a druggie..."* A frustration shared by many was the perception that they are "red-flagged" in the emergency department and that providers have a preconceived notion that they are drug-

seeking patients: *"I've already seen it before when they opened my file. They put a red thing up there and they put narcotic something, narcotic ban. So it means don't give that person narcotics. So right there they think 'oh junkie'."* Another participant shared a specific experience: *"The first thing I say to the nurse is 'I have an infection in my mouth or my gum or tooth whatever', and I said 'I need some type of penicillin or antibiotic because it's like getting close to my eye, hurts like hell' and right away [the nurse said] 'we're not giving out pain pills.' Did I say anything about pain pills? I don't want pain pills."*

One participant highlighted the hypocrisy associated with perceived stigma of opioid use with this example: *"[I am] always worried about their judgement, judgement, judgement. But you know they sit there on the weekend and you see he's down six cases of beer. Come on, how is that better than my friggin' medication?"*

Managing Addiction

The theme of managing addiction encompasses the experiences participants reported in accessing prescriptions and managing their supply (licit and illicit), their fear of new substances and of contracting blood-borne illnesses, and the challenge of escalating tolerance and dependence. Having access to opioids was reported as *"not that easy…you need to know the right people."*

Despite having a prescription, many participants reported turning to illicit supply due to lack of sustained access to a regular prescription, strict prescribing guidelines, and building dependence following licit use. A participant shared that after a surgery *"[the doctor] said 'OK I will prescribe you another 90 Percocet'…and when those were gone I called his office and he said, 'I'm sure your foot is healed by now, I cannot prescribe you anymore.' So that is when my girlfriend said she could get me some on the street…Like I was totally amazed that you could get them on the street."*

Participants shared their experience of increasing tolerance and dependence over time, for example: *"People who start small, they always start small like the percs. And then you need two percs. And then you need five percs. Then 30 percs ain't cutting it. Then you need oxys. Then you are upgrading. That's what it is now."* Another shared: *"your tolerance just becomes so high and you don't even know if you are masking, are you fixing the pain, are you fixing the need? Do I feel like shit or is my back sore? Which one is it?"*

Hesitancy towards opioid agonist therapy was also relayed by many participants. Many participants shared: *"It's a government, it's like a government thing. They got a hook on you. It's like you can't go out of town because you don't have carries. I do, but I'm just saying how the program works. If you don't have carries, oh you can't leave and you will be sick. You have to go every day. You've got to piss twice a week. If you don't pee then you don't get your pill or drink of Methadone. It's like a government scam too sometimes that place. And really they get addicted to that too."*

"The Methadone Clinic is such a fucking cop out. They are allowed to sell you heroin basically, that's what it is…You have to go there, sign whatever, $250 towards your OHIP, $8 a drink, they are heroin dealers. They are allowed to do it because it's controlled. They control you so that you don't go break into a house so you don't steal something which is bullshit."

“So of all the other things I’ve mentioned, but to come off Methadone, is the worst. I’ve lost teeth from it. My bones are fucking sore. Like it goes into your bones…So that Methadone sits in you forever, sits in your fat cells, you know.”

“Methadone is not really helping. Methadone is just replacing their street drug addiction with the Methadone... It’s not helping.”

Several participants reported the presence of purple heroin in Timiskaming, which is heroin mixed with fentanyl or carfentanil and sold under the name “purple H” or “purp”: *“Right now the biggest opiate is fentanyl with the purple. That’s a very bad drug. That’s like a death drug.”* Another participant shared *“I know a lot of people who have overdosed and died from it.”* Many expressed feelings of anxiety around this new substance: *“There’s this new crap that’s going around town that is called purple. I don’t do it, I’ve tried it but I didn’t like it. I exhaled my puff and the second I started exhaling, a coat of sweat started from the top of my head to the tip of my toes. By the time I was done exhaling this tiny hoot I was sick all weekend, just sick. A lot of people have OD’d and died from that, a lot of people I know.”*

The experiencing of withdrawing from opioids was perceived as extremely negative and something that participants wanted to avoid at all cost: *“Sick, like sick, like withdrawn, your legs and stomach turning in knots. Sweating, cold sweats…that’s all you’re thinking of, right. ‘I just want to feel good. I just want to feel good’.”* Participants described both the physical and mental challenges that accompany withdrawing from opioids: *“There’s physical pain and I think a lot of it is mental too. You have sore legs and upset stomach and throwing up and just you are in a lot of pain. All you think about is trying to find more drugs and often too you will think you saw something, like I saw a Percocet so I will go and look because I think I saw one but it’s like it’s in my head. I really didn’t see anything, not hallucinating but I don’t know. I kind of thought I saw something so I will look for it. My withdrawals are so bad I just want anything and then I will pay any amount of money to have something, even a small amount of something because of the withdrawals, because they are so bad.”*

