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Water Journey: emerging themes for research priorities for Indigenous Peoples in Canada and hepatitis C

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ABSTRACT

Indigenous Peoples in Canada (First Nations, Inuit and Métis) bear a disproportionate disease burden for hepatitis C (HCV). This issue must be framed within the context of historical and ongoing trauma. Newly available and highly effective HCV therapeutics have transformed the treatment landscape. A pressing need exists for Indigenous leadership in this area, as well as the development of programs, policies and comprehensive HCV research agenda that will realize health equity for Indigenous Peoples.

We conducted four concurrent sharing circles (one male, two female and one two-spirit/gender-diverse) in which Indigenous People with diverse lived HCV experience discussed HCV research priorities. Indigenous Elders guided the sharing circles, which were held as part of a wellness ceremony. The sharing circles were audio recorded, transcribed verbatim and analyzed qualitatively using a grounded theory-based approach. Participants discussed both individual and systems-level factors which impacted their life course with hepatitis C. Six cross-cutting themes emerged from the analysis of the sharing circle discussions: (1) strength, resilience and hope; (2) intersectionality; (3) barriers across the care continuum; (4) competing priorities in relation to hepatitis C; (5) health literacy; and (6) transformation. These findings present opportunities for ways forward that honour Indigenous Knowledges and Ways of Knowing.

The *Water Journey* themes were subsequently validated with other Indigenous communities, helping to build a comprehensive understanding of community-driven research and health priorities for HCV. This project highlights the criticality of involving Indigenous leadership in setting HCV research priorities, programs and policies pertaining to First Nations, Inuit and Métis, as well as the importance of the application of Indigenous research methodologies and Ways of Knowing that privilege community voice and lived experience. The themes identified in the *Water Journey* project must be taken into consideration across the realms of HCV research, policy, prevention programs and throughout the care continuum.

BACKGROUND

Water Journey is a community-based research project aimed at examining the research priorities for Indigenous Peoples in Canada (First Nations, Inuit and Métis) and hepatitis C. The purpose of *Water Journey* is to elucidate and explore culturally resonant ways in which to aid and support Indigenous Peoples who have been impacted by hepatitis C in their journeys of healing, wellness and self-empowerment. The knowledge and insight gained from this project will inform the development of a larger exploratory study focused on creating a comprehensive national research framework for Indigenous Peoples in Canada and hepatitis C.

This paper is the third in a three-part series of articles focused on the *Water Journey* project in this edition of the CJACBR. The first article, a scoping review titled “Community-directed research priorities for Indigenous peoples in Canada and hepatitis C” (pages 22 – 42) synthesizes the existing body of scholarly literature focused on Indigenous peoples and hepatitis C (Macklin et al., 2017). The second article, titled: “Water Journey: methods for exploring the research

priorities for Indigenous peoples in Canada and hepatitis C” (pages 44 – 59) discusses, in detail, the research methodologies utilized by the *Water Journey* project (Macklin et al., 2017).

INTRODUCTION

On 15 July 2015, a series of four concurrent sharing circles were held in Vancouver to discuss Indigenous Peoples’ experiences with hepatitis C. These sessions were later followed by two community validation sessions across Canada. This paper focuses exclusively on the results of the *Water Journey* sharing circles and community validation sessions. OCAP™ (Ownership, Control, Access, Possession) principles were embedded within all stages of the *Water Journey* project; from conceptualization, to actualization of the sharing circles, and finally to analysis and revisions of the findings (NAHO, 2005).

The *Water Journey* sharing circles were part of a larger event for Indigenous Peoples focused on healing and wellness. The sharing circles were conducted with a total of 32 participants, all of whom were Indigenous and had lived experience with hepatitis C. The four sharing circles (one male circle, two female circles and one two-spirit/gender-diverse circle) were held concurrently. Each circle was led by an Indigenous Elder. Further details regarding the research methodologies employed (including participant recruitment, ethical considerations and qualitative data analysis) can be found in the accompanying methodology paper (Macklin et al., 2017).

Briefly, each participant was invited to self-select into the sharing circle (e.g. male, female or two-spirit/gender diverse) that they most identified with in terms of their self-identified gender identity that day. Due to constraints related to resources, personnel and recruitment, our research team was unable to facilitate a separate transgender-only sharing circle. We recognize that not all transgender people feel comfortable speaking freely in the company of other groups. Again, we recognize this as a limitation of the study and an important consideration moving forward. Due to concerns related to confidentiality, minimal demographic information about participants was collected. While no age demographics were gathered, researchers noted that youth and young adults, participants from northern and Inuit communities, as well as Indigenous persons from rural locations were under-represented in the sharing circles. As such, attempts to include their voices were made during the community validation sessions, but this is also recognized as a limitation of our results.

