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# Hepatitis C Testing and Treatment Access Among People Who Inject Drugs

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Hepatitis C Testing and Treatment Access Among People Who Inject Drugs

by

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Bachelor of Science, Honours Health Sciences

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THESIS

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### Abstract

Hepatitis C (HCV) remains a global issue as it affects 2-3% of the world's population. Despite Canada's universal access to healthcare, barriers to accessing testing and treatment for HCV has contributed to approximately 250,000 Canadians living with chronic HCV. People who inject drugs (PWID) account for about 60% of all HCV cases in Canada, making them the primary target for public health interventions, namely prevention and harm reduction. Harm reduction efforts have proven effective to reduce the incidence of infectious diseases and to prevent overdoses, but there remains a large proportion of individuals living with the virus who are unaware of their status and who require treatment. Current HCV discourse lacks a local understanding of barriers and facilitators in the Canadian context. This study explored the experience of accessing HCV testing and treatment among PWID, identifying barriers and facilitators to HCV care throughout the individual's journey from diagnosis to cure within four domains of access: acceptability, availability, affordability, and geographic accessibility. The role of the client-provider relationship and the impact of harm reduction was also considered as it hinders or facilitates the accessibility of HCV testing and treatment. Qualitative interviews were conducted with clients (self-identified current or former intravenous substance user) and health providers in the Waterloo and Peel Regions of Ontario. Stigma and misinformation of HCV and substance use were regarded as systemic forces that perpetuate oppression, reflected throughout all access domains on a community and individual level. Facilitators and solutions identified in this study indicate a need to apply community health models and resources, more widely adopt harm reduction and patient-centred approaches to clinical care, and further consider or utilize intersectoral action to ensure equitable access to health services.

*Keywords:* access, barriers, harm reduction, health equity, hepatitis C, injection drug use

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*Rest in peace, Kalina and Stephen.*

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### List of Abbreviations

<b>ACE</b>	Adverse Childhood Experience Study
<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ASOs</b>	AIDS Service Organizations
<b>CAAN</b>	The Canadian Aboriginal AIDS Network
<b>CATIE</b>	Canadian AIDS Treatment Information Exchange
<b>CSC</b>	Correctional Services of Canada
<b>CTFPHC</b>	Canadian Task Force on Preventive Health Care
<b>DAAs</b>	Direct-acting Antivirals
<b>GCDP</b>	Global Commission on Drug Policy
<b>HCV</b>	Hepatitis C virus, also used as a reference to chronic hepatitis C
<b>HiAP</b>	Health in All Policies
<b>HIV</b>	Human Immunodeficiency Virus
<b>IDU</b>	Injection Drug Use
<b>LHIN</b>	Local Health Integration Network
<b>NSP</b>	Needle and Syringe Program, also termed Needle Exchange Program (NEP)
<b>OHCTF</b>	Ontario Hepatitis C Task Force
<b>PASAN</b>	Prisoners with HIV/AIDS Support Action Network
<b>PHAN</b>	Peel HIV/AIDS Network, a local AIDS service organization in the Peel Region of Ontario
<b>PHAC</b>	Public Health Agency of Canada
<b>PWID</b>	People (or Person) Who Inject Drugs, often used interchangeably with IDU
<b>PWUD</b>	People Who Use Drugs
<b>SDoH</b>	Social Determinants of Health
<b>STI</b>	Sexually Transmitted Infection
<b>WHO</b>	World Health Organization
<b>WRCPC</b>	Waterloo Region Crime Prevention Council
<b>WRIDS</b>	Waterloo Region Integrated Drugs Strategy

## 1. Introduction

### 1.1 Background

Hepatitis C remains a significant global medical and economic concern, currently affecting 2-3% of the world's population (see Hajarizadeh, Grebely & Dore, 2013) and 0.5% of the Canadian population in 2014 (Trubnikov, Yan, & Archibald, 2014). The hepatitis C virus (HCV) attacks the liver and can lead to liver cancer and failure (Khan et al., 2014). The liver is vital for responding to infections, filtering toxins from the blood, digestion, and hormone regulation (Ramadori, Moriconi, Malik, & Dudas, 2008). The process of liver failure usually occurs over several years where inflammation, fibrosis and cirrhosis will first occur. The slow progression of disease explains the asymptomatic nature of HCV (Myers et al., 2015). Consistent monitoring and healthy living are vital to preserving liver tissue and delaying progression.

HCV rates are approximately twice as high among Ontario men than women, and those aged 45 to 54 years account for the highest proportion of HCV cases by age (Remis & Liu, 2011). However, people who inject drugs (PWID) are the primary focus of HCV intervention since they account for 60-80% of new HCV infections (Remis & Liu, 2011). Transmission of HCV occurs through blood-to-blood contact, which places prisoners, street-involved youth, those who share substance use equipment, and those from countries with prevalence rates higher than Canada as high-risk populations (Haydon, Rehm, Fischer, Monga, & Adlaf, 2005; Remis & Liu, 2011).

Injection drug use (IDU) is also a risk factor for acquiring HIV (human immunodeficiency virus) through the practice of sharing injecting equipment. HIV transmission occurs from HIV-infected body fluids, including blood, and can lead to AIDS (acquired immunodeficiency syndrome) (Centers for Disease Control and Prevention, 2017). As a

consequence of shared transmission routes and similar risk factors, approximately 30% of HIV-positive PWID in Canada are co-infected with HCV and HIV (Lavanchy, 2009). Thus, secondary and tertiary prevention interventions are aimed at reducing the risk of HIV and HCV infection through harm reduction initiatives. Harm reduction efforts employed by public health units and community service organizations have been successful in reducing the incidence and prevalence of HIV and sexually transmitted infections (STIs). They also showed to reduce needle and equipment reuse and are cost-effective (Holtgrave, Pinkerton, Jones, Lurie, & Vlahov, 1998; Laufer, 2001; O'Connell et al., 2005; Spittal et al., 2003; Wodak & Cooney, 2006). Primary prevention efforts often promote behaviour avoidance or abstinence, but harm reduction also serves to promote primary prevention by knowing one's status through testing. Employing the same prevention methods but displaying differing rates of HIV and HCV suggest a need to more effectively address HCV (Rhodes, Davis, Rhodes, & Martin, 2004). For instance, HCV rates in Canada surpass those of HIV by a factor of four (Remis & Lui, 2011).

The social location of individuals (i.e., the collection of social demographics relating one's community) is an important factor for shaping health outcomes and health inequities (Hankivsky & Cormier, 2010). Social demographics that contribute to one's social location may include race, gender, income, housing, employment, and many more, which are also known as the social determinants of health (SDoH) (Raphael, 2009). For example, Canadian Indigenous communities are disproportionately affected by HCV as they are over-represented in the prison system, drug-using population and homeless population due to various economic, social, and health inequities (Ontario Hepatitis C Task Force [OHCTF], 2009), resulting from on-going systemic discrimination that reinforce colonialism. Provincial and national HCV disease surveillance data group "other visible minorities" for purposes of analysis (OHCTF, 2009).

Aggregating racial and ethnic data makes it difficult to monitor trends, determine risk and otherwise comprehend the unique experiences of individuals living with HCV in Canada.

There are several promising treatment therapies including direct-acting antiviral drugs (DAAs) for full viral suppression, with high success rates and minimal adverse effects (Myers et al., 2015). Despite the existence of highly effective treatments, there are low testing and treatment rates among high-risk, marginalized populations. Low testing rates have been primarily attributed to the asymptomatic and highly stigmatized nature of the disease, resulting in approximately one-third of Canadians unknowingly living with the virus and potentially transmitting HCV to others (Trubnikov, Yan, & Archibald, 2014). Among diagnosed individuals, barriers to treatment experienced by PWID in North America, Europe and Australia include: a high treatment cost and difficulty qualifying for treatment funding (OHCTF, 2009), limited knowledge of HCV among specializing health providers (Butt, 2008; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013), discrimination and stigma experienced in health settings (Butt, 2008; Neale, Tompkins, & Sheard, 2008; Treloar et al., 2011; van Boekel et al., 2013), and political influences such as drug criminalization (Grebely & Dore, 2014; Swan et al., 2010). These factors appear to be inter-related with stigma and oppression of PWID, which is internalized and associated with questioned worthiness to receive care and treatment (Butt, 2008; Treloar, Hull, Dore, & Grebely, 2012). This exacerbates illness by creating barriers to treatment, additional vulnerabilities and perpetuates injustice (Harris & Rhodes, 2013; Neale et al., 2008; Treloar et al., 2012; van Boekel et al., 2013).

Complications related to chronic HCV infection increases as individuals who are HCV-positive age and liver fibrosis progresses due to delayed treatment (Myers et al., 2014; Trubnikov et al., 2014). The anticipated economic impact of the total indirect and direct costs associated

with HCV-related treatment for PWID has been projected to cost \$3.96 billion from 2006 and 2026 (Werb et al., 2011). Adequately addressing HCV by promoting testing, early intervention and engagement with the healthcare system may significantly decrease the financial burden of HCV on the healthcare system and reduce these projected costs (Werb et al., 2011). Utilizing the concept of a care cascade (diagnosis, linkage to care, retention in care, treatment/therapy, and viral suppression) would be useful to monitor barriers and reveal gaps in care, which has been proven effective for HIV, and HCV-HIV co-infection (Hunt, 2007; Wood et al., 2004; Tyndall, Montaner & Kerr, 2006). An understanding of the HCV care cascade, from diagnosis to treatment, should be utilized in the Canadian context to contextualize epidemiological trends by identifying the barriers and facilitators to care and treatment, from the viewpoints of those seeking care and those providing it.

In summary, HCV is a disease with promising advances in treatment but remains a burden among PWID. This population experiences several social and structural barriers which impede access to treatment, or movement along the care cascade. It is therefore critical to gain knowledge of these challenges from various stakeholders to improve access. The present study aims to identify and understand these various challenges when accessing HCV testing and treatment in two regions of Ontario –Waterloo and Peel – as identified by clients and health providers.

## **1.2 Theoretical Framework**

The social determinants of health (SDoH), ecological systems theory, theories of power and empowerment, and intersectionality provide the theoretical lenses that have been applied in reviewing the literature, designing the present study, and synthesizing research findings. These prominent community and health psychology perspectives lend great strength to address

complex public health issues by valuing the concepts of health promotion, protection and equity as core competencies, providing a heuristic foundation for understanding and organizing the presented data (Nelson & Prilleltensky, 2010).

The social determinants of health (SDoH) are defined as the primary factors and living conditions that shape the health of individuals (Mikkonen & Raphael, 2010). The 14 social determinants of health summarized by Raphael (2009) include: Aboriginal status, disability, early life, education, employment and working conditions, food insecurity, health services, gender, housing, income and income distribution, race, social exclusion, social safety net, and unemployment and job security. These determinants contribute to various inequalities, that are experienced in different ways and at each level of society (Morrison, 2014). The World Health Organization (WHO) defines inequalities in health as “inequalities in people’s capability to function, which profoundly comprise freedom,” (WHO, 2007). Limiting a group’s access to social, cultural and economic resources defines social exclusion, which “creates a sense of powerlessness, hopelessness and depression that further diminish the possibilities of inclusion in society” (Mikkonen & Raphael, 2010). PWID may experience social exclusion through the denial of social goods, or through challenges acquiring or accessing social goods, such as health care (Edlin et al., 2005; Mikkonen & Raphael, 2010). Embedded in the SDoH framework are three interrelated theoretical directions: i) psychosocial approaches, ii) eco-social theories and multilevel frameworks, and iii) the social production of disease and the politics economy of health (WHO, 2007). These approaches coincide with the following theories and frameworks of ecological systems theory, power and intersectionality.

Ecological systems theory understands human experience holistically as it considers each systemic level “nested” within each other (Bronfenbrenner, 1977). This multi-level, multi-system

framework considers various settings and environmental aspects beyond the immediate situation containing the subject, conceptualized as a set of “nested” systems including the microsystem, meso-system, exo-system and macro-system (Bronfenbrenner, 1977). Applied to the present context, an ecological perspective will consider the various influences and relationships that shape HCV treatment accessibility by particularly considering the micro-, meso- and macro-levels of influence. In this framework, the microsystem encompasses the person and their immediate environment; the mesosystem refers to the interactions among other people or settings; and the macrosystem refers to the institutional and ideological patterns of culture and sub-culture (Bronfenbrenner, 1977). Exploring individual experiences requires this ecological approach in order to move beyond the individualistic health promotion model, and to better understand the prevailing ideas and ideologies that are present in society, which is a key factor that drives policy making (Prinja, 2010). Ecological models have also been noted to enhance human dignity by moving beyond explanations holding individuals responsible for harmful behaviours (Sallis, Owen, & Fisher, 2008) and assumes that people are active responders to their environments (Trickett, 2009).

Exploring the context of HCV testing and treatment access, the criminalization of substance use, and examining how PWID interact with care providers within and across these ecological settings requires an examination of power and oppression. Power may be defined as “the capacity and opportunity to fulfill or obstruct personal, relational or collective needs” (Prilleltensky, 2008) considered by capabilities and entitlements (Sen, 1999). Oppression may be defined as a state or a process with psychological and political dimensions, occurring in different pathways that are either directed inwards, towards oneself; or outward, towards others (Prilleltensky, 2008; Prilleltensky & Gonick, 1996). In Prilleletensky’s synthesis of power and

oppression, an integrated definition of oppression is summarized as “a series of asymmetric power relations between individuals, genders, classes, communities and nations [that] lead to conditions of misery, inequality, exploitation, marginalization, and social injustices” (Prilleltensky, 2008). Considering the dynamics of power and oppression in the narratives presented may reveal societal and structural influences that alter systems, resist oppression and foster wellness through control over personal and community life (Neal & Christens, 2014; Prilleltensky, 2008; Rappaport, 1987).

The four faces of power – “power over”, “direct” power, “indirect” power, and “power to” (Boulding, 1990; Rappaport, 1987) – further aid in contextualizing the experience of accessing and engaging with the health care system. For example, in Foucault’s concept of ‘bio-power,’ it is argued that social dominance over the body is pervasive and promoted by the medicalization and stigmatization of deviance (Foucault, 1979) which situates the health system and its practitioners with direct power, indirect power, and power over individuals. However, empowerment theory asserts that individuals may reclaim power through their engagement with such interactions to help adopt self-determination and autonomy (WHO, 2006). While many factors impact health, and these factor combinations may contribute to poor health outcomes, it may also provide means for resiliency. Thus, power and empowerment are conducive to investigating intrapersonal, interpersonal and institutional relations (Rappaport, 1987) that bolster the health utilization/distribution dichotomy. Having a high degree of individual empowerment among community members produces a strong social capital, including a sense of belonging and inclusivity, community participation and leadership (Israel, Checkoway, Schulz, & Zimmerman, 1994; WHO, 2006). This is especially relevant as factors contributing to the



accessibility of HCV testing and treatment will be identified from two differing perspectives – clients and health providers.

Power and empowerment may further aid in understanding the experiences and context of individuals. PWID often experience compounding layers of oppression in relation to multiple intersecting social identities, such as those relating to class, race, gender, ability, geography, etc. Intersectionality, referring to these various forms of intersecting oppressions, asserts that “oppression cannot be reduced to one fundamental type, and that oppressions work together in producing injustice” (Collins, 1990). Coined by Crenshaw (1989) to address the multifaceted experience of discrimination faced by Black women in the United States, intersectionality as an approach, practice and paradigm has been applied to policy analyses to deduce how policies contribute or ameliorate inequalities (Bishwakarma, Hunt, & Zajicek, 2007). Thus, intersectionality theory is useful for understanding how the various identities of individuals, and the SDoH, influence ones’ relationship to power, oppression and privilege (Crenshaw, 1991; McGibbon & McPherson, 2011). Rather than focusing on an additive model of oppression for intervention, an intersectionality approach (and intersectionality-based policy analysis) focuses on the relationship between intersecting factors and processes by which power and inequities are created and perpetuated (Dhamoon, 2011; Hankivsky et al., 2014).

The infectious disease and substance use discourses have been criticized for having narrowly conveyed understandings about the root causes of substance use, health inequities and access to health care (Hankivsky & Cormier, 2010; Smye, Browne, Varcoe, & Josewski, 2011). For instance, the various tools designed to track health inequities and aid in policy planning are focused mainly on single categories or binary variables, failing to investigate the interaction of different identities, systems and process (Hankivsky et al., 2014). This subsequently produces an

inadequate consideration and understanding of the downstream policy effects – that is, from policy to communities and individuals (Robertson, 2007; Woolford, 2001). Failing to acknowledge the production and maintenance of racialized relations in drug policy and health care serves as an example, where racialized communities are disproportionately targeted and affected by drug criminalization (Owusu-Bempah & Wortley, 2014). Clinical spaces have also been found to be discriminatory based on various social determinants, such as race and socioeconomic status (Malat et al., 2009; Olah, Gaisano, & Hwang, 2013). For example, Malat et al. (20089) discussed the ‘colour-blindness’ ideology in medical training and practice that ignores social, racial and cultural considerations in health care. Further, an audit study conducted by Olah et al. (2013) found that a caller seeking primary care who presented themselves from a high socio-economic status were significantly more likely to be offered an appointment, screening visit and placed on a waiting list than callers who presented themselves from a low socioeconomic status.

