This is the accepted manuscript of Fontaine, G., Presseau, J., Bruneau, J., Patey, A. M., van Allen, Z., Mortazhejri, S., Bordier Høj, S., Hung, J.-H. C., & Grimshaw, J. M. (2023). “Apparently, you can only be treated once”: A qualitative study exploring perceptions of hepatitis C and access to treatment among people who inject drugs visiting a needle and syringe program. International Journal of Drug Policy, 104124. https://doi.org/10.1016/j.drugpo.2023.104124. Licensed CC-BY-NC-ND 4.0.

Title: “Apparently, you can only be treated once”: A qualitative study exploring perceptions of hepatitis C and access to treatment among people who inject drugs visiting a needle and syringe program

Running title: Perceptions of hepatitis C and treatment

Guillaume Fontaine[1,2], Justin Presseau[1,3,4], Julie Bruneau[5,6], Andrea M. Patey[1,3,7], Zack van Allen[1,4], Sameh Mortazhejri[1,3], Stine Bordier Høj[5], Jui-Hsia Cleo Hung[1,3], and Jeremy M. Grimshaw[1,2,3]

[1]Centre for Implementation Research, Clinical Epidemiology Program, Ottawa Hospital Research Institute, 501 Smyth Road, ~~L1255, Box 711, Ottawa,~~ ON, Canada K1H 8L6

[2]Faculty of Medicine, University of Ottawa, 451 Smyth Road, Ottawa, ON, K1H 8M5

[3]School of Epidemiology and Public Health, University of Ottawa, 600 Peter Morand Crescent, Room 101, Ottawa, ON, Canada K1G 5Z3

[4]School of Psychology, University of Ottawa, 136 Jean-Jacques Lussier, Vanier Hall, Ottawa, ON, Canada K1N 6N5

[5]Research Centre, Université de Montréal Hospital Centre, 900 Saint Denis St, Montreal, QC, Canada, H2X 0A9

[6]Department of Family and Emergency Medicine, Université de Montréal, 2900, boulevard Édouard-Montpetit, Montréal, QC, Canada, H3T 1J4

[7]School of Rehabilitation Therapy, Queen’s University, Louise D Acton Building, 31 George St, Kingston, ON, Canada K7L 3N6

Corresponding author:

Guillaume Fontaine
Email: gfontaine@ohri.ca
Address: Centre for Practice-Changing Research
The Ottawa Hospital General Campus
501 Smyth Road, Box 711

Ottawa, ON, K1H 8L6

Alternate corresponding author:

Jeremy Grimshaw

Email: jgrimshaw@ohri.ca
Address: Centre for Practice-Changing Research
The Ottawa Hospital General Campus
501 Smyth Road
Ottawa, ON, K1H 8L6

Acknowledgements:

The study authors would like to thank all participants for taking part in this study. We would also like to thank Aïssata Sako (CRISM Quebec-Atlantic Node, Canada) and Manuela Mbacfou (CRISM Quebec-Atlantic Node, Canada) for support regarding study coordination and procedures, as well as Geneviève Boyer-Legault (CACTUS Montréal, Canada) and Noémie Harriet (CACTUS Montréal, Canada) for having facilitated contacts with participants.

Word count (excluding abstract, references, tables, and figures):

7,768

Declaration of competing interests:

None.

Funding:

This study is funded by the Canadian Network on Hepatitis C (CanHepC). CanHepC is funded by a joint initiative of the Canadian Institutes of Health Research (CIHR; NHC-142832) and the Public Health Agency of Canada (PHAC). GF is supported by a Banting Postdoctoral Fellowship (#202010BPF-453986-255367) from the Canadian Institutes of Health Research (CIHR), a Postdoctoral Fellowship Supplement from the University of Ottawa, and a Postdoctoral Fellowship from CanHepC. ZvA is supported by a CIHR Doctoral Award: Frederick Banting and Charles Best Canada Graduate Scholarship. JB holds a Canada Research Chair (Tier 1) in Addiction Medicine.

Clinical trial registration details:

Not applicable.

Abstract

Background: Access to hepatitis C care within harm reduction community organizations for people who inject drugs is crucial for achieving hepatitis C elimination. However, there is a lack of data on how perceptions of hepatitis C and treatment have changed among individuals visiting these organizations during the era of direct-acting antivirals (DAAs). This study aimed to explore the perceptions of hepatitis C and treatment access for (re)infection among individuals visiting a needle and syringe program in Canada.

Methods: Eighteen semi-structured interviews were conducted with individuals who recently injected drugs and visited a needle and syringe program. The interviews were guided by the Common-Sense Self-Regulation Model (CS-SRM) and aimed to explore cognitive and emotional representations of hepatitis C, perceptions of treatment, coping strategies and sources of information. Interviews were audio recorded, transcribed, and coded using thematic analysis.

Results: Most of the participants identified as male, were of white ethnicity and had a median age of 45. While most underscored the therapeutic advancements and the effectiveness of DAAs, they expressed confusion regarding the mechanisms of access to treatment, especially in cases of reinfection. Perceptions of the controllability of hepatitis C were significantly influenced by the stigmatizing discourse surrounding treatment access, cost, and public coverage. This influence extended to their intentions for seeking treatment. Participants emphasized the social consequences of hepatitis C, including stigma. Emotional representations of hepatitis C evolved along the care cascade, encompassing initial shock at diagnosis and later fear of reinfection following successful treatment.

Conclusion: Nearly a decade after the advent of DAAs, misinformation about treatment access persists. Findings underscore a nexus of internalized and institutionalized stigma associated with hepatitis C, drug use, and the challenges of cost and access to treatment, pointing to a clear need for education and service delivery optimisation in harm reduction community organizations.

Keywords: people who inject drugs, harm reduction, needle syringe program, hepatitis C, implementation science, qualitative research

Introduction

In July 2022, the World Health Organization released its new set of integrated global health sector strategies on HIV, viral hepatitis and sexually transmitted infections, calling for the elimination of chronic hepatitis C virus (HCV) infection as a public health threat by 2030 (World Health Organization, 2022). It defined elimination as a ~80% reduction in new HCV infections and a ~50% reduction in HCV mortality compared to 2020 levels (World Health Organization, 2022). These targets are potentially achievable because of the advent of simple and effective direct-acting antiviral (DAA) treatment (Backus et al., 2018; Ioannou et al., 2017; Nahon et al., 2017). In North America, injection drug use is associated with most new HCV infections (Degenhardt et al., 2017; Nelson et al., 2011). Recent estimates suggest that 14·8 million people (95% uncertainty interval [UI] 10·0–21·7) inject drugs globally and 174,500 people (UI 154,500–194,500) inject drugs in Canada (Degenhardt, 2023). The SIMPLIFY study has shown that HCV treatment should be offered to people who inject drugs irrespective of ongoing drug use (Grebely et al., 2018), and international guidelines have recommended treatment of people who inject drugs (Ghany et al., 2020). Thus, people who inject drugs should be prioritized for testing and treatment, with efforts made to identify and prevent reinfection (World Health Organization, 2022).

In Canada, alongside the important shifts in the HCV treatment landscape over the course of the last decade (Goodyear et al., 2021), there have been persistent gaps in HCV treatment uptake among people who inject drugs (Canadian Network on Hepatitis C, 2019; Lourenço, 2021; Public Health Agency of Canada, 2019). The *2017–2019 Tracks Survey* indicated that of all people who inject drugs in Canada aware of their HCV infection, only 10.6% had ever taken treatment and 3.8% were being treated (Tarasuk et al., 2020). In 2014, when direct-acting antivirals (DAAs) succeeded interferon-based (IFN) therapies as the treatment of choice for HCV infection, Canadian guidelines limited access to DAAs to those with advanced liver fibrosis or cirrhosis (Schanzer et al., 2018). While disease-stage restrictions were removed in 2018 (Shah et al., 2018), provinces and territories implemented the lifting of these limitations differently, and other restrictions are still in place (Bartlett et al., 2021; Saeed et al., 2020). In Canada, DAA treatment is now covered for most people who inject drugs under the public health insurance program, and there is no restriction for retreatment (Marshall, 2016; Shah et al., 2018).