The sharing circles were recorded and transcribed verbatim. Grounded theory-based analysis was utilized, whereby an inductive approach was employed to generate exhaustive and substantial codes from the data. Next, the codes were organized and collapsed, through which over-arching themes and sub-themes emerged. Validation sessions with community health providers and additional Indigenous persons with lived hepatitis C experience were later held in Ottawa (15 September 2015) and Manitoulin Island (29 October 2015). The community validation sessions also served to espouse OCAP™, as community members were able to impact information management processes during the review process, ensuring that the community ‘owned’ and ‘controlled’ the research and results, and had adequate ‘access’ to make decisions regarding the collective information which was gathered. Upon completion of the thematic analysis, initial preliminary themes from *Water Journey* were also shared with those who attended the sharing

circle event, and further feedback on the relevance of the emergent themes to their lived experience was solicited. All paper-based data related to the project is securely stored in a locked file cabinet at the medical practice of Dr. Alexandra King (who is the NPI of the Water Journey project and an Indigenous physician working with Indigenous people living with HCV). Dr. King is the only person to have access to these files. Finally, all electronic data related to the project is securely stored on an encrypted and password-protected virtual storage space at Simon Fraser University (the institution of co-author Dr. Malcolm King, an Indigenous professor and health researcher). Doctors Alex and Malcolm King, and the Project Coordinator are the only team members who have access to these files.

This article integrates the findings from analysis of the *Water Journey* sharing circles with feedback received from the community validation sessions. The aim of this article is to distill the complex realities of the male, female and two-spirit/gender diverse sharing circle participants into multiple and intertwined, yet distinct, themes which will inform recommendations and research priorities for Indigenous Peoples in Canada and hepatitis C. The themes presented in this document are supported by de-identified quotes from both the sharing circles and validation sessions.

Six key themes emerged from the collective discourse: (1) strength, resilience and hope; (2) intersectionality; (3) barriers across the continuum of care; (4) competing priorities in relation to hepatitis C; (5) health literacy; and (6) transformation. The themes encompass concepts at the individual, community and systems levels. From these themes, a set of recommendations and research priorities were generated to guide and inform future research, program and policy exploration related to Indigenous Peoples in Canada and hepatitis C.

RESULTS

Theme #1: Strength, Resilience and Hope

Western medicine has been critiqued as being deficit-based, overly disease-focused and offering narrow biomedical solutions. Contrasting this, participants of the sharing circles and validation sessions centred their attention on the collective strengths of Indigenous Peoples, finding positive examples of resilience and healing to celebrate and expand upon. Many of the sharing circle participants exhibited great strength and resilience in the face of a lifetime of adversity. Participants described poignant and powerful examples of strength, resilience and hope along their healing journeys.

Being active within the community and engaging with others were key ways in which people gained and displayed strength and resilience. For some, this included the act of coming to the sharing circles:

“You’re all active, I call you activists because you got out off the couch and you came down here. That’s action. So, you are the strong ones. You know, I always felt like I was weak until I met some of the other people with no voice living in the darkness.” ~Two-Spirit Circle

For other participants, sharing their stories were ways in which they displayed strength and resilience, regardless of their circumstances. Many emphasized the importance of using their stories as tools for teaching and learning. These individuals had the courage to speak about their lived experience of hepatitis C and to share their knowledge and wisdom for the benefit of others. As evidenced in the quote below, participants found sharing examples of their strength and resilience empowering.

“The more I learned, the more I helped others to learn more. I’m grateful I can share. It’s only made me stronger as an Indigenous woman.” ~Women’s Circle 1

This idea of using stories to build strength and resilience was also echoed in the validation sessions. As one participant said:

“With respect to resilience, I was using [similar] teaching methods at our forums. It’s demonstrated itself to be the most effective way - especially working with youth. Because when you give them all the stats, nothing sticks, but the stories ultimately impact and make a difference.” ~Validation Session 1

Some participants discussed that engaging with others affected by hepatitis C was empowering and gave them hope that there were many positive ways forward as an Indigenous person living with hepatitis C.

“...just hearing all of your stories. The resiliency, that really stands out to me in each and every one of you. And I just want to thank you for that...this is an issue that really does need to be brought to the forefront, and I think that your voices are going to be really strong in bringing this forward.” ~ Two-Spirit Circle

This strong, hopeful attitude prevailed throughout the sharing circle gathering. At the end of the sharing circle event, a final collective sharing circle was held where each participant was asked to say a word or phrase that described their feelings about the gathering. Participants chose words such as “Encouraged”, “One voice, one people, one victory”, “Empower”, “Love, peace and light”, “Resiliency”, “Believe in yourself”, “Always have faith” and “Together we can”.

