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Community-directed research priorities for Indigenous peoples in Canada and hepatitis C: a scoping review

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ABSTRACT

In 2011, approximately 1% of the Canadian population (332,500 people) was estimated to be positive for hepatitis C (HCV) antibodies. Currently, uncertainty exists with respect to HCV epidemiology in terms of actual prevalence, as well as gender and ethnicity breakdown. Yet, Indigenous peoples in Canada (First Nations, Inuit and Métis) are recognized as having a significantly increased HCV disease burden, as well as a disproportionately higher number of HCV positive women. This paper uses a strengths-based approach to explore and summarize key themes from the scholarly literature related to HCV and Indigenous populations in Canada, and elsewhere (n=37). Explicit in our approach is that this health inequity, and the higher prevalence of associated risk factors among Indigenous populations, are end manifestations of colonization. The purpose of this review is to synthesize what has been learned from the collective body of knowledge and make recommendations for future research and health practice directions. Results highlight the importance of addressing intersectional HCV risk factors, such as injection drug use, gender and youth, and further exploring the many "silences" in the HCV data. Recommendations from the review include an increased focus on (1) involving Indigenous peoples and communities in the process of deciding program and research priorities; (2) obtaining more comprehensive HCV data; (3) promoting cultural safety, culturally appropriate care and community-led research and (4) incorporating wise practices that are based on innovation, self-determination, integration of services, partnerships, wholism and traditional ways of knowing.

FORWARD

The authors of this document would like to begin by recognizing the strength and resilience of those Indigenous peoples in Canada in whom hepatitis C has impacted their lives.

We would like to honor these individuals and communities, while simultaneously acknowledging their many unique insights, skills, talents and assets that have yet to be fully harnessed and applied towards addressing the issue of hepatitis C among Indigenous peoples in Canada.

Our goal is not to proliferate negative stereotypes. This review, and the larger project that it will inform, seeks to promote a strengths-based approach to exploring the research priorities for Indigenous peoples and hepatitis C in Canada. We are mindful that many studies on hepatitis C among Indigenous peoples in the literature focus on illness rather than health, and deficits rather than our many collective strengths.

The aim of this document is to inform *Water Journey*, a community-based research project focused on having Indigenous peoples articulate what *they* believe to be the priority areas for hepatitis C research within Canada, and within their own lived experience and community contexts. In doing this, *Water Journey* seeks to draft a national hepatitis C research framework for Indigenous peoples in Canada, which will inform the creation of more effective and culturally relevant health services. Ultimately, the goal of *Water Journey* is to assist Indigenous

peoples in Canada affected by hepatitis C in their journeys of healing, wellness and self-empowerment.

Above all, we recognize that our research must not be solely based on the current literature, but also on the knowledge, wisdom and resilience of those Indigenous people who have undertaken (or are currently undertaking) these journeys of healing. To accomplish this, our approach will be grounded in our vibrant Indigenous culture, ceremony and traditions. Moreover, we must be cognizant of honoring our traditional codes of conduct, as well as Indigenous worldviews and systems of knowledge.

The *Water Journey* project endeavors to learn from Indigenous experience. We want to learn from stories. Within many Indigenous cultures, stories are used as tools for teaching and learning. Stories allow us to gain life lessons from a more personal perspective. Many Indigenous people with lived experience of hepatitis C show great strength and resilience in the face of a lifetime of adversity.

Finally, in listening to the stories Indigenous people have to tell, we need to ask ourselves:

1. How do we build upon this resilience?
2. How do we enable it in others?
3. In the wake of the changing hepatitis C landscape, how do we apply this to health practice to ensure that Indigenous peoples are not left behind?

INTRODUCTION

As of 2011, an estimated 332,500 Canadians, or approximately 0.96% of the Canadian population, were seropositive for hepatitis C virus (HCV) antibodies (Trubnikov et al., 2014). Indigenous peoples in Canada (First Nations, Inuit and Métis) comprise 4.3% of the population, yet comprehensive epidemiological data on the hepatitis C burden of Indigenous populations is lacking (PHAC, 2010). Moreover, a paucity of data exists on hepatitis C trends for specific sub-populations of Indigenous peoples, such as those living on-reserve and in rural settings (Trubnikov et al., 2014; PHAC, 2010). As a result, there is significant uncertainty in regards to the actual prevalence of hepatitis C among Indigenous populations in Canada, as well as uncertainty related to the geographical and gender breakdown of the current hepatitis C burden (PHAC, 2010).

The data that does exist, however, suggests that, in comparison to non-Indigenous Canadians, the prevalence of hepatitis C among Indigenous populations is higher (Buxton et al., 2010; Osioy, Simmons & Rempel, 2013; PHAC, 2010; PHAC, 2012; Plitt et al., 2010). In addition, Indigenous peoples in Canada are over-represented in many groups considered at high-risk for HCV transmission, such as those in unstable housing situations or engaging in injection drug use (CATIE, 2015; Craib et al., 2009; Sadler & Lee, 2013). Furthermore, increased rates of HIV

among Indigenous populations may be viewed as a correlate to increasing rates of hepatitis C, as hepatitis C parallels HIV and AIDS in many risk factors (Buxton et al., 2010; Plitt et al., 2010).