After disease-stage restrictions were lifted, HCV treatment uptake among people who inject drugs climbed in multiple provinces, but started to fall a year later, indicating "warehousing effect" as the backlog of eligible individuals who had been postponing treatment until DAAs were accessible was cleared (Saeed et al., 2020). These findings highlight the increasing importance of low-barrier settings, including community-based harm reduction services such as needle syringe programmes (NSPs), for identifying and linking individuals with ongoing injection drug use to specialized care (Cunningham et al., 2022; Cunningham, 2023; Jacka et al., 2020; World Health Organization, 2022).

Globally, and in Canada, there is a lack of qualitative evidence regarding the impact of DAA rollout (in policy and in practice) on perceptions of HCV infection, treatment eligibility and access, reinfection, and stigma in people who inject drugs. Most studies investigating the perceptions of HCV infection in people who inject drugs were conducted in the interferon era (Dowsett et al., 2017; Jones et al., 2014; Safo et al., 2015). In previous research conducted globally, people who inject drugs have depicted HCV infection as an inevitable consequence of injection drug use, as 'ubiquitous' and 'normalized' within some settings (Harris & Rhodes, 2012; Rhodes & Treloar, 2008; Wozniak et al., 2007). As treatment for reinfection among people who inject drugs becomes a key focus of HCV elimination efforts (World Health Organization, 2022), it is relevant to investigate how the perceptions of HCV, treatment and reinfection risk evolve alongside the care cascade—i.e., HCV prevention, testing, care and treatment, and cure (World Health Organization, 2016). Recent studies suggest intersecting stigmas (related to HCV treatment, substance use, co-infections and socioeconomic hardship) can influence post-treatment trajectories and perceptions of reinfection risk and treatment in people who inject drugs (Goodyear et al., 2021; Saine et al., 2020). An exploration of the perceived understanding of and feelings about HCV infection, DAA treatment and reinfection is needed in the Canadian context to design community-based, tailored harm reduction services (Boucher et al., 2017; Høj et al., 2019).

The Common-Sense Self-Regulation Model (CS-SRM) is a prominent social cognition approach developed by Leventhal and colleagues (Leventhal et al., 1992) to understand how individuals' perceptions of illness threats guide coping strategies to deal with those threats. Figure 1 presents the CS-SRM and its main components (Leventhal et al., 1992). The CS-SRM seeks to explain how individuals' behaviours towards an illness are shaped by their perceptions and beliefs regarding this illness (Leventhal et al., 1992). According to this model, people develop beliefs and emotions about an illness (illness representations) based on information stored in memory, and acquired through endogenous (e.g., symptoms experienced) or external (e.g., media, health care professionals) sources. These representations can be categorized into two main categories: cognitive illness representations and emotional illness representations. Cognitive illness representations can be further categorized into six categories: cause, coherence, consequences, identity, perceived control, and timeline. Emotional illness representations represent individuals' reflections on their emotional responses to the illness. Based on these illness representations, individuals develop, enact, appraise, and update a set of coping strategies. New experiences may lead to new illness representations, which in turn generate new coping strategies or update existing ones. Threatening information, such as illness symptoms, may activate associated illness-related information and motivate individuals to engage in coping strategies (Hagger et al., 2017; Hagger & Orbell, 2022).

[Insert Figure 1]

The CS-SRM may be particularly useful for more comprehensively exploring how people who inject drugs view HCV infection in terms of their cognitive and emotional representations and coping procedures—i.e., whether they will engage in the cascade of care and seek testing and treatment for (re)infection. To our knowledge, only one study applied the CS-SRM to investigate individuals' HCV illness perceptions; the study was conducted among predominantly Hispanic and African American people injecting drugs enrolled in an opioid-agonist treatment program in the United States before the roll-out of DAAs (Safo et al., 2015). Findings of the study highlighted the role of comparative benchmarks (e.g., HCV versus HIV) and personal experiences (e.g., proximity to fatal outcomes of HCV) in shaping individuals' conceptualization of HCV and their engagement in treatment (Safo et al., 2015). Given the expansion of effective and tolerable DAA treatments, and their potential impact on illness representations and coping strategies, the use of the CS-SRM to investigate the perceptions of people who inject drugs regarding HCV, treatment and reinfection in the present context is particularly relevant and timely. The aim of the current theory-informed qualitative study was to explore the cognitive and emotional representations of hepatitis C, perceptions of treatment, coping strategies and sources of information among people who inject drugs visiting a NSP in Montreal, Canada. The application of the CS-SRM to this study provides greater insights into the changing cognitive and emotional representations of HCV infection along the care cascade and may inform interventions to improve HCV care within harm reduction community organizations.

Methods

A qualitative descriptive study was conducted using semi-structured, in-person interviews based on the CS-SRM. The study was approved by the Centre Hospitalier de l'Université de Montréal Research Ethics Board (CHUM-REB# 21.197) and by the Ottawa Health Science Network Research Ethics Board (OHSN-REB# 20210655-01H). The study is reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) (Tong et al., 2007).

Setting and context

The study was conducted at CACTUS Montréal, a large urban harm reduction community organization for the prevention of sexually transmitted and blood-borne infections (STBBIs) in people who use drugs, sex workers, and trans people. The organization housed the first NSP in North America, launched in 1989, and now employs more than 80 people. In 2020-21, 70,939 people visited the organization through its different programs (e.g., NSP, supervised injection site, social involvement program for people who use drugs).

Sample and recruitment

All adult French- or English-speaking individuals with a recent visit (<3 months) to the NSP and with a recent history (<3 months) of injection drug use were eligible to participate in the study. Individuals reporting a cognitive impairment or a health condition that might impede participation in this study were not eligible. A researcher (GF) was present onsite to share posters and flashcards containing a plain language explanation of the study and contact information, and to identify potentially eligible individuals through convenience sampling. NSP staff assisted GF in identifying potential participants and in excluding individuals unfit to participate. To achieve an adequate sample for content validity, we used the 10 + 3 decision rule, whereby 10 initial interviews were conducted followed by an additional three interviews until no new themes were identified (Francis et al., 2009). We expected 15-20 CS-SRM interviews to be sufficient.

Once a potential participant had been identified, the study was presented and the Informed Consent Form (ICF) discussed. Once an individual agreed to participate, the ICF was provided to the individual and signed consent was obtained. Depending on the preferences of each participant, the individual in-person interview was scheduled at a convenient time in a dedicated private meeting room at the NSP. Interviews were conducted by GF, a male nurse and postdoctoral researcher experienced in qualitative research based at the Ottawa Hospital Research Institute with no prior links to the study setting. No relationship was established with participants prior to interviews. Participants were informed that the interviewer was interested in learning more about their views and experiences regarding HCV infection and treatment. A compensation of $20 CAD was provided upon completion of the interview.

Interview guide

The interview guide was developed based on the CS-SRM to explore views and experiences of people who inject drugs relating to HCV infection, reinfection risk and treatment. It was also designed to explore the coping strategies and sources of information regarding HCV infection. Previous CS-SRM interview guides and associated resources were used as a basis (Crawshaw et al., 2019; Mortazhejri et al., 2020). The different dimensions of the CS-SRM are presented in Table 1, alongside their definitions and examples of questions from the interview guide. The interview guide included between one and three questions for each of the CS-SRM dimensions, and for each of these, we inquired about whether individual's perceptions changed over time.

[Insert Table 1]

Analysis

Interviews were transcribed verbatim, anonymized, and translated from French to English by a professional translator. All transcripts were subsequently verified for accuracy by GF. All interviews were then independently double coded in NVivo 11 software or Microsoft Word by two authors (GF and AMP or ZvA). Coders met after coding the first transcript to discuss and resolve any discrepancies and develop a uniform coding scheme. A deductive approach was initially applied to coding and subsequently applied thematic analysis related to the dimensions of the CS-SRM. We added an additional dimension during coding, 'Sources of information,' to capture the difference sources of information mentioned by participants in relation to HCV and/or treatment, and how these influenced illness perceptions.

