Barriers To Accessing Hepatitis C Treatment For Individuals Who Have Experience With Injection Drug Use And Are Accessing Methadone Maintenance Treatment

by

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Dedication

This thesis is dedicated to all of the individuals who have shared their stories with me, both through this research and in my other work. Their determination, courage, humour and compassion, in the face of adversities, inspires me to continue this important work.

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Abstract

Hepatitis C (HCV) is an infectious disease of the liver which affects more than 250,000 Canadians; the majority of those living with the disease have experience with injection drug use. Treatment for HCV involves a strict protocol, has only a 50% success rate and has harsh side effects. Interest in HCV treatment among people who use drugs is high, but actual uptake of treatment remains low. The objective of this research was to explore the barriers to accessing HCV treatment for individuals who were accessing methadone. A mixed methods approach was used; a cross sectional survey and an in-depth interview were administered to clients of a methadone maintenance program. The two sets of data identified three main barriers to HCV treatment; stigma, the toxicity of treatment, and day-to-day struggles. Future research should be conducted to further explore how stigma guides decisions around HCV treatment, particularly in a methadone treatment setting.

Acknowledgments

This project was conducted in collaboration with Direction 180, a low threshold community based methadone maintenance program in Halifax, Nova Scotia. The support and guidance from Direction 180 clients and staff was invaluable to the success of this research.

Chapter 1: Introduction

1.1 Background

Hepatitis C is a disease of the liver and is contracted through blood-to-blood contact with infected blood. Chronic hepatitis C can lead to cirrhosis of the liver and liver cancer if left untreated. It has been estimated that over 170 million people worldwide are living with the hepatitis C virus (HCV). In Canada, 250,000 people are living with the virus (1), the majority of whom contracted the virus through injection drug use (2).

Treatment of HCV currently involves a combination of two drugs (pegylated interferon and ribaviron), which leads to a sustained virological response (SVR) in approximately 50% of cases (3). There are several adverse side effects to treatment, including fatigue, headache, fever and rigors, and psychiatric side effects (4). Between 10% and 14% of patients on HCV therapy report discontinuing treatment due to these adverse side effects (4). Those treated also often report difficulty maintaining normal routines due to the physical and psychological side effects (5).

One form of addiction treatment for individuals who inject drugs, opioids specifically, is methadone. Methadone is a prescribed medication which mimics the effects of opioids to reduce cravings of illicit drugs. Accessing methadone, especially in Nova Scotia, is difficult as a limited number of prescribing physicians and long wait times prevent many individuals from engaging in treatment when they are ready to make a change (6). Research suggests that methadone programs provide a unique opportunity to treat hepatitis C among clients who are already making changes in their lives (7, 8). Although drug treatment is no longer a prerequisite to HCV treatment (9), providing HCV treatment in this context may provide patients with the medical and social support to complete HCV treatment successfully.

Interest in HCV treatment among people who inject drugs is often reported as high, though actual uptake remains low. A key question is, why? Several barriers to accessing HCV treatment have been identified in the literature, which can be categorized as personal barriers, provider barriers and /or societal barriers. A patient may decline treatment for a variety of reasons, including lacking symptoms (10), fear of side effects (11), and a lack of knowledge of HCV (12). Provider barriers are often based on assumptions made by health care professionals that prevent individuals from being treated for HCV; for example, a provider may assume a lack of adherence to medication among individuals who inject drugs (13). Societal barriers evolve from the stigmatization of drug use, and can include such things as a lack of priority to treat people who use drugs among physicians, or silence around HCV issues among health care professionals and the public in general (5, 13).

1.2 Significance

Projections suggest that between 2010 and 2019, the global burden of hepatitis C will result in 165,000 deaths from chronic hepatitis C and just over 27,000 deaths from cancer related to hepatitis C. This equates to a loss of over 1.8 million life years and a medical cost of up to $54 billion (14). In Canada, the prevalence of HCV is rising (up 4% between 1998 and 2002) and is expected to continue rising until at least 2022 (2). Annual Canadian health care costs related to HCV in 2010 were predicted to be $1 billion (15). In Nova Scotia, although HCV infection rates have remained relatively stable over the past few years, the number of infections related to injection drug use has increased (16).

Hepatitis C, though it progresses slowly, can have profound effects on quality of life and length of life if left untreated. Unlike other chronic diseases with treatments (i.e. HIV, diabetes), there is an overwhelmingly low uptake of HCV treatment. Much research has been conducted to determine the factors associated with this low uptake, with a general consensus that a lack of knowledge or low knowledge about the disease and its treatment, and stigma associated with the disease, are two of the primary contributing factors. A continued interest in this area of research is needed in order to better understand the barriers to accessing treatment beyond knowledge, and to help to increase HCV treatment uptake rates.

1.3 Objectives

The primary objective of this research study was to identify barriers to accessing hepatitis C treatment for people who have experience with injection drug use and who are currently seeking methadone maintenance treatment. The specific research questions were:

(1) How do individuals who are willing to initiate HCV treatment differ from those who are not willing to initiate HCV treatment?

(2) What is the association between knowledge around transmission, progression and treatment of hepatitis C and willingness to initiate hepatitis C treatment?

(3) How do attitudes around hepatitis C treatment differ between individuals who are willing to initiate treatment and those who are not willing to initiate treatment?

(4) Among individuals who are not willing to initiate HCV treatment, what are the social and contextual factors that have impacted their decisions around hepatitis C treatment?

Chapter 2: Literature Review

I will begin this literature review by describing the burden of hepatitis C in Canada, the epidemiology of the virus and the conventional treatment. I will continue by describing the population of injection drug users and methadone maintenance patients in Canada, and methadone maintenance treatment itself. The largest section of this literature review will explore the barriers to hepatitis C treatment for those infected with the disease, including provider barriers, individual barriers, and structural and societal barriers. I will conclude the literature review by summarizing the main points of the review and describing how the objectives of this proposed research will compliment the current body of literature.

2.1 Prevalence & Burden of Hepatitis C

Hepatitis C is an infectious disease of the liver, caused by the hepatitis C virus (HCV). It has been estimated that 170 million people worldwide and over 250,000 in Canada are living with hepatitis C (1). In 2007, the Nova Scotia Department of Health Promotion and Protection released a report indicating that, between 1998 and 2007, just under 3,000 positive tests of hepatitis C were reported in Nova Scotia; 65% of these cases were linked to injection drug use (17). Key informants in the Halifax-Dartmouth area have estimated that more than 500 injection drug users live in the area, with hepatitis C being the most prevalent communicable disease among this population (18).

The prevalence of hepatitis C has risen in recent years and is expected to continue rising. In Canada, the prevalence of hepatitis C rose 4% from 1998 to 2002. Health Canada predicts that, by 2022, over 2,100,000 Quality Adjusted Life Years (QALY) will have been lost in the country due to hepatitis C. Approximately 4,700 Canadians die every year from hepatitis C related causes (2). Of the 338 liver transplants in Canada in 1998, 217 of them were hepatitis C related; each transplant can cost between $120,000 and $690,000 (15).

As described, the burden of hepatitis C in Canada is significant and the prevalence of the disease is increasing. The estimates for Canada are alarming, especially considering that approximately 90,000 HCV cases in Canada are estimated to be asymptomatic and undiagnosed (15). Because chronic hepatitis C progresses slowly but steadily to cirrhosis of the liver, prevention and treatment of the disease are important interventions. Preventing just 50% of new cases in one year would save Canada over 7 million dollars (15).

2.2 Epidemiology of Hepatitis C

In order to understand the significance of living with hepatitis C, it is important to understand the history and epidemiology of the disease, including modes of transmission and progression of the disease.

The hepatitis C virus was first identified in the US in 1989, and termed "non-A, non-B" viral hepatitis (19) and is a single stranded RNA genome (20). Six major genotypes of the virus have been identified, each with 2 or more sub types (21, 22), with genotype being found to be significantly associated with response to treatment (23).

The hepatitis C virus is spread through blood to blood contact. Prior to widespread screening of blood products, the main risk factor for infection was a history of blood transfusion (24), but due to increased screening and the introduction of sensitive tests to screen blood products, transfusion-transmission of HCV has become rare (25,26). Because HCV is highly transmittable through blood to blood contact, people who inject drugs are at a high risk of infection. Although other forms of transmission exist (i.e. sexual intercourse, mother to child transmission during childbirth), Health Canada has estimated that 55% of all HCV cases and 77% of all newly diagnosed cases of HCV in Canada are a result of injection drug use (2).

There are often no initial symptoms of HCV infection, and the virus tends to remain asymptomatic for many years; when individuals are unaware of their infection, there is an increased risk of transmission to others. Within ten to twenty years of initial infection, chronic HCV may progress to cirrhosis of the liver, and within twenty to forty years of initial infection, it can progress to liver cancer. Fifteen percent of hepatitis C cases will clear spontaneously (2).

Although infection with the HCV is a cause of chronic hepatitis, liver cirrhosis and hepatocellular cancer (27), not all cases of hepatitis C infection lead to liver disease (10). Approximately 80% of cases progress to chronic infection (which needs to be treated in order for an individual to clear the virus), while 20% progress only to an acute infection (which clears spontaneously within six months) (20). Progression of hepatitis C may be influenced by a number of factors, including but not limited to host factors (age, age at infection, sex), viral load and genotype, mode of infection, duration of infection, alcohol consumption and other epidemiological conditions (i.e. geographical location) (23).

As noted, injection drug use is a major risk factor for hepatitis C infection. Opiates are the most commonly injected drug in Canada; a brief study of the characteristics of opiates, especially their highly addictive nature, sheds light on how lifestyles are affected and shaped by these powerful drugs.

2.3 Opiates

Opiates are some of the most commonly used illicit drugs in Canada, as reported by several cohort studies of people who inject drugs (28-30) and the Royal Canadian Mounted Police (RCMP) (31). The RCMP report that while heroin has been the most commonly used drug in the country, prescription versions of opiates are becoming increasingly popular (31).

An environmental scan published in 2000 identified dilaudid and crack cocaine as the leading drugs of choice and the most commonly injected drugs in Atlantic Canada (32). A scan conducted in 2005 revealed similar results (dilaudid and crack cocaine as the leading drugs in the region), but also identified an increase in the use of OxyContin. These findings suggest that there has been a rise in the use of prescription drugs in the Atlantic Region (33).

Opiates are derived from the poppy plant and include opium, morphine, codeine, heroin and others. These psychoactive substances activate opioid receptors in the brain and through continued use, produce a dependent effect. They can be consumed through injection, ingestion or inhalation of fumes (34).

Dependence on opioids develops over time and is characterized not only by an increasingly heavy use of opioids, but by complex health conditions that include social, psychological and biological consequences. Many individuals who have become dependent on opioid experience homelessness, poverty, unemployment and social instability; these consequences not only affect the individual, but also family, friends and communities (34).

2.4 Injection Drug Use in Canada

In order to effectively treat hepatitis C among individuals who use injection drugs, it is important to understand the trends within this population and how particular social contexts act as barriers to accessing care, treatment and support.