Revised national hepatitis C screening and diagnostic guidelines, combined with the expanding use of new and more effective direct acting antiviral (DAA) treatments, have rapidly changed the hepatitis C landscape (CATIE, 2015). These new DAA therapies are better tolerated, have shorter treatment courses and show dramatically improved cure rates. Yet, they come at substantial financial cost, estimated to be between \$60,000-100,000 per person for a full treatment course (CATIE, 2015). Implicit in our understanding is that reducing rates of hepatitis C in Indigenous populations requires more than just the right medications - a greater understanding of the social context for why people acquire hepatitis C is needed.

In light of the lack of focus on hepatitis C within Indigenous populations in Canada, it is evident that, if Indigenous peoples are to take full advantage of the continuum of hepatitis C care (e.g. prevention programs, treatment interventions, new DAA therapeutics and post-treatment support services) a comprehensive exploration of research priorities must be undertaken. Moreover, it is important that these research priorities be informed not only by the existing literature, but also by the lived experience of Indigenous peoples affected by hepatitis C. To accomplish this, our research group conducted a sharing circle research event in July 2015 with Indigenous individuals with lived experience of hepatitis C. Titled *Water Journey*, the aim of this project was to elucidate and explore culturally resonant ways in which to aid Indigenous peoples in their healing journeys. The insight gained from the *Water Journey* sharing circles is now going on to inform the drafting of larger grant proposal focused on the development of a comprehensive framework on the research priorities for Indigenous peoples in Canada and hepatitis C.

An important step in moving forward to address issues related to disproportionate rates of hepatitis C among Indigenous peoples in Canada is reviewing the scholarly literature to see what research has already been done. Unique historical and social context that shape the life experiences of Indigenous peoples in Canada, and patterns of hepatitis C affect Indigenous peoples in unique ways compared to non-Indigenous Canadians. As such, there is a need to systematically assess which hepatitis C research, prevention, treatment and support initiatives for Indigenous peoples have been successful, and which have not.

This scoping review is the first paper in a three-part series of articles published in this edition of the CJACBR. The second paper, titled: “Water Journey: methods for exploring the research priorities for Indigenous peoples in Canada and hepatitis C” (pages 44 – 59) discusses the research methodologies utilized by the *Water Journey* project. The third paper, titled: “Water Journey: emerging themes for research priorities for Indigenous peoples in Canada and hepatitis C” (pages 61 – 79) highlights findings on the analysis of a series of sharing circles conducted with Indigenous persons with lived hepatitis C experience and presents research, program and policy recommendations for moving forward.

The purpose of the review is three-fold. First, it has informed the methodology and guiding questions of the *Water Journey* sharing circle event. Second, the review will function to ground our future research proposal in current knowledge. Third, it will help identify hepatitis C

research areas needing further elucidation within the context of Indigenous peoples in Canada. To meet these objectives, this review will draw out and summarize key themes from the peer-reviewed literature related to hepatitis C among Indigenous populations in Canada, and elsewhere. Further, the review will synthesize both major findings (with a focus on what has been learned from the collective body of knowledge) and current gaps in the research. Finally, the review will link key themes in the literature back to future research directions and priorities for Indigenous peoples and hepatitis C.

Accounting for rates of hepatitis C in Indigenous communities

Colonization is a key determinant of health and wellness for Indigenous peoples in Canada. Indigenous scholars have long suggested that any discussions related to substance misuse and concomitant vulnerability to HIV and hepatitis C be framed within the context of colonization, including the intergenerational trauma resulting from the residential school experience and child welfare systems (Craib et al., 2009). Despite the strength and resilience of First Nations, Inuit and Métis peoples, the ongoing effects of colonization (e.g. systemic racism, loss of language/culture, social exclusion, marginalization and persistent economic inequality) combine to enable a disproportionate number of Indigenous individuals and communities to be over-represented in behaviors considered high-risk, such as injection drug use (Christian & Spittal, 2008). These factors, in turn, may function to increase the risk of various blood-borne and sexually transmitted infections, such as HCV and HIV (Craib et al., 2009).

Methodology and search strategy

Using Arksey and O'Malley's (2005) methodological framework, a rapid scoping review was conducted in May 2015 on the scholarly literature focused on hepatitis C and Indigenous peoples. As the desire of the research team was to place an emphasis on exploring Canadian data, this review primarily focuses on Indigenous peoples in Canada (First Nations, Inuit and Métis). A secondary focus was placed on examining the hepatitis C literature in Indigenous populations in Australia, New Zealand and the United States - all of which have similar histories of colonization to Canada.

The aim of the rapid review was to explore 5 key research areas of the literature on Indigenous peoples and hepatitis C:

1. Epidemiology
2. Health service delivery and continuum of care
3. Health and wellness outcomes
4. Psychosocial issues, barriers to treatment and lived experience
5. Knowledge translation and parallels to HIV

As the goal of the research team was to systematically map the literature focused on Indigenous peoples and hepatitis C, as well as identify key concepts, themes, theories and sources of evidence related to this subject area, Arksey and O'Malley's (2005) methodological framework was chosen. This methodological approach was selected because scoping reviews are designed to

seek out and address gaps in the evidence base where little research has been conducted (Arksey & O'Malley, 2005). Furthermore, this approach was utilized because scoping reviews are designed to provide a rapid and comprehensive analysis of the extent, type, range and breadth of research that has been conducted on a specific research topic (Arksey & O'Malley, 2005).