The symptoms of the withdrawals had serious implications to the individual’s life, affecting work, their family and friends:

> *“I’d wake up, I’d look for my pills. If I couldn’t find any then I was stuck in bed until I could. Like it was horrible. I would get sick, having diarrhea and all that nasty stuff. Every single muscle in my body ached. So unless I had my fix for the day I couldn’t even go to work so I would end up losing jobs and all that other fun stuff.”*
>
> *“I guess it was kind of hard sometimes because sometimes you would have to miss family gatherings or we would send my [child] ahead with [their] grandma and then we wouldn’t go because we didn’t have anything so we couldn’t go. Those were the times when it was hard to keep it secret...”*

Facilitators and Barriers to Accessing Health Care Services

Many participants described the barriers and facilitators to accessing health care services. Having access to a physician through the methadone clinic was viewed as an accessible means of receiving primary care services and was relayed in a positive light, despite most physician interactions being conducted through telemedicine. The ability of the methadone clinic to provide specialized care to this priority population was noted as a facilitator by all participants who attended the clinic. Many reported having positive experiences and feelings regarding the methadone clinic and opioid agonist treatment: *"…it's been going very good with the methadone. I am glad we chose to go on it. It was like one of the best decisions we made…"*

Another facilitator of health care access was the use of medical marijuana as complement to alternative pain management therapy, especially in conjunction with opioid agonist therapy or when prescription dosages were being reduced. Participants also described the use of opioid contracts positively: *"…when [the doctor] there helped me out there that was amazing. I couldn't believe it. Just like that I've got a prescription and she said ya, if I obey the rules. I said no problem, I have no problem signing contracts. I have no problem giving a urine sample every time you need a urine sample and I won't have anything in my system except the morphine."*

However, a reported challenge with opioid contracts is that participants had to "start from scratch" rather than receive the dose they needed: *"It's not helping my pain and especially when they say take two of these a day or take two of these a day, well that's not what I used to take. It's like candy is what it's like. It's like I'm eating candy taking Tylenol. I would have to take 20 Tylenol 3s and Percocets six to eight of them, at a shot, one mouthful."*

One of the most commonly reported challenges participants reported in their endeavours to seek health services was the inability to receive timely access to care. Many participants lamented about the difficulties they had in finding a primary care provider. For those reporting prescription opioid use, this gap in care seems to be met with frequent visits to the emergency department: *"Sometimes I go up there [the emergency department] and I don't want to plead for it but I do. I want my medication but if you go up there and you want your medication it's like you're looking for a high, looking at it just to get the dope…It's almost like you have to have yourself set…before you even go up there to say the right thing so you don't get…the doctor thinking you know she is just here for the drugs."* Since there are no local options for primary care for orphan patients such as walk-in clinics, the emergency department serves as the only place to obtain a prescription: *"So every 45 days I've got to go back up [to the hospital]. But they've given me a repeat now so it's now every three months so it saves me a lot less stress that I know that I've still got one prescription that I can go and get when it's needed..."*

Participants also shared the struggles of transportation in rural areas where access to a vehicle is important when seeking mental health, addiction treatment, and primary care services: *"…either I don't have money to get up to the hospital or I've got to walk and going up the hill is killer…I'm out of breath, I've got to stop halfway. So it's either bus it or walk it, that's it."*

In addition to sharing barriers and facilitators to accessing health care services, participants expressed a wide range of reflections on their interactions with the health care system. Many emphasized the positive impact therapeutic relationships and non-judgemental attitudes have

had on their health care experience, for example: *"So I have a nurse practitioner, she helped me get my ODSP. She informed me of this program…Then that one referred me here. She referred me to there. I take part in this. So the health care providers…it's the ones that are sincere and empathetic and if they want to help somebody and somebody wants to help themselves, that's the number one for me. That's what helps. And then just the ones that go the extra mile you know what I mean?"* Other participants shared equally positive experiences: *"I told [my health care provider] that we were on the Methadone program and they, it didn't change the way they treat us at all, at all. It didn't change anything. They weren't judgemental at all. I love that place."* and *"It makes things great. To actually have a doctor that's listening to you and doesn't stare at you like you are some kind of lying junkie."*

Other positive reflections from participants included the availability of information on the internet such as agency websites and 211. A significant facilitator of access to health services reported was the timely availability of appointments. Participants reported a need to be seen in a timely manner and being able to access services with flexible hours such as on the weekends and in evenings. Participants also identified the importance of proper disposal of sharp waste and appreciated the community drop boxes currently installed throughout the district. They expressed the need for increased access to addictions services in the local community such as low barrier health clinics, rehab services, a safe consumption space and increased access to harm reduction supplies.