Canadian researchers have initiated several surveillance programs and cohort studies to describe the population of individuals who inject drugs. These programs and studies often involve implementing surveys in major cities across the country and have, to date, excluded locations in Nova Scotia. The surveys themselves have varying lenses, with some focusing on risk behaviours (30), others on drug history (29) and others on demographic characteristics of this population (35). Because of the legal implications of drug use, along with the societal and contextual stigmatization of people who inject, it is unlikely that these surveys fully capture the complexity of drug use in Canada. Recruitment for these surveys often takes place in Needle Exchange Programs (NEPs) and other Community Based Organizations (CBOs), and therefore may not capture individuals who do not seek care or support. Keeping in mind the limitations of these surveys, they do provide a general understanding of the characteristics of this population.

Surveys have demonstrated that people who inject drugs in Canada tend to be male, white and with an average age between 35 and 37 years of age. Studying this population has also revealed significant inequities in housing; reports indicate that only half of individuals report stable housing (28-30, 22) and that living in shelters or on the street are common housing situations (35). It has long been understood that housing has a significant effect on health and health outcomes and that adequate housing is associated with improved health status (36). A study conducted in the United States, for example, found that individuals who were homeless reported addiction treatment to be ineffective due to a lack of housing support available after treatment (37). Among HIV-infected individuals, who share many of the same risk factors as HCV-infected individuals, housing needs have been a significant barrier to HIV support and care (38), with a strong correlation between increased housing and decreased HIV risk behaviours and improved health outcomes (39). Further, unstably housed NEP clients reported sharing needles twice as often as stably housed clients (40). This evidence suggests that housing is a major contributor to risk factors associated with infectious diseases and health outcomes.

Considering that the population of people who inject drugs in Canada frequently experiences marginalized housing, it is not surprising that they also experience high rates of infection and difficulty accessing health related services. A multi-city study of people who use opiates found that, among those infected with hepatitis C, only half accessed any type of health care in the past six months (41) and that, on average, respondents accessed medical services less than once a month, compared to accessing NEPs almost 13 times per month (41). This pattern of accessing services may be the result of several circumstances. For example, people who use drugs may need to access NEPs more frequently than medical care, they may have easier physical easier access to NEPs than to medical services or they may experience several systematic barriers to accessing medical care that they do not experience when accessing NEPs.

Addictions, particularly opiate addictions, have been repeatedly associated with concurrent mental health conditions, which range from depression to antisocial behaviour to attention deficit hyperactive disorder (ADHD). High rates of psychiatric problems among individuals admitted for opioid addiction treatment have been noted (42). Among individuals seeking addiction treatment, depression has been associated with continued injection drug use during and after treatment (43). A national study in the United States found an association between non-medical use of prescription drugs and several mental health disorders, including panic disorders, depression, social phobia and agoraphobic symptoms (44). Specific to ADHD, individuals engaged in methadone maintenance treatment who reported ADHD symptoms prior to engaging in treatment were less likely to achieve abstinence from drugs nine months post admission (45). It is clear that mental health and addiction conditions often occur concurrently, and that mental health conditions often act as a barrier to accessing addiction treatment.

The co-morbidities of drug use, including marginalized housing, lack of medical care and associations with mental health, support a cycle of vulnerability within this population that creates barriers to accessing a variety of health and social services. It is important to understand the circumstances that propagate drug use in order to understand the context of both hepatitis C treatment and methadone maintenance treatment and the challenges associated with both.

2.5 Treatment of Hepatitis C

Conventional treatment of hepatitis C involves a combination of pegylated interferon and ribaviron this has been shown to lead to sustained virological response among, on average, 54% of not-previously treated adults. Sustained virological response (SVR) is defined as having undetectable HCV RNA 24 weeks after completion of treatment (3). For individuals with genotypes 2 or 3, more than 80% of cases achieve SVR through conventional treatment; individuals with genotype 1 tend to have only a 50% chance of achieving SVR (4). Optimal duration of treatment is based on viral genotype; individuals with genotype 1 require treatment for 48 weeks, while individuals with genotype 2 or 3 require treatment for 24 weeks (4). Although ongoing illicit drug use may complicate the decision to treat HCV infection, it is not a contraindication for treatment (9).

Side effects of hepatitis C treatment can be serious and adverse. It has been suggested that between 10% and 14% of patients treated with pegylated interferon and ribaviron discontinue treatment due to adverse side effects. The most common side effects include: fatigue, headache, fever and rigors, and psychiatric side effects (4). These side effects are especially problematic in patients with pre-existing psychiatric disorders, such as depression. It has been demonstrated that dose-dependent and reversible neuropsychiatric effects occur in 30-40% of individuals on hepatitis C treatment, with more severe effects observed in 10-20% of individuals. Psychiatric side effects to treatment are more common among individuals with a history of psychiatric problems compared to those without such history (46).

Beyond medically documented side effects, qualitative studies with individuals have demonstrated that treatment also has adverse effects on their daily lives. Participants of one such study reported that they struggled to maintain a meaningful life while undergoing HCV treatment, with the limitations imposed by treatment effecting their work, lifestyle, friends and family (5). Participants described HCV treatment as slowing them down and making their life very limited and withdrawn (5).

In the same study, Sgorbini and colleagues sought to describe the effects of undergoing hepatitis C treatment on individuals and their partners. In general, participants described a significant physiological and psychological effect on the quality of their lives due to HCV and its treatment; they described the difficulty of maintaining a meaningful relationship with their partners and experiencing stigma (5).

In March of 2011, the New England Journal of Medicine published two articles based on clinical trials which added a third drug, boceprevir, to the standard therapy for the treatment of chronic HCV genotype 1 infection (47, 48). The trials demonstrated a significantly increased rate of sustained virological response in both previously untreated and treated patients with HCV genotype 1, compared to those treated with standard therapy. The addition of boceprevir, although beneficial for sustained virological response, increased the side effects of the regimen, especially cases of anaemia (47, 48).

The results of these studies suggest that treatment of HCV will continue to be a complex and toxic regime.

The protocol of HCV treatment (i.e. injections) and the adverse side effects of the medication couple together to create a treatment experience that would be challenging even in ideal circumstances. When consideration is taken of the target population for this treatment, it becomes clear that there are significant barriers to both initiating and completing hepatitis C treatment.

2.6 Methadone Maintenance Treatment

Methadone maintenance treatment (MMT) is a form of substitution maintenance therapy. MMT is part of a harm reduction strategy in which reducing the harms associated with drug use is considered a critical component of addiction treatment and often combines pharmacotherapy with psychological rehabilitation and social support (34). Low threshold MMT programs are flexible in their requirements for care, while high threshold programs are less flexible. For example, an individual who drinks alcohol while accessing MMT would likely be discharged from a high threshold program but not from a low threshold program.

Methadone itself has been used as a treatment for opioid dependence since the 1960s and works by alleviating the symptoms of withdrawal and decreasing opioid cravings as well as the euphoric effects of other opioids (49). Methadone is long lasting and can therefore be taken once a day to prevent symptoms such as anxiety, restlessness and nausea for up to 24 hours (49).

2.7 Delivering Methadone Maintenance Treatment in Canada

In Canada, methadone can only be prescribed by a physician who has been granted an exemption under Section 56 of the *Controlled Drug and Substances Act*. The Office of Controlled Substances, Health Canada, facilitates methadone maintenance treatment through collaboration with provincial and territorial medical licensing organizations and governments. Methadone maintenance treatment is delivered through a variety of sources in Canada, including substance use treatment programs, community based health clinics, private medical clinics, physician offices, HIV clinics and correctional facilities (49).

There have been dramatic increases in demand for methadone maintenance treatment, especially among First Nations communities and correctional facilities, in recent years. In British Columbia, for example, the number of people on methadone rose from just under 3,000 in 1996 to over 11,000 in 2009 (50).

In Nova Scotia, MMT is available in three of the nine district health authorities; two clinics are located in Halifax, one in Truro and one in Sydney. Methadone is also available in private clinics and from prescribing physicians. There are 35 prescribing physicians in Nova Scotia, though it is difficult to determine how many are actively prescribing at any given time. Access to methadone is particularly difficult for individuals living in rural or remote parts of the province (50).

In 2002, Health Canada released a best practice guide to MMT (49); although every province agreed that this guide provided a framework for the ideal situation, demand has forced provinces to adjust the best practice. It was recognized that some individuals need more or less support than others and, in addition, a need for low threshold MMT was recognized, as not all individuals are ready to abstain completely from drugs and / or alcohol. Currently, governments are looking at ways to deliver methadone through multiple models (50).

In addition to understanding how MMT is distributed in Canada, it is important to understand the characteristics of MMT patients. Because hepatitis C is often treated in MMT patients, and the proposed research will focus on that population, a discussion of MMT patient characteristics follows.

2.8 Methadone Maintenance Patients

It has been estimated that approximately 1,000 individuals in Nova Scotia are currently accessing MMT (50). Addiction Prevention and Treatment Services (APTS) within Nova

Scotia’s Capital District Health Authority (CDHA) developed a database of client information in 1996. Data collected between the database inception and 2003 indicate that the majority of CDHA clients accessing MMT in Nova Scotia are male (74%), with an average age of 38 years. Between 1996 and 2003, there were 251 unique clients admitted to the CDHA MMT program (51). Active clients spent an average of just over 800 days in treatment, while discharged clients (voluntary or involuntary) spend less than half the time (314 days) in treatment (51). In terms of education and employment, approximately 30% had full or part time employment at the time of admission, and 40% had a university or college degree (51). This data has been gathered from clients admitted into tertiary treatment, and therefore who meet the requirements of this treatment protocol. This includes being ‘medically manageable’ and having attempted opioid treatment previously (51), which is often not characteristic of high risk opiate users, who are often accepted into low threshold MMT programs.

Canadian researchers gathered data from 533 illicit drug users across the county between 2002 (baseline) and 2005 (last follow up) to determine factors associated with methadone maintenance treatment uptake. At the last follow up, 133 participants had begun MMT, while 400 had not. Results indicated that those who were injecting drugs at baseline were more likely to report MMT uptake than those who were not injecting at baseline. The authors suggest that either people who inject drugs are more likely to seek MMT due to their more pronounced acute health and other problems, or MMT programs may be more likely to target injection drug users as compared to other drug users. The researchers also found increased MMT uptake among those with stable housing, providing evidence to suggestions that MMT cannot occur in isolation without particular social supports in place. Results of this study also suggest that other predictors of MMT uptake include heroin as drug of choice and alcohol use. Among MMT users, lower levels of both opioid and non-opioid drug use were observed at follow up (52).

2.9 Barriers to hepatitis C Treatment

Upon understanding the epidemiology of hepatitis C, the adverse conditions of HCV treatment and some characteristics of the individuals to which treatment is targeted, it follows relatively intuitively that this combination of factors creates barriers to accessing hepatitis C care, support and treatment. The remainder of this literature review will focus on these barriers, both in terms of specific barriers to hepatitis C treatment and general societal barriers to care, including stigmatization and discrimination.