Due to time, resource and feasibility constraints, it was collectively decided by the research team to exclude grey literature from the search in this review. As such, the research team chose to specifically search academic peer-reviewed articles and epidemiological studies related to hepatitis C in Indigenous populations. Twelve databases were systematically searched (Proquest, Web of Knowledge, Pubmed, Medline, CINAHL, University of Saskatchewan Indigenous Studies Portal, CAAN Journal, Journal of Aboriginal Health, International Journal of Indigenous Health, PsycINFO, Pimatisiwin, University of Alberta Library Database). With consultation from key informants, the following search terms were mapped out and utilized:

(Aborig* OR Indigen* OR "First Nation" OR "First Nations" OR Inuit OR Métis OR "American Indian" OR "Alaska Native" OR "Native Hawaiian" OR "Maori" OR "Torres Strait Islander")

AND

("hepatitis C" OR "hepatitis-C" OR HCV OR hepC OR "hep-c" OR "hep c")

After combing each database, 67 abstracts were retrieved and imported into *Mendeley* electronic referencing software. Any duplicate copies of studies were removed. Using specific exclusion/inclusion criteria, all abstracts were collectively reviewed by Macklin and A. King to determine which journal articles were relevant to the 5 key research areas stated above. Detailed information was then extracted from the articles and entered into a summary table in *Microsoft Excel* for comparative analysis.

Upon group discussions and consultation with the research team, abstracts were excluded from the literature review if they were:

1. published prior to 2008
2. a lab-based study

Note: due to the rapidly changing hepatitis C treatment landscape from 2008 onwards, articles published prior to 2008 were excluded from inclusion in the review.

Abstracts were explicitly included in the literature review (regardless of year published) if they were:

1. qualitative or social science-based
2. epidemiological
3. focused on hepatitis C lived experience

After reading the 67 abstracts, only 34 were deemed to meet the above criteria for inclusion into the review. An additional community document (CATIE Backgrounder) and 3 epidemiological studies not found in peer-reviewed databases (*I-track Phase 3*, *A-track* and Center for Disease Control study) were identified by members of the research team as highly relevant to the review and added to the list of included articles (bringing the total number of included articles to 37). Lastly, Arksey and O'Malley's (2005) article documenting the scoping review process is also contained within the reference list of this review.

The research team then reviewed the final approved articles in the comparative chart and met to discuss emergent findings. The full-text articles were then imported into the qualitative data analysis software *NVivo 10*© for coding and thematic analysis. Thematic coding was undertaken by one primary coder (Macklin), who was supported by two team members (A. King and Kallos). Next, the main research findings were mapped out with a specific attention paid to employing an Indigenous perspective to relate these findings to implications for hepatitis C policy, practice and potential gaps in the literature. Finally, the analytical codes, key findings, and gaps in the literature were shared with the research team for further refinement and then synthesized into a report.

RESULTS

Results from this review are drawn from a total of 37 included articles. In terms of country of origin, 26 articles examined Indigenous populations in Canada, 6 in the United States, 4 in Australia and 1 in both the United States and Canada. No articles were found from New Zealand. Of these 37 articles, 30 were epidemiological studies documenting HCV prevalence or incidence, with 19 of these articles examining HCV-related risk factors. A further 4 articles were qualitative studies, 3 articles were author commentaries and one article was a community-based document. In relation to target population, 20 of the epidemiological or qualitative studies had a primary focus on Indigenous peoples, whereas 14 involved mixed populations (i.e. both Indigenous and non-Indigenous).

Key findings from the review point to a number of emergent themes in the scholarly literature related to Indigenous peoples and hepatitis C. These include:

Varying estimates of the prevalence and incidence of hepatitis C in Indigenous communities

We identified 9 articles that included information related to the prevalence of incidence of HCV within large population cohorts. Indigenous peoples in Canada and elsewhere are not a homogenous group and studies of HCV prevalence estimates show large variation (PHAC, 2010; PHAC, 2012). In addition, few population-based studies of HCV prevalence within Indigenous communities are available (Uhanova et al., 2013). Furthermore, existing studies show a wide range of HCV prevalences within different sub-groups of Indigenous populations (PHAC, 2010; PHAC, 2012). In Canada, a 2010 summary of data from three national enhanced surveillance systems reported that the rate of HCV was almost five times higher among Indigenous peoples compared to the non-Indigenous population (PHAC, 2010). This equates to 4.34 cases per

100,000 in the Indigenous population compared to 0.90 per 100,000 in the non-Indigenous population (PHAC, 2010). Similarly, another 2005-2010 HCV surveillance report by the Public Health Agency of Canada (PHAC) estimated that 4.1% of Indigenous men and 1.9% of Indigenous women were positive for HCV, resulting in an overall prevalence of 3.0% (PHAC, 2010). The authors note, however, that this estimate should be viewed as more of a hypothesis than a conclusion, given the lack of representative data for Canadian Indigenous populations (PHAC, 2010). Moreover, between 1999-2004 in six health regions in British Columbia, Alberta, Manitoba, Ontario and New Brunswick, 15.2% of the incident cases of HCV could be attributed to Indigenous peoples (Osiowy, Simmons & Rempel, 2013).