Despite experiencing difficult life circumstances, many participants related their successes to their ability to be strong and resilient.

“So...the reason why I believe I’m still alive is because I looked into the face of my demons. I stopped pushing them behind me, and stopped pretending they weren’t there, and brought them out in front of me...so I could learn to love them, and that’s way harder to do than it is to say.” ~Women’s Circle 2

The sharing circles also revealed that many Indigenous People want to actively participate in the process of deciding the program and research priorities for hepatitis C within their communities. In light of this, it is evident that the development of a national research agenda for Indigenous

Peoples and hepatitis C in Canada must incorporate resiliency, empowerment and strengths-based interventions.

Theme #2: Intersectionality

The psychosocial and cultural realities of Indigenous persons living with hepatitis C are shaped by the interaction of many things. These factors include the complex, systematic injustices and inequities that many Indigenous People in Canada experience. Upstream health determinants (e.g. Indigeneity, gender, colonization), as well as other contributors such as injection drug use, homelessness, incarceration, and co-infection with HIV, affect one's experience with hepatitis C. All of these combine and interact to create complex situations for people living with hepatitis C. Some of these experiences may hinder one's healing journey; however, others, such as Indigeneity, gender and connection to culture, have the potential to promote resilience and support in people's journeys toward healing.

As one participant in the validation sessions said:

“Multi-generational trauma...that's enormous. That is absolutely huge. That is the reason why things are the way they are is because of all of that history.” ~Validation Session 2

In the women's and two-spirit circles, gender emerged as an important factor that mediated some participants' experiences with hepatitis C. Female and two-spirit participants found that gender had both positive and negative impacts on their journeys with hepatitis C. As seen in the quote below, some women found strength in their identities as Indigenous women:

“As a female, as a woman, I think the disease made me stronger to fight and obtain healing. Nothing was going to get in the way; nothing was going to stop me from living as long as I wanted to.” ~Women's Circle 1

However, participants did discuss the negative impacts of their gender and Indigenous identities, especially in conjunction with stereotyping and stigma.

“The only gender issue I have is...why is it when a female has hep C they presume that you either slept around or worked the street? Because that's the feedback that I got. You don't have to be from that, and if you are, so what? ...but that's the only gender issue that I encountered, which was hurtful, and to me, it was a barrier for me wanting to be public, wanting to participate in anything openly.” ~Women's Circle 1

“I guess my barriers as a woman is living in fear all my life.” ~Women's Circle 1

“I came out of the closet, I started on my healing journey. I started to find out who I was. And, I've ran into barriers, you know, because I don't present as a gay man ... I get lots of doctors going well you're not gay, are you?” ~Two Spirit Circle

“We're Aboriginal people. We're labelled.” ~Men's Circle

Often these labels: female, two-spirit, Aboriginal, hepatitis C positive interact in different ways, which affect each person's healing journey differently. The effects of racist and colonialist policies were also mentioned directly. Examples of the effects of such policies are illustrated in the quote below:

“I know this [hep c] has to do with residential school and the 60's scoop.” ~Women's Circle 2

Similarly, in the validation sessions, participants discussed how historical trauma has led to current health inequities:

“People have been resilient, we've seen it. It's all over the place, everywhere. They are still alive...there is still a culture and that in and of itself is an amazing thing. But this also has the tendency to bring along barriers... resiliency sometimes means putting up walls. And those walls may stop people from being able to access information.” ~Validation Session 2

Participants in the validation sessions also acknowledged that moving forward from historical trauma required cultural safety to be incorporated into interactions both inside and outside the healthcare setting.

“We have to start with...basics that incorporate the cultural safety and the cultural practices.” ~Validation Session 2

In the sharing circle discussions, many also referred to the distal effects of upstream intersectional determinants, such as poorer mental health outcomes, incarceration, increased risk of substance use, and HIV and hepatitis C infection. Injection drug use and homelessness were often discussed in connection with contracting hepatitis C. One participant identified how foster care and homelessness were related to getting hepatitis C:

I was in foster care also, my whole life, and I ran away from foster parents at the age of 10 because nobody was hearing me out, and hearing me cry. So, I turned to the streets; that's how I got my hep C” ~Women's Circle 1

Incarceration is highly associated with hepatitis C. Many people are diagnosed either entering or during incarceration. In the demographic survey completed by our sharing circle participants, 63% reported involvement with the criminal justice system. One participant discussed his experience with the prison system and how the lack of harm reduction programs, such as needle exchanges, place inmates at risk:

“So there are no places to get syringes, you make your own, or it's shared and shared. That's where mine came from [hepatitis C], so you know some day, the majority of those people, those men are going to go back to their communities with the disease.” ~Men's Circle

In addition to being at an increased risk of contracting hepatitis C while incarcerated, many issues related to testing and treatment exist in prisons. One participant discussed the impacts of being unable to have a smooth transition from prison care to community care:

“I didn’t really start paying attention to my hep C until I went to federal jail and went on the interferon treatment... But they don’t transfer files...to another province. I finished as much as I could on it. My tests were coming back negative but now they come back positive.”