2.9.1 Interest and Uptake of HCV Treatment

A consistent finding in the literature is that although interest in HCV treatment is often reported as high, actual uptake of treatment remains low. Hepatitis C treatment uptake among HCV positive individuals not in MMT has been reported to range from 6% (10,53) to 80% (11, 54), whereas among those receiving MMT, HCV treatment is between 50% (55, 56) and 80% (57).

A 2008 study with almost 200 hepatitis C virus positive individuals who use illicit drugs found that 77% of respondents were interested in treatment, with interest remaining high even when they were made aware of treatment conditions and possibilities of poor outcomes (12). Strathdee and colleagues (54) found that although 81.5% of treatment-naïve individuals were interested in treatment, only 27.3% had ever sought any health care from a provider; participants of this study had experience with injection drug use. One study, conducted in Vancouver, found that, among 2,118 hepatitis C infected individuals, only 1.1% had initiated treatment, and that the rate of new infections among this community-based inner city cohort was 25 times the rate of HCV treatment uptake (58). A study conducted in Europe collected launch and sales data from 21 countries. Researchers demonstrated that, up until 2005, only 3.5% of individuals living with hepatitis C in the countries studied had been treated, ranging from 16% in France to less than 1% in Poland (59). In the United States, between 2002 and 2007, it was found that 21% of individuals with hepatitis C had ever been treated, with this rate declining in recent years (60).

2.9.2 Personal Barriers

As suggested by Michael Volk in his 2010 paper, perhaps the first and largest barrier to hepatitis C treatment is the under-diagnosis of the disease. Under-diagnosis is a result of a combination of factors, including low priority of preventative action and lack of understanding regarding early diagnosis among primary care physicians, lack of health insurance and regular access to care among the at risk patient population, and the asymptomatic nature of hepatitis C (61).

Individuals may decline HCV treatment when it is offered or brought up by their health care professional. A 2010 retrospective review conducted in Hong Kong showed that 31.9% of patients who were referred to an outpatient clinic declined HCV treatment (62). In general, individual provide various reasons for declining treatment, which include lacking disease symptoms (10, 12, 63), fear or concern of treatment side effects (11, 12, 58, 64), lack of knowledge of HCV (12, 63), lack of knowledge of HCV treatment (10, 12), concerns around mental health (63) and concerns around the efficacy of treatment (64).

A 2010 study highlighted the importance of competing priorities for individuals when they consider treatment. Researchers interviewed 27 clients of an opiate substitution treatment program and found that parental responsibilities, homelessness and unstable housing, and other physical and mental health concerns were prioritized over HCV treatment. Participants also highlighted the conflict of these priorities and the low efficacy of treatment (65).

Researchers in Toronto also uncovered the conflict of treatment efficacy and competing priorities; they recruited HCV positive individuals who had experience with injection drug use and who were not undergoing addiction treatment and analyzed their willingness to initiate treatment. The possibility of required addiction treatment was reported as a barrier to HCV treatment by participants. Participants indicated that they would be willing to reduce their drug use, but only if treatment would guarantee they would be rid of HCV (11).

In a retrospective analysis of primary and contributing factors among participants who had not initiated HCV treatment, 12% of these participants declined treatment with side effect concerns as their primary reason, while the remainder were lost to follow up or not started on treatment due to a health care provider decision (i.e. HIV therapy more urgent) (66).

In 2011, researchers in the United States published findings suggesting that depression among people living with hepatitis C may amplify negative perceptions about barriers to accessing care. In a study of over 100 HCV positive individuals, they found that depression was independently associated with multiple perceived barriers to accessing hepatitis C treatment (67).

Among this research, lack of knowledge as a barrier to HCV treatment is particularly dominant. A more in depth look at this research follows.

2.9.3 Knowledge as a Barrier

There has been an assumption in recent literature that one of the main barriers to hepatitis C treatment is lack of knowledge of the disease and its treatment among people living with it. Researchers often suggest that increasing knowledge through education campaigns will increase treatment uptake. A closer look at several studies suggests that a lack of knowledge is often the result of several other, more complicated factors and that it might be more helpful to address those barriers rather than knowledge *per se*.

A qualitative study interviewed 77 clients engaged in a drug treatment program, each of whom self-disclosed that they were hepatitis C positive. Participants were asked to discuss their experiences with drug treatment, mental health treatment and living with hepatitis C. Researchers found that participants had experienced inconsistency in the management of their disease and, as a result, were unable to identify symptoms of the disease or interpret liver monitoring tests. Many participants were confused about the progression of the disease and few reported discussing treatment with their health care provider. The authors concluded that increased education is vital to ‘convincing’ individuals that HCV treatment is necessary (63).

Another study recruited participants from inner city community health clinics in Vancouver and Victoria. For participants who reported being hepatitis C positive and having not sought treatment, researchers asked them why they had not sought treatment. Twenty three percent of respondents indicated that they did not know enough about hepatitis C or its treatment to be interested in treatment. Again, researchers concluded that increased education on the long-term effects of hepatitis C was a key component in increasing treatment uptake (12).

In another study, where participants were recruited from a methadone clinic, researchers found low knowledge of disease progression, fairly consistent knowledge of transmission, but low knowledge about the existence of HCV treatment. Researchers suggested that this inconsistent knowledge resulted in a lack of understanding of the seriousness of the disease and treatment options. They concluded that education programs in methadone clinics would help to increase treatment uptake (56).

Finally, in another study of clients in a methadone program, researchers assessed knowledge through five questions related to hepatitis C. They, similarly to the above mentioned studies, found inconsistent knowledge among participants and concluded that lack of knowledge was a barrier to treatment (55).

Each of the described studies concluded that lack of knowledge acts as a barrier to treatment and suggests that increasing education would increase treatment uptake. The researchers in each study seem to draw conclusions based on an assumption that there is a relationship between knowledge and interest in treatment when, in fact, there may or may not be. For example, in some studies, participants themselves identify knowledge as a barrier to treatment (12, 63). In these cases, knowledge may act as a proxy for inconsistent HCV care or lack of desire to access HCV information for fear of experiencing stigma. Alternatively, participants may have responded in this way because they perceived it to be a socially acceptable response to being asked why they have not sought HCV treatment. While HCV knowledge among these populations is clearly inconsistent, it may be the result of other, more complicated, issues and not just lack of education programs.

In other studies, researchers actually tested knowledge through various methods and found low knowledge (56, 57). When researchers found low knowledge and low interest in treatment, they concluded that there might be a correlation. In fact, when researchers in Australia conducted univariate and multivariate tests to look at the relationship between knowledge and interest, they found that no relationship existed (57). Again, the conclusions drawn by researchers may be correct, but there may be deeper-rooted causes of this lack of knowledge that contribute to the barriers to treatment.

Along with knowledge and other personal barriers, there exists a broad spectrum of barriers that have been established and proliferated in society that make seeking HCV treatment difficult especially for this population. I will continue this discussion through a review of provider barriers and societal barriers to HCV treatment.

2.9.4 Provider Barriers

Often times, individuals who are referred to a liver specialist are never initiated on treatment. A 2011 survey with Swiss primary care practitioners (PCPs) found that PCPs had low HCV patient caseloads, and fewer than 20% did not monitor their chronic HCV patients. The authors suggest that the low caseloads may contribute to uncertainty in managing HCV (68). A national Canadian survey of specialists revealed that only 20% of responding physicians were likely to provide HCV treatment to an individual currently accessing a needle exchange program. Ninety-percent of respondents indicated that they would provide HCV treatment to a person who was stable on substitution therapy and not using drugs (69). Although the reasons why HCV positive individuals are not started on treatment by their health care providers can be due to the contraindications of treatment, sometimes they are due to assumptions made by providers.

Practice guidelines for hepatitis C diagnosis, management and treatment released by the American Association for the Study of Liver Diseases (4) contraindicate individuals with major uncontrolled depressive illness, solid organ transplant, autoimmune hepatitis, untreated thyroid disease, pregnancy or unwilling to comply with adequate contraception, severe concurrent medical conditions (i.e. severe hypertension, heart failure), or known hypersensitivity to HCV medications (4). One study reported that although 12% of HIV-HCV co-infected patients declined HCV treatment, a further 67% were not started on treatment as determined by health care providers (66). Another study reported that 53% of HCV positive individuals had absolute contraindications (56) and could not be started on treatment.

Although these guidelines do not contraindicate concurrent illicit drug use (4), research has suggested that health care providers often use other reasons when making decisions about treating HCV in their patients. A 2007 study followed individuals started on HCV treatment and found that beginning treatment was more strongly correlated with which provider was seeing the patient, rather than by the characteristics of the patients (62). A 2005 study looked at co-infected HIV/HCV positive homeless and marginally housed adults; almost 71% of these individuals were considered ineligible for HCV treatment by their care providers. Some of the reasons provided in qualitative interviews with care providers included presumed likelihood of poor medication adherence, depression and current injection drug use (13). A more recent study involved interviewing primary care providers and support staff at HIV clinics and reported both biological factors (i.e. instability of HIV disease) and psychosocial factors (i.e. presumed lack of adherence to medication) as reasons for not initiating treatment in HCV positive individuals (70). Researchers with the Australian Trial in Acute Hepatitis C (ATAHC) published case studies in 2007, demonstrating that, although individuals had chaotic and unstable lives, HCV treatment provided them with a sense of control and responsibility over their lives. The case studies show that individuals with current drug use or depression can be successfully treated for HCV (71).

Beyond the medical and biological contraindications of treatment, reasons for denying treatment as determined by health care providers often stem from an overarching theme of stigmatization of individuals with hepatitis C and its association with injection drug use that exists in society. This stigmatization, although it can exist at the individual level among health care providers, also often exists on a much larger scale in which the structure of society fosters stigmatization of marginalized populations.

2.9.5 Societal Barriers

Emerging research has suggested that stigmatization of individuals living with hepatitis C has a significant impact on the lives of those living with the disease. Stigmatization exists on a variety of levels, including within society and the public, within the health care system and within inter-personal relationships. The impact of stigmatization often leads to self-isolation which reduces willingness to access health services, manifesting into a significant barrier for accessing hepatitis C care, treatment and support (58).

The primary perceived causes of stigmatization, as identified by hepatitis C positive individuals, tend to stem from society's association of the disease with stigmatized behaviours; this includes not only injection drug use, but also sexual promiscuity (71). Those who obtain the disease through 'innocent' modes (i.e. injury or blood transfusion) of transmission still experience stigmatization due to the assumption of drug use (5).

Magdalena Harris published an article in 2009 based upon qualitative interviews with 40 people living with hepatitis C in New Zealand and Australia. The author herself was hepatitis C positive, and therefore engaged in interviews that were more interactive than traditional research. She noted that some participants internalized societal stigma of hepatitis C so much that they considered their hepatitis C to be less of a priority than other health issues; some participants thought of their hepatitis C as more than just a health issue, but also a 'moral designation' and a constant reminder of previous lifestyles. (72).