Power, oppression and stress may also influence the progression of one’s relationships with substances as a coping response (Raphael, 2009). Internalizing oppression invokes power over those who perpetuate stigma, further contributing to an unequal distribution of power and access to opportunities and resources exemplified by the SODH (Link & Phelan, 2001). Through the use of strain theory, Merton (1957) claims that such power imbalances may bestow a resultant strain on individuals and communities that often promote deviant or criminal adaptations for survival. Cognitive behavioural theories of mental health and addiction claim that learning or acquiring specific thinking patterns have been shown to lead to these negative emotions and reactions (Mitcheson et al., 2010). Since risk perceptions, behaviours and addiction are influenced by various factors and may differ across contexts, understanding the environments

in which risk behaviours and relationships occur have been noted to be essential (Rhodes et al., 1999). Thus, understanding and acknowledging the influence of the SDoH, applying the ecological model, challenging existing power dynamics, and employing a lens of intersectionality will contribute to a holistic understanding of the phenomena observed in a manner that promotes systemic change.

## **2. Literature Review**

### **2.1 Drug Policy, Public Health and HCV**

#### **2.1.1 The Historical Context**

The emergence of HCV-related barriers to treatment and negative experiences are largely attributed to HCV- and drug-related stigma. Stigma, as defined by Goffman's (1963) seminal theory, is a negative personal attribute or trait that discredits the individual in the eyes of society. HCV-related stigma is rooted in the history of drug criminalization viewed as a form of deviance contributing to conventional views of criminality, promiscuity, and untrustworthiness (Butt, 2008; Grebely et al., 2006).

#### **Drug policy and criminalization**

Canadian drug criminalization materialized through the first drug prohibition in 1908 with the Opium Act (Riley, 1998). Several iterations added other substances, such as other opiates, cocaine and cannabis, to form the Opium and Narcotic Act of 1929 (Riley, 1998). Despite the large allocation of enforcement resources, substance use rates rose sharply through the 1960s and early 1970s (Erickson, 1992). The resultant strain on courts pressured for the liberalization of Canada's drug laws, leading to an inquiry to describe and analyze the social costs and individual consequences of the criminalization policy. The 1969 inquiry by the Le

Dain Commission on non-medical use of drugs questioned the cost-effectiveness of the government's approach and unveiled that prohibition generated underground markets to sell opium consequently leading to addiction, disease transmission and negative views of drugs and drug users as thousands were incarcerated (Dias, 2003; Erickson, 1992; Riley, 1998).

Summarized by Erickson (1992), most forms of illicit drug use and arrests for cannabis declined, while arrests for cocaine increased in the 1980s. Canada's Drug Strategy (1987), also known as Bill C-7, was later implemented to address supply and demand reduction strategies, including enforcement, treatment and prevention. While an integrated national model and health promotion paradigm was valued, the enhanced power of law enforcement created tension and poor coordination in this approach (Riley, 1998). Criminal prohibition remained the dominant policy regarding illicit drugs until the 1990's with the introduction of harm reduction (Erickson, 1992), despite attempts in balancing paradigms, the public's demand for increased treatment, education and prevention, and the proven ineffectiveness to reduce disease transmission, overdose and other community harms (DeBeck, Wood, Montaner, & Kerr, 2009; Khenti, 2014; Morin, Eibl, Franklyn, & Marsh, 2017; Riley, 1998).

Throughout this punitive emergence of the *War on Drugs* the prominent functionalist paradigm commenced drug-related stigmas by labelling drug use as disruptive behaviour. Individuals using substances were viewed as deviants that disrupt society's normal functioning that the societal entity shared to preserve (Goode, 2014, p 150; Spencer, 1985), validated by laws that made these practices illegal. The moral panic established with increasing arrests and media-fueled fear of drugs and drug users resulted in labelling and repression, a mechanism apparent in HIV-related stigma (Woolford, 2001). Studies that investigated perceptions about PWUD found

that members of the public attributed substance use with lower productivity, extra health care costs, business loss, and significant law enforcement costs (Dias, 2003).

Engaging in risky behaviours and relocating to dangerous environments were adapted in response to harsher laws and evoked fear (Wood et al., 2004). Risky behaviour, such as equipment sharing, was commonly reported as PWID avoided criminal offence when obtaining or carrying sterile injection equipment in areas of routine police surveillance (Riley, 1998; Global Commission on Drug Policy [GCDP], 2012). Occupying abandoned buildings for housing and substance use also constructed favourable conditions for disease transmission (Riley, 1998; Wood et al., 2004) that contributed to a heightened risk environment. Over time, this produced a social norm, or component of drug culture (Rhodes et al., 1999).

Prohibition and criminalization failed to produce meaningful outcomes and became a key driver contributing to harms and creating obstacles to access health interventions (GCDP, 2012). Criminalization also disproportionately targets vulnerable populations, namely racialized communities (Khenti, 2014; Owusu-Bempah & Wortley, 2014), and has been strongly suggested to contribute to drug-related violence (Werb et al., 2010). In a review and commentary about Canadian drug policy, Riley (1998) reflects about the central irony: “We speak of drug dependence as an illness and yet we continue to treat those who choose the wrong sort of drugs as criminals, as evil.”

### **The AIDS epidemic and tainted blood**

The AIDS epidemic was another significant event that contributed to a Canadian strategy to promote and protect health and human rights in the 1980's to 1990's (Erickson, 1999), where the first confirmed Canadian case was reported in 1982 (Rutty & Sullivan, 2010). Several constraints such as economics, poor inter-governmental coordination and reluctance to act,

contributed to the initially poor public health response that was described as “fragmented confusion” (Rutty & Sullivan, 2010). In fact, the title “fragmented confusion” marked the first of three stages describing the AIDS epidemic from 1983-1986; Stage II (1987-1988) was titled “campaign trail and error,” and Stage III (1989-1993) was titled “targeted and sustained response” (Walters, 1989). The activism and demand for access to proper care, treatment and human rights later extended to other sexual health-related issues and HCV-related issues from increasing rates of HIV-HCV co-infection (Health Canada, 2011) and the discovery of contaminated blood and blood products (Rutty & Sullivan, 2010). The public health response to the AIDS epidemic has been referred to as the “teacher” due to its crisis management and approach to problem-solving. This influenced an integrated approach to prevention and promotion by including community education as a critical mechanism and reducing risk through harm reduction (Walters, 1989).

In response to the contamination of blood products and the increasing rates of HCV, the Hepatitis C Prevention, Support and Research Program was created in 1999 enhance Canada’s capacity to address HCV through prevention (Health Canada, 2000). Since its inception, a total of \$23 million has been invested in HCV research (Public Health Agency of Canada [PHAC], 2017). The first national document, *A Strategic Framework for Action*, outlined Canada’s future directions, priorities and long-term plans to address HCV in 2009 (PHAC, 2009). During the interim of a national strategy, AIDS Service Organizations (ASOs) and front-line workers took the role to deliver HCV information, the first supervised injection facility (Insite) opened in Vancouver, and the Canadian Public Health Association (CPHA) created the Canadian Hepatitis C Information Centre to collect and circulate HCV educational materials across the country (CATIE, 2017a). These commendable achievements contributed to the evolution of modern

public health policy and health service delivery. Their challenges of sustainable funding and support, however, remain an issue in the present context.

### **2.1.2 The Present Context**

The foundation of modern public health arose to address the needs of community members by valuing prevention, community-based support, care and treatment support, research and management, evaluation, and public involvement (Health Canada, 2000). While care, support and research operate at the municipal level, provincial and federal governing bodies (Health Canada, 2011) control health service delivery. This organization consequently results in several shifting priorities and ideologies from a “top-down” delivery model as higher levels of government influence national legislation and resource allocation.

An example of shifting priorities in response to government power is reflected in the changing priorities and titles of federal drug strategies. Prior to 2007, Canada’s Drug Strategy aimed to minimize harms associated with problematic substance use by incorporating four pillars, including: i) prevention of problematic drug use, ii) treatment of drug dependence, iii) law enforcement to supply of drugs, and iv) harm reduction measures to limit secondary effects of substance use (Collin, 2006). In 2007 this strategy was renamed the “National Anti-Drug Strategy” which eliminated the harm reduction pillar and committed to a law-enforcement based approach (Government of Canada, 2011). A stringent approach to drug enforcement was implemented through mandatory minimum sentences for drug possession and by creating the Safe Streets and Communities Act (Bill C-10) in 2012.

With another change in federal leadership, from the Conservative Party of Canada to the present Liberal Party of Canada (inducted in 2016), priorities, funding and conversations about substance use and harm reduction initiatives shifted again. Harm reduction was reinstated as a

core pillar of the re-named strategy, titled the “Canadian Drugs and Substances Strategy”. Canada also declared a nation-wide opioid crisis in response to the growing number of overdoses and deaths caused by opioids (Health Canada, 2017a; WRP, 2017). In 2017, the Good Samaritan Drug Overdose Act (Bill C-224) was implemented as a key component of the public health approach to the Strategy, and Federal action to address the opioid crisis by providing some legal protection for individuals seeking emergency help during an overdose. Additionally, Canada’s Minister of Health (Hon. Jane Philpott) also affirmed Canada’s commitment to eliminate hepatitis B and C by 2030 as part of the Global Strategy on Viral Hepatitis at the World Health Assembly. The WHO identified this hepatitis strategy as the first of its kind to introduce global targets for viral hepatitis (WHO, 2016a). Medium-term goals of the strategy include a 30% reduction in new cases of hepatitis B and C, and a 10% reduction in mortality by 2020 (WHO, 2016a). Key approaches to achieve such goals for hepatitis C are to focus on improving injection, blood and surgical safety, improving harm reduction for PWID, and increasing access to HCV treatment (WHO, 2016a).

Relatedly, negotiations with the pan-Canadian Pharmaceutical Alliance were underway to reduce the cost of HCV treatment drugs in some provinces to make treatment more accessible (CATIE, 2017b). Health Canada also approved the use and sale of point-of-care HCV antibody testing (OraQuick® HCV Rapid Antibody Test) in 2017 to expedite and increase the accessibility process of HCV testing (CATIE, 2017b). This test allows practitioners to collect a blood sample from a client from a finger prick to produce a result detecting HCV antibodies within 20 minutes. While this testing method does not reveal if a person currently has HCV, only that they have been exposed to HCV at some point in the past, the test is 98% accurate and may increase testing opportunities to the general Canadian population (Lee et al., 2011). Lastly, the



Public Health Agency of Canada (PHAC) formally recognized the considerable financial and social consequences of HCV, particularly on the healthcare system, affirming the need to prevent and control HCV transmission.

## 2.2 Harm Reduction

Harm reduction emerged in the United Kingdom as a public health strategy designed to reduce drug-related harm without requiring the cessation of drug use (MacMaster, 2004). This adopted approach throughout the world values pragmatism, a focus on harms, prioritizing goals, providing flexibility of intervention options, autonomy, and evaluation (Centre for Addiction and Mental Health, 2002). These six guiding principles of harm reduction are grounded in social justice that emphasizes respect and the right to choice (Marlatt, 1996). The introduction of harm reduction approaches and interventions have proven effective to reduce morbidity and mortality associated with risky health behaviours in comparison to the traditional abstinence-only approach (MacMaster, 2004). Harm reduction interventions have also been hypothesized to accelerate an individual's potential for change in their addiction as they "meet them where they are," with the possibility of moving towards abstinence over time (MacMaster, 2004).

Despite harm reduction's positive contributions, PWUD remain a highly marginalized population and experience many challenges to health care due to social norms and public policy (Butt et al., 2008; Treloar & Rhodes, 2009). Low HCV treatment uptake and persistent rates of HCV reveals the limitations of the harm reduction framework and its implementation as a public health philosophy and strategy across Canadian communities. As a philosophy for intervention, harm reduction has the ability to alter public perceptions, social norms, and increase community voice, but its application has been criticized for failing to address root causes of problematic substance use and associated social conditions that perpetuate inequities (Lloyd, 2010; Pauly,

2008; Smye et al., 2011). Thus, multiple factors affecting health and wellbeing are not addressed through this approach. The individualistic nature of public policy and harm reduction's value of patient autonomy has further been described as creating a "two lane" approach to intervention, separating those who can exercise self-control with those who lack it (Davis, Rhodes, & Martin, 2004). This notion resembles the health promotion framework that often highlight individual factors rather than community or systemic factors. Consequently, critics urge for the adoption of an intersectional and anti-oppression framework (Lloyd, 2010) with tools to "reflect an understanding of the systems of power and oppression that operate across the axes of race, class, gender, and ability" (Smye et al., 2011). An intersectional, anti-oppressive framework would therefore, shift responsibility away from individuals and hold structural factors accountable. Identifying how harm reduction is exercised in HCV-positive PWID may reveal if setting employing harm reduction can successfully accomplish this shift, or if this shift is presently occurring.

### **2.3 Barriers to HCV Care**

The low rate of HCV treatment uptake is critical to address as it is estimated that less than 1% of HCV-positive PWUD are receiving treatment (Grebely et al., 2006; Strathdee et al., 2005). Individual, relational and structural factors that influence access to HCV-related care has been identified to include: stigma in health settings, inadequate knowledge of HCV care and disease status, and housing, income and criminality.

#### **2.3.1 Stigma in health settings**

Stigma is central to the existence and experience of barriers to HCV testing and treatment. The strong association between substance use and HCV results in compounding forms of stigma enacted throughout society. Health care settings have been particularly identified as a

major discriminatory setting (Edlin et al., 2005; Treloar & Rhodes, 2009) and PWUD commonly believe that the health care received is unresponsive to their needs, judgmental and disrespectful (Edlin et al., 20015; O'Connor & Selwyn, 1996). HCV-positive individuals also report differing treatment in hospital and primary health settings, compared to other patients without HCV. Examples include: less attention received compared to non-drug using patients, being sent home prematurely, not being provided with care information, not allowed visitors, having less analgesia administered, having care withdrawn or refused, having their prescription medication threatened to discontinue, and intentionally being made to feel wasteful of valuable resources (Butt et al., 2008; Swan et al., 2010). Stigma experienced by people with HCV who do not use substances further validate the existence of HCV-related stigma in clinical settings, since they have also reported lower quality of care and assumptions of substance use (Butt, Paterson, & McGuinness, 2008). This suggests that HCV-positive PWUD encounter compounded stigma from the intersections of substance use and disease.

Compounding stigma in community and institutional settings often contribute to poor mental health as stigma becomes internalized. Self-blame, blame towards other individuals or groups, shame, embarrassment, low self-worth, fear, anger, depression, and isolation illustrate the internalization of stigma (Butt, 2008; Davis et al., 2004; Temple-Smith, Gifford, & Stoové, 2004). Consequently, individuals may avoid services, mistrust health providers, and anticipate future negative encounters (Butt, 2008; Edlin et al., 2005; Temple-Smith et al., 2004). Predicting recurrent negative encounters pose a concern for HCV care as this has been found to contribute to delayed care (Artenie et al., 2015; Neale et al., 2008). Understanding discrimination, interactions and relationships with health providers in multiple care settings is required. Often

reported in hospital settings, the client-provider interaction is unclear in the context of HCV testing and treatment.

### **2.3.2 Knowledge and awareness**

Education and outreach among clients and providers are the most influential individual-level factors associated with low treatment uptake (Harris & Rhodes, 2013). Community organizations, outreach workers and public health initiatives deliver training focused on safe injection and risk reduction for overdose and disease. Alarming, 21% of Canadians with chronic HCV remain unaware of their status (PHAC, 2012). Lacking knowledge about one's status, the disease and its treatment regime have been attributed to ignorance as individuals from previous studies reported being uninformed about risks in educational and health settings (Davis et al., 2004; Grebely et al., 2006). Inapt HCV education is reflected through inaccurate knowledge among PWID regarding modes of transmission, disease complications and interpretations of HCV screening tests (O'Brien, Day, Black, & Dolan, 2008; Stein, Maksad, & Clarke, 2001).

Social networks also act as a pathway for information sharing. A study by Swan (2010) revealed that discourse significantly influenced HCV perceptions among peers, which led to minimizing and normalizing HCV in comparison to HIV. The asymptomatic nature of HCV coupled with an undermined seriousness of the disease and fear of treatment establishes disinclination to seek care (Swan et al., 2010). A similar finding was discovered when analyzing perceptions of illicit substance users in Vancouver; A lack of information about HCV treatment, its availability, the absence of symptoms, and perceived side effects was reported as the most significant barriers to seeking HCV treatment (Grebely et al., 2008). The powerful influence of social networks reveals an area for intervention, but poorly executed interventions may further

exacerbate misinformation among networks and lead to negative perceptions of treatment. For instance, sharing HCV treatment stories and unfavourable side effects from older therapies have been shown to greatly influenced peers, deterring them from seeking treatment (Jordan et al., 2013; Swan et al., 2010). The heightened fear of treatment side effects and powerful influence of social networks reported from PWID in other high-income countries infer a common challenge to overcome short-term risk.