Results

Sample characteristics

Eighteen individuals were interviewed between October 22, 2021, and January 28, 2022. Table 2 presents the characteristics of participants. The median age was 45 years old (IQR 17), and approximately three quarters of the sample self-identified as male. Fifteen participants self-identified as white, and only three reported having stable housing. Stimulants were the most frequently used drug by 10 participants, followed by opioids by five participants. Polydrug use was reported by the majority, with 16 participants reporting using more than one type of drug in the past three months. Drugs injected in the past three months included opioids (9/18), both opioids and stimulants or some other combination (6/18), and stimulants (3/18). Five participants reported having received opioid agonist therapy in the past three months. Fourteen participants self-reported one or more past HCV infection(s), for a total of 18 prior HCV infections across the sample. Of those, nine were treated with DAAs, six were self-cured, and three were treated with IFN therapies. One participant mentioned having an active HCV infection. All interviews were conducted in French and the median duration was 21 minutes.

[Insert Table 2]

Cognitive illness representations regarding HCV infection

Identity: Label and symptoms attributed to HCV infection

While the majority of participants referred to HCV infection as ‘hepatitis C,’ a few also used the term ‘liver disease.’ Some individuals added qualifiers like ‘dangerous’ to convey the severity of the disease, although others disagreed and did not perceive it as a serious illness.

Individuals with a previous infection reported little to no symptoms. They described how the largely asymptomatic nature of HCV infection made it difficult to attribute potential symptoms experienced to the disease, especially in the early stages. Fatigue was identified as the most prevalent symptom. Some were aware of other possible signs and symptoms such as jaundice:

> "*So, I never saw any difference, never, never. It's sure that after the* [DAA] *treatment I felt better. Less tired, more…fatigue a bit, yes. That's what I had. Besides that, nothing. I didn't have jaundice, nothing of that. No, never.*" —Participant 12, male, two previous HCV infections treated with IFN therapy and DAAs

In those without a prior HCV infection, knowledge of symptoms was acquired mostly through interactions with HCV+ individuals in their social circle. Notably, symptoms described by those without a prior HCV infection tended to be more numerous and of higher intensity than symptoms described by those with a past infection, potentially indicating that people who have never had an infection overestimate the salience and severity of symptoms:

> "*It's often similar symptoms. Diseases transmitted in the blood and all that. Diarrhea, tooth aches, fatigue, weak immune system, you can't eat that, na na na. They're always similar for those diseases.*" —Participant 16, male, no previous HCV infection

Timeline: Beliefs about the onset, duration and fluctuation of HCV infection

Participants had difficulty in expressing beliefs about the rate of onset, duration, and fluctuation of HCV infection. In those with one or more past HCV infection(s), due to absence of, or hardly discernable, symptoms, many struggled in describing the onset and progression of the illness:

> "*I caught it two years ago. I didn't have time to see it* [before self-cure]. *I don't know when it came back either. Did it come back shortly after, had it just come back, I don't know.*" —Participant 3, male, two previous HCV infections, first self-cured, second treated with DAAs

For some who were treated quickly after their diagnosis (<3 months), HCV infection was perceived as acute in nature. Conversely, participants who lived with the diagnosis for a longer period of time (> 5 years), the temporal effects and associated consequences were described in more detail. Individuals who had been living with HCV for an extended duration reported experiencing symptoms more frequently. This prolonged exposure to the infection heightened their awareness of its potential complications and long-term health risks, and the fear of developing severe complications such as cirrhosis or cancer became more prominent. The possibility of death related to the infection became a source of anxiety and concern:

> "*I was scared of dying at one point. Yes, it's scary to think of dying. At one point, you realize that death is near. Because it had been seven years that I had it and at one point I could feel it. I was pale. I wasn't sleeping. It had been two years that I hadn't slept. You could see it.*" —Participant 18, male, previous HCV infection treated with DAAs

Individuals who had not experienced a past HCV infection generally exhibited limited knowledge about the onset and progression of the illness. They often had little information about the initial stages of infection, the potential symptoms that could manifest, and the long-term consequences of untreated HCV infection.

Cause: Beliefs about the causal antecedent(s) of HCV infection

Most participants had a good understanding of the behavioral and social causes of HCV infection. Those who had experienced a past HCV infection often attributed their infection to a specific event rather than a general risk behavior, particularly highlighting contact with contaminated injection materials. Among the 18 participants, 16 specifically mentioned syringe sharing/intravenous blood exchange as the primary means of transmission:

> "*Intravenous is the method of choice, if you are looking for hepatitis, give your needle to someone else and there's a good chance that when it comes back, you will get it. I never share my materials.*" —Participant 1, male, no previous HCV infection

When discussing the mechanisms of HCV transmission, several individuals also referred to their social network and interactions with individuals engaging in high-risk behaviors. They acknowledged the role of their social environment in potential exposure to the virus. Many were uncertain about the risk of HCV transmission associated with sexual activity. Yet, some believed that unprotected sexual contact was the main mechanism of transmission:

> "*I think it's more sexual relations because I share my pipes and my stupid stuff with everyone. I don't think I have it, but I don't know. I think that if you have sores or something there it could transmitted. But I don't know.*" —Participant 16, male, no previous HCV infection

Consequences: Beliefs about the impact(s) of HCV infection

The perceived consequences of HCV infection had strong functional dimensions, extending beyond the potential medical outcomes such as liver cirrhosis and liver cancer. Participants vividly described the wide-ranging impact of HCV infection on multiple aspects of their lives, including their professional and daily life, social relationships, overall lifestyle, and general well-being. For some, the infection marked the beginning of a series of unfortunate events, including loss of employment. This often triggered a chain reaction, leading to life-changing consequences that affected their financial stability, social standing, and overall quality of life:

> "*I was going through financial problems, I couldn't work. Family conflicts too. Discouragement and all that.* [My HCV infection] *killed my relationship, yes. When I think about that, it killed my relationship. Instead of being in full swing in my early thirties. I had bought a house by a lake, a motel. I bought a boat and all those things. I fell hard, went bankrupt. I was exhausted then I relapsed. We separated two years later. That's where it started*." —Participant 12, male, two previous HCV infections, treated with IFN therapy and DAAs

> "*I had to start everything over again, leave my job so I could concentrate only on working on my hepatitis, it was demoralizing*." —Participant 7, male, two previous HCV infections, treated with DAAs twice

Additionally, participants shared how HCV infection influenced their social relationships, leading to feelings of isolation, and strained interactions with family, friends, and partners. The fear of transmitting the virus to loved ones or facing judgment and discrimination further compounded the social consequences of the infection. They shared their experiences of anticipating and encountering stigma from various groups, including coworkers, healthcare professionals, police officers, prison staff, family members, and friends:

> "*I lost a lot of friends. My sister didn't want me to go near her, even now. She's scared for her children. Even if I got the treatment for hepatitis C, she's scared for her children.*" —Participant 18, male, previous HCV infection treated with DAAs

The lifestyle of individuals with HCV infection was often profoundly affected. Some described how the need for medical appointments, treatments, and lifestyle modifications disrupted their routines and limited their ability to engage in activities they once enjoyed. The infection brought about changes in diet, substance use, sleep patterns and overall physical and mental well-being:

> "*I was also scared to drink. I was scared to eat. I was scared of everything because I thought I'd have an internal hemorrhage.* […] *I was also hyper-aggressive* [during treatment]. […] *Someone looked at me sideways, I didn't even want to talk to them.*" — Participant 18, male, previous HCV infection treated with DAAs

While most participants reported experiencing consequences of HCV infection in various aspects of their lives, some disagreed and stated that HCV infection had no consequences on their professional and daily life, social relationships, or other areas. They expressed a sense of resilience and a belief that life continued as normal, despite their illness. They mentioned not receiving criticism, comments, or experiencing negative attitudes from those around them, suggesting a lack of perceived stigma or discrimination. Some participants attributed the absence of consequences to their choice of not discussing their HCV infection openly.