Researchers in 2004 suggested that hepatitis C is not only a medical diagnosis, but also a social diagnosis. The authors suggested that the association of hepatitis C with injection drug use carries a significant social stigma generally caused by fear (fear of illness, fear of contagion and fear of death) from the public. The lack of awareness of the impact of hepatitis C as a disease, ignorance about transmission and socio-cultural views about injection drug use support the acceptance of stigmatization within society (73).

Within the health care setting, researchers have suggested that departmental and institutional policies regarding HCV treatment availability and eligibility reinforce the social stigma attached to hepatitis C. Even when there is no intent to stigmatize, structural forces within institutions can lead to poor treatment of certain populations which often manifest as stigmatization (74). With respect to people who inject drugs who are hepatitis C positive, research has demonstrated that interdepartmental communication, a system-wide structural factor, influences the type and quality of health care received by the target population (53). Qualitative studies with individuals have revealed their awareness of the stigma within the health care setting, identifying their physician as stigmatizing towards them (75).

A research study conducted in Nova Scotia in 2007 looked at how institutional and structural factors shape the interactions between health care practitioners and people infected with hepatitis C. Five major themes emerged from this qualitative research, conducted through interviews with health care providers; available resources, hospital-wide policies and procedures, emergency department policies and procedures, communication and reporting procedures and the physical environment. For example, smoking policies within institutions, wait times in emergency departments, signage within hospitals and confidentiality at triage were all identified by health care practitioners as possible sources of structural stigmatization of the target population (74).

Direct stigmatization in the health care setting often stems from an assumption that HCV resulted from injection drug use and the stigmatization of that behaviour (5, 77). The association of HCV with stigmatizing behaviours can create perceptions (and realities) of being treated differently from individuals with other chronic diseases by health care providers (5). A lack of knowledge about hepatitis C within the healthcare setting leads to prejudice and stigmatization (5, 73).

Individuals often discuss the stigmatization they experience from friends and family due to their hepatitis C diagnosis, which often exists as strained interactions and tension (77). Feelings of being left alone, pushed aside, and abandoned by their families pushes individuals into further social isolation and interferes with their ability to cope with the disease (77).

The research outlined above demonstrates that significant stigmatization exists in many forms and from many sources, which fosters feelings of isolation within individuals and decreases their willingness to engage with society, especially in health care settings. A critical component to eliminating stigma and increasing access to health care is the identification of the sources and experience of stigma in the target population.

2.9.6 Facilitators

Although much of the current literature describes barriers to accessing hepatitis C treatment, some studies highlight important facilitating factors which improve access to and uptake of HCV treatment.

A qualitative study conducted in 2010 highlighted four facilitating factors, including previous experience with illness management, strong patient-provider relationships, gaining sober time and facing treatment ‘head-on’ (78). Participants from another qualitative study suggested that getting information from health care professionals altered their misconceptions about treatment and eased their fears. They also said that seeing peers go through treatment successfully encouraged them to seek treatment, and coping strategies such as positive thinking and personal determination helped them accept treatment. Social and practical supports were also important in making the decision to access treatment (79). Another study found that participants in a substance use program considered HCV treatment when they perceived clinicians as knowledgeable and genuinely caring about their well-being (80).

2.10 Summary of Literature

The prevalence of hepatitis C is increasing in Canada, especially among injection drug users who are at an elevated risk of contracting the disease due to the nature of the disease and its modes of transmission. Treatment of hepatitis C involves medications that are highly toxic and are associated with a wide range of side effects, most of which have negative impacts on leading productive lives for the duration of treatment. Populations of individuals infected with hepatitis C often experience many barriers to accessing various types of care and support, especially treatment for hepatitis C. Barriers to accessing treatment range from not experiencing chronic hepatitis C symptoms to assumptions that patients will not be adherent to medication to society's acceptance of stigmatization of the behaviours associated with hepatitis C. The multifaceted layers of barriers coupled with the experience of injection drug use and methadone maintenance treatment make accessing hepatitis C treatment difficult.

There are a considerable number of studies on the barriers to accessing hepatitis C treatment in an effort to treat more people and decrease the burden of disease. To date, much of this research has focused on either knowledge or stigma as the two main barriers to treatment. Much of the research assumes that an increase in knowledge (of the disease itself and of treatment) will increase an individual's willingness to access treatment. These studies often test participant's knowledge, conclude that the lack of knowledge is directly correlated to their lack of interest in treatment, and suggest education programs to increase interest in treatment. On the other hand, research which looks at stigma as a barrier often looks at how stigma isolates people or makes people reluctant to access health care for fear of being treated poorly.

The current study is unique insofar as it explores the barriers among a population who are currently accessing methadone and have thus also presumably begun to make other changes in their lives, and who also have considerable resources for information through MMT clinic staff. Many of the barriers identified in the literature (i.e. accessing addiction treatment, not having access to primary health care) are not present in this population, yet uptake of treatment remains low. This allows us to take a more direct approach to identifying the barriers to treatment, focusing on barriers to HCV treatment itself rather than to accessing health care in general. In addition, this research explores the two main barriers (knowledge and stigma) to treatment as overlapping and dynamic, rather than separate. To our knowledge, there has been little research which explores how knowledge and stigma influence each other and the overarching effect of this relationship.

Chapter 3: Method

3.1 Objectives

The primary objective of this research study was to identify barriers to accessing hepatitis C treatment for people who have experience with injection drug use and who are currently seeking methadone maintenance treatment (MMT). The specific research questions were:

(1) How do individuals who are willing to initiate HCV treatment differ from those who are not willing to initiate HCV treatment?

(2) What is the association between knowledge around transmission, progression and treatment of hepatitis C and willingness to initiate hepatitis C treatment?

(3) How do attitudes around hepatitis C treatment differ between individuals who are willing to initiate treatment and those who are not willing to initiate treatment?

(4) Among individuals who are not willing to initiate HCV treatment, what are the social and contextual factors that have impacted their decisions around hepatitis C treatment?

3.2 Study Design

It was determined that the best way to answer the research questions was through a mixed method design. Therefore, this study involves two components, a cross-sectional survey and a qualitative interview.

3.3 Sample

Clients from a low threshold methadone maintenance treatment program, Direction 180, were approached to be participants in this study. The clinic is located in downtown Halifax, Nova Scotia and serves individuals who have experience with opiate drug use, most of whom attend the clinic daily for witnessed methadone consumption. The clinic targets individuals with a history of injecting drugs, as they are at a greater risk of HIV, hepatitis C and overdose than individuals without a history of injecting. One hundred and sixty clients access methadone from this clinic, with approximately half infected with hepatitis C. Approximately 70 clients who were known to be hepatitis C positive were approached to participate in the researcher-administered survey; a total of 60 consented and participated in the questionnaire. Twelve clients were identified by clinic staff as meeting the inclusion criteria for the qualitative component. These were individuals who were HCV positive, had been accessing MMT for at least 12 months, and had expressed to staff that they were not interested in HCV treatment. The research team was able to contact and enrol ten individuals for an interview.

3.4 Survey

The survey addressed the first three objectives, focusing on quantifiable barriers to treatment. It began with several questions on social and demographic characteristics, and moved into the focus of the research project by assessing the participant's willingness to initiate treatment, knowledge around hepatitis C and opinions and attitudes around treatment. The survey consisted of four sections:

1. Background Characteristics: This section included socio-demographic information, smoking history, alcohol history, education, employment, housing, relationships, incarceration, drug use, health history, and methadone maintenance treatment history
2. Willingness to initiate treatment: This section asked respondents to assess how willing they would be to initiate hepatitis C treatment, based on a 5-point Likert scale, under various scenarios or conditions.
3. Knowledge of hepatitis C transmission, progression and treatment: This section tested participant's knowledge of the disease and its treatment. Statements asked participants to answer 'true/false/don't know' related either to transmission, progression or treatment.
4. Attitudes around about hepatitis C treatment: This section assessed participant's opinions and attitudes related to hepatitis C treatment with questions about treatment posed on a 5-point Likert scale.

Please see attached Appendix 1: Survey.

3.5 Survey Development

The survey is unique to the proposed research study, developed through collaboration with the target population, service providers and the thesis committee. The survey was developed based on review of the literature, key informant focus groups and interviews, and review of relevant, existing validated surveys. The survey was pre-tested and reviewed by Direction 180 clients and staff, and the research team.

The background characteristics section was based on conversations with key informants around the type of information of interest and the types of questions to be asked. Many other questions were adapted from validated surveys including: the Canadian Community Health Survey (81); Canada's Alcohol & Other Drug Use Survey (82); the I-Track Questionnaire (83); and the National Population Health Survey (84). Some questions were unique to this research study.

The true/false statements for the knowledge section of the survey were developed using both information covered in previous research studies (10, 12, 63), and through consultation with Direction 180 staff and clients. The statements used were deemed relevant and important for this population by staff, clients and the research team.

The attitudes around treatment section was also developed with input from Direction 180 staff and clients; discussions with clients provided insight into important personal barriers to treatment, while Direction 180 staff provided information on reasons why previous or current clients are not willing to initiate HCV treatment. Statements were presented and participants were asked to respond. Statements assessed participant attitudes towards length of treatment, treatment side effects, efficacy of treatment, the effect on work, school or family life and the effect on physical and mental health. Participants were also asked about their overall confidence in completing treatment successfully. For example, one item was "Treatment involves too much time commitment", while another was "Treatment would affect my physical health too much".

Assessment of intention to initiate treatment was informed by a review of previous research studies (55). Because of the gap between those interested in treatment and those who actually initiate treatment, this section was developed in such a way that it would capture those individuals who would be willing to initiate treatment within six months.

Upon development of the survey, it was pre-tested. First, a group of care providers met to review the questionnaire in detail. This group included the Executive Director of Direction 180, one nurse and one physician who work at Direction 180. Discussions focused on the structure and content of questions and response options. Based on feedback, the questionnaire was revised and further pre-testing was completed with five clients who were hepatitis C negative but at high risk for infection. The questionnaire was administered individually to each of the five clients, with a discussion following each administration. Feedback from clients included rewording questions for clarity, adding additional questions, and modification of responses. Pre-testing with clients was particularly helpful as, during the administration of the questionnaire, it became evident which questions needed more detail. Overall, clients felt comfortable answering all of the questions, understood what was being asked of them and felt that the questionnaire captured the issues important to them.

3.6 Survey Recruitment and Administration

All survey participants were contacted through Direction 180 clinic staff. Any client who was accessing methadone from Direction 180 and known to be hepatitis C positive was eligible to participate in the survey. Potential participants were initially approached by their nurse or case worker through a regularly scheduled appointment, where the staff introduced the research study. Upon agreeing to discuss the project further, the staff either directed the client to the interviewer immediately or set up an appointment for the client to meet with the interviewer on another day. All participants were engaged in a discussion around informed consent and provided informed consent.