Several participants shared that they wish they had more health teaching on the addictive nature of opioids before starting their prescription or trying them:

> *"There are times when I wish I did never start the morphine. I never knew the withdrawal symptoms. I didn't know anything of what would happen to be addicted to the medications…I wish, like I said at the beginning, they would have told me this. Tell me the side effects before you tell me the effects. Tell me you are going to be fucked for life. You're going to need this. And I wish I was because it fucked me up man…And it's their fault I think. It's my fault for breaking my back but it's not my fault for giving me all those meds and then saying 'you gotta problem.' What? You fucking gave it to me. So like I took it because you said to. You are the one prescribing it to me. You are the one who thought that it would be good for what I had done to me. You know so you gave it to me. Help me to get off it now. But there is no off of it. It's go to the methadone."*

Discussion

Many of the themes that arose in this research study are found in similar studies but the lived experience of opioid use of individuals in Timiskaming is unique, with transportation, access to health care, and stigma presenting as powerful forces compounded by rurality. The underlying impact of rurality was present in the theme of stigma, where participants highlighted individual, community, and health care stigma. Participants shared the challenges they had with repairing their reputation, their lack of anonymity, being recognized or red-flagged by health care providers, and the hypocrisy of socially acceptable substances.

Experiences of stigma may result in feelings of worthlessness, depression, isolation, anger, anxiety, and fear (Dinos et al., 2004; Zickmund et al., 2003). Feelings of worthlessness associated with the stigma of having a socially unacceptable disease such as illicit drug use may inadvertently be reinforced by the attitudes and responses of health care providers, which reduces the likelihood of people accessing care in the future and affects patient outcomes (Browne, Johnson, Bottorf, Grewal, & Hilton, 2002; Kreiger, 1999; Stevens, 1992; Varcoe, 2004). Exploring interventions to improve individuals' perception of stigma in addition to supporting community health care providers in professional development opportunities that address substance use may be a recommended course of action. Delaying health care access was noted by many participants who had reported negative experiences in the health care system, which as noted, will impact their health outcomes. Additionally, a targeted stigma reduction campaign to the general public may be indicated to offer perspective and instigate conversations about substance use in Timiskaming.

The Mental Health Commission of Canada (2019) released a report summarizing evidence-informed recommendations for stigma reduction. These actions include developing comprehensive stigma reduction and intervention strategies for front-line providers, addressing ethical dilemmas experienced by first responders and front-line providers regarding high-recidivism clients, increasing the use of non-stigmatizing language, and establishing best practice guidelines for opioid-related language. In addition to community-based interventions, there is a strong need for leadership at the national and provincial levels to address the systemic societal stigma associated with opioid use.

The theme of quality of life also presented rich data that encapsulated Maslow's Hierarchy of Needs. Participants reported challenges in meeting many basic needs such as food and shelter that precluded them from sustaining healthy relationships and from achieving work and educational goals. This was further emphasized by the burden that seeking their next fix had on their activities of daily living, personal safety, and dignity. Participants shared that their opioid use stemmed from both chronic pain management and the desire to achieve emotional numbing.

One participant identified that *"most people do drugs or drink because of their childhood. Really, that's the truth of it. They are mentally, physically, sexually abused. And they try to do it to bury the pain."* Many interviewees were open in sharing a range of adverse life events such as the death of a loved one, physical injuries, neglect, witnessing family violence, and parental substance use. These adverse life events are identified in the literature as Adverse Childhood Experiences (ACEs). ACEs are defined as potentially traumatic events that occur in childhood

(0-17 years) such as experiencing violence, abuse, or neglect; witnessing violence in the home; or having a family member attempt or die by suicide (Centers for Disease Control, 2019).

Additionally, ACEs can be defined as aspects of a child's environment that can undermine their sense of safety, stability, and bonding such as growing up in a household with substance use, mental health problems, or instability due to parental separation or incarceration of a parent, sibling or other member of the household (Centers for Disease Control, 2019). As the number of ACEs increase, so does the risk of negative health outcomes such as lack of physical activity, smoking, alcoholism, drug use, and missed work or physical and mental health outcomes such as severe obesity, diabetes, depression, suicide attempts, heart disease, cancer, stroke, COPD, and broken bones (Dube et al., 2003). ACEs scores have a graded relationship with substance use. Increasing awareness of ACEs as a common risk factor for addiction could be a potential area of focus with both health care providers and the general public (Dube et al., 2003). There has been a recent focus on local trauma-informed professional development opportunities for community social service agencies and health care providers driven by law enforcement and the Temiskaming District Violence Against Women Coordinating Committee which should continue to be fostered and supported.