Health providers may exacerbate barriers to HCV care by sharing inaccurate information with patients due to their own gaps of knowledge regarding the subject. The reluctance and inability of health practitioners to provide adequate service to patients present an additional barrier to care. Lacking education, training and experience with complex populations further leads to avoiding discussion about HCV and making the appropriate referral to seropositive patients (Myles, Mugford, Zhao, Krahn, & Wang, 2011). A Canada-wide survey administered to specializing physicians highlighted hesitation for initiating treatment with HCV positive patients as their likelihood of adherence was questioned, despite evidence proving that PWID can undergo therapy safely and efficiently (Myles et al., 2011). Current intravenous substance use was the greatest contributing factor for denying a specialist referral and HCV antiretroviral therapy in Australia (Stoové, Gifford, & Dore, 2005). The ability for physicians to revoke treatment and referrals exemplifies their inherent power as a health practitioner. Lacking professional education and training for substance use, addictions, infectious disease, and social justice is likely to influence healthcare delivery and contribute to a patient's avoidance and negative views of treatment since these interactions are bi-directional. Lacking meaningful HCV, mental health and substance use training may also result in unrealistic expectations and frustrations for both physicians and patients (Edlin et al., 2005). Identifying that physicians may

lack the appropriate information and tools to provide care to this client population may challenge prevailing assumptions of withholding treatment due to stigma alone.

### **2.3.3 Housing, income and incarceration**

The social determinants of health inarguably contribute to the initiation and progression of substance use, mental health and infectious disease. Poverty, unemployment, lack of social support, education and quality housing has especially been shown to exacerbate substance use and barriers to care (Cooper, 2008; Edlin, 2002; Pauly, 2008). Challenges securing and maintaining affordable housing, or any housing means, have been problematic for all Canadians since the 1980s (Chesnay, Bellot, & Sylvestre, 2013). This has been attributed to structural changes in welfare and housing programs, and to the gentrification of urban spaces (Chesnay et al., 2013; Hulchanski et al., 2009). Toronto’s social housing wait list in 2017 indicates that only 3,001 applicants were housed and 92,252 applicants remain active on the waiting list (City of Toronto, 2018). Lacking affordable housing translates to a significant dependence of housing services and shelters; of which also encounter challenges related to adequate resources, safety and capacity. An estimated 35,000 Canadians are homeless<sup>1</sup> on a given night (Gaetz, Gulliver & Richter, 2014). Legislative policies, such as the Safe Streets Act, have been criticised for contributing to a problematic social construction of how people experiencing homelessness are viewed (see Chesnay, Bellot & Sylvestre, 2013). Views of deviancy or bring dangerous figures, and undeserving of assistance – or deserving of their situation – (Chesnay et al., 2013; Esmonde, 2002) similarly characterize presumptions about PWUD. Interestingly, criminal activity was reported by PWUD in the UK as being advantageous since their involvement with the criminal

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<sup>1</sup> Homeless, or experiencing homelessness, may refer to a variety of housing circumstances characterized by “unstable and unfit housing situations” (Hulchanski et al., 2009).

justice system was believed to lead them to faster housing-related support (Neale et al., 2008).

Though beneficial to the individual in receiving immediate support, these actions may perpetuate negative views about PWUD and people experiencing homelessness.

Involvement with the criminal justice system, constant oppression and labeling may lead individuals to self-identify as criminals (Becker, 1964). Being trapped in a cyclic system of limited financial resources and opportunities also contribute to differing priorities and additional health care concerns for low-income PWID. The intersection of substance use, ill health and limited resources yield considerable challenges to utilize health services, and when seeking or maintaining employment. For example: the absence of a permanent address is problematic in health settings requiring some form of registration or identification (Harris & Rhodes, 2013; Neale et al., 2008); challenges adhering to strict medication routines and managing side effects may be exacerbated without a stable living environment or income to pay for treatments (Mosack et al., 2005); and medical settings have been reported as discriminatory or unwelcoming to homeless individuals and individuals who appear to be in a low socio-economic class (Olah et al., 2013; Wen, Hudak, & Hwang, 2007). Attending medical appointments and accessing pharmacies during limited operating times, facing recurrent acts of stigma in the workplace, enduring illness and sustaining substance use may specifically impede sustainable employment (Neale et al., 2008). Seeking basic survival needs and generating revenue for drug-related expenses may consequently take priority over obtaining timely and potentially expensive therapy (Artenie et al., 2015). Street-involved youth who use substances have supported this reality by admitting that the potential threat of liver disease, which does not have imminent symptoms, was not as important to them in comparison to other challenges faced (Roy, Nonn, Haley, & Cox,

2007). Treatment adherence may also be questioned as the perceived importance of HCV is minimized.

Another major concern for disease transmission and substance use is incarceration, since rates of HCV and HIV infection among prisoners are commonly higher than found in the community (Zakaria, Thompson, Jarvis, & Borgatta, 2010). In fact, according to the Correctional Services of Canada (CSC) HCV is the largest communicable disease burden in its prisons (CSC, 2008). The main factors contributing to higher infection rates in prisons include lacking harm reduction services and subsequent equipment sharing, barriers to infectious disease testing and treatment, and engaging in high-risk behaviours before admittance (Calzavara et al., 2007; Kouyoumdjian et al, 2016; Poulin et al., 2007; Zakaria et al., 2010). A study conducted by the CSC concluded that “Canadian federal inmates have access to, and make use of harm-reduction items...and HIV/HCV testing and treatment services” (Zakaria et al., 2010). However, researchers and advocates have challenged the availability of harm reduction materials (aside from bleach) and specific health services in Canadian prisons, such as opioid substitution therapy (Kouyoumdjian et al, 2016; Zakaria et al., 2010).

A joint lawsuit was made in 2012 against the Government of Canada for the inadequate availability of sterile injection equipment and prevention of HIV and HCV in Canadian federal prisons, launched by a former prisoner (Steven Simons), the Canadian HIV/AIDS Legal Network, Prisoners with HIV/AIDS Support Action Network (PASAN), CATIE, the Canadian Aboriginal AIDS Network (CAAN) (Canadian HIV/AIDS Legal Network, 2010). Given that an estimated 30%-50% incarcerated individuals have a history of injection drug use (Calzavara et al., 2007; Poulin et al., 2007) and that drug-related crimes accounted for 4.4% of crimes in Canada for 2016 (Statistics Canada, 2017b), having the necessary substance use related and



mental health services available is imperative for recovery, rehabilitation and prevention. Evidence has shown that upon release, people with problematic substance use are also at a heightened risk of overdose as challenges such as securing basic survival needs and coping with stress or substance dependency are experienced (Kouyoumdjian et al, 2016; Zakaria et al., 2010). This further exemplifies the interplay between structural, social and individual factors.

## **2.4 Conclusions from the Literature**

The effectiveness and cost-savings of harm reduction services have been confirmed in the Canadian context, but the existence of barriers to health and social service access, and emphasis on individual health behaviour, impede the potential for creating systemic change. Prevailing stigmatizing views, the criminality of substance use and undermined importance of HCV is reflected in the number of Canadians currently living with HCV. Moving towards HCV eradication in Canada requires the consideration of all barriers and influences as they operate simultaneously across the HCV treatment cascade. Differing structural factors that exist between countries do not lead to generalizable study findings when exploring solutions in the Canadian context. Canadian literature also lacks the perspectives of health practitioners and the experience of PWID outside of major cities. Thus, a solution-focused approach is warranted to enrich critical discourse by understanding the phenomenon holistically by exploring HCV testing and treatment access from more than one stakeholder group, and clearly defining the components of service access.

## **3. Current Study**

### **3.1 Research Questions and Objectives**

The purpose of this study was to explore the experience of accessing HCV testing and treatment among people who inject drugs among different stakeholders – health providers and

clients. The relationship between health providers and clients, and implications of harm reduction as means for disease prevention and health promotion, were underlying considerations.

The research questions are:

- 1) What is the experience of accessing HCV testing and treatment from the perspectives of PWID and health providers?
- 2) How does the client-provider relationship hinder or facilitate the accessibility of HCV testing and treatment for PWID?
- 3) How can harm reduction principles and interventions improve the client-provider relationship and increase the accessibility of HCV testing and treatment for PWID?

The questions will be attended to in the following objectives, to:

- a) Understand the experience of HCV testing and treatment among PWID and health providers;
- b) Identify barriers and facilitators to HCV testing and treatment access from the perspective of PWID and health providers;
- c) Explore the relationship between clients and providers, and identify factors of the relationship that may influence HCV testing and treatment access for PWID; and
- d) Critically analyze the role of harm reduction, as a philosophy and intervention, for improving healthcare relations and access to HCV care.

### **3.2 Research Context**

The HCV access study was conducted in the Peel Region and Waterloo Region of Ontario, supported by three partnering organizations – the Peel HIV/AIDS Network (PHAN), Bloom Clinic, and Sanguen Health Centre. PHAN and Bloom Clinic have established partnerships throughout health clinics in the Region as an outreach and treatment centre, where

PHAN serves individuals throughout Peel Region who are living, affected, and at risk for HIV/AIDS and HCV comorbidity, while Bloom Clinic specializes in HCV-specific outreach and clinical care at the Brampton Community Health Centre. In Waterloo Region, Sanguen operates similarly to Bloom Clinic as they aim to meet the needs of people living with or at risk for HCV within a clinical setting, but operate their clinic in the community and utilize a community health van, rather than in a larger health institution. The abovementioned organizations deliver programming and services surrounding support, education, advocacy, and harm reduction in their communities, but differing care settings, funding, and primary foci may reflect or impact regional differences.

Harm reduction interventions, including needle syringe programs, safe crack-pipe distribution, condom distribution and education, are funded through the Ontario public health units. The public health units also assist with resource distribution and education through 'Healthy Sexuality' clinics and rapid HIV testing. Additionally, the Peel Public Health Unit is responsible for operating the mobile harm reduction clinic, whereas Sanguen Health Centre is a community health service that initiated, and currently maintains, the mobile harm reduction clinic across Waterloo Region.

Overall, the two regions are unique and not commonly researched. The Peel Region has the second highest population of people in Ontario comprised of 1.3 million inhabitants, while Waterloo Region is home to 535,154 people (Statistics Canada, 2017a). Both regions have steady population growth with large influxes of immigrant resettlement, contributing to higher rates of visible minorities residing in these areas compared to the provincial average of 25.9%; Visible minority groups account for 61.2% of Peel Region's population and almost 20% in the Waterloo Region (Statistics Canada, 2017a).

Upon the implementation of harm reduction in Ontario, rates of HCV steadily declined for several years until reaching a plateau between 2006 and 2010. However, HCV remains the infectious disease responsible for the most years of life lost and reduced functioning (Kwong et al., 2010). HCV rates in the Peel and Waterloo regions have continued to decrease slowly, but the Waterloo Region encountered a notable increase between 2009 and 2010 (Remis & Liu, 2011). Overall, Peel Region reports a higher number of people living with HCV than the Waterloo Region (22.5 per 100,000 and 19.5 per 100,000, respectively). The most common risk factor contributing to HCV in the Waterloo Region is injection drug use (Region of Waterloo Public Health, 2015).

The differing epidemiology of HCV in these two regions is not surprising given the extensive coordination and effort addressing infectious disease, overdose, and drug use in Waterloo Region, which greatly lacks in Peel Region. The Waterloo Integrated Drugs Strategy (WRIDS) incorporates prevention throughout the lifespan, harm reduction, recovery and rehabilitation, the criminal justice system, and integration and collaboration rooted in expertise and experience, as key priority areas of the strategy (WRCPC, 2011). The Peel Region lacks a comparable drug strategy and refers all drug-related inquiries to community health and service organizations. Peel's proximity to the large, urban centre of Toronto, as part of the Greater Toronto Area, may contribute to the way in which members of Peel Region access services, compared to Waterloo Region. The community impact of the WRIDS has not yet been established,

The temporal progression of this study is situated in a rather ambivalent period. Opioid-related deaths have increased almost a four-fold over the past 25 years (Gomes, Greaves, Martins, et al., 2017) and preliminary surveillance data from 2017 shows that opioid-related

deaths involving fentanyl or fentanyl analogues more than doubled in January to June of 2017 in comparison to the same time period in 2016, presenting the current “opioid crisis” and urgency to increase harm reduction interventions, overdose kit availability (e.g. Naloxone and Narcan), and professional training (Health Canada, 2017a). Concurrently, public policy celebrated a favourable advance for HCV treatment access in Ontario as more HCV treatment therapies became approved for funding coverage through the Ontario Drug Benefit Program (Grant, 2017). The Ontario Ministry of Health and Long Term Care (MOHLTC) further announced changing criteria for treatment coverage to be more inclusive of all patients living with HCV. In a phased approach, treatment will be available regardless of disease severity (MOHLTC, 2017). The potential impact of legislative changes on the present study and its interpretation is continually changing as new advancements in medicine and policy are regularly occurring. The growing attention on preventing overdose and distributing overdose kits through harm reduction networks and pharmacies may shift priorities in each region during this time of crisis. Likewise, HCV prevention, testing and treatment may benefit from the increased harm reduction efforts or may further stigmatize views about PWID.

### **3.3 Defining Access**

The WHO and members of the United Nations have endorsed declarations to address health inequities and improve access to health services. The fundamental values of Canada’s health system include fairness and equity (Health Canada, 2012). An equitable health system is defined as “one that provides its population with access to services according to needs and independent of the capacity to pay, thus safeguarding the right to health” (WHO, 2010). However, like equity, access is neither precisely debatable nor measurable in a definitive manner, posing challenges for researchers and debate among societies (WHO, 2011).

The Canadian Health Act (1984) includes accessibility as one of the five principles to “protect, promote and restore the physical and mental well-being of residents of Canada to facilitate reasonable access to health services without financial or other barriers.” Vague definitions of the words “reasonable” and “access” have created controversy from varying interpretations, effectively altering health delivery across the country (Birch, Eyles, & Newbold, 1993); In fact, medically necessary services are defined by each provincial and territorial health insurance plan separately (Health Canada, 2011). Numerous framework and models are employed to evaluate the ambiguous experience of service delivery, use, or access. Health utilization frameworks consider predisposition factors (e.g., family composition, social structure), enabling factors (e.g., income, insurance), and need to explore the factors that influence an individual’s engagement with the health system (Anderson, 1973). As an operational proxy for health care access (O’Donnell, 2007), utilization frameworks that lack explanatory variables often represent a homogeneous, hierarchical, additive approach to utilization (Arling, 1985 pp.370) and tend to be quantitative.

The conceptual framework of health care access by Peters et al., (2008) will form the basis of defining and understanding accessibility in this study by exploring the four domains of access: geographic accessibility, availability, affordability and acceptability (Figure 1). The presented framework is congruent with Health Canada’s *Framework for Health Promotion* that values fundamental requirements to attain optimal health (Health Canada, 1986) holistically through interactions, rather than an additive representation of resources contributing to health. Each domain considers supply and demand elements, reflective of its integration of the Anderson and Newman framework of health service utilization and the domains of Tanahashi’s framework for effective health coverage. The Anderson and Newman health utilization framework identifies

three main characteristics that influence an individual's access and use of health services, including predisposing factors (socio-cultural characteristics existing prior to illness), enabling factors (logistical aspects of obtaining care), and need factors (the immediate cause of health service use; Andersen & Newman, 1973). The Tanahashi's framework mirrors similar domains of availability, accessibility, acceptability, contact and effective coverage of health services (Tanahashi, 1978).

In the presented framework, *geographic accessibility* refers to the physical distance or travel time to service location in relation to the user; *Availability* refers to the appropriate type of care available to those in need, including wait times, hours of operation, and type of service provider; *Affordability* (also termed financial accessibility) refers to the relationship between the price of services and the willingness or ability to pay; and *Acceptability* refers to the responsiveness of health providers to the social and cultural expectations of individuals and their communities (Peters et al., 2008).