All surveys were conducted at Direction 180 in a private office and were conducted one-on-one with each participant. All survey participants were provided with $10 honorarium.

3.7 Coding Quantitative Data

To describe knowledge levels, each participant’s true and false knowledge responses were re-categorized into “correct” (for correct responses) and “incorrect” (for incorrect or unsure answers). For each knowledge section, a score of 1 was defined as having more (or the same number of) correct responses than the median number of correct responses for all participants, while a score of 0 was defined as having less correct responses than the median number of correct responses for all participants. Each participant was given an overall score of 0 or 1 based on their responses for each of the transmission, progression and knowledge sections. An overall score of 1 was defined as having a score of 1 for at least two of the three categories of knowledge, while an overall score of 0 was defined as having a score of 0 for at least two of the three categories of knowledge. This scoring system was based on a system suggested by Doab and colleagues (2005), addressing knowledge and attitudes about treatment for hepatitis C; these researchers dichotomized knowledge around a median combined score and gave each participant a score of 'good' or 'poor' knowledge (57). Our scoring differed in that we assign '0' or '1' to each knowledge section, and also assigned an overall knowledge score.

Attitudes and opinions were collected on a 5-point Likert Scale; the scale was collapsed to a 3-point scale for analysis: "agree" (strongly agree or agree), "neutral" (neither agree nor disagree) and "disagree" (disagree or strongly disagree). The attitude and opinion section was not treated as a scale but as individual items.

To describe a participant's intention to initiate treatment, each participant was categorized as either "willing" or "other". For each participant, their *overall intention* to initiate treatment (from the first question in this section) was reported. Participants were then given a *conditional overall intention* score of either "willing" or "other". Participants who reported being "very willing" or "probably willing" to initiate treatment for all four questions will be categorized as being 'willing' to initiate treatment. Participants with any response less than 'probably willing' were categorized as "other". The method of providing conditions of treatment to assess willingness has been used in previous studies (11, 55) although this particular method of scoring responses has not, to my knowledge, been conducted previously.

3.8 Quantitative Analysis

The dataset was stratified on willingness to initiate treatment, with participants falling into one of two categories, ‘willing’ or ‘other”, as described earlier.

Descriptive analysis was conducted to describe the background characteristics of the sample. Categorical data is expressed in frequencies and percentages; continuous data is expressed in means and standard deviations.

To test for differences between ‘willing’ and ‘not willing’, the Chi-Square test was used to test for differences in proportions for categorical variables (i.e. age). Fisher’s Exact test was used when cell count was below 5. The t-test was used to test for differences in means for continuous variables. A p-value of <0.05 was considered significant, while a p-value between 0.05 and 0.1 was considered borderline significant, or approaching significance.

A multivariate analysis using logistic regression was conducted to test the association between variables and willingness to initiate HCV treatment. Variables were considered for inclusion in the multivariate analysis if they had a p-value of less than 0.05 or were deemed as relevant a priori.

3.9 Qualitative Interviews

Qualitative interviews with ten clients who were not willing to initiate HCV treatment were used to address the fourth objective, exploring how the lived experience of hepatitis C has shaped participants’ decisions about HCV treatment. Each interview began with the probe: ‘Tell me a little bit about what it’s been like living with hepatitis C’. Following this initial probe, the interview was guided through four themes: (1) life with hepatitis C, (2) relationships with family and friends, (3) experiences with services, and (4) self perceptions. For each theme, there were several probes.

Please see attached Appendix 2: Interview Guide.

3.10 Interview Development

The interview guide was modeled on reviewed literature, particularly qualitative studies looking at lived experiences of individuals living with hepatitis C, and through consultation with the research team.

Prior to initiating interviews, the interview guide was piloted with a group of three individuals who were hepatitis C positive. This pilot group discussed the four themes in general and then discussed the probing questions in detail. Participants were asked to think about the questions and comment on their clarity, whether or not they were relevant and whether or not they found any question(s) to be inappropriate. Upon feedback from this group, the questions were modified slightly.

3.11 Interview Recruitment and Administration

Interview participants were purposely selected. Through consultation with Direction 180 staff, ten clients were identified who met the selection criteria. Selection criteria included: must have sought methadone maintenance from Direction 180 for at least 12 months (so that they are well known to the staff), have a history of injecting opioids (as per the objectives of the study), have expressed little interest in hepatitis C treatment (to examine factors that influence this decision) and be deemed psychologically and emotionally stable at the time of the interview. Twelve individuals were identified by staff, and ten of those individuals were contacted and enrolled.

Each interview was led by myself and was audio-recorded. Each interview participant received $20.

3.12 Qualitative Analysis

Upon completion of the qualitative interviews, they were transcribed and analyzed.

A constant comparative analysis was used to analyze the transcripts. Constant comparative analysis is a method of qualitative analysis drawn from Grounded Theory in which information is coded into emerging themes. An inductive approach was taken to data analysis, in which themes developed from the data rather than from preconceived ideas or theories. In constant comparative analysis, data is constantly revisited during analysis, with each piece of information (i.e. interview) being compared to every other piece of information (i.e. interview) (85).

The first step in the analysis was open coding, where a code was attributed to phrases, paragraphs or sections of the interviews. The codes represented an idea or theme. The codes were written as comments on each transcript in a word processing software program. The codes were categorized into overarching themes, and each theme was given a name.

The interviews were conducted, transcribed and analyzed in pairs of two. The first two interviews were analyzed before the second two were conducted, which in turn were analyzed before the next two were conducted, and so on. This process allowed consideration of the themes which evolved from previous interviews to be considered in subsequent interviews. Upon completion of all interviews, the initial transcripts were reviewed again, with consideration of all themes.

After all transcripts were coded, a separate document was created for each of the themes identified. Parts of the transcripts assigned to each theme were inserted into the appropriate document, so that each theme had a full selection of codes relating to it. For each theme, a one page summary was written, which described all of the different issues that were raised under the theme; there was no collapsing or generalization of codes at this stage. Once the ‘one pager’ was complete, axial coding began. Axial coding involved thinking about how the issues under one theme related and connected to each other. Each theme was given a name, and a narrative was written to describe the theme in relation to the interviews. Quotes were chosen which represented the theme; quotes were stripped of any identifying information.

3.13 Confidentiality and Privacy

All questionnaires and interview transcripts were stripped of any identifying information. Names of participants were not linked to their questionnaire. Transcripts were stripped of identifying information and the audio tape was destroyed. Quotes used in the final report were stripped of any identifying information and used in an un-identifying context to ensure confidentiality.

Chapter 4: Quantitative Results

This chapter will describe the results of the survey and analysis of the data. The variables were grouped into categories (i.e. alcohol and drug history, employment and housing) and are presented in this way. Each section begins with a general description of the population and then discusses any differences between those who were willing to initiate treatment and those who were not.

4.2 Objective # 1

A total of 60 individuals participated in the cross sectional survey. Overall, 37 participants indicated that they were not willing to initiate HCV treatment within the next six months. Twenty-three participants expressed that they would be willing to initiate treatment within six months.

4.2.1 Demographic Characteristics

As presented in Table 1, the average age of participants was 42 years; 39 (65%) participants were male. Almost half (45%) of participants were single or never married, and the majority had completed at least some high school education. As seen in Table 1, there were no differences in age, gender, education or marital status between those who were willing to initiate HCV treatment and those who were unwilling to initiate HCV treatment.

Table 1: Basic Demographic Characteristics among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
Age, mean (SD), year	42 (10.3)	44 (10.8)	41 (10.2)	0.3238
Gender, n (%)				0.6382
Male	40 (66.7)	17 (73.9)	23 (59.4)	-
Female	20 (33.3)	6 (26.1)	14 (37.8)	-
White / Caucasian, n (%)	51 (86.4)	20 (87.0)	30 (85.7)	0.8115
Highest level of school completed, n (%)				0.9863
Did not complete High School	24 (40.0)	10 (43.5)	14 (37.8)	-
High School / GED	18 (30.0)	7 (30.4)	11 (29.7)	-
Some Post-High School	18 (30.0)	6 (26.1)	12 (32.4)	-
Marital Status, n (%)				0.2114
Single / Never Married	27 (45.0)	14 (60.8)	13 (35.1)	-
Common Law / Married	16 (26.7)	5 (21.7)	11 (29.7)	-
Separated / Divorced / Widowed	17 (28.3)	4 (17.4)	13 (25.1)	-

** p-value < 0.10; **p-value <0.05*

4.2.2 Alcohol, Tobacco and Drug Use

Overall, as presented in Table 2, all participants indicated that they had smoked at least 100 cigarettes in their lifetime, with the mean age at first cigarette of just under 12 years. Close to 90% of participants were daily smokers, with an average of 9 cigarettes smoked per day. Ninety percent of participants indicated that they had had a drink of alcohol in their lifetime. On average, participants had tried or used 7 of the drugs listed on the survey (which included cannabis, magic mushrooms, ecstasy, LSD, cocaine powder, crack, amphetamine, crystal methamphetamine, ketamine, and heroin). Participants indicated that they had first tried illicit drugs as early as 13 years of age. The majority of participants had tried or used cannabis, magic mushrooms, ecstasy, speed, cocaine, crack, acid and/or heroin. The average age at which participants first tried or used each drug were under 30 years, with the youngest being the mean age of onset for cannabis (12.8 years), and the oldest being the mean age of onset for crystal methamphetamine (28.1 years).

Both groups of individuals had their first cigarette between the ages of 11 and 12, as can be seen in Table 2, and both groups smoked their first cigarette at the same age. Those individuals who were not willing to initiate HCV treatment smoked, on average, five cigarettes less per day than those who were willing to initiate HCV treatment. Similar percentages of individuals in both groups were current daily smokers and had had a drink of alcohol in their lifetimes.

Moreover, equal proportions of individuals from both groups had tried / used cannabis, magic mushrooms, ecstasy, LSD, cocaine, crack, amphetamines, crystal meth, ketamine and / or heroin. Both groups tried / used illicit drugs at the same age. Those unwilling to initiate HCV treatment tried cannabis for the first time roughly two years younger than those who were willing to initiate HCV treatment. For all of the other drugs, both groups of individuals tried or used each at approximately the same age.