Perceived control: Beliefs regarding the controllability and curability of HCV infection

Beliefs regarding the curability and controllability of HCV infection were centered around the different characteristics of treatments. Over the past decade, the HCV treatment landscape has evolved significantly, transitioning from IFN therapies with severe side effects and complex drug-drug interactions, to DAAs with high cure rates, minimal side effects and shorter treatment durations. Most demonstrated a general awareness of the potential for HCV to be cured. Ten out of 18 participants had direct experience with past or current versions of HCV treatments (either IFN therapies, DAAs, or both). Many compared IFN and DAA treatments, even if they had not experienced both, underlining the lengthy duration and important side effects of the former and the short duration, fewer side effects and effectiveness of the latter. Their responses reflected an understanding of the advancements in treatment options and the effectiveness of the new DAAs:

> "[The DAA treatment] *was a 6-week program if I'm not mistaken. It was a pill a day. Pills worth $800.* […] *It went fast. The treatment was easy. Just swallow a pill. A big pill, mind you, but only one pill. It was pretty easy. There weren't any problems relating to this.* […] *I've seen very sick people* [on the IFN treatment]. *It was an injection per week, and it made them really sick all week. I've seen people like that before the new treatment arrived. I know that the previous treatment was rock and roll. For me it was really easy.*" —Participant 3, male, two previous HCV infections, first self-cured, second treatment with DAAs

The evolving treatment landscape for HCV infection has not only improved the prospects for curing the infection but also shaped individuals' beliefs about the feasibility of completing treatment. The improved tolerability and shorter duration of treatment with DAAs seemed to enhance their confidence in completing treatment:

> "*I did the old Interferon program at the time. I got the whole thing. I was losing my hair and my skin at the end. It was really intense.* […] *Big side effects. Severe depression, always throwing up, I was in bed almost 24/7 for six months. At the end of the treatment, I barely touched my skin, and it would peel off like I had leprosy. It was very intrusive as a treatment.* […] *Now, today I know that the treatment is much shorter and less intrusive so I think it would handle it better.*" —Participant 5, female, previous HCV infection treated with IFN therapy

However, some participants who had undergone IFN therapies expressed apprehension about DAA treatments, anticipating the side effects, and were seemingly unaware that side effects of IFN therapies do not apply to DAA treatments:

> "*The treatment? I would not do it again.* […] *The disease itself causes lesions, and so does the treatment. It's even worse. But you end up being cured.*" —Participant 9, male, previous HCV infection treated with IFN therapy

Treatment access, cost and coverage by public health insurance emerged as a significant concerns for the majority of individuals, especially those who had previously undergone treatment for hepatitis C. Many believed that they could only be treated once or twice because of the high cost of the treatment, and expressed confusion about the mechanisms of access to DAA treatments. This belief reflected a common misconception about limitations in treatment availability, especially for reinfection:

> "*The disease should not be only about money, there must be a humane element.* […] *Why is it $80,000, how do they use it, and why does it remain like that.? Why do we pay the $80,000? Why does it cost that much?* […] *I could catch it again. Apparently, you can only be treated once.*" —Participant 2, female, previous HCV infection treated with DAAs

Participants expressed uncertainty about the specific processes and criteria that determined who could receive DAA treatments and how they could navigate the system to access the treatment:

> "*We'd been waiting for it for a while and it was very expensive, it seems. It cost a fortune. I remember the doctor had told me be careful because they won't pay it twice. I don't know if he said that to scare me, in any case. You had to make a special request to the RAMQ* [provincial public health insurance]*, it's true. A special request to the RAMQ to get the treatment. And to wait to be approved before starting.*" —Participant 12, male, two previous HCV infections

Notably, while some individuals were aware that the infection could be self-cured, many were not aware of how this can unfold, and some stated they would not seek the support of a health care professional until they have waited a few months to see if they heal on their own. This indicates a preference for a wait-and-see approach among some individuals.

Coherence: Understanding of HCV infection

The level of understanding of hepatitis C varied significantly. Almost all participants knew that that the disease affected the liver to some extent, with some participants mentioning the infection could affect blood filtration and lead to cirrhosis and liver cancer. HIV was used by some as a benchmark for understanding HCV, often to suggest the HCV is more resistant:

> "*The bug looks rougher than HIV. A drop of blood with HIV on the table isn't serious. It dies almost immediately, it seems. But hepatitis seems a little tougher.*" —Participant 12, male, two previous HCV infections

Notably, some mentioned that their goal was not to understand the intricacies hepatitis C, but rather to learn how to prevent contracting the infection and transmitting it to others. One participant mentioned that he didn't feel the need to understand the disease because he was treated right away with DAAs. Their experience of being treated quickly might have alleviated the need for in-depth knowledge about hepatitis C, but they still underlined the need to better understand the mechanisms of transmission:

> "*I don't have the need to understand because as soon as I learned I had it they treated me right away. It left right away. I didn't really need any more information. I would have*

> *needed more information on how not to catch it. If there are many ways. Now, it's just the needles.*" —Participant 3, male, two previous HCV infections

Emotional illness representations regarding HCV infection

Individuals who had never diagnosed with HCV infection expressed a strong fear of the disease and of its potential consequences. However, in individuals with past or current HCV infections, distinct emotional illness representations emerged at the time of diagnosis, during the process of linkage to care and treatment, after achieving a cure, and in cases of reinfection.

Diagnosis

Many individuals expressed how they first felt fear, stress, anxiety and shock regarding their diagnosis, the potential complications of HCV infection, and the possible impact on their personal and professional lives:

> "*I freaked out. I was not in a good mood.* […] *Because I've never had a disease before, I've always been careful for everything, and when you are careful and you catch something like this, it's not a lot of fun.*" —Participant 10, male, current HCV infection

For some individuals, this initial shock was replaced by fear of stigma, doubts about how the future would unfold regarding their illness, as well as their personal and professional lives, and demoralization:

> "*Yes, telling my girlfriend, she would be angry, or afraid. That's pretty much it. Nothing else, except whether it follows you, will I be able to treat it? Will I be accepted? Those things caused anxiety – I have chronic anxiety. That's it. The stress piled on my shoulders.*" —Participant 13, male, previous HCV infection

Treatment

For most individuals, emotional reactions to the diagnosis shifted from concerned to relaxed and pleased when they were linked to appropriate care. Discussions with health care providers allowed most individuals to be acquire knowledge about the disease and treatment, which was reassuring for some:

> "*Immediately, when I found out that it was curable, there was less panic, but it is unpleasant.*" —Participant 8, female, previous HCV infection, treated with DAAs

Most individuals did not express fear regarding starting the DAA treatment:

> "*Compensation was there. They registered me for the program right away and I started. I wasn't scared.*" —Participant 3, male, two previous HCV infections, treated with DAAs

However, IFN therapies were associated with strongly negative emotional representations related to the side effects and duration of the treatment. In addition, some individuals reported negative emotions associated with their experiences of dehumanizing and stigmatizing clinical encounters with some health care providers. Some of these experiences were in the context of HCV treatment, and others concerned healthcare in general.

Post-cure

The lack of awareness among many individuals regarding the possibility of multiple treatments for HCV infection resulted in chronic anxiety even after being cured. One stated:

> "*Except now that I'm cured, I'm scared to get it because* […] *It's only paid once the treatment.*" —Participant 2, female, previous HCV infection

The fear of reinfection was further compounded by the realization of how easily one could become infected:

> "*I am even more afraid today because considering how easy it was for me to catch it.*" —Participant 6, male, previous HCV infection

These statements underscore the persistent anxiety and worries that individuals with previous HCV infection faced, despite being successfully treated. The belief that treatment was a one-time opportunity coupled with the awareness of the ease of transmission contributed to ongoing concerns about the potential for reacquiring the infection.

Reinfection

In individuals infected twice (and aware that the infection could be treated multiple times), emotional illness representations regarding reinfection, if any, were less pronounced and more oriented towards frustration and disappointment rather than the fear, anxiety or shock experienced upon learning of their first infection.