In British Columbia, it was estimated that the incidence of HCV is twice as high among Indigenous peoples compared to non-Indigenous peoples (Craib et al., 2009). Likewise, in 2006, 13.5% of all reported HCV cases in Alberta were among Indigenous persons (Plitt et al., 2010). Similarly, a 12-year retrospective study in Manitoba found that, of 5018 cases of HCV reported, 671 (13.4%) were attributed to First Nations individuals (Uhanova et al., 2013). This study also revealed a 4.5-fold increase in age-adjusted prevalence from 1995 to 2002 (Uhanova et al., 2013). Lastly, the *A-track* pilot study (involving 1045 participants) monitored the prevalence of HCV and other related blood-borne infections among an Aboriginal population in Regina from 2011-2012 and reported an overall lifetime HCV seropositivity of 41.6% ("seropositive" includes those with a chronic HCV infection, as well as those who have spontaneously cleared the disease or undergone successful treatment) (PHAC, 2012).

Elevated rates of HCV among Indigenous populations in the United States are also an issue (Centers for Disease Control and Prevention, 2012). Surveillance data from a 2010-2011 study by the Center for Disease Control reported that, among all ethnicities for which there was data, acute HCV incidence rates and age-adjusted HCV mortality rates were the highest in American Indian/Alaska Native populations (Centers for Disease Control and Prevention, 2012). Lastly, in our literature search, population-based HCV prevalence estimates of Indigenous peoples in Australia and New Zealand could not be found.

Intersectional risk factors related to Indigenous peoples and hepatitis C

Substance use and injection drug use

We found 8 articles that examined the association between HCV, substance use and Indigenous peoples. An overarching theme that emerged from the scoping review was the intersection of Indigeneity, HCV and substance use, particularly in relation to injection drug use. Persons who inject drugs (PWID) represent an important group at risk in Canada's HCV epidemic (Alavi et al., 2013; Craib et al., 2009; PHAC, 2010; Plitt et al., 2010). For example, in a study of 275 PWID in Edmonton, 70.6% self-identified as Indigenous and overall HCV prevalence was 66.1% (Plitt et al., 2010). Injection-related correlates for HCV transmission include factors such as earlier age of first injection, longer length of time injecting, needle sharing and borrowing, daily injection and frequent cocaine injection, emphasizing the importance of harm reduction and safe injection habits among in PWID (Craib et al., 2009; Plitt et al., 2010)

Two studies discussed rates of HCV among Indigenous populations as part of the "broken spirit diseases" (i.e. diseases that are mediated by both historical/personal trauma and participation in substance use behaviors considered high-risk for blood-borne and other disease acquisition) (Uhanova et al., 2013; Rempel & Uhanova, 2012). Utilizing data from people who inject drugs in multiple Canadian cities, the *I-track Phase 3* study reported an overall HCV seroprevalence of 68.0%, with 36.3% of study participants identifying as Indigenous (PHAC, 2012). Compared with the non-Indigenous participants in the *I-track* study, Indigenous participants reported less frequent use of needle exchange programs, less frequent condom use at last sexual encounter, more frequent borrowing of injection equipment and younger age at first injection drug use (PHAC, 2010). Finally, results of an additional study reported solvent use to be significantly associated with increased rates of HCV transmission (Shaw et al., 2010).

Gender

Six articles were found that specifically focused on the intersection between gender, Indigeneity and HCV. Disconcertingly, studies have shown that those Indigenous persons newly living with HCV are more likely to be female (Mehrabadi et al., 2008; PHAC, 2010; PHAC 2012; Uhanova et al., 2013). For example, in a 12-year retrospective study in Manitoba, First Nations females had an average prevalence of HCV that was 3.9 times that of non-First Nations females, whereas First Nations males had an average prevalence of HCV 1.5 times that of non-First Nations males (Uhanova et al., 2013). The intersection of Indigeneity, gender and HCV was also illustrated by the results of the *I-track Phase 3* study, in which the Indigenous female HCV population (44.5%) was shown to be almost double that of the non-Indigenous female HCV population (24.7%) (PHAC, 2012). In addition, the *Enhanced Hepatitis Strain Surveillance System* (2002-2008) reported a similar increase in HCV risk for Indigenous women (PHAC, 2010). Conversely, the *A-track* study reported an overall lifetime HCV seropositivity of 46.1% for Indigenous males and 36.9% for Indigenous females (PHAC, 2012). However, of those *A-track* participants who were classified as aged 29 or less, 47.1% were female compared to 37.5% male, indicating that younger Indigenous persons with HCV populations were more likely to be female (PHAC, 2012).

Female Indigenous study participants in Edmonton were significantly more likely to report sharing needles in the previous 6 months in comparison to Indigenous males (20% vs. 3.7%) (Plitt et al., 2010). Moreover, the *Cedar Project* found that almost two-thirds of the young Indigenous women in the study who injected drugs were positive for HCV at baseline, which was 30% higher than the prevalence in young Indigenous men who injected drugs (Mehrabadi et al., 2008). The results of various studies highlight the multiple dimensions of vulnerability faced by young Indigenous females, including sexual abuse, addiction, survival sex work, incarceration, and transitioning to injection drug use, which can all contribute to an increased risk of HCV transmission. (Mehrabadi et al., 2008; PHAC 2010, PHAC, 2012; Uhanova et al., 2013; Rempel & Uhanova, 2012). Combined, these factors lead to a greater likelihood of behaviour considered high-risk, such as unsafe sex and unsafe injection practices, especially when many young Indigenous women are intimately involved with men who are usually older and who use injection drugs themselves (Mehrabadi et al., 2008).