Table 2: Cigarette, Alcohol & Drug Use among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
Smoked a total of 100 cigarettes or more, n (%)	60 (100)	23 (100)	37 (100)	1.0000
Age at first cigarette, mean (SD), year	11.7 (4.6)	12 (4.3)	11 (4.9)	0.8059
Current Daily smokers, n (%)	53 (89.8)	19 (82.6)	32 (94.1)	0.4054
Daily cigarettes, mean (SD), number	16.69 (9.0)	19.6 (10.0)	14.6 (7.1)	0.0368**
Number of drugs ever used or tried, mean (SD), number	6.8 (2.4)	6.8 (2.5)	6.9 (2.2)	0.8735
Age at first illicit drug use, mean (SD), year	12.7 (3.3)	13.6 (4.3)	12.2 (2.2)	0.1297
Has had a drink in lifetime, n (%)	54 (90.0)	21 (91.2)	31 (88.6)	1.0000
Illicit drug use (ever used or tried), n (%)				
Cannabis	57 (96.6)	23 (100)	32 (94.1)	0.5100
Magic Mushrooms	43 (72.9)	15 (65.2)	28 (49.1)	0.1404
Ecstasy	36 (61.0)	14 (60.9)	21 (61.8)	0.9457
LSD (acid)	48 (81.4)	18 (78.3)	29 (85.3)	0.5036
Cocaine (powder)	55 (93.2)	21 (91.3)	33 (97.1)	0.5590
Crack (rock)	55 (93.2)	22 (95.6)	32 (94.1)	1.0000
Amphetamine	30 (50.8)	8 (34.8)	19 (55.9)	0.1767
Crystal meth	23 (39.0)	12 (52.2)	22 (64.7)	0.3441
Ketamine	14 (23.7)	3 (13.0)	11 (32.4)	0.1244
Heroin	38 (64.4)	17 (73.9)	21 (61.8)	0.3398
Age at first Illicit drug use, mean (SD), year				
Cannabis	12.8 (3.6)	14.2 (4.3)	12.3 (2.4)	0.0390**
Magic Mushrooms	16.2 (4.1)	16.8 (2.6)	16.8 (2.6)	0.7876
Ecstasy	25.5 (10.2)	28.2 (10.2)	25.0 (8.7)	0.3438
LSD (acid)	15.6 (3.2)	15.2 (3.0)	16.1 (3.2)	0.3680
Cocaine (powder)	19.5 (7.0)	19.4 (7.4)	20.1 (6.1)	0.7170
Crack (rock)	23.9 (9.4)	23.3 (8.8)	25.0 (9.1)	0.5078
Amphetamine	17.0 (5.9)	15.5 (4.1)	19.2 (5.4)	0.0522
Crystal meth	28.1 (10.0)	27.4 (3.6)	29.6 (9.1)	0.6201
Ketamine	24.2 (10.0)	24.7 (7.1)	33.5 (4.9)	0.1306
Heroin	22.20 (9.9)	21.9 (9.1)	23.6 (9.5)	0.6015

** p-value < 0.10; **p-value <0.05*

4.2.3 Employment, Housing and Incarceration

Overall, as demonstrated in Table 3, just fewer than 30% of participants were employed at the time of the survey and over 70% were unstably housed. In the past five years, participants indicated that they had moved over 13 times. Over 85% of participants had spent time in provincial or federal prison and, of those individuals, just fewer than 60% had spent over one year incarcerated. There were no differences seen between the two groups, with the exception that those who were willing to initiate treatment were more likely to have spent more than one year incarcerated than those not willing to initiate treatment (p=0.02). The difference in employment status approached significance (p=0.07) with those willing to initiate treatment more likely to be employed.

Table 3: Employment, Housing & Incarceration among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
Currently Employed, n (%)	17 (28.3)	3 (13.0)	13 (37.1)	0.0707*
Housing Unstable, n (%)	43 (71.7)	14 (60.9)	29 (78.4)	0.1703
Mean times moved in past 5 years, mean (SD), number	5.57 (13.2)	2.5 (2.0)	4.7 (16.8)	0.1487
Spent time in prison, n (%)	51 (86.4)	19 (82.6)	33 (89.2)	0.4110
Spent more than a year in prison, n (%)	35 (58.3)	16 (84.4)	19 (57.6)	0.0288**

** p-value < 0.10; **p-value <0.05*

4.2.4 Injection Drug Use

The vast majority of participants indicated that they had used injection drugs in the past, as seen in Table 4. The average age at first injection drug use was 22 years. Over 85% of participants had spent more than one year injecting drugs. The majority of participants had not injected in over 12 months, though 15% had injected in the past 30 days and 25% had injected within the past 12 months. Over 50% indicated that they had shared needles in the past, and over 70% indicated that they had shared other drug paraphernalia in the past. There were no statistically significant differences in these injection drug use behaviours between those willing and unwilling to initiate treatment.

Table 4: Injection Drug Use among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
History of Injection Drug Use, n (%)	59 (98.3)	23 (100)	34 (94.6)	1.0000
Age at first injection drug use, mean (SD), years	22.48 (8.8)	21.65 (2.0)	23.39 (1.5)	0.4762
Spent more than 1 year injecting drugs, n (%)	50 (86.2)	20 (87.0)	30 (85.7)	1.0000
Most recent injection drug use, n (%)				0.5133
Injected in past 30 days	9 (15.0)	3 (13.0)	6 (16.2)	-
Injected in past 12 months	15 (25.0)	4 (17.4)	11 (29.7)	-
Injected over 12 months ago	36 (60.0)	16 (27.6)	20 (54.0)	-
Ever Shared Needles, n (%)	32 (53.3)	13 (56.5)	17 (50.0)	0.8718
Ever Shared other drug paraphernalia, n (%)	43 (73.3)	18 (78.3)	25 (58.1)	0.8563

** p-value < 0.10; **p-value <0.05*

4.2.5 Physical and Mental Health

As demonstrated in Table 5, participants self-reported on their physical and mental health. Eight percent of participants rated their physical health as excellent or very good, while 30 percent rated it as good, and over 60% rated their physical health as fair or poor. Participants rated their mental health as better, with over 25% rating it as excellent or very good, 33% rated it as good and 40% reported it as fair or poor. Just under 40% of participants recalled having been diagnosed with a physical health ailment, while just over 60% recalled a mental health diagnosis.

Table 5: Physical & Mental Health among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-Value
Physical Health (self rated), n (%)				0.7799
Excellent / Very Good	5 (8.3)	3 (13.0)	2 (5.4)	-
Good	18 (30.0)	7 (30.4)	11 (37.0)	-
Fair / Poor	37 (61.7)	13 (56.5)	24 (62.2)	-
Mental Health (self rated), n (%)				0.5889
Excellent / Very Good	16 (26.7)	4 (17.4)	12 (32.4)	-
Good	20 (33.3)	8 (34.8)	12 (32.4)	-
Fair / Poor	24 (40.0)	11 (47.8)	13 (35.1)	-
Physical Health Diagnosis, n (%)	22 (37.9)	7 (30.4)	15 (42.9)	0.3290
Mental Health Diagnosis, n (%)	36 (62.1)	12 (52.2)	24 (68.6)	0.2636

** p-value < 0.10; **p-value <0.05*

4.2.6 Hepatitis C

Overall, participants had been living with hepatitis C for just over eight years, as seen in Table 6. The majority of participants indicated that they had been infected through injecting drugs or sharing needles, while 12% were infected through other drug use, 13% did not know the source of their infection and 15% had been infected through another method (i.e. transfusions, tattooing). The majority of participants reported that their most recent HCV test occurred at Direction 180, while for 20% it had been in prison, 17% in a hospital or clinic, and 13% were unsure of where their most recent test was. Seventy percent of participants had discussed HCV treatment with a health care professional. Individuals who were willing to initiate treatment had been diagnosed with HCV for longer period of time than those who were not willing to initiate treatment, although this relationship did not reach statistical significance (p=0.06). There were no differences between the two groups in terms of HCV infection mode, location of most recent HCV test or whether or not they had been approached about HCV treatment in the past.

Table 6: Hepatitis C among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
Length of HCV infection, mean (SD), years	8.3 (6.71)	10.4 (7.7)	7.0 (5.6)	0.0558*
HCV infection mode, n (%)				0.9436
Injecting drugs / sharing needles	36 (60.0)	14 (60.9)	22 (59.4)	-
Other Drug Use	7 (11.7)	3 (13.0)	4 (10.8)	-
Other	9(15.0)	3 (13.0)	6 (16.2)	-
Don't Know	8 (13.3)	3 (13.0)	5 (13.5)	-
Most Recent HCV test location, n (%)				0.4496
Direction 180	35 (58.3)	16 (69.6)	19 (51.4)	-
Hospital / Physician / Clinic	10 (16.7)	2 (8.6)	8 (32.6)	-
Prison	12 (20.0)	5 (21.7)	7 (18.9)	-
Other	3 (5.0)	0 (0)	3 (8.1)	-
Has been asked about HCV treatment, n (%)	42 (70.0)	18 (78.3)	24 (64.9)	0.5805

** p-value < 0.10; **p-value <0.05*

4.2.7 Methadone Maintenance Treatment

On average, participants had been accessing methadone for approximately six years, and had started on methadone twice. In terms of length of MMT, those who were willing to initiate treatment were more likely to have been accessing methadone for longer (7.1 years) than those not interested in treatment (4.7 years) (p=0.0397).

Table 7: Methadone Maintenance Treatment among participants who were and were not willing to initiate HCV treatment

Characteristic	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
Length of MMT, mean (SD), years	5.9(4.4)	7.1 (5.2)	4.7 (3.5)	0.0397**
Number of times on MMT, mean (SD), times	1.7 (1.4)	1.4 (0.7)	1.9 (1.8)	0.2563

** p-value < 0.10; **p-value <0.05*

4.3 Objective # 2

The second objective looked at the association between knowledge (of hepatitis C and its treatment) and willingness to initiate treatment. Three categories of knowledge were explored; transmission, progression and treatment of HCV.

4.3.1 Trends in Transmission Knowledge

Table 8 presents results comparing transmission knowledge by intention to initiate HCV treatment. Overall, there were moderate levels of knowledge around transmission of hepatitis C. Over 90% of participants knew that HCV was spread through blood to blood contact, that HIV infection does not make a person immune to HCV and that injection drug use was one of the main ways to contract HCV. Over half of participants knew that a person can have more than one HCV genotype, a mother or father does not pass HCV to their child, unprotected sex does not always lead to infection, even if there is no blood HCV can still be present, smoking crack can lead to infection and that there is no vaccination against HCV. Less than 40% knew that HCV was not spread through breast milk.

It appears that individuals who were willing to initiate treatment had higher levels of knowledge about the virus itself (i.e. blood-to-blood transmission, main route of infection, genotypes) than those who were unwilling to initiate treatment. Individuals who were unwilling to initiate treatment tended to know more about the sexual / reproductive transmission of hepatitis C than those willing to initiate treatment.