~Women’s Circle 2

Even if treatment is started in prisons, there are dangers for those who are incarcerated. Testing and treating hepatitis C can lead to increased stigmatization of the individual. In the validation sessions, participants discussed issues with testing, stigmatization and support in prisons:

“The other thing is that, historically, they didn’t want to be tested, or if they were hep C positive, they wouldn’t go on treatment because you are already so vulnerable in prison.”

~Validation Session 1

“The medical staff at the municipal and provincial institution here in Ottawa, they don’t even test the inmates, they don’t screen. And they don’t even let [support organizations] in.”

~Validation Session 1

The issue of treating people living with hepatitis C in prisons is closely tied to interferon-based treatments for hepatitis C, which had long treatment courses and often debilitating side effects. Not only were people having issues with maintaining their treatment regimens when they transferred from community to prison or vice versa, but they were also being ‘outed’ in prisons by the treatment side effects. Fortunately, the newer direct acting antiviral (DAA) treatments have shorter courses and are more easily tolerated. However, current policy related to hepatitis C in prisons has yet to realize the potential of these new medications.

The prison system is just one example where complex factors - environments, behaviours and policies - interact with Indigeneity. These factors are experienced in unique ways by Indigenous Peoples, resulting in unique patterns of hepatitis C transmission, as well as distinct considerations with regards to prevention, treatment, support and healing.

Theme # 3: Barriers across the Continuum of Care

In comparison to their non-Indigenous counterparts, Indigenous People living with hepatitis C often have difficult or strained relationships with the healthcare system, which can influence the types of programs, policies, treatment and care that they can, or will, access. Legacies of colonialism and racist health policies have left many Indigenous People with a deep mistrust of the health care system. Moreover, upstream determinants of health combine with other structural issues to create barriers within the continuum of hepatitis C care for Indigenous Peoples.

At the systems level, issues such as cultural safety and geography, may impede the ability of some Indigenous Peoples to access services. In the validation sessions, participants discussed

how clinic hours, locations or visibility affected access to services. This sentiment is evidenced in the quote below:

“Our geographical context- transportation and infrastructure up here...the treatment programs ...they exist, but how do you get to them? How do you deal with other needs while you are trying to meet those appointments and follow through with your other treatment?”

~Validation Session 2

In addition to geographical location, issues around safety and confidentiality were raised. For many people living with hepatitis C, stigma is another barrier which impedes or deters people from accessing care. Participants in the validation sessions discussed how clinic hours, locations and visibility greatly affected the working middle class of people living with hepatitis C.

“There is a middle class of people that do have hepatitis C... if you have a full-time job, if you are sort of in that working middle class area, you can’t take time off work for treatment, for appointments, there are all of those competing issues. So on the one hand, you may have transportation...to get to your appointments, but it’s not a safe space. Even within agencies and organizations and that’s because of the systemic issues.” ~Validation Session 2

In the sharing circles, participants expressed feelings of anxiety and fear related to both receiving treatment and the health outcomes of having hepatitis C. Again, this fear of treatment was related to the harsh side effects, long treatment courses and low success rates of interferon-based regimens. Subsequently, many participants expressed experiencing fear that was interfering with their willingness to try the new DAA treatments:

“My doctor is really good and she wants me on [the new drugs] but I’m scared. It’s the meds. I’m really sick of meds.” ~Women’s Circle 2

“With regards to treatment and that, I’m looking forward to it, but yet, I’m a little bit scared. Anybody’s scared, I am anyway, because of the fact I don’t know what kind of reaction I would have.” ~Two-Spirit Circle

“[The interferon-based treatments are] really harsh, a harsh treatment. It was really hard; as I said it broke my spirit down.” ~Women’s Circle 1

“I was really scared because my hair started falling out and I was sick. I didn’t have motivation to get up and take care of myself and it started taking over my body. Hep C [treatment] started taking over my life. I’m scared the new treatment is going to do the same thing.” ~Women’s Circle 2

Participants discussed that the fear of side effects was a barrier to entering into care and continuing on treatment. Despite this fear, participants who had access to the new treatments reported positive experiences with regards to side-effects.