> "*It was "God dammit, not again!"* […] *I knew the treatments, I knew I had a good immune system, so it wouldn't take time to get cured. But the facts of knowing that it had*

> *come back again, and just because of one evening with the girl… Disappointed.*" — Participant 7, male, two previous HCV infections

Coping strategies

Problem-Focused Coping: Attempts to address the illness

Most individuals mentioned seeking medical support as one of the top coping strategies they used or would use, with many highlighting the importance of initiating and following the treatment and listening to healthcare professionals' recommendations. Several individuals mentioned they enacted or would enact behavioural changes to alleviate their illness, including to stop drinking alcohol, change their diet, rest, and exercise:

> "*I listened to what they told me, the recommendations. Don't drink and things like that. I don't drink anyway so it's not too hard for me not to drink but I like to have a glass of wine when I eat and I didn't do it. I knew I wasn't supposed to. It didn't bother me.*" — Participant 3, male, two previous HCV infections

Seeking social support: Attempts to seek instrumental and emotional support from others

Very few mentioned that they would seek social support to cope with their illness. Some mentioned the importance of people living in the streets helping each other during difficult times, with one individual stating:

> "*And in case someone among us has caught it, we will tell them to get the treatment and that we will be there for them, help them and accompany them. We are friends, that's why I'm here. That's how we help each other out. We are street guys, but our friendship is very strong, we are there to help each other, we are not there to hurt each other, why put each other down? We are equal, so we are there to help each other. Obviously, I would have friends to accompany me.*" —Participant 7, male, two previous HCV infections

Avoidance/denial: Cognitive or behavioural attempts to ignore the existence of the illness

Some individuals resorted to avoidance or denial as a coping mechanism to deal with the reality of their HCV infection. This manifested in cognitive or behavioral attempts to ignore the existence of the illness. One described how alcohol helped them maintain a sense of normalcy and stabilize their mood, despite the associated risks:

> “*What helped with having a normal behaviour, instead of having the ups and downs and the fatigue, the depression… It was alcohol. I drank and I maintained a stable mood. It made me hungry. But it also gave me a problem with alcohol, because I was drinking a lot; when I woke up, and all the way to bed. So I drank from 7 AM to 1 AM.*” — Participant 7, male, two previous HCV infections

Interestingly, when asked if they would want to know if they currently had an HCV infection, most participants expressed a desire to be aware of their status so they could initiate treatment and take proactive steps towards managing their health.

External sources of information

Four types of external sources of information regarding HCV infection and treatment were described by individuals: a) family and peers, including those that have experienced HCV infection and treatment, b) healthcare providers and NSP workers, c) printed materials, including pamphlets and posters at the NSP and supervised injection site, and d) other sources, such as browsing the Internet and research projects they are involved in. A notable finding was that some participants had limited access to accurate information sources regarding hepatitis C, and expressed distrust towards healthcare professionals:

> Q: “*Where did you get your information about hepatitis C? Where did you learn the things that you know?*”
>
> R: “*The street. People in the street… Much more than doctors, doctors don’t know anything.*” —Participant 9, male, previous HCV infection

This finding highlights the need for improved communication and trust-building between healthcare professionals and individuals affected by hepatitis C. It also underscores the importance of providing accurate and accessible information from reliable sources.

Discussion

This study sheds light on the persistence of misinformation about DAA treatment access among people who inject drugs visiting a NSP in Canada. Despite the widely recognized efficacy and safety of DAA treatment, people who inject drugs report encountering stigmatizing discourse regarding treatment access, such as clinicians emphasizing the high cost of treatment and expressing concerns about the government potentially not covering additional rounds of treatment. These experiences influence how HCV infection is understood in terms of its curability and controllability, affecting the motivations and intentions of individuals seeking treatment for reinfection. These findings highlight the urgent need for increased awareness and education around the availability and accessibility of DAA treatments. Addressing misconceptions about treatment limitations and providing clear information about the pathways to access these treatments can help alleviate concerns and empower individuals to seek the care they need for hepatitis C. Our findings reveal additional concerns and knowledge gaps, including uncertainties regarding transmission risks of HCV through sexual activity, previous adverse experiences with IFN therapies, and the enduring stigma associated with HCV infection. These findings emphasize the necessity for tailored measures to address these issues, as there are still critical gaps in accurate information and support despite existing knowledge.

Cognitive representations related to the *cause, coherence* and *consequences* of HCV infection were characterized by a greater knowledge of transmission risks from injecting drug use than sexual activity and by a general disinterest in understanding the disease and in its health consequences. Individuals expressed a stronger desire to learn preventive measures to avoid contracting HCV and transmitting it to their loved ones. Some individuals also held misconceptions regarding unrelated symptoms or had an incorrect understanding of the underlying pathophysiology of the illness. These findings underline the importance of and opportunity for trusted sources of information within community organizations serving people who inject drugs; misinformation is a common problem within these settings and can lead to pervasive knowledge gaps (Boucher et al., 2017; Goodyear et al., 2021). Sources of information in relation to HCV infection varied widely according to life experience and social context. Younger individuals tended to rely more on informal sources, such as peers, while individuals with more life and health experiences had established networks of trusted information sources within and outside the NSP, including contacts with workers, nurses, and involvement in research projects. To address the identified common concerns and knowledge gaps in this study and enhance access to accurate information within NSPs, various strategies can be employed. These may involve leveraging NSP workers to provide information and organizing discussion groups with nurses to address gaps in understanding disease progression, transmission mechanisms, and treatment options. By implementing such strategies, we can bridge knowledge gaps and ensure individuals have access to reliable information within NSPs.

Cognitive representations related to the curability and controllability of HCV infection were dominated by conflicting perceptions of current and past forms of treatment, as well as by confusion and internalized stigma around treatment eligibility. Most participants had direct experience with DAA and/or IFN therapies or were in contact with others who had been treated. Negative perceptions of IFN-based therapies were prevalent, highlighting their detrimental effects on themselves, acquaintances, or loved ones. In contrast, DAA treatment was generally perceived positively. However, there were gaps in knowledge about recent advancements in HCV treatment, and many expressed uncertainties about eligibility and access to DAA treatment. Concerns were raised about the cost and regulatory aspects associated with DAA treatment, and a misconception persisted that treatment could only be undergone once. Our findings are aligned with a study conducted in British Columbia, Canada, suggesting that evolving HCV treatments in terms of eligibility, side effects and mechanisms of access influence attitudes, motivations and opportunities related to DAA treatment among people who inject drugs (Goodyear et al., 2021). These factors have implications for enhancing access to HCV care among individuals visiting NSPs, particularly for individuals reinfected with previous experiences of treatment (Amoako et al., 2021). Reinfection following treatment for recent HCV infection among individuals with high risk behaviours such as people who inject drugs is expected (Martinello et al., 2017; Rossi et al., 2018; Valencia et al., 2019), and is a growing concern if HCV elimination is to be achieved (Grebely et al., 2021; Marshall et al., 2022). As (re)treatment of people who are actively injecting is critical to HCV elimination, perceptions of ‘once only’ treatment among people who inject drugs could contribute to people delaying treatment until they are no longer injecting. Strategies such as regular post-treatment HCV assessment for early detection and retreatment (Grebely et al., 2021), should be complemented by strategies to minimize internalized and institutionalized stigma around treatment, and ongoing education regarding treatment eligibility and accessibility in the Quebec context. The trusted sources of information identified in this study can be utilized to facilitate clear and simplified communication and educational efforts on treatment eligibility and access within NSPs. Furthermore, shifting the discourse away from cost concerns and emphasizing instead the importance of comprehensive treatment is critical to help reduce stigma and improve treatment outcomes.