Table 8: Transmission Knowledge among participants who were and were not willing to initiate HCV treatment

Statement n (%), number of participants who responded correctly	Overall (n = 60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)
The hepatitis C virus is spread through blood to blood contact (True)	55 (92.0)	22 (95.6)	33 (89.2)
Only those with HIV can get hepatitis C (False)	56 (93.3)	22 (95.6)	34 (91.9)
Injection drug use is one of the main ways to get hepatitis C (True)	54 (90.0)	23 (100)	31 (83.8)
A person can have more than one kind of hepatitis C (True)	41 (68.3)	17 (73.9)	24 (64.9)
A mother will always pass hepatitis C on to her unborn child (False)	31 (51.7)	11 (47.3)	20 (54.0)
A father will always pass hepatitis C on to his unborn child (False)	43 (70.0)	15 (65.2)	28 (75.6)
A mother with hepatitis C should never breastfeed (False)	22 (36.7)	9 (39.1)	13 (35.1)
Unprotected sex between a man and a woman always spreads hepatitis C (False)	44 (73.3)	15 (65.2)	29 (78.4)
Even if you don't see blood, hepatitis C can still be present (True)	45 (75.0)	18 (78.3)	27 (73.0)
Smoking crack can lead to hepatitis C infection (True)	35 (58.3)	13 (56.5)	22 (59.4)
People can be vaccinated against hepatitis C (False)	32 (53.3)	12 (52.2)	20 (54.0)

4.3.2 Trends in Progression Knowledge

Table 9 presents knowledge about HCV progression by willingness to initiate HCV treatment. Overall, there was a high knowledge for 6 of the 8 questions on progression. All participants knew that chronic infection leads to liver damage. Over 80% of participants knew that infection can lead to liver cancer, HCV progresses differently in each person, age affects progression, drinking affects progression and that a healthy lifestyle slows progression. Only five individuals knew that HCV infections progress faster in men than women, and only 45% knew that HIV infection speeds up progression.

Over 90% of individuals who were willing to initiate treatment knew that HCV can lead to liver cancer, while only 70% of those who were unwilling to initiate treatment knew this. There were large discrepancies in knowledge in terms of co-infection with HIV, the effect of age on progression, and that HCV progresses differently in everyone, with those not willing to initiate HCV treatment tending to know more.

Table 9: Knowledge of HCV Progression among participants who were and were not willing to initiate HCV treatment

Statement n (%), number of participants who responded correctly	Overall (n = 60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)
Long term hepatitis C infections cause liver damage (True)	60 (100)	23 (100)	36 (100)
Infection with hepatitis C can lead to liver cancer (True)	48 (80.0)	21 (91)	26 (72)
Hepatitis C follows the same path in everyone (False)	51 (85.0)	17 (74)	33 (92)
Hepatitis C infections progress faster in men than women (True)	5 (8.3)	2 (7)	3 (8)
Age does not affect the progress of hepatitis C (False)	25 (82)	8 (35)	17 (47)
Drinking does not affect the progress of hepatitis C (False)	49 (82)	19 (83)	29 (81)
Being infected with HIV speeds up liver damage from hepatitis C (True)	27 (45)	8 (35)	19 (52)
Eating healthy and maintaining a healthy weight is important for slowing progression (True)	55 (92)	20 (87)	34 (94)

4.3.3 Trends in Treatment Knowledge

Table 10 presents treatment knowledge by willingness to initiate HCV treatment. There were moderate levels of knowledge for most items. Over 80% of participants knew that individuals can be re-infected with hepatitis C after treatment, that treatment lasts between six and 12 months, that medication adherence affects sustained viral response, and the side effects of treatment. Only 72% knew that treatment was not guaranteed to cure HCV, while just over 75% knew that treatment existed and that treatment involves a weekly needle and daily pills. Less than 70% knew that treatment does not work the same for all genotypes and only 32% were aware that treatment may cause birth defects in children.

In terms of knowledge around the treatment of HCV (table 10), individuals willing to initiate treatment knew more about the details of the treatment protocol (i.e. medications, length of treatment) than those unwilling to initiate treatment. On the other hand, individuals who were unwilling to initiate treatment tended to know more about some of the negative aspects of treatment (i.e. that treatment does not work the same for all genotypes, or that missing medications matters in successfully clearing the virus).

Table 10: Knowledge of HCV Treatment among participants who were and were not willing to initiate HCV treatment

Statement n (%), number of participants who responded correctly	Overall (n = 60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)
Once a person gets rid of hepatitis C, then can never get it again (False)	51 (85)	20 (87)	30 (83)
There is no guaranteed cure for hepatitis C (True)	43 (72)	18 (78)	24 (68)
There are medications that can get rid of the virus for some people (True)	45 (75)	18 (78)	26 (72)
Treatment involves a weekly needle and daily pills (True)	47 (78)	20 (87)	26 (72)
Treatment lasts between 6 and 12 months, maybe longer (True)	51 (85)	20 (87)	30 (83)
Treatment works the same for all genotypes (False)	41 (68)	14 (61)	27 (75)
Missing several days of medication doesn't matter (False)	49 (82)	17 (74)	31 (86)
There are no side effects of treatment (False)	52 (87)	18 (78)	33 (92)
Hepatitis C medications in men or women do not cause birth defects in their children (False)	19 (32)	10 (43)	9 (25)

4.3.4 Univariate Associations between Knowledge and Willingness

Four associations were tested; (1) transmission knowledge and willingness to initiate treatment; (2) progression knowledge and willingness to initiate treatment; (3) treatment knowledge and willingness to initiate treatment; (4) overall knowledge and willingness to initiate treatment.

As mentioned previously, the knowledge items were categorized as relating to transmission, progression or treatment of HCV. For each knowledge scale, a test of reliability was conducted using Cronbach's Alpha to assess whether these items hang together as knowledge scales. Table 11 presents the alpha's for each of the knowledge scales and the overall knowledge scale, and the interpretation of the alpha. Results indicate that the transmission, treatment, and overall knowledge sections each constitute a scale and can be analyzed by looking at total scores. The items relating to progression, however, do not constitute a scale, are not measuring the same thing and therefore were analyzed as separate items.

Table 11: Cronbach's Alpha for transmission, progression, treatment and overall knowledge scales

Knowledge Scale	**Number of Items**	**Cronbach's Alpha**	**Interpretation**
Transmission	11	0.63	Fair
Progression	8	0.47	Poor
Treatment	9	0.65	Fair
Overall	28	0.78	Good

Table 12 presents the number and percentage of participants who had 'good' knowledge for each of the three knowledge scales (transmission, treatment and overall). 'Good' knowledge was assigned when a participant had the same or more correct responses in a category as the median number of correct responses for the group. The table provides information for the overall sample and stratified on willingness to initiate treatment. Table 12 also provides the p-value for the association between each type of knowledge and willingness to initiate HCV treatment. The results indicate no association between any of the knowledge scales and willingness to initiate HCV treatment.

Table 12: Association between knowledge and willingness to initiate HCV treatment among participants who were and were not willing to initiate HCV treatment

Type of Knowledge	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-value
Transmission, n (%)	37 (63.8)	15 (65.2)	22 (62.9)	0.8548
Treatment, n (%)	39 (67.2)	15 (62.2)	24 (68.6)	0.7901
Overall Knowledge, n (%)	48 (82.8)	18 (78.3)	30 (85.7)	0.4963

Table 13 presents knowledge items which relate to progression of HCV. Results indicate that there is no association between knowledge of any of the items with willingness to initiate HCV treatment except for one item. Individuals who were not willing to initiate

HCV treatment were more likely to know that hepatitis C progresses differently in different individuals (p=0.01).

Table 13: Association between progression knowledge items and willingness to initiate HCV treatment

Statement n (%), number of participants who responded correctly	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)	P-Value
Long term hepatitis C infections cause liver damage	23 (100)	36 (100)	1.000
Infection with hepatitis C can lead to liver cancer	21 (91)	26 (72)	0.3293
Hepatitis C follows the same path in everyone	17 (74)	33 (92)	0.0134*
Hepatitis C infections progress faster in men than women	2 (7)	3 (8)	0.9868
Age does not affect the progress of hepatitis C	8 (35)	17 (47)	0.3613
Drinking does not affect the progress of hepatitis C	19 (83)	29 (81)	0.7034
Being infected with HIV speeds up liver damage from hepatitis C	8 (35)	19 (52)	0.0607
Eating healthy and maintaining a healthy weight is important for slowing progression	20 (87)	34 (94)	0.0607

4.3.5 Multivariate analysis

A logistic regression model was developed using the two categorical knowledge scale variables (transmission and treatment), plus two other variables of interest, MMT length and time spent in prison. The knowledge variables included in the multivariate analysis were based on the association of interest; the remaining two variables were included based on the associations noted with willingness to initiate treatment in the crude analysis. The number of variables in the multivariate model was limited primarily due to concerns about sample size and power.

Both categorical knowledge variables (transmission and treatment) were included in the model because the association between willingness and knowledge is a central objective of this research. Because analysis of the progression items suggested that they do not hang together in a knowledge scale, a progression knowledge variable was not included in the model. Only one progression item showed statistical significance but was not included in the model; it was not included because the model was limited in the number of variables it could hold, it was decided that other variables were more relevant than one piece of knowledge.

Multivariate analyses, as presented in Table 14, revealed no associations between transmission or treatment knowledge and willingness to initiate treatment, nor between spending more than one year in jail and willingness. Results did indicate, however, an association between MMT length and willingness to initiate HCV treatment (p=0.05); longer MMT length was associated with increased willingness to initiate HCV treatment.

Table 14: Logistic Model with 4 explanatory variables

Variable	Estimate	Wald X-squared estimate	P-Value
Transmission knowledge (categorical)	0.6740	0.0951	0.0951
Treatment knowledge (categorical)	-0.816	0.0456	0.8309
MMT Length (continuous)	0.1620	3.9540	0.0468
Jail Time (categorical)	-1.7975	3.7333	0.0533

4.4 Objective # 3

Table 15 presents attitudes and opinions of participants by willingness to initiate HCV treatment. Overall, the majority of participants agreed that treatment was effective enough and did not involve too much commitment. They agreed that treatment would affect their physical and mental health too much. An equal proportion of participants agreed and disagreed that side effects of treatment were too harsh. Just over 20% of participants agreed that work or school obligations would interfere with treatment. Personal relationships and dependants did not appear to be a concern, as only 32% agreed that personal relationships would be affected, only 15% agreed that they had too many people depending on them to start treatment and only 12% had children that needed to be taken care of. Only 5% indicated that they did not care about the effects of HCV and just under 70% agreed that they thought they could complete treatment successfully.

Differences between those who were willing to initiate HCV treatment and those who were not were not calculated for this section on attitudes and opinions. This was not done for several reasons. The first is that the research team felt that there was no accurate way of creating an attitude score from the scaled Likert response of each participant. The team also felt that, because of the small sample size and subsequent low cell counts, it would be inefficient to look at the differences between groups for each item.

Twenty-two percent of those not willing to initiate treatment agreed or strongly agreed that treatment was not effective enough, compared to approximately 9% of those willing to initiate treatment. Thirty two percent of those who were not willing to initiate treatment agreed or strongly agreed that treatment involves too much commitment, as compared to 26% among those who were willing to initiate treatment. Participants who were not willing to initiate treatment were generally more worried about treatment affecting their physical and mental health too much, and that the side effects of treatment would be too harsh. They also indicated that they had other people or children relying on them too much as a reason not to take on treatment. In fact, participants who were not willing to initiate treatment agreed or strongly agreed more often to all but one of the statements than those willing to initiate treatment. Just fewer than 80% of participants who were willing to initiate treatment agreed or strongly agreed that they could complete treatment successfully, while only 60% of those not willing to initiate treatment agreed with this statement.