Youth

We identified seven articles that examined hepatitis C in relation to Indigenous youth populations. As evidenced through an evaluation of the HCV demographics in six health regions across Canada, in comparison to non-Indigenous Canadians, Indigenous persons living with HCV are more likely to be younger (PHAC, 2012; Mehrabadi et al., 2008). One study highlighted that Indigenous persons were diagnosed with chronic HCV on average five years earlier in comparison to non-Indigenous persons (Rempel & Uhanova, 2012). In his 2008 commentary article published in *The Lancet*, Chief Wayne Christian (of the *Splats'in/Secwepemc* Nation) stated "Many young people in our communities are addicted, suffering in isolation, and still grappling with the legacy of physical and sexual trauma that has been passed down from one generation to the next" (Christian & Spittal, 2008, p.1). These words are echoed in the results of the *Cedar Project*, in which 45 out of 148 young Indigenous persons who injected drugs (30.4%) became positive for HCV over a two-year study period, further illustrating that young Indigenous people are at very high risk of hepatitis C seroconversion early in their injection careers (Mehrabadi et al., 2008). The authors of the *Cedar Project* study postulate that historical and sexual traumas may compel young Indigenous people to experiment with injection drugs in hopes of numbing deep rooted feelings of shame and isolation, as many of the young people involved in the study have been removed from the care of their biological parents (55.0%) (Miller et al., 2011). Moreover, many youth may be unaware of the intergenerational effects that the residential school system has had on themselves, their families and their communities (Miller et al., 2011).

The intersection of homelessness, youth, Indigeneity and HCV is another salient theme from the literature (Marshall et al., 2008). Findings from the *Enhanced Street Youth Surveillance Study* indicated that the prevalence of HCV among Indigenous street-involved youth was almost double that of non-Indigenous street-involved youth (7.4% vs. 4.4%, respectively) (PHAC, 2010). Even more distressing, HCV prevalence was 1.7 times higher among the females in this study, compared to their male counterparts and, among those aged 20-24 years compared to those aged 15-19 years, rates were 4.2 times higher (PHAC, 2010). Likewise, a study of Indigenous street-involved youth in Winnipeg found a high overall HCV prevalence in this subgroup, with 47.7% of those who were injecting drugs testing positive for HCV, but only 3.7% testing positive among those who did not inject drugs (PHAC, 2010). Rates of HCV among youth who are new initiates to injection drug use underscores the urgent need for targeted and culturally appropriate prevention strategies aimed at supporting Indigenous youth at-risk (Mehrabadi et al., 2008). As such, Indigenous youth must be afforded the opportunity to provide leadership and input in the development of prevention programming and initiatives (Mehrabadi et al., 2008).

Incarceration

We identified 5 articles that contained information related to HCV, Indigenous populations and incarceration. Incarceration and its link to an increased risk of HCV transmission is another important consideration for Indigenous populations (Luciani et al., 2014; Van der Poorten, Kenny & George, 2008). An Australian study of the prevalence and risk factors for HCV in Indigenous and non-Indigenous adolescents with criminal justice system involvement found very high rates of HCV, with Indigenous adolescents having a rate of HCV seven times that of the

national average (Van der Poorten, Kenny & George, 2008). Furthermore, having a history of incarceration or having parents who had been incarcerated doubled the risk of HCV in study participants (Van der Poorten, Kenny & George, 2008). The results of the *Cedar Project* also indicated that young Indigenous people who inject drugs were more likely to have been incarcerated, to struggle with mental health issues and to have been denied shelter because of their drug use (Miller et al., 2011). Finally, a high prevalence of HCV (25% to 40%) and over-representation of Indigenous peoples with HCV has been documented among populations who are incarcerated in Canada (Uhanova et al., 2013). Additional studies in Canada, as well as Australia, also found that current and previous imprisonment was associated with high rates of HCV transmission (Luciani et al., 2014; Rempel & Uhanova, 2012)

HIV/HCV co-infection

We found five articles that contained references to HIV/HCV co-infection among Indigenous populations. HIV and HCV share common modes of transmission and co-infection is not uncommon among certain Indigenous populations (PHAC, 2012; Rourke et al., 2011; Tarasuk et al., 2014). Findings from the *I-track Phase 3* study revealed that, among a cohort of Indigenous persons who inject drugs, 24% of those who were antibody-positive for HCV were also positive for HIV (PHAC, 2012). Similarly, through cross-linking positive cases of HIV to HCV reporting databases in BC, the prevalence of HIV/HCV co-infection among those who self-identified as Indigenous was found to be 20.8% (Buxton et al., 2010). In another Canadian HIV/HCV co-infection cohort, 13% of participants self-identified as Indigenous (Klein et al., 2013). In regards to geographical trends, this study showed that HIV/HCV co-infection rates were highest in British Columbia, with Indigenous persons having a co-infection rate 7 times that of non-Indigenous persons (Klein et al., 2013). Further, a study of HCV seropositive Indigenous street-involved youth found the prevalence of HIV/HCV co-infection to be 10%. (PHAC, 2010). Additionally, HIV/HCV co-infection has been shown to be associated with other intersectional factors such as homelessness, substance use, involvement in survival or transactional sex trade and a history of incarceration (Buxton et al., 2010; Rourke et al., 2011). In sum, existing evidence of a disproportionate burden of HIV/HCV co-infection among some Indigenous populations underscores the urgent need for a multi-pronged approach that integrates prevention, harm reduction and programs to support entry and adherence to both HIV and HCV treatment (Buxton et al., 2010).