“But with the new Harvoni treatment, it's just totally amazing, everyone is getting a really good report card, with little effects or no effects at all and getting cured.” ~Men's Circle

“And, I was able to start these treatments. It was harsh, almost like radiation, but now I'm on this other treatment, it's called Harvoni, and it's from the States and it's not being given out to just anybody.” ~Women's Circle 1

In the sharing circles, participants who had discussed their fear towards treatment were receptive to the positive stories shared by other participants. This warm reception shows that although there is fear of treatment, individuals are open to possibilities, especially when presented from trusted sources, such as peers. As mentioned in the first theme: Strength, Resilience and Hope; participants highlighted the importance of being able to share their stories and learn from others to help overcome fear and anxiety. Support services were also discussed as another way to combat barriers such as fear. In the sharing circles, participants described their positive experience with formal support services, especially those support services that were geared towards Indigenous Peoples.

“I did talk to a social worker quite a bit, and she said that she had [hepatitis C], too, but with her treatment she got rid of it. And, I think that was a big factor for me leading a support group, where people can get together and talk about their experiences.” ~Women's Circle 1

“But nowadays, there's so many places you could go to: there's the needle exchange, there's outreach workers, Cedar project and all those places people can go.” ~Women's Circle 1

Despite some participants feeling supported by services, many others in the sharing circles and validation sessions commented on a lack of support services. For some, this was due to program structure, as seen below:

“The Centre for Disease Control said “well, you should go to a hep C support group on Tuesday between the hours of 1 and 3”. Now what if we're at work or if we're laid up in bed or something like that? Who has that time?” ~Men's Circle

In the validation sessions, healthcare providers also discussed the lack of follow-up support and care. From a provider point of view, program structure often did not allow for follow-up with patients:

“In the clinical setting, you don't always get to hear the after story. You don't get to follow-up and hear the successes...our program doesn't have it built in where we can have a post-treatment group or we can have a year later follow-up” ~Validation Session 1

For others in the sharing circles, lack of information about where to find services was a barrier.

“There was no support. I tried looking for a support group...I felt so alone, I felt I was the only one who had hep C.” ~Women's Circle 1

Although some participants were connected with support services, the overwhelming message pointed to the need for wholistic services to help one cope with the emotional, physical, mental and spiritual burden of hepatitis C. Many of these services are not located within the current hepatitis C care continuum and, therefore, participants had to go elsewhere to meet their healing needs. For example, participants discussed the positive effects of traditional medicines and healing:

“All I know is that...when I'm working with the [traditional] medicines I just feel better. It doesn't matter what's going on in the day.” ~Two-Spirit Circle

“Smudging and praying, it's just been very helpful for me... just being able to be a part of that. That would last a long time with me, to motivate, give me strength. So I always look forward to those days.” ~Two-Spirit Circle

“I've sat with my Elders, who I'm very blessed to have access to, and they have really helped me heal from that, and I'm walking this journey for a reason, just like the other journeys that I've walked.” ~Women's Circle 1

In sum, despite the many barriers identified across the care continuum, participants pointed to promising solutions at the systems, community and individual levels, such as programs that improve cultural safety, peer support programs and services that integrate culture and traditional medicine.

Theme #4: Competing priorities in relation to hepatitis C

As with many of the other themes, the priority of hepatitis C in one's life is a complex theme in which systemic and individual factors influence how much attention an individual (or healthcare provider) gives to one's hepatitis C at any point in time. This struggle to balance one's hepatitis C diagnosis with other priorities was reflected in the sharing circles and validation sessions.

People living with hepatitis C may also have chronic diseases. At the clinical level, a common theme for participants who had comorbidities was that hepatitis C was often given a low priority by physicians. In the past, healthcare providers often only treated hepatitis C when it was in its advanced stages, or only treated patients who were either highly motivated to enter and sustain treatment or could access the large tertiary hospital-based programs. Our participants discussed the impacts of these clinical guidelines:

“Having hep C excluded me from many trials...because they wouldn't look at people with comorbidities. I asked to be on the list to do the treatments back in 2009-10 and they said no, it would probably kill you.” ~Women's Circle 1

“They want to focus on my HIV rather than my hep C. So I don't even know what's going on with [my hepatitis C].” ~ Women's Circle 2

“I was told by a nurse years ago that ‘Oh don’t worry, you aren’t going to die from this. They will find a cure’.” ~Validation Session 1

Consequently, many people living with hepatitis C have accepted that treating hepatitis C is not a priority. Rather, they have learned from healthcare providers to prioritize their comorbid diseases.