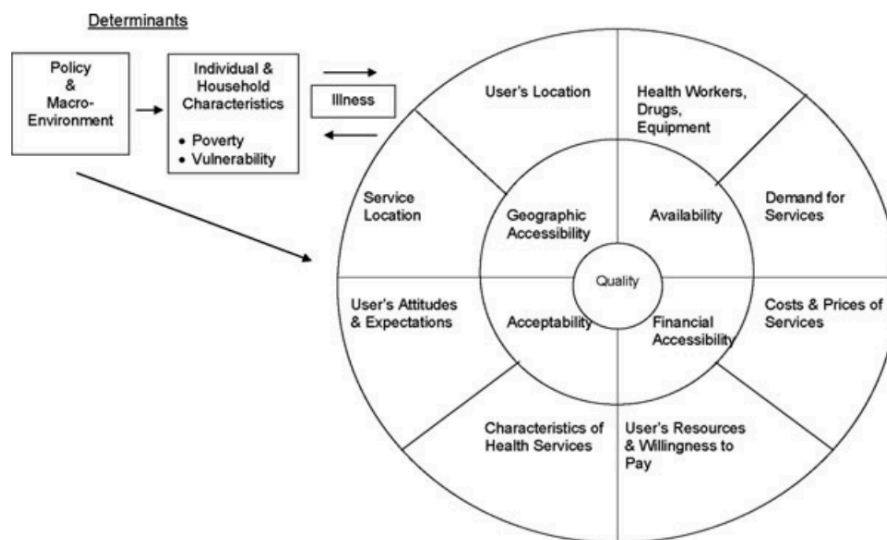


Figure 1. Conceptual framework for accessing health services (Peters et al., 2008)

### 3.4 The Cascade of Care

The “Cascade of Care” framework, introduced from HIV/AIDS monitoring, has been adopted as a model for monitoring the different stages in addiction of chronic illness treatment (Janjua et al., 2016). The stages presented in a care cascade generally include diagnosis, linkage to care, received diagnosis, initiating treatment or therapy, adhering to and completing therapy, and continued abstinence or recovery. Using the care cascade is effective for monitoring the effectiveness of prevention efforts since it clearly outlines areas for improvement (Nosyk et al., 2014). Data presented in a care cascade, represented in proportions, helps policy makers and health system planners project the financial impacts of treatments and revisit budgets to allocate, or reallocate, funding to improve a specific stage (Janjua et al., 2016). In relation to funding and resource provisions, trends unveiled in the care cascade are especially useful for health professionals, clinicians and community health organizations as a way to track their success.

The HCV treatment cascade (or care cascade) in British Columbia is the only published HCV treatment cascade in Canada, but the HIV care cascade has been more widely used in the country, including Ontario. Developments in HCV treatment access may soon establish an HCV treatment cascade as more individuals may have access to treatment. Negotiations with the pan-Canadian Pharmaceutical Alliance were announced in February 2017 to improve the cost of HCV treatment drugs in the provinces (CATIE, 2017b). Suitably, the concept of the care cascade will be considered in the present study when contextualizing the experiences of client participants as they moved from testing to treatment.



## 4. Methods

### 4.1 Research Paradigm

A constructivist paradigm was employed for the creation and interpretation of the HCV barriers study. The core assumption that there are multiple realities based on people's experiences in context reflects the conceptual framework and purpose of this study (Nelson & Prilleltensky, 2010). As a researcher, the social construction of knowledge is understood as produced and shared through interactions, experiences and interpretations (Berger & Luckmann, 1991). This ontology is congruent with my personal belief that everyone interprets experiences and interactions in different ways, as influenced by past and present social and physical location. This paradigm also asserts that the researcher and the participant are interrelated in the construction of knowledge, that research is value-bound, and constructions are dependent on the participant-researcher interaction (Guba & Lincoln, 1994; Nelson & Prilleltensky, 2010). The methodology should be qualitative to allow for this interaction and to help elucidate participants' experiences in a way that respects their realities that may not be accomplished with quantitative methods. Underlying explanations of experience should be unveiled to gather a holistic, intersectional interpretation of human experience.

Valuing the co-creation of knowledge also requires personal reflexivity. To ground my position in the present research, I recognize my privilege as a White, cis-gendered woman who has conducted the present study at an academic institution. Although I identify as an "outsider" who does not inject drugs or live with HCV, my previous involvement with the research topic and community partners, personal values, and application of community psychology theories and principles will lend strength to the reflexive praxis. I also recognize that I may hold certain assumptions or preconceptions shaped by my past and academic training. Education in the health

sciences may lend a bias favouring health providers due to a similar undergraduate experience that tends to emphasize and promote the bio-medical model of health. However, this may provide an advantage for understanding the foundational knowledge and beliefs taught to those in the medical profession. Member checking, journaling and maintaining communication with advisors, has helped maintain personal reflexivity throughout the research process to remain integral to the participants, particularly through the interpretation of results.

#### **4.2 Language and Terminology**

Language and labels can be stigmatizing and oppressive, ignoring the totality of person (WRCPC, 2011). As such, the terms “substance use,” “drug use,” “substance use disorder,” “problematic substance/drug use,” “addiction,” “people who inject drugs (PWID),” and “people who use drugs (PWUD)” will replace “substance abuser,” “addicts,” “injection drug users,” and “drug users.” Additionally, “clients” will refer to participants during their experience with health or social services, or engagement with the health system. These terms are congruent with suggested language guidelines from EQUIP Health Care (2017) and the Waterloo Region Crime Prevention Council (WRCPC) in effort to use language that is respectful, non-pejorative and accurate of communities and participating individuals (WRCPC, 2011).

#### **4.3 Sample and Procedure**

Study participants were recruited from the Ontario Regions of Peel and Waterloo. Residents of the Peel or Waterloo Region aged 18 years or older self-identifying as a current or former intravenous substance user who had sought HCV testing and/or treatment within the last two years were eligible as a ‘client participant.’ Licensed health providers practicing in the Peel or Waterloo Region reporting interactions with clients who use substances within the last two years were also eligible as ‘provider participants.’

Client and provider participants were recruited with the assistance from staff at partnering organizations. Client recruitment posters were displayed in the offices of Sanguen Health Centre, the Peel HIV/AIDS Network and the Bloom Clinic. With the assistance of staff, posters were also distributed to other community service organizations and community health centres in the regions. A Craigslist ad was also posted to reach individuals who may not access the spaces in which posters were displayed. Recruitment letters were mailed to physician offices, public health units and community health centres and were followed up with a telephone call. A snowball sampling technique was also attempted, a referral process to reach additional participants through professional and social networks, since it reinforces the concept of social knowledge as a dynamic and emergent process (Noy, 2008).

Interviews conducted with participants occurred in their respective regions at an organization or place of work convenient to them. The interviews varied in length between 45 to 65 minutes. Participants also completed a brief, open-ended demographic survey. Following the interview, client participants were provided \$25 as compensation for their time. The study protocol was approved by the Research Ethics Board of Wilfrid Laurier University.

#### **4.4 Data Analysis**

Demographic survey data from participants were compiled and tabulated using descriptive statistics. Audio-recorded interviews were transcribed, managed and analyzed using NVivo qualitative software (© QSR International Pty Ltd.). The interview data were analyzed through a series of coding cycles using a grounded theory approach to allow for the natural emergence of patterns and theory via thematic analysis (Braun & Clarke, 2006). The process of coding, or conceptual ordering, closely mirrored the process outlined by Strauss and Corbin (1990). Recognizing the constant interplay between the researcher and act of researching,

objectivity and sensitivity were balanced by taking memos, challenging personal assumptions and member-checking with participants to ensure the interpretations presented match their experiences (Strauss & Corbin, 2008).

The two-cycle coding process was both inductive and deductive. First cycle coding processes employed initial/open and in-vivo methods to gather a sense of the present concepts to create a coding book (Saldaña, 2016). As interviews were re-read, eclectic coding transitioned first and second coding cycles to begin organizing emergent codes. Due to the variety of phenomena explored from participants, the initial organization of codes was recorded by taking memos to track conceptualization of the emergent findings (Padgett, 2012).

Member check sessions occurred with four participants where participants were able to further discuss the topic and review emerging themes. A research associate was employed to assist with transcription and data analysis, where they employed the same analytic process for a sub-sample of interviews and discussed coding comparisons to minimize potential biases. Participant, supervisor and expert feedback ensured trustworthiness when refining codes using axial and pattern methods during the final coding cycle (Lincoln & Guba, 1985). Attention to both commonalities and differences between clients and providers were also reflected upon. Interviews were reviewed again and theory emerged from the formation of themes and subthemes (Braun & Clarke, 2006).

#### **4.5 Ethical Considerations**

Disclosing substance use and illness while reflecting on past experiences are sensitive subjects. The Research Ethics Board of Wilfrid Laurier University thoroughly reviewed ethical considerations during the acceptance process. Participants were provided with an informed consent letter that outlined the purpose, goals, procedures, and potential risks and benefits of

participation. Consent was obtained prior to interviewing and three options were posed for quotation use: a) consent to use and report de-identified quotations in reporting; b) consent to use and report de-identified quotations in reporting after a member-check and/or review; or c) consent to use knowledge without quotations. Providing the three consent options allowed participants to control the ownership of their stories and contribute to a positive interaction. This step was also congruent with the constructivist paradigm used.

Only one participant refrained from being quoted and two participants underwent a member-check session to review their interview transcript and/or further discuss the topic. Quotations included in reporting have undergone measures to assure anonymity, such as removing identifying information and only disclosing their regional location for quotations. Participants who specified names of other individuals were also de-identified during transcription. Further, pronouns used by health providers while providing examples of client interactions have been neutralized.

## 5. Results

The client sample comprised of eight client participants with four individuals from each region. Half of the client sample identified as female (n=4) and half as male (n=4), also evenly distributed by region. The vast majority of the clients identified as White (n=7) and ranged in age from 28 to 58 years. Educational attainment was evenly distributed among participants in the Peel Region, while the majority of Waterloo participants report high school completion (n=3). All client participants had previously tested positive for HCV. At the time of interview, one participant recently completed their HCV treatment, one participant was mid-way in their HCV treatment, and one participant was scheduled to commence treatment the following week. Only

one participant, who was from the Peel Region, had not undergone or sought HCV treatment. Table 1 provides a full description of the client sample.

The provider sample also comprised of eight participants, with four providers from each region. Health providers included Family Medicine Physicians (n=2 Waterloo), physician specialists (n=1 Waterloo, n=1 Peel), Social Workers (n=1 Waterloo, n=1 Peel), a Community Youth Worker (n=1 Peel), and a Public Health Nurse (n=1 Peel). By professional degree there was a greater representation of medical practitioners, specifically physicians, in the Waterloo region than the Peel sample. However, all of the medical practitioners from the Waterloo Region were based in community settings. Table 2 provides a full description of the provider sample.

The experiences of HCV testing and treatment from the perspective of client study participants is presented through four major sections to reflect the meta-themes that emerged as they reflected upon their treatment journey, resembling stages of the care cascade and aspects of the conceptual framework. A dragon analogy for HCV was adopted from a client's involvement with an HCV support community calling themselves the "Dragon Slayers<sup>2</sup>," exemplified in the following section titles:

- I. Life before the dragon: The injecting lifestyle and health determinants
- II. Meeting the dragon: HCV testing and treatment motivation
- III. Slaying the dragon: Accessibility and the experience of HCV treatment
- IV. Farewell to the dragon: Resilience and persistent challenges

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<sup>2</sup> The Facebook © Community "HCV – The Dragon Slayer" was created by Don Crockock who claimed the title as a "Dragon Slayer" in the Waterloo Region in 2015. A dragon is also used in the logo of Sanguen Health Centre.

Table 1.

*Client Participant Demographic Characteristics*

Characteristics	Waterloo Region n (%)	Peel Region n (%)	Total n (%)
<b>Age</b>			
18-29 years	1 (25%)	-	1 (12.5%)
30-44 years	-	2 (50%)	2 (25%)
45-59 years	3 (75%)	2 (50%)	5 (62.5%)
Age (mean)	45.25 years	40.25 years	42.75 years
<b>Gender</b>			
Male	2 (50%)	2 (50%)	4 (50%)
Female	2 (50%)	2 (50%)	4 (50%)
<b>Education</b>			
Less than high school/GED	3 (75%)	-	3 (37.5%)
High school grad/GED	-	1 (25%)	1 (12.5%)
Post-Secondary	1 (25%)	3 (75%)	4 (50%)
<b>Length of Residency in Region</b>			
<5 years	-	1 (25%)	1 (12.5%)
5-10 years	3 (75%)	1 (25%)	4 (50%)
11-20 years	-	1 (25%)	1 (12.5%)
>20 years	1 (25%)	1 (25%)	2 (25%)
<b>HCV Treatment Status</b>			
Completed treatment	3 (75%)	2 (50%)	5 (62.5%)
Treatment in progress	1 (25%)	1 (25%)	2 (25%)
Not treated	-	1 (25%)	1 (12.5%)
Has a valid health card	4 (100%)	4 (100%)	8 (100%)
Has a family physician	4 (100%)	4 (100%)	8 (100%)

Table 2.

*Provider Participant Demographic Characteristics*

Characteristics	Waterloo Region n (%)	Peel Region n (%)	Total n (%)
<b>Age</b>			
30-44 years	3 (75%)	4 (100%)	7 (85.7%)
45-59 years	-	-	-
60-65 years	-	-	-
65- 79 years	1 (25%)	-	1 (12.5%)
Age (mean)	45.75 years	34.5 years	42.75 years
<b>Gender</b>			
Male	3 (75%)	2 (50%)	5 (52.5%)
Female	1 (25%)	2 (50%)	3 (37.5%)
<b>Professional Degree</b>			
MD <sup>1</sup>	3 (75%)	1 (25%)	4 (50%)
MSW <sup>2</sup>	1 (25%)	1 (25%)	2 (25%)
CSW <sup>3</sup>	-	1 (25%)	1 (12.5%)
RN <sup>4</sup>	-	1 (25%)	1 (12.5%)

<sup>1</sup>MD, Medical Doctor

<sup>2</sup>MSW, Master of Social Work

<sup>3</sup>CSW, Community Service Worker

<sup>4</sup>RN, Registered Nurse

Although the narratives are represented in a linear manner, it is important to note that each participant's journey was complex and unique, occurring in differing temporal progressions and pathway; that is, the trajectory along the care cascade was not necessarily linear. In this way, the representation of participant narratives using this analogy serves as an organizing framework.

The injecting lifestyle and health determinants discussed in the first section are reflective in the "determinants" section of the conceptual framework, while testing and treatment motivation are outcomes of both the determinants and accessibility barriers. Factors contributing to the acceptability, availability, affordability and geographic accessibility of HCV treatment are



comparatively discussed in the third section. Finally, the fourth section illuminates the feeling of a ‘second chance’ following treatment, and unveils broader challenges in the health system that influence HCV care and health outcomes among PWID.

## 5.1 Life before the dragon: The injecting lifestyle and health determinants

Both clients and providers described the injecting lifestyle and harm reduction practices, but providers furthered this discussion to help explain why the nature of the injecting lifestyle exists by considering the environment and political contexts.

### 5.1.1 The Injecting Lifestyle

Client participants were not asked to disclose their substance use beyond self-identification of current or former injection drug use for study criteria, or other life experiences that may have influenced their substance use. However, several participants naturally discussed their relationship with substances as the injecting lifestyle explained the engagement, or lack thereof, with HCV testing and treatment. Clients unanimously identified lifestyle and behavioural factors as barriers to HCV care and general health care. Mental health, trauma and addiction particularly influenced client participants’ perception of health and the world around them. Clients regarded these factors as the primary barriers to testing, treatment and general healthcare utilization. Health and social services in general were perceived to lack importance and were purposely avoided, regardless of their accessibility:

*You give up, you don’t care. You feel dead inside anyways so it doesn’t matter what anyone else in the world is going to diagnose you with. You’ve already made up your mind in how you want to spend the rest of your life at that time. Hopefully a lot of people wake up like I did. It’s a very lonely life. (Client, Peel Region)*

Avoiding services and procrastination explained how substance use impeded the use of all health services:

*They (people who use substances) just procrastinate 'cause they always do, you know? They get busy and forget about it for a while. And 'cause they also don't want to know...they don't want to deal with it. (Client, Waterloo)*

Having a certain level of readiness was implied as a prerequisite for HCV testing and generally interacting with practitioners. 'Readiness' meant taking action in the pursuit of wellbeing with full engagement and dedication to a lifestyle change. In the interim, the forgetful nature of people who use substances made attending appointments difficult: *"time quickly passed after the next hit, and then you'd forget"* (Client, Peel Region). Lacking readiness and delaying care implied that HCV was not a priority.

HCV testing and treatment readiness also coincided with stress and trauma. Clients from both regions explained that their use of substances served as a means for coping with trauma, anxiety and depression:

*I do dwell on a lot of stuff, stuff that you could actually probably make a horror movie out of. You know, like things that have happened to you since you were little...I have kids, but how did it go so wrong that all of a sudden I had nothing? I didn't grow up to think that I would suck dick for a living. I had dreams too, and goals... When I started using drugs, I didn't start with a little bit- I just went big time. I prayed that I'd die. (Client, Waterloo Region)*

Persistent or increased substance use was also said to progress over time by consuming more "severe" or "risky" substances and by using substances in dangerous, or "risky" methods (such as intravenous use) to cope with additional stressors such as family, income and stigma.