Issues related to health outcomes and the continuum of HCV care

We found 15 articles that mentioned HCV-related health outcomes and/or issues related to the continuum of HCV care for Indigenous peoples. Multiple studies suggest that Indigenous people living with HCV experience a number of failure points across the continuum of care, including poor health outcomes, reduced rates of screening, reduced access to treatment, as well as reduced research inclusion and participation (Alavi et al., 2013; Marshall et al., 2008; Rempel & Uhanova, 2012; Tarasuk et al., 2014; Minuk et al., 2013; Davis, Kulatunga & Hajkowitz, 2013). Furthermore, higher rates of co-morbid factors such as diabetes, HIV/AIDS or excessive alcohol use contribute to a greatly reduced life expectancy in Indigenous people with chronic HCV (Rempel & Uhanova, 2012). A Manitoba study found that First Nations persons with chronic HCV died on average 12 years younger than non-First Nations persons with chronic HCV

(Rempel & Uhanova, 2012). Similarly, results from the *PRAIRIE* study showed that Indigenous participants who were positive for HCV presented with higher viral loads at baseline in comparison to non-Indigenous participants (Minuk et al., 2013). Other studies have shown an increased rate of (and accelerated development to) HCV-related end-stage liver disease within Indigenous populations (McMahon et al., 2010; Rempel & Uhanova, 2012).

Existing literature shows that a disproportionate number of Indigenous persons living with HCV experience lower rates of treatment uptake, reduced treatment adherence or not receiving treatment at all (Alavi et al., 2013; Alavi et al., 2015; Livingston et al., 2012; Plitt et al., 2010). A 2010 study in Edmonton of Indigenous persons who were positive for HCV and using injection drugs found that only half were currently under medical care (Plitt et al., 2010). Similarly, only 18% of Indigenous people diagnosed with hepatitis C at a North Dakota medical facility went on to receive treatment (Hossain, Guerrero & Sahmoun, 2014). Common reasons for not receiving treatment include lack of access to specialists, lack of referrals, concomitant or decompensated liver disease, difficulty in attending appointments, and alcohol or substance abuse (Hossain, Guerrero & Sahmoun, 2014; McMahon et al., 2010; Minuk et al., 2013). These factors highlight that, to better enable Indigenous people living with HCV navigate the continuum of care, there is a need for more comprehensive and culturally appropriate multidisciplinary approaches (Barlow et al., 2008; Hossain, Guerrero & Sahmoun, 2014). This can, in part, be accomplished through utilization of integrated teams of primary care providers, mental health providers, social workers, pharmacists and community support services (Hossain, Guerrero & Sahmoun, 2014). However, within these teams, the role of traditional healers and traditional medicine needs to be further explored. Similar to the findings of the above studies, the authors of the *Cedar Project* concluded that "treatment delivery for optimal adherence among young, HCV positive Aboriginal people who inject drugs must be individually tailored, enriched with ancillary psychosocial supports and provided within a culturally safe setting" (Spittal et al., 2012, p.9).

Silences in the data and study limitations

A further 18 articles revealed significant silences in the epidemiological data related to HCV in Indigenous communities in Canada. Most notably, there has been a lack of studies published within the past five years. Gaps in the data are evidenced by the wide variation of hepatitis C prevalence estimates that have been reported among First Nations, Inuit and Métis peoples (Centers for Disease Control and Prevention, 2012; PHAC, 2010; PHAC, 2012). Additionally, few large cohort population-based studies have been undertaken, with most studies focusing only on select groups of individuals living in high-risk, mostly urban settings (Uhanova et al., 2013). Subsequently, findings from many studies may not be generalizable to the Indigenous population in Canada as a whole (PHAC, 2010).

Within epidemiological surveys, there is a need for an increased focus on exploring the rates of HCV among the Indigenous generation born between 1945 and 1965 (Trubnikov et al., 2014). Moreover, the current systems for categorizing Indigenous peoples do not provide a reliable or comprehensive picture of the HCV burden among Indigenous populations (Osiowy, Simmons & Rempel, 2013; Sadler & Lee, 2013; Uhanova et al., 2013). Problems with HCV data collection and surveillance are further hindered by varying definitions of how "Indigenous" is reported in

HCV statistics, leading to unrepresentative or incomplete estimates of HCV prevalence in these populations (Sadler & Lee, 2013). Within epidemiological surveys, many of the definitions of "Indigenous" are set by provincial or federal health insurance systems (Sadler & Lee, 2013). Due to historical and political reasons, this has the potential to restrict who is eligible for registration as a recognized First Nations person (Sadler & Lee, 2013). Similarly, a large number of epidemiological studies do not utilize self-reported ethnicity data (PHAC, 2010). Combined, these factors may lead to persons who would self-identify as First Nations, Inuit or Métis not being categorized in study data as "Indigenous", thereby potentially underestimating the overall burden of chronic HCV among Indigenous peoples (Sadler & Lee, 2013).