“I’m really just adjusting to my HIV and other issues, and it’s not on the forefront of anything that I do. I think about HIV, but I don’t think about the Hep C part.” ~Two-Spirit Circle

Due to the presence of intersecting health determinants and environmental/behavioural risk factors, it may be appropriate, in some instances, for both the individual and healthcare providers to focus less on hepatitis C treatment. As previously discussed, Indigenous People living with hepatitis C face a myriad of barriers, but also have a variety of strengths. At times, certain barriers, such as drug addiction, food insecurity or unstable housing, require a higher priority than hepatitis C treatment. Yet, there is a paucity of support services to aid with these problems, and thus these additional issues may stall or delay addressing hepatitis C for many people. This topic was discussed at length in one of the validation sessions. Healthcare professionals acknowledged that placing a low priority on hepatitis C is often appropriate:

“If we are... really being strategic about taking a wholistic approach to individual needs...we as service providers...need to put hep C lower on our list of priorities in terms of our own response. Some people are OK living with hepatitis C and have other comorbidities. And some people are going to think about income security and housing way more than hepatitis C.” ~Validation Session 1

For individuals living with hepatitis C, placing low priority on their disease (i.e. not pursuing treatment) may be a coping mechanism. Many participants expressed that they “forgot” or “ignored” that they had hepatitis C.

“And I’m already at the last stage. I’ve got liver cirrhosis. And that could lead to cancer too at any time. But, it’s one thing I don’t worry about. I don’t prioritize that in my life. Whatever’s going to happen, will happen.” ~Women’s Circle 1

“I didn’t pay attention at all to the Hep C, it was the drugs; that was my life...I even forgot that I had been diagnosed.” ~Women’s Circle 2

With new DAA treatments, hepatitis C can often be treated earlier - well before the development of serious liver issues. This has opened the door to treating a much larger cohort of patients. However, it is evident that the lingering effects of past treatment policies mean that many healthcare professionals still avoid addressing or referring a person for hepatitis C treatment.

New hepatitis C therapeutics are providing hope. However, discussions by sharing circle participants highlighted that increased efforts must be undertaken to increase awareness of

hepatitis C, improve prevention strategies and explain the available treatment options in a culturally appropriate way.

Theme #5: Health Literacy

Much of the discussion in both the sharing circles and validation sessions centred on the need for improved health literacy for both healthcare providers and people at risk for or living with hepatitis C. For many, the issue of literacy was seen as a key issue and as a starting point to moving forward.

“The health literacy piece... I kind of zoomed in on that one because I think it’s sort of the starting point for a lot of the other pieces. If we don’t have the information, if we don’t have the literacy, if we [as health providers] don’t know what we are talking about...then it’s difficult to tap into and deal with the barriers.” ~Validation Session 2

From a healthcare provider point of view, there was evidence that many, especially those who did not specialize in liver disease or who were in rural settings, were lacking literacy regarding hepatitis C testing and treatment. Participants of both sharing circle and validation sessions discussed the need for healthcare providers to be more health literate to better inform and treat their patients. As evidenced by the quotes below, participants experienced first-hand the effects of poor health literacy in healthcare providers:

“I don’t think that every nurse and every doctor is trained in even the basics of hepatitis C. I’ve been mistreated in hospitals, I’ve been mistreated in my pregnancy, and, on diagnosis...I was told that I had hepatitis C and they left the room.” Women’s Circle 1

In the validation sessions, specific concerns regarding the health literacy of service providers surfaced:

“When I got my viral load for the first time, the nurse practitioner gave me my numbers, I asked her if that was good or bad and she didn’t know.” ~Validation Session 2

“There is a huge health literacy gap, still... And, you know, when we hear it most is particularly in small towns where people who don’t necessarily specialize in hepatology or liver issues.” ~Validation Session 1

For some participants, this issue surfaced as confusing messaging about their hepatitis C status:

“I’ve been HIV [positive] for many years now...one doctor said I didn’t have hep C. One said I had hep C. I don’t know what’s going on. I think it went away.” ~Men’s Circle

As shown above, participants voiced concerns about how some providers, especially in rural settings, were ill-equipped to deal with hepatitis C. This lack of literacy translates to confused

patients, likely delayed engagement in the hepatitis C care continuum and potentially poorer health outcomes.

“You are making things worse for people... what you are getting in so far as pre and post-test counselling is ‘Well, you know, [hepatitis C] takes a long time to work its way through your system so you will be alright, you are newly infected’.” ~Validation Session 2

The issue of health literacy also extends beyond disease-specific knowledge. Some participants also identified that some providers were unfamiliar with, or unsure how to deal with participants’ life circumstances. Key to engaging people in meaningful discussions about their health and providing individualized care is a solid understanding of the Indigenous determinants of health, as well as environmental and behavioural risk factors (Gracey & King, 2009; King, Smith & Gracey, 2009).

At the individual level, issues around patient health literacy also surfaced. Participants identified that often they were unaware of what having hepatitis C meant. Others reported hearing conflicting knowledge or a lack of availability of knowledge.