Unresolved trauma, mental health concerns and guilt from incidents occurring while under the influence of substances were especially difficult to cope with during times of abstinence, either induced from detox attempts or during long intervals between use. When consumed by addiction, substance use took priority as it denoted survival:

*Most people don't assume that they are going to live another year or two anyways. When somebody's really doing a lot of drug use, you're not even thinking about next year;*

*you're thinking about the next buzz and that's all that matters in your life, and you don't care about anything else. (Client, Peel Region)*

Criminality and incarceration were also realities encapsulated in the lifestyle. Four client participants (n=2 Peel, n=2 Waterloo) discussed their involvement with the criminal justice system as a result of drug possession and illicit substance use.

### **5.1.2 Health Determinants**

Providers reflected on socio-cultural factors occurring over the life-course that increase vulnerability to substance use. The initiation of substance use was viewed as the product of a weak foundation of health determinants, particularly education, early childhood development, income and housing. Among these determinants, education was said to contribute to poor literacy skills that produce challenges in everyday life, including navigating the health system. For example, one physician discussed how poor literacy skills produce challenges when completing applications for insurance, social programming, legal matters, and other everyday encounters: *“A lot of [the programs] require someone to fill out an application, so that means someone has to have a support with them very often, to kind of help them with that. And a lot of them don't understand it”* (Provider, Waterloo Region).

Another physician emphasized the significance of early childhood development in reducing vulnerabilities that influence substance use, mental health, income and overall wellbeing. The Adverse Childhood Experience (ACE) Study was drawn upon to support the need to invest in early childhood development to prevent trauma and negative coping strategies, such as substance abuse, later in life:

*We're falling on our face with early childhood development in Canada [...] I always feel that if an addict was in a steady environment and had a good family upbringing, that if they became an addict in their 20s or 30s, I betcha' they'd get much better because they'll probably have the foundation and developmental structure. If they mess up*

*because of a trauma and becomes an addict, they're more likely to get on track.*  
(Provider, Waterloo Region)

Drug criminality was discussed as further exacerbating these disparities by forcing prosecuted users back in to the very environments in which they were apprehended. A client from the Peel Region discussed this cycle, where incarceration affected their housing, employment and educational desires. The following provider also articulated the relationship between the social determinants, incarceration and drug use, emphasizing that stable housing is especially important when considering recovery:

*Stable housing is a very, very important thing and once again note that a lot of them can't call to see if a [safe] bed is available until the day they get out [of prison]. So they literally have to get out and be homeless before they can actually start making phone calls [...] They hit the streets and they have nowhere to go. All that they have is on their backs and 'Life sucks, so I'm going to either try to find trying to find a phone to make calls to jump through the hoops to access resources and call [my care provider]' or 'I'm going to find my drug dealer and when I get my hit of crack, I'll feel better,' or 'I know a friend where I know I can sleep on their couch and they're who I used to use with before.' And the cycle continues... (Provider, Peel Region)*

## **5.2 Meeting the Dragon: Testing and Treatment Motivation**

### **5.2.1 HCV testing motivation and experience**

The majority of client participants revealed that testing for HCV was often passive, meaning it was not specifically sought in that moment. For instance, one participant was unknowingly tested for HCV while donating blood; two participants were tested for HCV as part of a yearly physical; and two participants were tested for HCV as a patient in the emergency department. The three resultant clients voluntarily tested for HCV: one testing at the AIDS Committee of Cambridge, Kitchener, Waterloo and Area (ACCKWA) and two while incarcerated.

Motivation for HCV testing included wanting to take ownership of their health and life, wanting confirmation of a pre-conceived feeling of having HCV, and viewing testing as a healthy and responsible practice given their risk factor of injection drug use. Despite the variation in testing location, most clients revealed that they anticipated a positive test. All three of these clients also tested for HIV at the same time. The testing locations were also described as being accessible, in that they did not experience transportation difficulties; did not pay for services; did not encounter difficulties with hours or scheduling; felt free from judgment; and received the results within a reasonable timeframe.

Even though clients admitted to avoiding disease transmission through harm reduction practices, they shared that a positive result was viewed as inevitable and ordinary in their networks.

One participant was informed of their status in a letter sent by the Canadian Blood Services following blood donation. Lacking personal contact and coming as a surprise, this person felt disbelief, shame, and a “*sense that life is over*”. For them, the news had been particularly difficult since they made radical life changes and persevered through its obstacles: “*I was living, I was healthy. I have given up the drug use. I changed my lifestyle.*” The lifestyle changes this person underwent were questioned in value as they felt that they could not fully escape from their past lifestyle, living with HCV. In this example, the participant described feeling at a crossroad, in that they could either cope through substance use or persist on the new path by embarking on treatment.

### **5.2.2 Seeking HCV treatment**

#### ***Personal motivation***

Each client that underwent treatment described a motivating factor or event that produced strength to engage with testing, treatment and recovery. This included family and social support,

experiences of a shameful or embarrassing event, and sensing a strong desire to control their health:

*Just the fact that there were other people that helped me believe in myself and got my self-esteem up to do [HCV treatment] helped. (Client, Peel Region)*

*It's not just you going through it, it's [your family] going through it too [...] I was embarrassed. I felt disgusted and I was 68 pounds. I was a walking shell of nothing. (Client, Waterloo Region)*

*My granddaughter. She's the light of my life. That was the positive [...] That got me through it [...] You have to have something to look forward to. There has to be a reason to go through treatment. (Client, Peel Region)*

Desperation was universally reported in pursuit of the next “fix” to prevent dope sickness, or during times of dope sickness, that later lead to feelings of shame and a desire to change individual behaviour. However, not all participants attributed a single event as being responsible for creating their turning point. One participant described the following example of a life-changing event that sparked their turning point:

*When I was out West I got really, really bad into heroin and the one time I was really dope sick I found a needle, and like there were no needles around, I couldn't find another needle anywhere it was 2 in the morning. I was so dope sick and I just needed to get it in me. And then I remembered seeing a needle on the ground somewhere, so I went back and it was still there. I don't know, [it's] something I'm ashamed of 'cause like it was rusty and on the ground. Like who knows who's it was? And I used it just because I didn't care. I wanted it to not be sick. Yeah, I've never gotten to that point after I left BC [...] I don't want to hit that point because that was like the lowest part of my life. (Client, Waterloo Region)*

Witnessing peers or family members endure the negative consequences associated with untreated HCV also contributed to a heightened importance of seeking and adhering to HCV treatment after a positive diagnosis:

*Well if you don't [get treated] you're going to die. It's your choice. It's not going to go away. It's only going to get worse and you are going to get extremely ill. So you can look at short-term side effect or long-term illness where you're wasting away. I watched my brother go through it. It's horrendous to watch someone actually die of hepatitis [C]. (Client, Peel Region)*

Health providers also discussed the need for patient self-awareness and motivation as these were strong contributing factors to accessing care and successfully undergoing HCV treatment. The impact of substance use on seeking care and perceiving treatment with importance was congruent with previous accounts from clients. A provider reflected on this effect in a patient:

*So I have a patient [...] I have seen them before and I know they use crystal meth regularly and doesn't see it as a problem [...] but they haven't followed up [with treatment] because they're doing their own thing and the drugs kind of them keep from following a pattern or focusing on any specific motivation. (Provider, Waterloo Region)*

Care providers often felt an obligation to facilitate the process of wellness by motivating clients to realize their potential and “*help form a believable picture of themselves without drugs,*” (Provider, Waterloo Region). Empowering clients was especially important for individuals struggling to separate addiction from their self-identity. This was the preliminary set of challenges associated with service engagement and treatment readiness, and providers were cognizant of additional problems that were to arise in the proceeding journey to recovery.

Outreach and peer support programs also helped facilitate the process of engagement for prospective and recovered clients in the community. Identified by both clients and providers as an effective method for engaging in harm reduction, outreach programs also served to engage clients with other health professionals by initiating relationships through small acts, like providing nail clippers and having staff members remember the client's name. One participant in the Waterloo Region attributed their linkage to care, and existence, with outreach workers: “*The connection between the outreach here... If that wasn't there, I wouldn't be here. I won't lie.*”

### **5.3 Slaying the dragon: Accessibility and the experience of HCV treatment**

Client and provider participants identified barriers and facilitators to accessing HCV care as it reflected a continuum of engagement with the larger health system. Services offered in

community and traditional settings posed several avenues for care, making linkages between services and routes for engagement complex. Table 3 displays the organization of this sub-theme in describing the experience of HCV treatment through the four domains of accessibility. The two columns identify aspects of each sub-theme to showcase the comparison of client and provider perceptions.

Table 3.

*Access to Treatment Theme Structure*

Sub-Theme	Identified aspect of sub-theme	
	Client Participants	Provider Participants
Acceptability	<ul style="list-style-type: none"> <li>- Client-Provider relationship</li> <li>- Stigma</li> </ul>	<ul style="list-style-type: none"> <li>- Client-Provider relationship</li> <li>- Stigma</li> <li>- Expectations</li> </ul>
Availability	<ul style="list-style-type: none"> <li>- Wait times and referrals</li> <li>- Hours of operation</li> </ul>	<ul style="list-style-type: none"> <li>- Wait times and referrals</li> <li>- Hours of operation</li> <li>- Health cards</li> </ul>
Affordability	<ul style="list-style-type: none"> <li>- Household resources</li> <li>- Insurance</li> <li>- Cost of HCV treatment</li> </ul>	<ul style="list-style-type: none"> <li>- Household resources</li> <li>- Insurance</li> </ul>
Geographic Accessibility	<ul style="list-style-type: none"> <li>- Service location</li> <li>- Transportation</li> <li>- Community health van</li> <li>- Mental Health</li> </ul>	<ul style="list-style-type: none"> <li>- Service location</li> <li>- Transportation</li> <li>- Community health van</li> </ul>

### 5.3.1 Acceptability

Clients and providers described acceptability in various settings as it pertained to health care access and HCV treatment. Stigma was noted as a central concept in the acceptability domain and overall experience of living with HCV, using substances, and seeking HCV treatment. The client-provider relationship was similarly discussed by clients and providers, influencing differing expectations in the relationship noted by providers.



### Stigma

Drug-related and HCV-related stigmas were identified as a barrier operating within multiple settings in everyday life. Within health settings, discriminatory acts were recalled by client and provider participants as occurring most frequently in hospitals and primary care settings (private and walk-in). Community-based services and community health centres were disparately described as accepting and safe. Examples of discrimination in hospital and primary care clinics included: denial of medication and therapies; avoidance by staff; and poor interpersonal skills such as victim-blaming, rudeness and not listening to patient concerns. While hospitals and primary care clinics were noted as problematic settings, hospitals were regarded as the most problematic care setting, which clients subsequently try to avoid. Primary care settings were believed to be improving over time.

When asked about relationships with health practitioners and challenges faced in the treatment journey, client participants discussed HCV in relation to other illnesses. Comparing HCV to other illnesses, such as cancer, evoked frustration because they believed that other diseases and illness receive greater empathy and support:

*Stigma. It's the problem, the very reason [...] If you have cancer people look at you and say 'Oh, I'm so sorry for you.' If you have an addiction or get hepatitis from your use of drugs, they say 'you deserve that.' And it's just so ridiculous that this disease is 'Okay, we'll give you sympathy but because you're an addict, you're not going to get the sympathy you need and the support you need. It's bullshit. (Client, Peel Region)*

Clients articulated how the internalization of stigma and oppression produced a sense of shame and guilt. Settings that were known to be especially stigmatizing, or were settings where they had previously felt discrimination, became settings to avoid. These settings mainly constituted emergency rooms, primary care (or walk-in) clinics, and shelters, but lead to the avoidance of accessing most health and social settings:

*Being at your worst isn't something that you want to portray. People get more ashamed of themselves and introverted when that happens. (Client, Waterloo Region)*

*To a large degree, I know people who don't want other people to know they're sick because immediately they are stigmatized. You're looked [at] as [if] you're dirty and that this person is untouchable [and] you don't want to go near them. (Client, Waterloo Region)*

Health providers discussed the impact of stigma in health settings by sharing client experiences disclosed to them. One physician in the Waterloo region brought up the common assumption that people who use substances are constantly seeking medication from physicians:

*...People get a sense that they are treated in a particular way because they are identified as a drug user. Comments that I hear are things like 'oh, you're a drug user, you just want drugs from us...' (Physician, Waterloo Region)*

*... And [when] they go to a random walk in clinic, there's a lot of judgement and bias that occur; and reservations of giving a prescription of, you know, something that they think they might misuse. (Provider, Peel Region)*

Reflecting on the impact of stigma to individuals, providers asserted that stigmatization encountered over time results in blame and oppression onto clients:

*I think that many people feel very guilty about what they've done, but also very guilty about who they are. They perceive themselves as being nobody's [...] It's not just their perception that 'they messed up' but they start believing the stigma that they're no good. I think that's some of the battle we have. (Provider, Waterloo Region)*

### **The client-provider relationship**

Clients noted that quick, often rushed appointments affected the client-provider relationship by reinforcing the power imbalance and displaying a lack of empathy. A client discussed their current relationship with their family physician as being positive, but only following years of negative encounters and having severe mental health concerns discredited:

*In the past, he has underestimated when I tell him something's wrong. Sometimes he doesn't think that I know the severity [...] They sometimes have a superiority complex...they're human and should realize that people are all the same and we need to be spoken to on the same level, not condescending. (Client, Peel Region)*

Failing to actively listen to patient concerns enumerated the power imbalance and egotistical nature of those who hold power.

“Not being interrogated or pushed too far”, being “listened to”, displaying “understanding” and “sympathy” were characterized by clients as contributing factors to a trusting and positive relationship with practitioners. Health providers discussed similar characteristics as being effective to foster a welcoming space for a positive interaction, adding that having a “genuine concern” and being “reliable” were especially important. Displaying authenticity was a characteristic that could not be forged or taught, insinuating that providers delivering exceptional care have an innate sense of empathy and passion:

*I keep saying 'we have many defeats, but we're not yet defeated.' And that attitude that you haven't beaten me yet - I still want to beat this. And that, I think, a patient reads that. They sense 'Oh okay, they're trying.' Hope comes from your trust and the power of caring for people, or compassion. So my definition of hope comes from your faith and the power of loving people, looking after them or caring about them. And that's still pretty powerful. (Provider, Waterloo Region)*

The process of building trust was deemed lengthy, yet foundational for positive interactions, building relationships and continued engagement with care:

*With any therapeutic relationship... there's always a level of trust that needs to be developed. That's one of the first things you need to do if you will, as a worker or as a community support, in working with a lot of people. (Provider, Peel Region)*

Client participants also mirrored familiarity and knowledge of medical history as important factors in the client-provider relationship. A participant exemplified this as she explained her preference of accessing her family physician in comparison to walk-in clinics: “I’d rather not go to a walk-in just ‘cause they don’t know me and my history” (Client, Peel Region).

Some clients referred to themselves as being very open to their current family physician and HCV specialist despite negative past encounters. Being honest with providers was not only

regarded as necessary for obtaining appropriate care but was also implied as their way of creating space for a positive relationship. Clients also explained that interactions with support workers or counsellors heavily influenced their attendance at appointments and changed perceptions of health professionals. Positive interactions with outreach workers from community health centres helped restore trust and confidence with medical professionals: “*Yeah it [outreach] helped just being able to be more confident with like medical people and stuff*” (Client, Peel Region).

Providers further reflected on the open and forthcoming nature of clients in relation to the frequency of interactions: sometimes the level of openness, comfort and trust could only be established after several interactions, whereas other times clients were completely forthcoming upon the first interaction. Through practice, the Waterloo physicians learned to be flexible, not stick to a particular script and simply listen to patients:

*I basically just allowed them to talk to me about the concerns they had and the issues that were at the forefront of their mind with respect to anxiety, history of trauma, and the kinds of symptoms they were experiencing as a result of those things. I just kind of sat there and let them talk to me rather than try to tell them about hepatitis C. I think that in doing that, it gave them a bit more comfort coming back for the next steps.* (Provider, Waterloo Region)

Policy and criminality were also thought to contribute to reluctance amongst clients to disclose certain information about their health behaviours and concerns:

*There's good reasons people have for not necessarily being as forthcoming as they could about things like history of drug use and current activities in that way [...] or if someone is involved in illegal activities, obviously there's reluctance in being as open as possible.* (Provider, Waterloo Region)

Having clients re-tell their stories or health concerns to multiple providers in the same service or organization was considered redundant by providers, especially in collaborative settings.