Another gap in the research identified by this literature review was a lack of studies related to evaluating the continuum of HCV care for Indigenous peoples. Sparse data exists on the examination of HCV treatment uptake in Indigenous populations, particularly in relation to recent trends and factors associated with new DAA therapies and revised treatment protocols (Alavi et al., 2014; CATIE, 2015). In addition, examinations and evaluations of rural care cascades in relation to Indigenous peoples and HCV were found to be largely absent in the literature. Moreover, few studies have examined the barriers faced by Indigenous peoples in Canada living with HCV (particularly those in rural, remote and on-reserve settings) in accessing care and support services (Alavi et al., 2013; Braitstein et al., 2005; Uhanova et al., 2013). Furthermore, there has been little examination on HCV in relation to its effect on the wellness and quality of life of Indigenous persons, such as fatigue, depression, perceptions to care and community resilience (Braitstein et al., 2005; Pearce et al., 2015; Treloar et al., 2016). Many studies have also failed to address the role that stigma plays in affecting the identity and healing journey of Indigenous peoples living with HCV (Treloar et al., 2016). Finally, a major silence in the data is that many HCV studies do not explicitly address underlying Indigenous determinants of health, such as colonialism, intergenerational trauma, socioeconomic status, marginalization and racism (Rourke et al., 2011).

Ways forward: program and research priorities

In systematically reviewing the literature, a number of program and research priorities for HCV and Indigenous peoples in Canada emerged:

A need for more comprehensive data

The results from this review underscore the need for additional population-based studies to gain a more reliable estimate of HCV among Indigenous peoples in Canada, specifically in relation to HCV prevalences outside of urban settings (Livingston et al., 2012). Current evidence suggests an urgent need for more large prospective studies to evaluate the effectiveness of HCV treatment models with the goal of enhancing screening and treatment uptake, particularly in population sub-groups within high-risk settings (PHAC, 2012; Uhanova et al., 2013). An amalgam of studies also recommend further research aimed at gaining a better understanding of how HCV and Indigeneity intersect with factors such as injection drug use, gender and youth, and how this can be applied to health practice (Craib et al., 2009; Miller et al., 2011; PHAC, 2010; Uhanova et al., 2013). Furthermore, the examination of HCV among Indigenous peoples must be done through a decolonizing lens, taking into account historical and physical trauma, as well as

broader individual, community, socioeconomic and political contexts (Miller et al., 2011). Finally, the complex interplay between the impact of colonization, residential schools, racialized care, and generations of mistrust of provincial and federal health services should be acknowledged and further elucidated (Pearce et al., 2015).

Cultural safety, culturally appropriate care and community-led research

Cultural safety acknowledges the power imbalances between the health care provider and a person (patient) while simultaneously emphasizing "relationships of trust", in which the Indigenous person determines if the care being delivered to them is "safe" or not (Barlow et al., 2008, p.161). Further efforts to improve cultural safety within health service delivery must be made a priority (Lowe, 2008; Spittal et al., 2012). The cultural appropriateness of the clinical encounter and diagnosis has been shown to reduce self-perceived stigma and shame for Indigenous persons receiving HCV care and is an important factor in establishing better engagement with HCV care and treatment (Treloar et al., 2016). Health care providers must also be cognizant that the decision by a person living with HCV to participate in traditional practices (such as smudges, sweat lodges, fasting and other ceremonies) is very personal in nature and varies according to family, community, spiritual, and cultural backgrounds, as well as individual experiences and beliefs (Barlow et al., 2008). Community-based participatory research and culturally appropriate programs developed *by* and *for* Indigenous communities will be important in expanding and increasing the uptake of prevention, screening, treatment and support services for Indigenous people living with HCV (Alavi et al., 2013; Barlow et al., 2008). Lastly, in planning and implementing these programs, there is a need for increased application of Indigenous research methodologies and Indigenous ways of knowing (Barlow et al., 2008).

An integrated hepatitis C framework

An examination of the literature highlighted the criticality of supporting an integrated HCV framework for Indigenous people in Canada that recognizes prevention, screening/testing, treatment and support services as mutually supporting facets of a comprehensive and effective response to HCV (CATIE, 2015). Further, this integrated framework must be incorporated across the continuum of new and existing HCV services to make linkages across programs more efficient and effective (CATIE, 2015). Additional focus is also needed to improve access to multidisciplinary teams to support both entry into treatment and treatment adherence for Indigenous peoples living with HCV (Alavi et al., 2013; Alavi et al., 2015; Klein et al., 2013). The above considerations will become increasingly important as newer, more effective direct-acting antiviral therapies become more available (Klein et al., 2013).

Interventions, innovation and wise practices

A number of "wise practices" related to HCV interventions and prevention strategies emerged from this scoping review. In addressing HCV in Indigenous populations, the importance of community engagement and building stronger community partnerships were highlighted in several articles (Barlow et al., 2008; Craib et al., 2009; Miller et al., 2011). To accomplish this, all members of the community need to be part of the solution, including youth, Elders, nurses, front-line health workers and community leaders (Barlow et al., 2008). Interventions must be

based on flexible, trust-based relationships that seek to build upon Indigenous peoples' resiliency in the face of intergenerational and lifetime traumas (Spittal et al., 2012). Furthermore, leveraging these partnerships requires networking (amongst First Nations, Inuit and Métis organizations, youth organizations, mainstream health services and community health providers) to ensure that prevention and care services are being provided in a culturally safe manner and that traditional healing services are available (Spittal et al., 2012; Barlow et al., 2008). Lastly, connection to traditional culture and speaking one's traditional Indigenous language have been shown to function as buffers that protect Indigenous communities (especially young Indigenous individuals) from severe negative health outcomes, such as vulnerability to HIV and HCV infection (Pearce et al., 2015).