Emotional perceptions of HCV infection were closely intertwined with individuals' understanding of the illness timeline. People who inject drugs experienced a range of emotions at different stages of the care cascade. Upon receiving their initial diagnosis, our findings indicate that most individuals felt fear, stress, anxiety, and shock related to the disease and its potential complications. Over time, these emotions transformed into regret due to engaging in high-risk behaviors, unhappiness, demoralization, and uncertainty about their future. Some individuals were not concerned about their diagnosis, citing other priorities in their life, and highlighting the absence of symptoms. These findings align with previous studies conducted among people who inject drugs and other individuals engaging in high-risk behaviours (Dowsett et al., 2017; Hosseini-Hooshyar et al., 2020; Marshall et al., 2022). During the linkage to care and treatment phases, individuals found reassurance in learning about the curability of HCV infection and expressed satisfaction with the DAA treatment. Following successful treatment, some individuals expressed extreme fear of reinfection, recognizing how easily they acquired the infection initially. Concerns about treatment eligibility and access also contributed to their fear of reinfection, as previously reported (Goodyear et al., 2021). Thus, emotional representations of illness varied among individuals, reflecting resilience as they actively managed and cured their HCV infection, while others continued to experience ongoing concerns due to their drug use. Our findings underscore the importance of tailored emotional support and reassurance at every stage of the care cascade, with particular emphasis on diagnosis and post-cure support. Although DAA treatment is generally less emotionally demanding than IFN therapies (Whiteley et al., 2016), addressing emotional well-being remains critical.

This study has several strengths and limitations. The diverse sample allowed the exploration of cognitive and emotional illness representations in people who inject drugs without a prior HCV infection, and in individuals with one or more HCV infection(s). Our sample also included individuals who completed IFN therapies, DAAs and both, offering a wide range of perspectives on treatment. The use of a theory-informed approach in conducting interviews allowed for direct comparisons with previous studies conducted using the CS-SRM, providing valuable insights into how individuals in this population experience and cope with HCV. Limitations include the fact that most of our sample was composed of middle-aged individuals self-identifying as white, limiting our ability to investigate how illness representations differ across axes of ethnocultural identity. Second, the presence of only one individual with an active

HCV infection might have resulted in an underrepresentation of people in need of (but not accessing) treatment. Lastly, our study was conducted in a single large urban community organization serving people who inject drugs in Montreal, Canada. While this organization is the largest in the province, we were not able to investigate how illness representations might have been influenced by other settings.

Conclusion

Despite nearly a decade of widespread availability of DAAs, significant misinformation regarding eligibility for (re)treatment persists, emphasizing the ongoing need for targeted efforts to address this issue. Achieving HCV micro-elimination among people who inject drugs in Quebec, Canada requires harm reduction community organizations to provide tailored and non-stigmatizing HCV prevention, testing and treatment services. This study highlights common concerns, knowledge gaps, coping strategies, and sources of information utilized by people who inject drugs in relation to HCV infection. To increase access to accurate information regarding HCV infection and treatment, NSP workers and nurses could be leveraged, and measures such as testing as a form of linkage to care and efficient mechanisms of retreatment can help reduce stigma. Furthermore, investigations in the barriers and enablers to HCV care perceived and experienced by people who inject drugs and individuals working in harm reduction community organizations should be undertaken using state-of-the-art implementation frameworks (Ruiz et al., 2022). By undertaking such investigations, we can gain valuable insights into the complex interplay of factors that shape HCV care experiences within the harm reduction community and inform the development of strategies aimed at optimizing HCV care delivery, improving treatment outcomes, and ultimately advancing progress towards the elimination of hepatitis C.

References

Amoako, A., Ortiz-Paredes, D., Engler, K., Lebouché, B., & Klein, M. B. (2021). Patient and provider perceived barriers and facilitators to direct acting antiviral hepatitis C treatment among priority populations in high income countries: A knowledge synthesis. *International Journal of Drug Policy*, *96*, 103247. https://doi.org/10.1016/j.drugpo.2021.103247

Backus, L. I., Belperio, P. S., Shahoumian, T. A., & Mole, L. A. (2018). Direct-acting antiviral sustained virologic response: Impact on mortality in patients without advanced liver disease. *Hepatology*, *68*(3), 827-838. https://doi.org/10.1002/hep.29811

Bartlett, S., Gennip, J., Marshall, A. D., Bonn, M., Fuchs, D., Yetman, G., Butler-McPhee, J., Cooper, C. L., Gallagher, L., Kronfli, N., Williams, S., Bruneau, J., Feld, J. J., Janjua, N., Klein, M., & Grebely, J. (2021, May 12-15). *Policies for reimbursement of direct-acting antiviral treatment for hepatitis C virus infection in Canada: "A Patchwork Of Obstruction."* Canadian Liver Meeting, [Virtual]. https://www.actionhepatitiscanada.ca/uploads/8/3/3/9/83398604/clm_2021-poster_bartlett_v2.pd

Boucher, L. M., Marshall, Z., Martin, A., Larose-Hébert, K., Flynn, J. V., & Lalonde, C., ... & Kendall, C. (2017). Expanding conceptualizations of harm reduction: results from a qualitative community-based participatory research study with people who inject drugs. *Harm Reduction Journal*, *14*(1), 1-18. https://doi.org/10.1186/s12954-017-0145-2

Canadian Network on Hepatitis C. (2019). *Blueprint to inform hepatitis C elimination efforts in Canada*. www.canhepc.ca/sites/default/files/media/documents/blueprint_hcv_2019_05.pdf

Crawshaw, J., Presseau, J., van Allen, Z., Pinheiro Carvalho, L., Jordison, K., English, S., Fergusson, D. A., Lauzier, F., Turgeon, A. F., Sarti, A. J., Martin, C., D'Aragon, F., Li, A. H., Knoll, G., Ball, I., Brehaut, J., Burns, K. E. A., Fortin, M. C., Weiss, M., . . . Canadian Donation and Transplantation Research Program and the Canadian Critical Care Trials Group. (2019). Exploring the experiences and perspectives of substitute decision-makers involved in decisions about deceased organ donation: a qualitative study protocol. *BMJ Open*, *9*(12), e034594. https://doi.org/10.1136/bmjopen-2019-034594

Cunningham, E. B., Wheeler, A., Hajarizadeh, B., French, C. E., Roche, R., Marshall, A. D., Fontaine, G., Conway, A., Valencia, B. M., Bajis, S., Presseau, J., Ward, J., Degenhardt, L., Dore, G. J., Hickman, M., Vickerman, P., & Grebely, J. (2022). Interventions to enhance testing, linkage to care, and treatment initiation for hepatitis C virus infection: a systematic review and meta-analysis. *The Lancet Gastroenterology & Hepatology*, *7*(5), 426-445. https://doi.org/10.1016/S2468-1253(21)00471-4

Cunningham, E. B., Wheeler, A., Hajarizadeh, B., French, C. E., Roche, R., Marshall, A. D., ... & Grebely, J. (2023). Interventions to enhance testing and linkage to treatment for hepatitis C infection for people who inject drugs: A systematic review and meta-analysis. *International Journal of Drug Policy*, *111*, 103917. https://doi.org/10.1016/j.drugpo.2022.103917

Degenhardt, L., Peacock, A., Colledge, S., Leung, J., Grebely, J., Vickerman, P., Stone, J., Cunningham, E. B., Trickey, A., Dumchev, K., & Lynskey, M. (2017). Global prevalence of injecting drug use and sociodemographic characteristics and prevalence of HIV, HBV, and HCV in people who inject drugs: a multistage systematic review. *The Lancet Global Health*, *5*(12), e1192-e1207. https://doi.org/10.1016/S2214-109X(17)30375-3

Degenhardt, L., Webb, P., Colledge-Frisby, S., Ireland, J., Wheeler, A., Ottaviano, S., ... & Grebely, J. (2023). Epidemiology of injecting drug use, prevalence of injecting-related harm, and exposure to behavioural and environmental risks among people who inject drugs: a systematic review. *The Lancet Global Health*. https://doi.org/10.1016/S2214-109X(23)00057-8

Dowsett, L. E., Coward, S., Lorenzetti, D. L., MacKean, G., & Clement, F. (2017). Living with Hepatitis C Virus: A Systematic Review and Narrative Synthesis of Qualitative Literature. *Canadian Journal of Gastroenterology and Hepatology*, 3268650. https://doi.org/10.1155/2017/3268650

Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2009). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology and Health*, *25*(10), 1229-1245. https://doi.org/10.1080/08870440903194015

Ghany, M. G., Morgan, T. R., & AASLD-IDSA hepatitis C guidance panel. (2020). Hepatitis C guidance 2019 update: American Association for the Study of Liver Diseases–Infectious Diseases Society of America recommendations for testing, managing, and treating hepatitis C virus infection. *Hepatology*, *71*(2), 686-721. https://doi.org/10.1002/hep.31060

Goodyear, T., Brown, H., Browne, A. J., Hoong, P., Ti, L., & Knight, R. (2021). "I want to get better, but…": identifying the perceptions and experiences of people who inject drugs with respect to evolving hepatitis C virus treatments. *International Journal for Equity in Health*, *20*(1), 1-14. https://doi.org/10.1186/s12939-021-01420-7

Grebely, J., Collins, A. B., Artenie, A. A., Sutherland, R., Meyer, J. P., & Barocas, J. A., ... & Treloar, C. (2021). Progress and remaining challenges to address hepatitis C, other infectious diseases, and drug-related harms to improve the health of people who use drugs. *International Journal of Drug Policy*, *96*, 103469. https://doi.org/10.1016/j.drugpo.2021.103469

Grebely, J., Dalgard, O., Conway, B., Cunningham, E. B., Bruggmann, P., Hajarizadeh, B., Amin, J., Bruneau, J., Hellard, M., Litwin, A. H., Marks, P., Quiene, S., Siriragavan, S., Applegate, T. L., Swan, T., Byrne, J., Lacalamita, M., Dunlop, A., Matthews, G. V., . . . SIMPLIFY Study Group. (2018). Sofosbuvir and velpatasvir for hepatitis C virus infection in people with recent injection drug use (SIMPLIFY): an open-label, single-arm, phase 4, multicentre trial. *The Lancet Gastroenterology & Hepatology*, *3*(3), 153-161. https://doi.org/10.1016/S2468-1253(17)30404-1

Hagger, M. S., Koch, S., Chatzisarantis, N. L., & Orbell, S. (2017). The common sense model of self-regulation: Meta-analysis and test of a process model. *Psychological Bulletin*, *143*(11), 1117-1154. https://doi.org/10.1037/bul0000118

Hagger, M. S., & Orbell, S. (2022). The common sense model of illness selfregulation: a conceptual review and proposed extended model. *Health Psychology Review*, *16*(3), 344-377. https://doi.org/10.1080/17437199.2021.1878050

Harris, M., & Rhodes, T. (2012). Venous access and care: harnessing pragmatics in harm reduction for people who inject drugs. *Addiction*, *107*(6), 1090-1096. https://doi.org/10.1111/j.1360-0443.2011.03749.x

Høj, S. B., Jacka, B., Minoyan, N., Artenie, A. A., & Bruneau, J. (2019). Conceptualising access in the direct-acting antiviral era: An integrated framework to inform research and practice in HCV care for people who inject drugs. *International Journal of Drug Policy*, *72*, 11-23. https://doi.org/10.1016/j.drugpo.2019.04.001

Hosseini-Hooshyar, S., Martinello, M., Yee, J., Read, P., Baker, D., & Post, J. J., et al. (2020). Low hepatitis C virus reinfection rate despite ongoing risk following universal access to direct-acting antiviral therapy among people living with HIV. *AIDS*, *34*(1347–1358). https://doi.org/10.1097/QAD.0000000000002562

Ioannou, G. N., Green, P. K., & Berry, K. (2017). HCV eradication induced by direct-acting antiviral agents reduces the risk of hepatocellular carcinoma. *Journal of Hepatology*(17), 32273-32270. https://doi.org/10.1016/j.jhep.2017.08.030

Jacka, B., Larney, S., Degenhardt, L., Janjua, N., Høj, S., Krajden, M., & .. & Bruneau, J. (2020). Prevalence of injecting drug use and coverage of interventions to prevent HIV and hepatitis C virus infection among people who inject drugs in Canada. *American Journal of Public Health*, *110*(1), 45-50. https://doi.org/10.2105/AJPH.2019.305379

Jones, L., Atkinson, A., Bates, G., McCoy, E., Porcellato, L., & Beynon, C. (2014). Views and experiences of hepatitis C testing and diagnosis among people who inject drugs: systematic review of qualitative research. *International Journal of Drug Policy*, *25*, 204-211. https://doi.org/10.10.1016/j.drugpo.2013.11.004

Leventhal, H., Diefenbach, M. A., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, *16*(2), 143–163. https://doi.org/10.1007/BF01173486

Lourenço, L., Kelly, M., Tarasuk, J., Stairs, K., Bryson, M., Popovic, N., & Aho, J. (2021). The hepatitis C epidemic in Canada: an overview of recent trends in surveillance, injection drug use, harm reduction and treatment. *Canada Communicable Disease Report*, 505-514. https://doi.org/10.14745/ccdr.v47i12a01

Marshall, A. D., Martinello, M., Treloar, C., & Matthews, G. V. (2022). Perceptions of hepatitis C treatment and reinfection risk among HIV-positive men who have sex with men and engage in high risk behaviours for hepatitis C transmission: The CEASE qualitative study. *International Journal of Drug Policy*, *109*, 103828. https://doi.org/10.1016/j.drugpo.2022.103828

Marshall, A. D., Saeed, S., Barrett, L., Cooper, C. L., Treloar, C., Bruneau, J., Feld, J. J., Gallagher, L., Klein, M. B., Krajden, M., Shoukry, N. H., Taylor, L. E., Grebely, J., & the Canadian Network on Hepatitis C. (2016). Restrictions for reimbursement of direct-acting antiviral treatment for hepatitis C virus infection in Canada: a descriptive study. *CMAJ Open*, *4*(4), E605-E614. https://doi.org/10.9778/cmajo.20160008

Martinello, M., Grebely, J., Petoumenos, K., Gane, E., Hellard, M., & Shaw, D. (2017). HCV reinfection incidence among individuals treated for recent infection. *Journal of Viral Hepatitis*, *24*(5), 359-370. https://doi.org/10.1111/jvh.12666

Mortazhejri, S., Patey, A. M., Stacey, D., Bhatia, R. S., Abdulla, A., Grimshaw, J., & et al. Understanding determinants of patients' decisions to attend their family physician and to take antibiotics for upper respiratory tract infections: a qualitative descriptive study. BMC Fam Pract 21. (2020). Understanding determinants of patients' decisions to attend their family physician and to take antibiotics for upper respiratory tract infections: a qualitative descriptive study. *BMC Family Practice*, *21*, Article number: 119. https://doi.org/10.1186/s12875-020-01196-9

Nahon, P., Bourcier, V., Layese, R., Audureau, E., Cagnot, C., Marcellin, P., &, & Ouzan, D. (2017). Eradication of hepatitis C virus infection in patients with cirrhosis reduces risk of liver and non-liver complications. *Gastroenterology*, *152*(1), 142-156. https://doi.org/10.1053/j.gastro.2016.09.009

Nelson, P., Mathers, B., Cowie B, Hagan H, Jarlais DD, & Horyniak D, e. a. (2011). The epidemiology of viral hepatitis among people who inject drugs: results of global systematic reviews. *The Lancet*, *378*(9791), 571-583. https://doi.org/10.1016/S0140-6736(11)61097-0.