“I didn’t know what Hep C was, HIV or things like that back in the day... So, the doctor goes you got Hep C, so I said fine. That was it.” ~Men’s Circle

Healthcare providers are only one source of knowledge. Participants were clear on the need for more knowledge in the appropriate format and sources, at the appropriate time.

“I wish we had something...that would talk about the 4 stages...a brochure...that explains what the stages are. And how they are reached and something like that. I’ve seen one poster, only one little poster ... that says ‘this is what hep C is.’” ~Men’s Circle

“But I think after today I probably want to get more information about this. And put my guard down and start learning how to identify with others.” ~Women’s circle 2

Some participants identified that, although much information is gained from talking with peers, often this information was mixed with horror stories from other peoples’ negative experiences with interferon-based treatments, or misinformation in general.

“I was going to do hep C medication one year ago. And I heard about all of the horror stories about it so I changed my mind. I didn’t take it.” ~Men’s Circle

“When I first found out I had hep C I was scared. You know, the first thing you do is you ask somebody... they would say: ‘It’s this, it’s that; you’re going to have to do this, you’re going to have to do that’. I bought into that.” ~Men’s Circle

Participants often expressed a need for knowledge from trusted sources. Knowledge is needed for an individual to be able to actively engage on a journey towards healing and wellness, as well as make informed choices about their treatment. Evidence from the sharing circles and validation

sessions show that health literacy is a pivotal theme and provides direction for moving forward with research priorities.

Theme #6: Transformation

The final key theme from *Water Journey* was the importance of transformation along one's healing journey with hepatitis C. As healing is more than just a physical cure, it should be noted that this transformation was not necessarily towards clinical outcomes. Rather, participants often discussed pivotal life experiences that represented positive transformation in their healing journeys with hepatitis C. These turning points often consisted of shifts in thinking or how participants viewed themselves.

Many of the individuals described a turning, activity or cause in their life that gave them a sense of purpose. The activities themselves were unique to each individual. Examples of transformation along one's healing journey with hepatitis C included such things as cultural and spiritual involvement, volunteering, activism and providing support for others or a loved one. The theme of transformation highlights that the consideration of one's emotional, mental, social and spiritual healing is paramount in facilitating wellness both during and after hepatitis C treatment.

"But, I think what's saving me right now is my spiritual journey and my roots. My original roots and my culture. The people who love me unconditionally and who support me." ~Two-Spirit Circle

So, I started to learn culture and tradition, I started on my healing journey. I started to come out of the darkness and into the light." ~Two-Spirit Circle

For some participants, transformation occurred through helping others and creating their own support networks.

"I knew going to support groups would help, right. So, asking for help, allowing people to help me, allowing myself to help other people...that really has added value to my life and added health to my world." ~Two-Spirit Circle

"So, I got clean...And I was volunteering at the time with women in recovery houses, and I realized when I spoke that my story motivated them, and they benefited from it. So, that was news to me, I didn't know that I could influence people that way, so that became something I did." ~Two-Spirit Circle

For other participants, re-discovering their Indigenous and other identities was a turning point for their transformations, and a source of strength and courage:

"For me, I have done a lot of work within myself...finding my identity and who I was, and working on those dark areas of myself." ~Women's Circle 1

“My daughter called me up and said, you’re going to be a grandpa, and that’s why she called. So, I decided to live with my disease instead of dying with it. That was my turning point.”
~Two-Spirit Circle

“I wanted to know why some people were doing well and some people were getting sick, right? So, I made a list of what the winners were doing and what the losers were doing. And I realized the first thing I needed to do was come out of the closet. I needed to love myself...I needed to get rid of the shame that I was filled with. If I wouldn’t have accepted my identity, I wouldn’t be alive today.” ~Two-Spirit circle

In whatever form, finding a sense of purpose in life enables one’s capacity to engage in healing. Many of those who did not have this capacity were “limited” by their disease. In contrast, many of those who found such purpose were “empowered” or “enabled” by their hepatitis C diagnosis and able to overcome difficulties in their life through their strength and resilience.

“Hepatitis C was a wake-up call. A time in your life [to think about] what you do, what you want to be, what you want to do.” ~Validation Session 1

“I was recklessly using a lot of drugs and a lot of alcohol...when I went on my Hepatitis C treatment, I quit drinking entirely. And so, for me, Hepatitis C treatment, believe it or not...actually saved my life, and I’m one of those people that will say I’m grateful.”
~Women’s Circle 1

Participants also discussed that positive interactions with healthcare providers and engagement in care led to transformative experiences. Participants in both the sharing circles and the validation sessions described how support from a therapeutic alliance with a provider was a key transformative experience. This transformative experience was independent of disease outcomes.