Knowledge sharing among staff members in a multi-disciplinary team setting was therefore

viewed by providers as an effective strategy to avoid miscommunication and to clarify concerns in order to foster strong relationships with clients and improve satisfaction:

*We take a firm approach to build a strong relationship with them... You really just [need] to listen to their story and you don't want them to tell it too many times. We try to stick to it once through the whole organization, and with their permission, I'll support them by transferring that knowledge. And that's big because they don't have to feel like you're starting from square one building relationships again. (Provider, Peel Region)*

### **Expectations**

Providers attributed differing expectations in the care interaction with the many challenges they experience in care delivery and building relationships. While honesty often facilitated appropriate care delivery, clients disclosing all information to providers also revealed an internal challenge amongst providers as they attend to the clients' needs and concerns. All providers acknowledged the delicate balance of maintaining trusting relationships with their clients, ensuring client safety and their individual capacity to care for clients:

*I have heard things like, 'I'm not working with [my social worker] anymore because he went to my doctor and got me formed, and got me admitted, and I didn't want him to do that so I can't trust them anymore.' So there's a delicate balance between your professional relationship and expectations. (Provider, Peel Region)*

Providers revealed that negative actions from clients, such as being yelled to or sworn at, are often a result of differing expectations or patient's lack of knowledge regarding internal protocols. These acts pose personal and clinical challenges but resulting negative reactions from clients were generally understood by providers:

*...sometimes it's a matter of someone maybe not necessarily getting what they want from a healthcare provider, but where that healthcare provider's perspective for the right reasons are not perceived by the patients as the right reason. (Provider, Waterloo Region)*

The very nature of their clinical practices, and other clinical settings in general, were reflected as perpetuating an intricate or challenging system for clients to access, which often bestows

assumptions and expectations of how clients should act in their setting. One physician commented on this institutional problem that must be overcome when working with this patient population:

*We expect them to follow a prescribed rule: you have to make your appointment, you have to be here on time, you have to be nice when you are here... If you're someone who wants to have things orderly and manages all your risks, it's not going to work so well because IV drug users don't live that way. (Provider, Waterloo Region)*

### 5.3.2 Availability

Reflecting on their interactions with providers, clients identified wait times, referrals and clinic operating hours as barriers affecting the availability of care. Providers similarly identified wait times, referrals and clinic hours, but also discussed health cards as a barrier for their clients.

#### Wait times and referrals

All client participants reported having a family physician during the time of interview, but described the process of acquiring a family physician as challenging and lengthy:

*I have picked a doctor central to the area I live in so he's close... it took a while. I was living in Ontario for over 10 years probably, before I actually found the family doctor. (Client, Peel Region)*

Appointments with primary care physicians in private clinics had minimal wait times, but consequently resulted in brief appointments where clients felt rushed. Clients and providers in both regions noted the lacking infrastructure and resources to accommodate the high demand for community and specialized services. Clients who long awaited HCV treatment approval felt that the virus lingering in their body was a reminder of their past that prevented behavioural and lifestyle changes. Both participant groups identified the need for prompt service, and providers specifically emphasized the importance of quick transitions along the care cascade. In recognizing the challenges of seeking care among this client population due to substance

dependence, one provider commented that, *“there’s a window of opportunity a person can give you [and that] it must be utilized.”*

Having access to mental health or addictions counsellors were important to clients throughout the cascade. Addiction and mental health service unavailability were believed to increase client stress and contribute to worsening mental health, including suicide:

*Anything to do with mental illness takes months and months, and months - simply a year before you can get in to see a psychiatrist. The wait times are ridiculous and I think, in my own personal opinion, that there’s people out there committing suicide and getting dramatically worse in their mental illness because of the wait times and the stress that’s put on them for the things they have to do. (Client, Peel Region)*

Access to mental health services was also a significant barrier when applying for HCV treatment coverage and the Ontario Disability Support Program (ODSP) since psychiatric consultations are often required. Although providers in the Waterloo Region comment on the progress made with mental health services in the region becoming more accessible, they continue to recognize the exceeding demand for services:

*This region’s access to addiction treatment services is lacking. I mean, there are services but there are only so many, and a lot of them are at capacity. A lot of them.*

*We have probably a 6-9 month [wait list] to see a psychiatrist in Cambridge. So if you have an addiction, good luck, right? [...] In Cambridge, our hospital doesn't have any addictions treatment.*

*I had to teach myself in order to get by [because] no one would see them!*

Clients commented on the need for a holistic, multi-disciplinary approach, where HCV treatment and mental health must be treated together. Described as puzzle pieces, one client discussed that, *“you can’t have one without the other. I think it’s all part of the same package; it’s one person”* (Client, Peel Region). Clients who completed HCV treatment at Sanguen Health Centre or at the Bloom Clinic appreciated the team approach, attributing it to their recurrent engagements with clinic staff. Health providers recognized the importance of multidisciplinary

teams to stimulate positive and recurrent engagement, but noted that another considerable advantage was that team approaches can distribute the workload, naturally reducing patient wait times. The following physician describes their practice as being manageable and relatively accessible in terms of wait times due to the several nurses staffed in the clinic:

*We struggle with wait times, but that's where having nurses as part of the clinical program helps alleviate that. My schedule is busy and is booked for a number of weeks in advance. (Provider, Waterloo Region)*

However, this physician is mindful of the clinic's capacity as campaigns and outreach teams become more efficient in testing members in the community for HCV: “[wait times] are something that's always on our minds, [and] we have to be careful about not stretching beyond our capacity.”

At Sanguen Health Centre, eliminating a prescribed referral from another doctor has been implemented as a way to increase the clinic's accessibility: “If someone presents here and wants to be seen, we'll see them” (Provider, Waterloo Region). This is especially important as another provider points out that, “One barrier is just their referral pattern and their linkage to care” (Provider, Peel Region).

### **Health cards**

During the process of referral from primary care to an HCV specialist, providers unveiled the impact of health cards. The absence of a health card, either stolen or lost, was said to be prevalent among people living in precarious housing conditions or on the street, creating a roadblock in the process since other clinics do not provide services without it. Acquiring health cards for patients at one physician's clinic was said to be the greatest challenge that this physician faced upon their hire:

*I didn't care that I wasn't paid very much. What I was worried about was without a health card; I can't get anything done without them! I can't get blood tests done, can't*



*get x-rays done, can't get specialists to see them if they need it...I can't get any other service rolling. I can't even get ODSP done without a health card. (Provider, Waterloo Region)*

The differing specializations among health providers were found to be associated with differing views regarding the importance of health cards along the cascade. For instance, providers working in a larger team setting with greater resources did not view health cards with the same level of concern as providers working in a smaller, more individualistic practice. In multi-disciplinary settings, colleagues were able to assist clients in obtaining their health cards and manage bureaucratic issues. Though health cards were not seen to prevent HCV treatment access entirely, some recognized that health cards could impact the rate of movement along the cascade. Further, the inability to maintain a health card revealed other factors in the client's life that could impact treatment readiness:

*I'm not sure if we're encountering too many people that the only reason we haven't been able to get them on treatment is because they don't have a health card. If someone's not at a point where they can get a health card it's because there are a whole lot of other stuff going on with them that's preventing them from getting treatment anyways. (Provider, Waterloo Region)*

Clients did not speak about health cards as hindering the process of diagnostics and therapy.

### **5.3.3 Affordability**

The expensive cost of HCV treatment was well known to client participants, as well as funding opportunities to help cover the cost of treatment (either in part or in full) such as ODSP and pharmaceutical compassionate care programs. Client participants also recognized that assistance was available from the clinics and organizations from which they received HCV treatment to help prepare applications or advocate for care:

*It's extremely expensive, but organizations will get you the funding you need and the treatment you need [...] If you're positive, there's help available. (Client, Peel Region)*

Only one participant (Peel Region) was required to pay approximately 30% of their treatment cost out-of-pocket. He recognized that without a subsidy he “*wouldn't have been able to afford it on my own.*” A client in the Waterloo Region encountered this financial barrier to HCV treatment when their application for full treatment coverage was denied five times because their liver was not considered “*damaged enough*”. Fortunately, the new treatment guidelines and eligibility approved three study participants prior to participating in this study.

Due to the high cost of treatment and challenges experienced with applications in the past, all clients regarded their coverage as a “*privilege*” and “*blessing.*” But, they cautioned that there might be limited opportunities for coverage in the future as policies could change and treatment coverage might only be covered once:

*[Dr. 'X'] didn't want me to go on it unless I was 100% focused and ambitious, because it's a one-time thing. So if you screw it up, the government's not gonna wanna keep funding that. (Client, Peel Region)*

While all participants agreed that some degree of readiness was essential to commence HCV treatment, the views were disparate between clients in each region. For instance, those in Peel implied that treatment readiness translated to a complete lifestyle change of abstinence, while those in Waterloo also undertook lifestyle changes but were not expected to abstain from all substances; Rather, Waterloo clients noted reducing substance intake and abstaining from certain types of substances.

Providers noted the financial limitations faced by some clients when considering the SDoH: “*Look at the medical system...there's a direct correlation between health outcomes and socio-economic status that's well articulated. So those are really the barriers,*” (Physician, Peel Region). While the ability to pay for HCV was not often discussed explicitly as a barrier in

seeking or obtaining HCV treatment, one provider noted the change in treatment coverage guidelines while considering their clinic's capacity to treat community members with HCV.

#### **5.3.4 Geographic accessibility**

Congruent with the framework, service location and means of transportation to attend appointments were identified by both participant groups. Overall, geographic accessibility was identified as a minor barrier for seeking and completing HCV treatment in comparison to acceptability, availability, and affordability from the perspective of clients, whereas providers regarded transportation as a significant factor. Community-led efforts from Sanguen Health Centre and Peel Public Health mitigated geographical barriers through the use of community health vans. Mental health was additionally identified by the client group as a contributing barrier when physically accessing these spaces.

##### **Service location and transportation**

Almost all client participants reported having a family physician during the time of the interview in their neighbourhood, despite the lengthy and challenging process. The avoidance of medical services and only accessing care from walk-in clinics or hospitals for emergency-related concerns were frequently reported during the interim of locating a family physician in their neighbourhoods: “...I just dealt with it. If it's really serious, I just go to the hospital” (Client, Peel Region).

Some client participants discussed the challenge of relocation – either relocating themselves or the relocation of services. Following a geographical move, client participants avoided seeking new health providers when they were uncertain of their length of residency in the new location. The complexity and nuisance of researching providers in their new area also

served as a deterrent for accessing health services. A health provider in the Peel Region discussed this challenge of relocation that frequently occurs among transient youth clients:

*I can't get them general practitioners because they might not be [living] in the area to be a new client to stay on long term. They don't have a permanent address so we use our address to support them for the time being. But in the meantime, they're trying to move to Brampton and then we need to find another doctor, [and] finding a practitioner is tough right now. (Provider, Peel Region)*

In the event of clinic relocation, even minimal location changes were said to produce transportation complications that could make public transportation inaccessible or lengthy. A client in the Waterloo Region, whose family physician's office move, exemplified this challenge where longer travel times resulted in diminished visit frequency, despite being ill:

*I don't call as much as I should and go up and see her as much as I should when I get sick. I'm just like 'ugh, I don't want to go up there.' (Client, Waterloo Region)*

Clients discussed geographic location and transportation differently when visiting a specialist for HCV, mental health, or methadone treatment compared to general health services. Despite experiencing transportation challenges, clients were less concerned with these challenges when visiting specialized clinics due to the limited number of specialists in the region and minimal visit frequency they would endure.

Health providers reported service location and transportation as a significant factor to consider for their clients, commenting that “*just getting the transportation to get them there helps,*” (Provider, Waterloo Region). Providing bus tickets to clients experiencing geographic and/or financial challenges was regarded as an effective solution to minimize barriers when accessing any health or social service. In relation to HCV-related care, 75% of client participants reported little or no transportation concerns as a result of this compensation from Sanguen Health Centre, the Bloom Clinic, other community health organizations (specifically the Peel Addiction Recovery Clinic (PARC), AIDS Committee of Cambridge, Kitchener, Waterloo and Area

(ACCKWA), and the Working Centre) or care coordinators. Albeit a facilitator to many, one client participant questioned the sustainability of transportation coverage in clinics. This client expressed relief for acquiring additional funding to compensate transportation costs during treatment:

*These people [at the clinic] also provide us with bus tickets, but one day they might be out. So I think having a bus pass is going to be a really crucial thing. (Client, Peel Region)*

In the Waterloo Region, one client participant identified anxiety and mental health as a barrier to accessing health services since crowded spaces, such as that experienced in public transportation, exacerbates their condition. Providing bus tickets were ineffective for this individual, so the clinical team at Sanguen compensated the cost of taxis to ensure this client could attend their appointments without being concerned about their anxiety or financing alternate transportation.

### **Community health vans**

Health vans operate in both the Waterloo Region and Peel Region via Sanguen Health Centre and Peel Public Health in an effort to further minimize geographic barriers for HCV testing, outreach and harm reduction by continuously relocating the service location close to clients. Providers in both regions highly regarded the vans as being accessible, and an effective grassroots strategy, for HCV testing and engaging clients with health care during follow-up:

*I think it's very accessible and open [by] having a mobile outreach program – a community health van to actually go out and access people rather than the other way around to having various clinical locations. (Provider, Waterloo Region)*

*That may look like a little bit, but it's huge to [clients] and it matters a lot. (Provider, Waterloo Region)*

A provider assisting with the health van in the Peel Region discussed some of the challenges associated with the van's size and the region's large geographic boundaries. They revealed that a

large quantity of supplies cannot be accommodated on the van, resulting in frequent re-loading trips in times of high demand. Re-loading, compounded with long distances to travel and encountering traffic, were said to sometimes create long wait times for clients. This consequently affects the number of clients that can be attended to with their van.

#### 5.4 Farewell to the Dragon: Resilience and Persistent Challenges

##### 5.4.1 A second chance

Although clients and providers previously identified access to mental health resources as a preliminary step to address HCV, providers in the Waterloo Region signified the influence that engagement with HCV-care had on seeking other health services. Often resulting as a consequence of long wait times and limited resources, HCV testing and treatment acted as a gateway to seek other services to assert ownership of one's life by addressing problematic substance use and mental health:

*They may not care if their teeth are falling out or that they're malnourished, but they are for some reason okay with asking about hep c because that's maybe something you could test quickly and decide from there [...] I think more often I see that they're like 'yeah, I don't know if I could treat my addiction, but I'd like to see somebody about my hep C. (Provider, Waterloo Region)*

Another provider in the Waterloo Region discovered this among their patient population, hoping that they can continue to serve as a link for both HCV treatment and addiction:

*I see that a lot of times where that's been the first step in dealing with the other issues. Like, I'm able to do something about this, let's do something about these other things as well... The more people that we can engage in treatment for hepatitis C will mean that we are engaging more people in treatment for addiction as well. (Provider, Waterloo Region)*

##### 5.4.2 Persistent challenges

Several factors were identified as persistent challenges that inhibit progress or future improvements to increase the accessibility of HCV treatment, including: knowledge and training

of HCV and related topics, resources and funding for HCV treatment and harm reduction interventions, and the Canadian healthcare system's funding model for physicians.

### **Knowledge and training**

All participants discussed the need for increased knowledge about HCV, harm reduction, substance use, and mental health among the general population; and increased, or improved, training for health providers on these topics.

***The general population.*** Participants discussed the lack of knowledge regarding HCV among the general population, largely attributing their misinformation with enacted discrimination. The association of HCV and substance use were reinforced in these dialogues by clients:

*Not a lot of people know [about HCV] ... Like a lot of people are like, 'Oh, I had no idea' but I guess yea when you're not in the drug world you don't really think of that stuff that much right a lot of people think hep-C 'oh it's a drug user's disease right?' Or something like that, when really it's not. (Client, Peel Region)*

A National HCV strategy and campaign were suggested methods for increasing public awareness, reducing stigma and informing service provision. A National HCV strategy that clearly outlines the government's plan, financial commitments, targets and priorities for treatment were described by one provider as components that would contribute to a solution. Some clients also acknowledged that a commitment from all levels of government would be helpful, but most clients emphasized the importance of educational campaigns to increase knowledge about HCV and to dispel the myths associated with HCV. The commercial for the HCV therapy Harvoni® aired in the United States, was noted by clients and providers as an effective example for providing more information about HCV. Despite its primary use as a marketing tool by the pharmaceutical company, the commercial was highly regarded in its depiction of HCV that did not associate HCV to substance use or PWID; rather, it was depicted

similarly to other pharmaceutical commercials. Clients suggested that this commercial should be widely circulated in the interim of creating a Canadian campaign. Another participant recalled local STD awareness initiatives that included informative flyers distributed around the Waterloo Region, suggesting that this campaign should be expanded for HCV.