Public Health Agency of Canada. (2019). *Accelerating our response: Government of Canada five-year action on plan on sexually transmitted and blood-borne infections*. https://www.canada.ca/content/dam/hc-sc/documents/services/reports-publications/accelerating-our-response-five-year-action-plan-sexually-transmitted-blood-borne-infections/stbbi-federal-action-plan-en.pdf

Rhodes, T., & Treloar, C. (2008). The social production of hepatitis C risk among injecting drug users: a qualitative synthesis. *Addiction*, *103*, 1593–1603. https://doi.org/10.1111/j.1360-0443.2008.02306.x

Rossi, C., Butt, Z. A., Wong, S., Buxton, J. A., Islam, N., Yu, A., ... &, & Team, T. B. H. T. C. (2018). Hepatitis C virus reinfection after successful treatment with direct-acting antiviral therapy in a large population-based cohort. *Journal of Hepatology*, *69*(5), 1007-1014. https://doi.org/10.1016/j.jhep.2018.07.025

Ruiz, A. S., Fontaine, G., Patey, A. M., Grimshaw, J. M., Presseau, J., & Cox, J., ... & Kronfli, N. (2022). Identifying barriers and enablers to opt-out hepatitis C virus screening in provincial prisons in Quebec, Canada: A multilevel, multi-theory informed qualitative study with correctional and healthcare professional stakeholders. *International Journal of Drug Policy*, *109*, 103837. https://doi.org/10.1016/j.drugpo.2022.103837

Saeed, S., Strumpf, E., Moodie, E. E., Wong, L., Cox, J., Walmsley, S., Tyndall, M. W., Cooper, C., Conway, B., Hull, M., Martel-Laferriere, V., Gill, J., Wong, A., Vachon, M. L., & Klein, M. B. (2020). Eliminating structural barriers: the impact of unrestricted access on hepatitis C treatment uptake among people living with human immunodeficiency virus. *Clinical Infectious Diseases*, *71*(2), 363-371. https://doi.org/10.1093/cid/ciz833

Safo, S. A., Batchelder, A., Peyser, D., & Litwin, A. H. (2015). The common sense model applied to hepatitis C: a qualitative analysis of the impact of disease comparison and witnessed death on hepatitis C illness perception. *Harm Reduction Journal*, *12*(1), 1-8. https://doi.org/10.1186/s12954-015-0054-1

Saine, M. E., Szymczak, J. E., Moore, T. M., Bamford, L. P., Barg, F. K., Schnittker, J., Holmes, J. H., Mitra, N., & Lo Re III, V. (2020). Determinants of Stigma among Patients with Hepatitis C Virus (HCV) Infection. *Journal of Viral Hepatitis*. https://doi.org/10.1111/jvh.13343

Schanzer, D., Pogany, L., Aho, J., Tomas, K., Gale-Rowe, M., Kwong, J. C., Janjua, N. Z., & Feld, J. (2018). Impact of availability of direct-acting antivirals for hepatitis C on Canadian hospitalization rates, 2012-2016. *Canadian Communicable Diseases Reports*, *44*(7-8), 150-156. https://doi.org/10.14745/ccdr.v44i78a01

Shah, H., Bilodeau, M., Burak, K. W., Cooper, C., Klein, M., Ramji, A., Smyth, D., & Feld, J. J. (2018). The management of chronic hepatitis C: 2018 guideline update from the Canadian Association for the Study of the Liver. *Canadian Medical Association Journal*, *190*(22), e677-e687. https://doi.org/10.1503/cmaj.170453

Tarasuk, J., Zhang, J., Lemyre, A., Cholette, F., Bryson, M., & Paquette, D. (2020). National findings from the Tracks survey of people who inject drugs in Canada, Phase 4, 2017–2019. *Canada Communicable Disease Report*, *46*(5), 138-148. https://doi.org/10.14745/ccdr.v46i05a07

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

Valencia, J., Alvaro-Meca, A., Troya, J., Cuevas, G., Gutiérrez, J., & Morro, A., ... & Ryan, P. (2019). High rates of early HCV reinfection after DAA treatment in people with recent drug use attended at mobile harm reduction units. *International Journal of Drug Policy*, *72*, 181-188. https://doi.org/10.1016/j.drugpo.2019.06.016

Whiteley, D., Whittaker, A., Elliott, L., & Cunningham-Burley, S. (2016). The lived experience of interferon-free treatments for hepatitis C: A thematic analysis. *International Journal of Drug Policy*, *38*, 21-28. https://doi.org/10.1016/j.drugpo.2016.10.013

World Health Organization. (2016). Monitoring and evaluation for viral hepatitis B and C: Recommended indicators and framework Technical Report. http://apps.who.int/iris/bitstream/10665/204790/1/9789241510288_eng.pdf

World Health Organization. (2022). *Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030*. World Health Organization. https://apps.who.int/iris/rest/bitstreams/1451670/retrieve

Wozniak, L., Prakash, M., Taylor, M., & Wild, T. C. (2007). Everybody’s got it, but . . . : situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada. *Int J Drug Policy*, *18*, 388–396. https://doi.org/10.1016/j.drugpo.2007.02.006

Tables

Table 1. CS-SRM dimensions and definitions, and example questions from interview guide.

CS-SRM dimensions	Classic definition	Definition relating to hepatitis C	Example question(s) from interview guide
***1.* Cognitive illness representations**			
1.1. Identity	How symptoms are experienced and attributed to the illness along with the label given to the illness itself.	How the person labeled hepatitis C and whether they experienced its symptoms.	*Have you ever experienced any symptoms related to hepatitis C and if so, what were they?*
1.2. Timeline	Beliefs about the rate of onset, the duration, and fluctuation in the illness (e.g., acute, chronic).	How long they believed hepatitis C would last or lasted and whether it fluctuated.	*How long did you experience the symptoms? Did your symptoms fluctuate?*
1.3. Cause	Beliefs about the causal antecedents of the illness (e.g., genetics, infection, diet, aging, or other exacerbating factors).	What they believed would cause or caused hepatitis C.	*How do you think you acquired (and could reacquire) hepatitis C? What caused it?*
1.4. Consequences	Beliefs about the likely impact of the illness on life events (e.g., work, family, personal relationships).	How serious they believed hepatitis C was or would be.	*What were the consequences of hepatitis C infection on you? Has it affected your working life or daily life?*
1.5. Perceived control	Beliefs regarding the controllability/curability of the illness.	The extent to which they believed that hepatitis C was controllable/curable.	*Can an hepatitis C infection be cured? How? If not, can the infection be controlled?*
1.6. Coherence	The patient's understanding about the illness, how they 'make sense' of it.	Their understanding of hepatitis C.	*How well do you feel you understand hepatitis C and the treatment options? Does it all make sense to you?*
2. Emotional illness representations	Beliefs about the emotional impact of the illness.	What emotions did they feel when they learned about their hepatitis C diagnosis/would they feel?	*How does/did hepatitis C and its symptoms make you feel? Does/did it make you angry, scared, upset or depressed?*
3. Coping strategies	Strategies to cope with illness, updated based on success/failure in dealing with previous illness episodes.	Which strategies did they use/would use to deal with hepatitis C?	*How do/did you usually manage your symptoms and illness? Does/did it help?*

CS-SRM dimensions	Classic definition	Definition relating to hepatitis C	Example question(s) from interview guide
4. Situational stimuli/sources of information	Lay information stored in memory, information from expert sources, and experienced somatic and symptomatic information.	Endogenous sources of information on hepatitis C, such as experienced symptoms and somatic responses, or from external sources (e.g., physician).	*Apart from your personal experiences, how do you get information about hepatitis C and its treatment/care? Where do you usually look for information?*

Table 2. Characteristics of study participants (N = 18).

	Participants, No. (%)
Age, y	
18-39	5 (28)
40-59	12 (67)
>60	1 (6)
Gender	
Female	5 (28)
Male	13 (72)
Ethnicity	
White	15 (83)
Indigenous/Metis	3 (17)
Housing situation	
No housing	10 (56)
Transitional	5 (28)
Stable	3 (17)
Drugs injected, past three months	
Opioid	9 (50)
Stimulant	3 (17)
Opioid & Stimulant/Other combination	6 (33)

Opioid agonist therapy, past three months	
Yes	5 (28)
No	13 (72)
Past hepatitis C virus (HCV) infection(s)	
None	4 (22)
1	10 (56)
>1	4 (22)
Treatment(s) completed	
None	8 (44)
Interferon-based (IFN) therapy	2 (11)
Direct-acting antivirals (DAAs)	7 (39)
IFN & DAAs	1 (6)

Figure legends

Figure 1. The Common-Sense Self-Regulation Model (CS-SRM), adapted from Hagger and Orbell (2022).