Many participants also highlighted the interpersonal impacts of opioid use where relationships become strained or strengthened depending on the feelings associated with their opioid use. Those who had supportive social networks reported positive relationships and those who expressed awareness of their families' guilt, disdain, or stigma reported negative health outcomes such as social isolation. Many participants shared that they lost friendships in their recovery journey as it became too difficult to be around others who use substances.

Parenthood was a poignant subtheme that highlighted the difficulties parents experienced interacting and caring for their children, whether or not they had custody. Research shows that mothers who use drugs are more likely to have their children in foster care for longer periods and they may experience increased risk of termination of parental rights (Kenny & Barrington, 2018). Juxtaposed with pervasive stigma, women's social networks following child custody loss can be severely disadvantaged with limited social support which impacts marginalization, decreases chances for reunification with children, and has a negative effect on quality of life (Kenny & Barrington, 2018). Radcliffe (2009) identifies that health and social services need to advocate for parents who use substances and make efforts to maximize their clients' chances to engage in treatment and recovery. The commonality to all parents who shared their experiences was a strong motivation for self-improvement and recovery.

The theme of managing addiction highlighted the impact that lack of access to primary health care and a sustained prescription can have on participants' wellbeing. Additionally, many expressed hesitancy and misconceptions about opioid agonist therapy that could be a point of future health teaching and communication efforts. This could be an opportunity for community health care providers and health care agencies to collaborate on developing common messaging and health teaching tools. The fear of new substances such as purple heroin was palpable and present throughout the interviews, highlighting the need for provincial or national efforts to respond to these changing trends, such as availability of drug testing equipment, safe supply, and safe consumption sites.

While much of the above has provided insight into the lived experience of opioid use in Timiskaming, the reported facilitators and barriers to accessing health care services provided rich answers to the second research question: What are the health needs of individuals who use opioids in Timiskaming? This information illuminated the compounding impact of rurality on individuals who use opioids in Timiskaming. Lack of access to a regular primary care provider was a challenge experienced by most participants and despite some reporting facilitators such as ease of access to primary care through the methadone clinic and jail, this is a long-standing area of concern for our communities. Additionally, lack of transportation posed a significant barrier to accessing health care services which is another challenge experienced by all consumers of the health care system across the district.

Participants also identified other factors that facilitated their access to the health care system including the availability of appointments, access to readily available information on the internet, and friendly environments in the agencies they are accessing. Most importantly, participants reported the positive impact that therapeutic relationships had on their health care experience, particularly with health care providers who had a non-judgemental approach to their substance use. Importantly, many shared the view that they initiated their opioid use without awareness of the addictive properties of opioids and lamented the need to have resources and available education: *"…something out there to let you know before you jump into that water... Don't jump in."*

Many participants expressed their desire for future engagement opportunities for individuals who use substances. They encouraged increased promotion efforts for initiatives targeting individuals with lived experience*: "…anything that's there that is offered that I can participate in, that I can take part in and you know that I'm able to, I will do."* Community agencies should continue to explore opportunities to engage individuals with lived experience as there is strong interest and readiness for this.

Limitations

Limitations to this research study included convenience sampling, holding interviews in the English language, and transportation and rurality challenges. The recruitment process was successful but was only limited to consumers of the THU harm reduction program and their peers. Snowball sampling was highly effective in this population for this project and is recommended for future local research with hard-to-reach populations. Interviews were also only available in the English language, which restricted the sample in a catchment area with a significant Francophone population. Although transportation costs were covered for participants, only those who are able to access the harm reduction program were recruited and individuals who use opioids in rural and remote communities may have been excluded unintentionally.

Conclusion

This research project provides unique insight into the lived experience of opioid use in Timiskaming and expands the literature on this subject in rural and northern Ontario. The study also aimed to empower and lend a voice to those who have not historically been engaged in local research or planning initiatives. Lived experience research is critical in small, rural communities as most evidence-generating projects, particularly on opioids, have been concentrated in urban centres. The Timiskaming Health Unit will disseminate the results of this paper with local health care providers and stakeholders in the hope that the findings will provide valuable insight and instigate local discussions. As the results of the research identified, the local response to national concerns about the use of opioids is a multi-sectorial responsibility that requires collaboration and innovation infused with caring and anti-stigma efforts. After all, *"…once people start accepting it as a fact of being, that there is drug addicts and junkies, people who rely on certain prescribed and non-prescribed drugs daily to get through their days, maybe we will have a better understanding and are better able to deal with it. This denying it or shaming it isn't helping."*

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Appendix A: Recruitment Leaflet

Appendix B: Interview Guide

Please tell me about your history of opioid use and/or substance use?

How do you currently use/did you use opioids?

How have opioids affected your daily life?

Please describe your health needs.

What health care services do you access?

What is it like for you when you access health care services?

What makes it easier to access health care services?

What makes it harder for you to access health care services?

What could our community do better to help you?