One provider discussed the impact of the opioid crisis in relation to increasing knowledge and empathy regarding substance use. Increasing knowledge more generally about substance use was also noted by participants as being effective for promoting harm reduction interventions and another avenue to approach HCV:

*There's still a lot of misconceptions out there. I think this opioid crisis, um, and the awareness around that has – I think the general population is much more aware of the kind of realities around drug use. And the fact that that these are people that we're talking about, these are other human beings, people that are dying, people that - it's not right that they are dying and that there are some things that we can do to prevent that. And I think I have seen more acceptance of that in the general population and more of a positive approach to that as it's perceived, that's presented in the media accounts of this problem that's going on here in the community. I think we got some supportive and sympathetic voices in the print media here in town. (Provider, Waterloo Region)*

**Health providers.** Despite years of training, all of the provider participants commented that generally, health providers lack adequate knowledge to serve patients with mental health, addictions and/or HCV concerns. Such ignorance directly impacts the client-provider relationship when providers fail to properly acknowledge their client's concerns or make discriminating remarks. Both clients and providers affirm that all health providers need more, and improved, education to adequately serve people that are known as “complex patients”:

*I think they need more education regarding bedside manner. \*Laughs\* Oh the way they treat their patients... They need to become educated in addiction because addiction is rampant in our society and there's so many forms of addiction. Whether it be eating disorders, drugs, cell phones, they're all additions. People have these problems and they should be taught how to deal with them and how to help people and I don't think they are. I don't think any of that is taught in medical school and I don't think most doctors follow-up with it afterwards because addiction hasn't been a very important issue in the past and it's still not. (Client, Peel Region)*



In the providers' critique of their education, they asserted that it lacked the fundamental training of core competencies in community medicine, mental health and substance use. This was especially salient in medical practices where all but one physician felt unprepared following residency, since they lacked experience with the population and a holistic understanding of the topics:

*A lot of times I wouldn't have been very sure about treating IV drug users because I had very little experience and background and it's kind of hard to know how to deal with that, so you just kind of do the best you can. But I guess I realized the more I saw people, the more confident I got because you realize that you'll never have all the answers, you'll never know all the drugs or all the street names of the drugs that people use, and you'll never know all the slang people use; but you start to see patterns of addiction and patterns of lifestyles. And so that becomes clearer as time goes on. I just wish that were taught better in medical training [and] medical school. (Physician, Waterloo Region)*

*Going from family medicine to this type of work was an enormous leap. I knew no more about psychiatry than the average family doctor did, and that was very little; And, I knew almost nothing at all about addiction. In my medical training we had nothing. Nothing taught us about additions- zero, not anything at all. When I gave a talk to some residents in family medicine a couple years ago about addiction, I asked them first 'How much have you had about addiction so far in your curriculum?'[...] 'Zero.' [...] The training for family doctors and addiction is still visibly poor, and addiction is becoming - each year it's getting to be a bigger and bigger medical issue, costing the healthcare system enormous amounts of money. (Physician, Waterloo Region)*

The two Social Workers and the Community Youth Worker similarly felt that their formal education lacked adequate knowledge about vulnerable populations and complex topics, but they gained relevant experience during placements.

Aside from professional training, clients discussed that lacking lived experience and first-hand knowledge resulted in providers unable to fully understand their situations:

*If only you guys could hire like addicts to be addiction counselors. Because you guys don't really understand where we're coming from; it's kind of like a textbook thing. And I get that, just trying to do a job, but you guys don't really get it until you've been there. (Client, Peel Region)*

Providers discussed this topic similarly, where they sometimes encounter difficulty comprehending patient information about substances and practices. This challenge is overcome by listening and learning from patients, rather than approaching the topic as an expert. Listening to patients and experience were also noted as factors contributing to feeling confident in providing care to these clients:

*It's experience in years of working with people, trying to find solutions [and] recognizing the kind of mistakes that you've made...I learn a lot from the patients themselves.*  
(Provider, Waterloo Region)

### **Resources and funding**

The dynamic political nature of illness and resource allocation was also discussed as a persistent challenge that leaves many on edge. Participants expressed uncertainty in the government's ability to sustainably respond to HCV and allocate appropriate resources beyond the next few years. Not having a national HCV strategy, as previously noted to positively impact HCV awareness, was also identified as problematic in relation to the sustainability of the government's response and resources. The following quotes exemplify this dialogue from both clients and providers:

*Politicians are short term people [...] all they care about is the re-election. If they were going to spend billions of dollars to care for all of the hepatitis in the country, where's the money coming from?* (Client, Peel Region)

*We're just scratching the surface of what we can do with that kind of community health innovative and sustainable funding is always the first thing at the top of the list in terms of improving.* (Provider, Waterloo Region)

Increasing funding for harm reduction programs and addiction centres was also warranted. Client and provider participants from both regions admire the progress achieved to include the harm reduction and patient-centred philosophies in care, and the attempt to establish connectivity between services, but assert the need to continue such progress:

*No I think there's still a ton still needs to be done. I think this community has come a long way and different community agencies have come a long way and recognizing harm reduction philosophies and the benefits of that as opposed to just say no, kind of approach to things, but boy we have a long way to go, absolutely. (Provider, Waterloo Region)*

Funding and resource challenges were extended beyond programs and health systems to other policies and programing concerning the determinants of health, specifically housing.

Previously acknowledged as an influence to seeking care and perpetuating a cycle of addiction and criminality by clients and providers, the scarcity of housing was said to have several implications for treatment adherence and engagement:

*You can't treat a person - a homeless person. It's next to impossible. Especially when they're living in shelters where they are going to get kicked out because they already have mental issues, addictions, and you are trying to treat them so they miss their treatments, [and] the treatment doesn't work. And when you are talking about this amount of money - if you blow this treatment because you got in a fight because you were drunk - you're not going to get back in a treatment program, so you are going to die. So housing again, the whole. (Client, Peel Region)*

With the rise of opioid-related concerns, several clients added that access to safe injection sites, in conjunction with housing, would produce the most significant effect for linking community members to testing and care, and for preventing overdose, HCV and HIV transmission. While only a few providers noted supervised injection or consumption sites, efforts to increase secondary and tertiary prevention were identified by all providers. Specifically, testing and treatment were discussed in effort to reduce transmission:

*I mean, the biggest barrier is identifying someone who has hepatitis c, right? Maybe 50% of more of people who have hep C, we haven't even identified them. So it's taking the efforts to engage most risk populations and that's not always easy. (Provider, Waterloo Region)*

*The best prevention for further infection is treating as many people as you can [...] The more people that we can treat, the less likely we are for someone to [be] put in the position of being re-infected. And that's the way we need to look at it. Not so much looking at an individual who's using drugs and saying, 'should we be giving treatment to*

*a person who might get re-infected?’ You know, that won’t get us anywhere. (Provider, Waterloo Region)*

### **Health care funding model**

Health providers discussed the Canadian health care funding model for physicians as a factor that indirectly impedes HCV treatment access. Providers described that the model of funding might deter physicians from practicing in a community health centre (salary-based) because these settings often attract more “complex patients.” Physicians practicing in community health centres may consequently require more time with clients and endure more personal challenges, whereas physicians in private settings (fee-for-service) may examine multiple clients in the same time-frame. Additionally, community settings were said to be more lenient and understanding for missed or late appointments, whereas private clinics tend to charge the client:

*...look at the medical system. It protects the less perspicacious among us and there’s a direct correlation between health outcomes and socio-economic status that’s well articulated. So those are really the barriers. (Provider, Peel Region)*

*I think we have a system that doesn’t allow them to provide the right care. So if you are a family health physician who’s paid by the patient, you want easy patients or maybe it’s not that you want easy patients, but you’re not going to want the most difficult ones... So patients who don’t show up on time, patients who are often missing appointments – those sorts of things will become frustrating for a lot of docs because of the funding model they have or maybe because of their philosophy. (Provider, Waterloo Region)*

## **6. Discussion**

The purpose of this research was to gather insight about the experiences of HCV testing and treatment for people who inject drugs, discussed from two differing perspectives (clients and health providers). The conceptual framework proved useful to identify various barriers and facilitators influencing the access of HCV testing and treatment in the Peel and Waterloo Regions while considering individual, relational and structural influences. Inquiry targeting four domains of accessibility allowed the two perspectives to be compared, revealing convergent

areas of understanding as well as divergent views or factors. Overall, client and provider groups identified similar factors within each accessibility domain and made similar recommendations for improvement.

Exploring the client-provider relationship directly within the acceptability domain and indirectly through the comparison of narratives alludes to the dynamics of power in these health settings and the importance of building trusting relationships and practicing through a patient-centred approach, since health practitioners may hinder and facilitate care. The narratives of client participants along the care cascade indicate the need for scaling-up harm reduction principles and interventions, exemplified through the community health vans and outreach programs serving as a linkage to care. Persistent challenges such as knowledge and training of caregivers, funding and resources for health services, stigma about PWID, and the funding model of the health system, suggest the need for structural, transformative change within and beyond the health system. Thus, conclusions are concentrated on the implications for how public health policy and systems can engage more effectively with PWID through intervention on different ecological levels.

### **6.1 HCV Service Access**

The identified barriers and facilitators to HCV testing and treatment noted by study participants are further discussed as they occur in the micro-, meso- and macro-level of the ecological systems framework. Key influences depicted at the micro-level depicted in the narratives of participants were lifestyle factors, personal motivation, health determinants, the ability to pay for HCV treatment, and stigma. Factors within the acceptability domain represented relational influences, including stigma, the client-provider relationship and differing

expectations. Finally, knowledge about HCV, institutional settings, processes and policies exemplify macro-level influences.

### **6.1.1 Micro-level (Individual) Influences**

Health determinants and early life experiences contributed to the injecting lifestyle and the experience of seeking care. The narratives of clients depicted HCV as being inevitable and ordinary within their networks, part of the injecting lifestyle. Consistent with study findings, Davis, Rhodes and Martin (2004) postulate that such normalcy may contribute to unconcerned views of the illness as it coexists with injection drug use. Unconcerned views may explain a lack of motivation for engaging with HCV testing, treatment, or health services more generally. Unconcerned views, however, may be attributed to the notion that HCV may not be the most prominent threat or concern of a person who actively uses substances (Davis & Rhodes, 2004). Rather, concerns pertaining to housing, income and obtaining substances were noted as often taking priority. Substance use initiation was attributed to various socio-cultural factors and traumatic events occurring over the life course. Education and poor literacy were said to create challenges in navigating the health system and contributing to healthcare decisions, which may extend to other facets of everyday life such as navigating transportation for appointments and obtaining employment or housing. The cycle of criminality was also discussed as it produced a cyclic process upon which individuals often returned to their earlier lifestyle as they struggled to seek and maintain housing and employment. An individual's inability to pay for treatment exemplified the financial inaccessibility of HCV treatment (or affordability), as participants unanimously identified the high cost of treatment. In spite of the new treatment guidelines and coverage that aims to mitigate this financial barrier, the experience of stigma may continue to

impede the success of treatment by avoiding or delaying components in the treatment cascade (Butt, 2008).

Feelings of disbelief, shame, a sense that life was over, and feeling trapped in the injecting persona were examples of self-stigma and disempowerment reported by client participants that affected everyday life. While these emotional outcomes are consistent with the literature (Butt, 2008; Harris & Rhodes, 2013; Neale et al., 2008), Butt et al. (2008) suggest that the impact of stigma should be analyzed over time. During different phases in the illness experience, or movement along the care cascade, responses and perceptions may change (Alonzo & Reynolds, 1995), dispelling self-blame as an inevitable consequence of stigma (Butt et al., 2008). Intersecting forms of discrimination may also affect the individuals' experiences differently, but were not adequately investigated in the present study due to the small sample. However, stigma and discrimination were reported as it related to perceived socioeconomic status and criminality (e.g., use of ODSP, current living arrangements, and criminal record), in conjunction with drug-related and disease-related forms of stigma. Further, power in the interpersonal domain was reflected in participant narratives as oppression influenced everyday life and shaped experiences and influenced conscious thought (Collins, 1990). These differing forms of stigma, discrimination and oppression proved to not be mutually exclusive of one another, but rather intersecting in different settings to shape their experiences, both perceived and enacted.

Self-empowerment and resilience were also exemplified by the three client participants who actively sought HCV testing and among all the client participants as they described turning points that contributed to seeking care. Actively seeking HCV treatment was associated with ownership and healthy practices. Turning points, due to the accumulation of positive and/or

negative events, contributed to each clients' engagement with the treatment cascade. Participants said these lifestyle changes were self-initiated, which would re-claim power over their life and show that they were self-aware, responsible social actors by practicing healthy behaviours (Armstrong, 1995; Peterson, 2000). Clients asserting personal responsibility and viewing treatment access as a privilege mirrors earlier debates of health care rights and the early role of public health. In the 1970s, Knowles was popular in the United States for suggesting that the "idea of a 'right' to health should be replaced by the idea of an individual's moral obligation to preserve one's own health...a public duty if you will" (Knowles, 1977). While clients may have made positive behavioural and lifestyle changes, the emphasis of moral obligation contributed to unhealthy perceptions of self though shame and guilt. The desire to engage in healthy behaviours, determined by society's concept of healthy behaviours, further implicates the influence of ideology and power.

Behaviour, social values and the process of stigma are shaped by cultural, psychological and biological processes that extend beyond the individual (Brandt, 1997; Knowles, 1977; Weiss, 2006); But, these processes influence individual experiences. The ways in which these social values operate in the relational and structural levels will be further discussed to contextualize individual experience.

### **6.1.2 Meso-level (Relational) Influences**

Factors identified within the relational level of the ecological framework mainly comprised of those within the acceptability domain of access including stigma, the patient-provider relationship and expectations. Outreach, as a component of harm reduction initiatives, exemplified another avenue for engaging with clients by forming relationships with peer support staff or other non-clinical staff members (i.e., social workers). Characteristics of a positive and



trusting relationship were similarly identified by clients and providers, including not feeling rushed or interrogated, being listened to, feeling that the provider understood the client's concerns, displayed empathy, were reliable, and authentic. Discussion groups held with current and former PWUD and service providers in multiple Canadian cities affirmed the importance of the identified characteristics that contribute to, or impede, positive therapeutic relationships as they are shared across different locations (Allman et al., 2007).

Emergency departments were identified as the most problematic clinical setting. Being denied medications, blamed by emergency department staff for their condition, avoided by staff, and having concerns discredited, mirrored findings from the reviewed literature (Allman et al., 2007; Butt, 2008; Temple-Smith et al., 2004). Client participants interestingly identified a positive trend in family medicine, where these clinical settings appeared less discriminatory over time. The alleged attitude and conduct shift in primary care may be influenced by differing approaches to care and the settings in which care is provided. Care settings (i.e., private practice versus community health centres) may contribute to different perceptions, experiences and relationships with providers as they were also said to adopt more empathetic approaches to care and an understanding of harm reduction. Providers in multi-disciplinary and community-based services exemplified strong interpersonal skills as they were perceived as welcoming and friendly. Meeting expectations, needs, and minimizing harm have proven to be favourable, and any accounts of disrespect, judgement, stereotyping or bias against have proven to lead to avoidance (Reid & Klee, 1999; McLaughlin, McKenna & Leslie, 2000).

Having trusting relationships with healthcare providers has been correlated with the willingness to share information and engage in care; in turn, governing overall health outcomes (Osterag et al., 2006). Providers inherently hold power as the gatekeepers to the health system

(Health Council of Canada, 2010). In addition to approaching clients with empathy and demonstrating strong interpersonal skills, providers must also acknowledge their power and consider their impact on clients. For example, providers may fail to recognize their perpetuation of stigmatizing messages or ways in which they are reinforcing their power by dismissing patient concerns. Particular acts noted by client participants that reinforce the power dynamic in the client-provider relationship included rushed appointments, failing to actively listen to patient concerns, lacking shared decision making or patient autonomy, and lacking lived experience. Ignorance of power in the client-provider relationship as the gatekeepers to referrals, diagnostic testing and prescriptions, or producing a false representation of patient autonomy (Health Council of Canada, 2010), could further produce injustice and centralize power in these settings. Another example of how providers exerted their power over clients was through their differing approaches to assessing HCV treatment readiness and promoting behaviour change. Clients from the two regions reported different messaging from health providers regarding HCV treatment, where clients from the Peel Region required sobriety before initiating HCV treatment and clients from the Waterloo Region reduced their overall intake of substances and abstained from using “harder” substances, like opioids. In the Peel Region, abstinence was relayed as a prerequisite or a factor that would contribute to more favourable outcomes. However, factors such as treatment interactions, concurrent mental health disorders and living conditions may

The internalization of shame, guilt, and fear of future stigmatization also affect the perception of stigma (Scambler & Hopkins, 1986). Emotional factors could misinterpret the actions of providers (Butt, 2008) and produce different perceptions about the interaction and expectation of care. This feedback loop was illustrated by provider participants when describing

some of the challenges they face, often a product of miscommunication and differing expectations.

### **6.1.3 Macro-level (Institutional and Structural) Influences**

Macro-level influences discussed by study participants included the larger influence of stigma when accessing health services and HCV-care, and challenges faced within the healthcare system and from public policy. The individual and relational experiences related to HCV testing and treatment motivation and access may be thought of as the effects of public policy and other structural factors.