“When I get to know them, I make a connection with them, which is good to have with your doctor...a really good connection, and just be yourself.” ~Women’s Circle 1

“And in my own eyes, my transformation was fostered by clinical care...doctors, nurses cared...that made me care for my health which I had largely ignored completely...I was substance using for many, many years. The transformation part for me was getting involved in care, caring for myself and then slowly, over time I did skill building.” ~Validation Session 1

These positive experiences provide a guide or starting point from which one can work. Although each individual’s transformation began for different reasons and looked different, the common theme among them all was a positive and supportive environment.

CONCLUSIONS AND RECOMMENDATIONS

From the six major themes arise a series of recommendations for policy and programming related to Indigenous Peoples in Canada and hepatitis C, as well as directions for future research. The recommendations are split into key concepts – core considerations which must be

incorporated across the spectrum to affect the most positive change, and actionable ideas – examples of programs and services that have the greatest potential to aid and support Indigenous Peoples living with hepatitis C in their healing journeys.

Core concepts

To begin, future research directions need to *meaningfully* involve Indigenous People and Indigenous Ways of Knowing at all stages of program and policy development. Individuals and communities have shown readiness and eagerness to be actively involved in research, program development and policy creation. In light of this, the first core concept is the need for an increased focus on community-based participatory research programs that are designed *by* and *for* Indigenous individuals and communities.

The second core concept that presented across the themes is the need for cultural safety and the inclusion of cultural practices at all stages of research, and throughout policy and program development. For many Indigenous People, healthcare services and settings are not seen as ‘safe’ places. Many providers and healthcare settings lack the cultural safety and awareness needed to avoid perpetuating the harms of past colonial and racist policies. It is therefore critical that services along the hepatitis C care continuum be culturally appropriate. In addition, approaches that integrate and promote cultural safety can help to reduce stigma, another major barrier identified across all of the themes.

Actionable ideas

Findings from the *Water Journey* project highlight that sharing stories was linked to having strength, resilience, and hope; and was proven to be a good way of communicating information among peers. Researchers must consider how to best include Indigenous People living with hepatitis C to harness the wisdom, power and strength in their stories.

Core Concept	Actionable Ideas
<ol style="list-style-type: none"> 1. Enhance hepatitis C support services – before, during and after care 	<ol style="list-style-type: none"> a. Increase access to peer support and peer navigation services b. Address the emotional, mental, social and spiritual domains of healing within the care continuum c. Promote traditional healing and Elder support services d. Explore land-based cultural retreats as healing and support interventions
<ol style="list-style-type: none"> 2. Strengthen primary, secondary and tertiary hepatitis C prevention initiatives 	<ol style="list-style-type: none"> a. Increase awareness of how hepatitis C is transmitted b. Harm reduction c. Youth-specific strategies

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| 3. Address the Indigenous determinants of health, such as colonization, racism and marginalization, as well as critical socioeconomic considerations such as housing, income and food security, and childcare services | <ul style="list-style-type: none"> a. As a way to engage people into care and support them in the care/cure continuum b. As a form of prevention, after-care and supporting people on their wellness journeys |
| 4. Advance capacity within and around the criminal justice system | <ul style="list-style-type: none"> a. Implementation of prevention, harm reduction and treatment services b. Access to new DAA therapeutics |
| 5. Improve health literacy at the community, healthcare provider and individual levels | <ul style="list-style-type: none"> a. Right place, right time, right method for delivery of information b. Involve Indigenous communities in how to best develop literacy so that it is culturally appropriate |

Table 1: Future research directions that align with themes from *Water Journey*

In summary, the *Water Journey* project aims to elucidate and explore culturally resonant ways in which to aid and support the Indigenous Peoples in Canada affected by hepatitis C in their journeys of healing, wellness and self-empowerment. Several cross-cutting themes emerged from the analysis of the *Water Journey* sharing circles and validation sessions, with both individual and system-level factors impacting Indigenous peoples' life course experience with hepatitis C. These themes include the strength and resiliency of First Nations, Inuit and Métis Peoples living with hepatitis C, as well as their families and communities; intersections of multiple risk and protective factors; barriers within the continuum of hepatitis C care; competing priorities in one's life; health literacy; and the importance of transformation and finding purpose along one's healing journey with hepatitis C.

Results from the *Water Journey* project highlight the criticality of Indigenous leadership and involving Indigenous communities in the process of deciding hepatitis C program and research priorities. Within this, there must be a focus on innovation, self-determination, service integration, cultural safety, wholism, Indigenous values and the application of strengths-based approaches. Most importantly, if we are to better support First Nations, Inuit and Métis Peoples in their journeys toward healing, and reduce rates of hepatitis C in our communities, the themes identified by the *Water Journey* project must be taken into consideration across the realms of research, policy, prevention programs and the continuum of hepatitis C care.

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