Various articles recommended the upscaling and streamlining of culturally appropriate prevention, harm reduction and treatment programs (Alavi et al., 2014; Barlow et al., 2008; Lowe, 2008; Sadler & Lee, 2013). Although newer, more effective HCV therapies are providing hope, prevention must still be made a priority (Rempel & Uhanova, 2012). Findings from this review underscore the need for meaningful strategies aimed at preventing the initiation into injection drug use, particularly for Indigenous youth (Craib et al., 2009; Miller et al., 2011; Spittal et al., 2012). Outside of prevention programs, increased efforts must also be made to engage young people in harm reduction services (such as the provision of safe injection equipment) as well as in HIV and HCV testing and treatment services (Craib et al., 2009; Miller et al., 2011; Spittal et al., 2012). Recently, a prevention initiative aimed at Indigenous youth that integrated traditional teachings and sharing circles demonstrated effectiveness in increasing awareness of HCV and knowledge of the way that the virus is transmitted (Lowe, 2008). Telemedicine and e-health services may also have potential in increasing access to HCV support services for some Indigenous populations, particularly those in rural and remote locations (Barlow et al., 2008). Moreover, prioritization of public health resources needs to be focused on the development of innovative new prevention programs that confront intersectional HCV risk factors such as youth, sexual abuse, sex work, homelessness, injection drug use and incarceration (Barlow et al., 2008).

Reflecting the wholistic worldview of Indigenous peoples, care models should seek to address the emotional, mental, physical, spiritual and social components of health, and co-morbid factors, such as addiction, must be treated together with HCV (Barlow et al., 2008). Similarly, the importance of providing treatment choices and support services for people "at all places in their healing journey" is a key consideration, including support in the process of coming to terms with a diagnosis and managing medication side effects (Barlow et al., 2008, p.156). This, along with culturally safe care, supports those Indigenous people living with hepatitis C in a range of personal and health choices along their journey towards wellness (Barlow et al., 2008; Treloar et al., 2016).

Limitations of this review

There were several specific issues that may have contributed to the limited number of studies located for this scoping review. First, due to time, resource and feasibility constraints, our team collectively decided to limit the search to the peer-reviewed academic literature. We recognize

that many new and innovative programs are being conducted by community organizations. The potential exists that many promising new programs are not being disseminated through peer-reviewed channels. Therefore, we recommend that any subsequent literature reviews on Indigenous HCV integrate both grey literature and community-based documents such as program reports, community websites and agency evaluations. Second, information included in this review is limited through historical researcher/community relations, whereby some communities may be reluctant to disseminate the results of community programs to unaffiliated health organizations or through traditional peer-review networks. In a future review, this limitation may be mitigated through relationship building and collaboration with Indigenous community health organizations and asking them to contribute any program results or data that they believe are particularly salient to Indigenous HCV.

Third, North-American studies (particularly Canadian studies) were over-represented in this review. This is likely due to factors such as publishing bias and North American studies having greater resources available to disseminate findings through major peer-reviewed channels. Last, we recommend that any future reviews include all relevant data from such subsequent studies as the *Cedar Project*, *BC Centre for Excellence in HIV/AIDS* studies (e.g. *VIDUS*, *ACCESS* and *AESHA*), and any other future large cohort studies examining hepatitis C in Indigenous individuals and communities across Canada. Finally, we recommend additional consultation with key community and academic informants regarding the most influential HCV papers, with explicit consideration paid to their applicability to Indigenous peoples, as well as the degree of contextualization for Indigenous people required.

CONCLUSION

To the best of our knowledge, this is the first scoping review conducted on Indigenous peoples and hepatitis C. Our review utilized a systematic approach to gain a comprehensive understanding of the kinds of research and work that has been done in the area of hepatitis C among Indigenous populations in Canada, and elsewhere. Our analysis of the literature revealed three overarching themes within the peer-reviewed literature. First is the presence of significant silences in the data related to hepatitis C within Indigenous populations, particularly in relation to accurate estimates of prevalence and qualitative analyses of barriers to care, wellness, psychosocial issues and lived experience. Second was the presence of multiple intersectional factors that affect Indigenous peoples' experiences with hepatitis C, such as injection drug use, gender, youth, homelessness and co-infection with HIV. If gains are to be made in reducing rates of hepatitis C in Indigenous populations, these intersections must be taken into consideration across the realms of research, policy, prevention programs and the continuum of hepatitis C care. The last overarching theme was the criticality of involving Indigenous peoples and communities in the process of deciding program and research priorities. Within this, there must be a focus on innovation, self-determination, integration of services, cultural safety, wholism and traditional values.

To conclude, this review confirms our hypothesis that there is a need for a more in-depth examination of the research priorities for Indigenous peoples in Canada and hepatitis C. Without this, there will be little assurance that hepatitis C rates in First Nations, Inuit and Métis peoples

do not worsen. Furthermore, our review aligns with and supports the *Water Journey* project and its aim to conduct a series of sharing circles to gain insight from the experiences of Indigenous peoples living with hepatitis C. Moving forward, our next objectives will be to expand our research network and apply the knowledge gained from *Water Journey* in the development of a more comprehensive national research framework. The findings of this literature review should serve as an important foundation for future research directions within the area of hepatitis C and Indigenous peoples in Canada.

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