#### **Knowledge and education**

Participants unanimously identified the need to increase knowledge and awareness about HCV among the entire population and to enhance the competencies of health practitioners. Inadequate education and professional health training about HCV and substance use was said to contribute to ignorance and perpetuate stigma, which may occur unintentionally. Henderson et al. (2008) found that despite staff's willingness and commitment to provide care to "problematic substance users", staff still treated these patients differently because of their training which produced innate biases. Thus, client and provider study participants discussed the need for increasing knowledge about HCV as it was hypothesized to reduce stigmas, increase HCV testing and linkage to care, and increase the capacity of health practitioners to test, refer and treat people. Examples of education campaigns noted included a national HCV campaign, a local campaign to encompass sexual health and infectious disease more broadly, and use of the media to positively portray people living with HCV, such as the commercial for Harvoni®. In particular, the media has been noted to have a strong potential for influencing members of the public as a strong ally in equity work (PHAC, 2014). Using clear language and messaging that is

accessible to the intended audience and collaborating with various stakeholders are notable considerations for health education (PHAC, 2014). A health equity collaboration in Saskatoon further revealed five conditions that contributed to its success and productivity, including: i) respecting all participants, ii) creating conditions that allow all stakeholders to have a voice, iii) involving people with lived experience, iv) establishing a common ground, and v) considering time (PHAC, 2014). While a comprehensive education strategy to enhance the knowledge of HCV among the general population may require several campaigns indented for different audiences and communities, these conditions should be considered integral. All institutions, and public education more generally, must better educate all members of the public in order to dispel myths and cease the process of stigma.

Public health education and messaging also has implications for one's awareness of health status. Lacking knowledge about the risk factors for acquiring an illness, or fear of discrimination and shame contributes to delayed HCV treatment and interaction with care providers, but it may also contribute to delays in testing (Chesney & Smith, 1999). In the context of infectious diseases, testing is a critical step to gain insight about health status and subsequently being able to make informed decisions about care and behaviour (Chesney & Smith, 1999). However, with limited resource, public messaging aims to shift toward promoting behaviours that prevent the risk factor in effort to minimize the amount of individuals to undergo testing. This is represented by the Canadian Task Force on Preventive Health Care (CTFPHC)'s proposal to restrict testing to only those perceived at risk due to the expenses that might incur by increasing the number of seropositive individuals requiring treatment (CTFPHC, 2017). Engaging more people to the care cascade is believed to further inequities as a limited number of people would have the financial means to pay out-of-pocket (CTFPHC, 2017), but delaying

treatment has been modeled to show a surge of health-related expenses in comparison (Trubnikov et al., 2014; Werb et al., 2011). More importantly, withholding information about one's health on the assumption of wealth is inhumane and discriminatory. Only testing high-risk individuals may further increase the association of HCV with intravenous substance use and reinforce HCV as a social norm among the injecting community (Erickson, 1999).

### **Referrals, wait time and service fluidity**

In the clinical context, enhanced knowledge through professional training and increased fluidity between providers and services could aid in the movement of clients along the care cascade. Making prompt referrals upon identifying risk factors and completing diagnostic procedures would facilitate this process, but one's progression from diagnosis to treatment revealed difficulties as clients experienced long wait times for specialized services. Lost or stolen health cards were said to delay this process further, albeit a unique finding related to the context of Ontario. The two streams of referral at Sanguen Health Centre – referral from another provider and self-referral – was particularly interesting. Allowing any community member to seek HCV care increases access by reducing other healthcare interactions before seeking their services. This approach also shifts power in two ways – By not requiring a formal referral from another physician, this diminishes the level of power physicians hold as “gatekeepers” and it allows clients to have power over their healthcare decisions, such as choosing the care setting. As recognized by one study participant, this process may have a negative consequence that leads to inaccessibility due to long wait times, such as those experienced by other specialized services of substance use therapy and mental health.

Wait times are directly related to the concept of supply and demand, where the demand in both regions for services exceeds the resources to provide care. For example, the Mississauga-

Halton and Waterloo-Wellington regions experienced the two longest wait periods for residential addictions treatment in the province (WRCPC, 2011). Further, a situational assessment of HCV services in the Waterloo Region formally acknowledged the lacking number of specialized physicians, nurses and healthcare workers treating patients with HCV (2010). Leveraging community partnerships, through use of support groups and allied health professionals, were important for maintaining client relationships and treatment progress during the interim of waiting for specialized services. However, health systems have been shown to create barriers to comprehensive care due to being highly compartmentalized in nature (Harris & Rhodes, 2013). Participants consequently suggested that more integrated, community care models of health delivery could better fulfil their needs.

Integrated models of care have also been shown to improve system navigation, contribute to heightened patient satisfaction and can promote collaboration among health professionals (WHO, 2016b). The ability to replicate this model in all settings is dependent upon cost and infrastructure, which may also pose concerns for producing geographic, environmental or social barriers. Establishing and increasing partnerships between health setting and other community services and building upon existing programs and infrastructure in communities may serve as an alternate approach to increase service fluidity. Examples of this include: adding HCV testing at STD and HIV clinics, and telemedicine and distance-learning programs in HCV care to allow primary care physicians to monitor HCV therapy (Sena et al., 2016). Hosting community support programs within clinical spaces and with staff members could also help form positive relationships and associations with the health system. Waterloo client participants highly regarded the peer-support programs at Sanguen, resulting in participants gaining a support system, being linked to health care and shifting perspectives of medical practitioners. An

evaluation of the HCV group program at the South Riverdale Community Health Centre in Toronto found that the program was successful in forming relationships, learning and exchanging knowledge while operating in an institutional setting (Woolhouse et al., 2013). These examples display the connections between the macro-, meso- and micro- ecological levels, where experiences and expectations collectively influence one another through feedback loops. Treloar (2013) recommends that trust should be examined beyond the client-provider relationship, suggesting that healthcare interactions may also be influenced by trust in the broader health and social system that governs life.

### **Public policy**

Establishing stronger relationships across settings, enhancing knowledge, improving training, and increasing resources to reduce wait times and increase linkages to care and testing would not reach its full potential to influence the HCV care cascade without also intervening on the structural determinants of health and policies that reproduce inequalities. In addition to greater access to HCV treatment, participants urged for increasing or redistributing resources for housing, education, healthcare and community services since the determinants of health directly influence service access, lifestyle factors and mental health. Findings from the Waterloo Region's substance use study further support housing needs in the Waterloo Region, as they address the availability of housing to be imperative for supporting all people who use substances in the region (Region of Waterloo Public Health, 2017). Considering the macro-level variables provide context to understand the individual experiences. For example, transportation challenges and complaints of service locations were described as the individual experienced them, but the cause of these challenges result from systemic factors related to income and urban planning, where services tend to be centralized in city centres which pushes away marginalized

populations in the process of gentrification (Parlette, 2012). Due to the complexity of the present issue, intersectoral action should be implemented (or strengthened if existing in practice); that is, the collaboration of several sectors to design and implement public policies to improve the lives of community members (PHAC & WHO, 2008).

The Waterloo Region Integrated Drugs Strategy (WRIDS) serves as an example of intersectoral action, where health practitioners, policymakers, researchers, law enforcement, and community members collaboratively aim to address problematic substance use and its harms or consequences (WRCPC, 2011). The success of the WRIDS may be reflected in their region-wide campaigns, events, and planning for safe consumption sites. The model adopted by the WRIDS may serve to inform action in Peel Region. Having a regional and multi-sectoral response in Waterloo Region might contribute to regional differences, such as access to services and resources, interactions with health and service providers, and a sense of belonging and safety in the community, as it has been noted to influence policies (PHAC, 2007). Furthermore, structures that support such action, “can facilitate collaboration and help public health practitioners influence action on health equity” (PHAC, 2014). Intersectoral approaches can be employed at various levels of governance or jurisdiction and have the potential to address complex, multifaceted issues (PHAC, 2007). The inclusion of political partners in this approach may help influence progressive action on controversial topics, but conflicts may exist, and priorities can shift (PHAC, 2007).

Building on intersectoral collaboration and healthy public policy, Health in All Policies (HiAP) aims to improve population health by addressing factors beyond the health system (Sihto, Ollila & Koivusalo, 2006). The underlying theory of HiAP is that the various sectors of society contribute to the health of the population; policies, determinants and the population's health are



conceptualized as a chain of causation (Sihto, Ollila & Koivusalo, 2006). Structural, long-term commitments to policy reform are warranted given that participants identified multiple interrelated factors perpetuating inequities (i.e., housing, income, drug laws). Seeking innovation may be especially significant given the present opioid crisis, the upcoming legalization and regulation of cannabis in Canada (Government of Canada, 2017), and with the growing number of supervised consumption/injection sites across the country (Health Canada, 2017b).

## **6.2 Harm Reduction**

In the present study, contemporary harm reduction interventions have impacted individual behaviour through risk reduction practices, relationships with health providers and interactions with the broader community. Harm reduction's concept and its foundational set of values have appeared to make way into the practice of medicine in community settings exemplified by such linkages, interactions and the identified improvement of physician attitudes by client participants in clinical settings.

The contrasting views of harm reduction practice in client participants' networks suggest that acquiring safe and sterile equipment is easily attainable and the practice of sharing equipment is not universal. However, data from the Waterloo Region Substance Use Study revealed that within the last year, 25% of PWID in the Waterloo Region had injected substances with a previously used needle, and 21% of PWID have lent their used needle to someone else (WRPH, 2017). The continued practice of equipment sharing – despite study participants claiming NSPs to be accessible – may have several explanations, including access barriers, choosing not to access NSPs or practice harm reduction. The consequences of desperation described by both client and physician participants may also account for this, suggesting that harm reduction may be ineffective in these moments as some individuals may not be in a

position to take such precautions to reduce disease transmission (Mosack, Abbott, Singer, Weeks, & Rohena, 2005). This has been noted as a challenge especially faced by lower-income, urban PWUD in the context of HIV prevention (Mosack et al., 2005). While future inquiries could examine the individual behaviours, attitudes and accessibility of injecting equipment in times of desperation, the implementation of safe consumption sites and expanding outreach on the mobile community health van could reduce perpetuating individual responsibilities of reducing harm.

The current adoption of harm reduction appears to slowly break away from an individualistic concept of health promotion (Davis et al., 2004) through the use of community-based approaches, employing peer support workers and increasing service accessibility. Despite increasing service access, individual accountability and motivation remained as barriers to service utilization and overall behaviour change. Sallis, Owen and Fisher (2008) stated that behaviour change could be maximized when individuals are both motivated and educated to make choices that are supported by their environment and political structures. Additional narratives are required to adequately determine if services are, in fact, adopting the philosophy and practice of harm reduction in different networks, and to better assess environmental and political support that may support members of the public.

A key pillar of harm reduction is that initiatives are user-driven, but harm reduction alone cannot accommodate the needs of all community members given the varying intersections of social identity, social location and participation (Werb et al, 2017). The notion that harm reduction is meant to complement other public health approaches may be quickly forgotten, and this emphasis may reduce public opposition (Hwang, 2006). A more general investigation exploring harm reduction measures in sectors outside of health care would also contribute to a

greater understanding of its uptake and impact in a community context (i.e., community acceptance or community resistance). Further inquiry on these process would expose the nuances of power concerning substance use and illness that operate within these different settings.

### **6.3 Research Implications and Recommendations**

This study was the first to investigate HCV testing and treatment access among PWID in the Peel and Waterloo Regions utilizing a defined framework to conceptualize access to services. The implicit pragmatic and solutions-focused approach to this study leads to several recommendations reported by study participants. Thus, the present set of recommendations summarize the key recommendations that promote structural reform.

#### **Community organizations and services, and municipal government recommendations:**

- Increase the availability and scope of practice for mobile harm reduction and health vans (i.e., multiple vans, extended hours of operation, include HCV-rapid testing); Enhance community voice and service outcomes by utilizing the expertise of people with lived experience.
- Create, or further develop, a municipal strategy to respond to substance-related issues and needs that comprises diverse, multi-sectoral stakeholders and community members (e.g. WRIDS).
- Further investigate the experiences of communities and its members who are affected by HCV, or at risk of acquiring HCV, to gain insight about needs in a local context. These processes should be conducted in conjunction with community members and use a variety of methods for consultation and feedback, including community forums, assessments and evaluations.

**Provincial and Federal government recommendations:**

- Clarify the definitions of "accessibility" or "access to health services" in Federal legislation to be congruent with Canada's commitments made to the UN and WHO. Terms and definitions should be clear and consistent to avoid ambiguous interpretations (e.g. reasonable access in the Canada Health Act, 1984).
- Review the structure, roles and connections of Local Health Integration Networks (LHIN) to effectively and efficiently liaisons between various stakeholders and to standardize quality and access, to fulfill the health needs of Ontarians.
- Continue to reform primary care practice by promoting multidisciplinary care teams and move away from the fee-for-service model.
- Promote and incentivize intersectoral action and social participation, and work towards a Health in all Policies approach (HiAP) to create healthy public policy that considers the SDoH.

**6.4 Limitations**

This study provides an additional layer of evidence to local barriers and facilitators to healthcare and treatment access as it exists in multiple contexts, but the subject should be further explored to gather more perspectives over time, as several limitations exist. Since participation was voluntary and convenience sampling was used, a generalizable experience of HCV care, relationships and challenges among clients and participants in the entirety of each region cannot be inferred. Retroactively recalling these experiences may have also influenced the perception and reporting of these encounters.

The sensitivity of the topic and stigma associated with HCV and drug use may have contributed to challenges faced during client recruitment. Client participants reflected a relatively engaged sample since all but one participant had undergone HCV treatment, but each client recounted their experience in differing stages of the treatment cascade. The client participant sample lacks adequate representation of both regions' vastly growing cultural demographic and dispersion amongst its cities and townships. Given the small sample size and scope of the present study, the experience of HCV testing and treatment based on age, gender or race could not be accomplished. Collecting additional demographic information may have been beneficial for unpacking the influences of income and housing from the perspective of clients. However, it is important to note that intravenous substance use and subsequent HCV acquisition is not mutually exclusive to income level. The study was unable to account for more diverse narratives to reflect the intersections mentioned above.

In previously acknowledging my self-identity as an "outsider" to intravenous drug use and as an academic researcher, these characteristics may have also served as a deterrent for clients to participate in the study. Having previous engagement and internal recognition with each partnering organization and their clients may have facilitated greater recruitment and engagement. However, such engagement could have caused concerns about confidentiality and conflicts of interest.

Finally, this study was conducted during the opioid crisis. The urgency to deal with personal, community and patient needs likely impacted the availability of many health providers to participate and diminished importance from clients to participate. Reasonable assumptions for recruitment challenges include limited time, lacking the time or interest to participate, lacking incentives, lacking a previously established connection or sharing a professional network with

the researcher, and conducting interviews at the sites of community partners (which may be inaccessible or unwelcoming to potential client participants).

## 7. Conclusion

This study identified accessibility concerns along the care cascade through the exploration of HCV testing and treatment among PWID in the Waterloo and Peel Regions. Clients and providers identified similar accessibility barriers and facilitators within each access domain, suggesting congruent understandings of HCV service access for PWID. To strengthen the client-provider relationship and overall quality of HCV services, understanding the complexity of the problem and facilitating a safe space for clients requires adequate provider training (Allman et al., 2007). Promoting a patient-centred, collaborative approach across health settings would enhance system fluidity and redistribute power and resources. Enacting a shared value of improving access and patient experience (LHIN, 2011) would enjoin stakeholders, including community members. In the present study, HCV testing and treatment is not adequately acceptable, available, affordable or geographically accessible since all clients experienced at least one barrier from each accessibility domain. In adhering to the Canada Health Act, improvements must occur to ensure reasonable access to health services, treatment and procedures are guaranteed.

Future research must further investigate the topic by investigating additional factors from both perspectives of service providers and services users that influence health inequities and disparities in the country. Identifying the role and relationship of other health providers that serve PWID should also be explored, involving pharmacists and dentists. Tackling the burden of HCV coincides with all harm reduction and public health endeavours. As safe consumption facilities become approved, it is imperative that different systems commit to reducing illness and

health inequities through collaboration. Recruiting a larger sample of participants from each city and township making up the two regions would further contextualize epidemiological data that reveals differing rates of harm reduction practices and service availability. Additional perspectives would also illuminate more diverse experiences conducive to an intersectional analysis that examines the operation of power. Moreover, future inquiries may investigate these geographical regions based on the boundaries of their LHIN rather than municipal boundaries.

Within the ecological framework, the role of power and oppression was reinforced at each level. For instance, stigma was a barrier that did not act alone; as a process, stigma was depicted on the individual level as a product of social factors and perceptions (Tanahashi, 1978). The continued existence of stigma and other identified barriers presented from both regions indicate the inability of institutions, professionals and society to manage injustices and adequately respond to illness. Facilitators and solutions identified in this study imply that community-based and collaborative interventions are effective and preferred. Findings indicate the need to further adopt a harm reduction paradigm and patient-centred approach to care, increase resources, consider the role of power along the care cascade, and promote multi-sectoral policy-making to ensure reasonable and equitable access to services.

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