Table 15: Attitudes and Opinions of participants who were willing and not willing to initiate HCV treatment

Statement n (%), number of participants who responded	Overall (n=60)	Willing to initiate treatment for HCV (n = 23)	Not willing to initiate treatment for HCV (n = 37)
Treatment is not effective enough			
Strongly Disagree / Disagree	33 (55.0)	16 (69.6)	17 (53.1)
Neither agree nor disagree	17 (28.3)	5 (21.7)	12 (32.4)
Agree / Strongly Agree	10 (16.7)	2 (8.7)	8 (21.6)
Treatment involves too much commitment			
Strongly Disagree / Disagree	37 (61.7)	16 (69.6)	21 (56.8)
Neither agree nor disagree	5 (8.3)	1 (4.4)	4 (10.8)
Agree / Strongly Agree	18 (30)	6 (26.1)	12 (32.4)
Treatment can affect my physical health too much			
Strongly Disagree / Disagree	17 (28)	7 (30.4)	10 (27.0)
Neither agree nor disagree	8 (13.3)	4 (17.4)	4 (10.8)
Agree / Strongly Agree	35 (58.3)	12 (52.2)	23 (62.2)
Treatment can affect my mental health too much			
Strongly Disagree / Disagree	20 (33.3)	11 (47.8)	9 (24.3)
Neither agree nor disagree	9 (15.0)	3 (13.0)	6 (16.2)
Agree / Strongly Agree	31 (51.7)	9 (39.1)	22 (59.4)
The side effects of treatment are too harsh			
Strongly Disagree / Disagree	24 (40.0)	12 (52.2)	12 (32.4)
Neither agree nor disagree	12 (20.0)	4 (17.4)	8 (21.6)
Agree / Strongly Agree	24 (40.0)	7 (30.4)	17 (46.0)
Treatment will affect my personal relationships too much			
Strongly Disagree / Disagree	29 (48.3)	14 (60.9)	15 (40.5)
Neither agree nor disagree	12 (20)	3 (13.0)	9 (24.3)
Agree / Strongly Agree	19 (31.7)	6 (26.1)	13 (35.1)
It would be too discouraging if treatment did not work			
Strongly Disagree / Disagree	15 (25.0)	8 (34.8)	7 (18.9)
Neither agree nor disagree	11 (18.3)	2 (8.7)	9 (25.8)
Agree / Strongly Agree	33 (55.0)	12 (52.2)	21 (56.8)
I don't care about the effects of hepatitis C			
Strongly Disagree / Disagree	52 (86.7)	20 (86.9)	32 (86.5)
Neither agree nor disagree	6 (10.0)	2 (8.7)	4 (10.8)
Agree / Strongly Agree	3 (5.0)	1 (4.3)	2 (5.4)
I am not ready for treatment because of school obligations			
Strongly Disagree / Disagree	47 (78.3)	19 (82.6)	28 (75.7)
Neither agree nor disagree	9 (15.0)	3 (13.0)	6 (1.6)
Agree / Strongly Agree	3 (5.0)	1 (4.3)	2 (5.4)
I am not ready for treatment because of work obligations			
Strongly Disagree / Disagree	45 (75.0)	18 (78.3)	27 (73.0)
Neither agree nor disagree	11 (18.3)	4 (17.4)	7 (18.9)
Agree / Strongly Agree	4 (6.7)	1 (4.3)	3 (8.1)
I have too many people depending on my right now; I can't be sick			
Strongly Disagree / Disagree	39 (65.0)	18 (78.26)	21 (56.76)
Neither agree nor disagree	12 (20.0)	4 (17.39)	8 (21.62)
Agree / Strongly Agree	9 (15.0)	1 (4.35)	8 (21.62)
I am not ready for treatment because I have children who need me to look after them			
Strongly Disagree / Disagree	44 (73.3)	18 (78.3)	26 (70.3)
Neither agree nor disagree	9 (15.0)	4 (17.4)	5 (13.5)
Agree / Strongly Agree	7 (11.7)	1 (4.3)	6 (16.2)
I am confident that I could complete treatment successfully			
Strongly Disagree / Disagree	10 (16.7)	3 (13.0)	7 (18.9)
Neither agree nor disagree	9 (15.0)	2 (8.7)	7 (18.9)
Agree / Strongly Agree	41 (68.3)	18 (78.3)	23 (62.2)

4.5 Summary of Quantitative Results

Overall, there were very few statistically significant differences between those willing to initiate HCV treatment and those who were not. The few limited differences observed were around the number of cigarettes smoked each day, age at onset of cannabis use, time spent in jail and duration of time on methadone. Some additional relationships approached statistical significance; these relationships were around length of time being diagnosed with HCV and employment status.

There was no clear association between knowledge of HCV transmission and treatment with willingness to initiate treatment. Trends in the data suggest that those who were willing to initiate treatment may be less knowledgeable in terms of progression of the disease and more about treatment protocol, while those who were unwilling to initiate treatment were more knowledgeable in terms of sexual and reproductive transmission and the negative aspects of treatment. These trends were not statistically significant and therefore further study would need to be conducted to make any further conclusions.

Differences in opinions and attitudes towards treatment between the two groups were difficult to assess due to the nature of the questions and low cell count. In general, it appeared as though those who were willing to initiate treatment had more positive views on treatment. Further research would be required to confirm this idea.

Chapter 5: Qualitative Results

A qualitative approach addressed the final objective of this research, namely, to describe the social and contextual factors that have impacted individuals' decisions around hepatitis C treatment. Ten interviews were conducted with clients of Direction 180, five with women and five with men. Approximately half of the participants also self-disclosed that they were co-infected with HIV during the interview.

Five major themes emerged from analysis of the interviews: the personal and emotional impact of HCV; the stigma associated with drugs, sex and poverty; having and getting information; being back on track; and having other priorities.

5.1 The Personal and Emotional impact of HCV

The first theme that emerged was how living with HCV had affected participants' daily lives. Many participants, the women in particular, were emotional as they discussed the practical and personal impact of having hepatitis C. The most predominant sub-theme was the idea that the HCV diagnosis was something that was always on participants' minds or in the back of their minds. It appeared as though the diagnosis shadowed all other aspects of their lives, including other thoughts, activities and interactions. Over time, this created a heavy emotional burden for individuals, which, for some, led to depression or other mental health concerns. It appeared that this preoccupation with HCV stemmed from the fear of people finding out about their diagnosis. One participant described the emotional impact in the following quote:

> *There is not a day that goes by that I don't think about my hep C and how it is going to affect somebody or some people that aren't educated on it and find out about it. (05)*

Other participants described how being diagnosed with HCV did not have an impact on them while in 'active addiction' or while they were using drugs. In their recovery, however, the HCV diagnosis acts as a reminder of their past drug use and a mark of regret and shame. As one participant articulated:

> *In active addiction I didn't care. But now that I am clean, it's always like the monkey on your back. (02)*

Some participants suggested that a period of denial of their diagnosis led to physical health ailments. Many participants saw a link between the emotional impact of their HCV diagnosis and their physical health. One explained that her diagnosis, which occurred in a correctional institution, led to a period of denial that had serious consequences for her health.

> *I hid it for a long time. I went into denial and I suppose that affected me very badly physically. Because I didn't get any treatment. I rebelled I guess, because I didn't want anyone to know. Its stupid looking back at it now, but at the time, I was given no options, no help. I get teary-eyed talking about it. But when you're in that predicament, it's hard. (03)*

Other participants discussed their desire to make positive and healthy changes in recovery; this desire seemed to have developed over time in relation to their ongoing HCV infection. Interestingly, none of these participants talked about treating their hepatitis C; rather, they suggested other, more far-reaching ways in which they wanted to change their lives for the better. For example, participants discussed moving to another city, developing a new, substance-free social network or working towards better understanding themselves. For many participants, it appeared as though they link their HCV diagnosis to regret or aspects of their lives they want to change.

Many participants explained that they wanted treatment but were scared of its negative complications. Some seemed to think about the costs and benefits of this in terms of whether treatment would enable them to "move on", to distance themselves from their pasts. For many participants, the feeling of losing their identity was linked to their hepatitis C diagnosis. Many were more focused on getting back to 'being themselves' than they were about treating their HCV. They linked their HCV with a loss of identity early on, and were now thinking a lot about how to get that back.

> *I am not [name] anymore. I don't know who I am anymore. [Name] is the guy who lives in the woods, and hunting and fishing and taking pictures of animals and doing stuff like that. Gotta get back to that, to be [name] again (06).*

One participant discussed his suicidal thoughts throughout the interview. He said that he struggles every day with thoughts of suicide and depression, though said that he knows he will not kill himself. He also said that the HCV medication has the potential to make these thoughts worse, and he is scared to take the medication because he does not want to kill himself; he wants to make a change in his life

> *Yeah because I really don't want to kill myself. I just don't. I want to change my life that's all. I want something different for me. Its not that I want to die it's just that I want to get out of my life that I am in. (09)*

On a practical level, participants discussed being more aware of themselves around others and being more careful about sharing things like razors, toothbrushes or utensils, as well as drug related equipment. Some participants discussed making sure they had their own mug or plate at home that they did not share with others.

5.2 Stigma: Drugs, Sex and Poverty

As part of the emotional impact of hepatitis C, all of the participants described experiencing or perceiving stigmatization to some degree. Participants discussed being treated differently and feeling looked down upon. This experience of stigma was perhaps the most robust theme, and it seemed to underlie each of the others to some degree. Some participants expressed sadness in relation to experiencing stigma, while others expressed anger or resentment towards those who treated them poorly.

Many participants reflected on feeling that they were looked down upon, that they were damaged in some way, or not good enough. Participants suggested that they were seen only as 'the disease' and not as a whole person. Being looked upon as dirty, a 'low-life' and a second class citizen were all associated with being hepatitis C positive.

> *Damaged goods. Basically. Its like you're no good because you have hepatitis. They don't see you as a person anymore, they see you as the disease. (02)*

> *I mean I am an addict, but I am certainly not dirty… I mean just because people have this disease, doesn't mean we are less of a person. I come from a very good family, you know, educated, I went to university, I just happened to get stuck along the way (01).*
>
> *Like, when people find out that I got it, I feel like I'm not up to people's standards, that I am just another low life that has Hep C, I mean I have been told that. But, it does, it makes you feel like a second-class citizen is what it does, basically… I am not a second-class citizen, I am not and that's how I felt. (01)*

Many believed that the stigmatization stems from the association of hepatitis C with drug use, sex and poverty. As two participants explained:

> *It's the drug use. It's the drug use. As soon as they see why I have hep C or why I got it, their opinion changes. (01)*
>
> *I think the bottom line is they, they perceive it to be a drug and sex thing, and poverty. I think that's, them three things is what they put it as. (09)*

Another participant talked about the assumption that individuals who engage in drug use or sex work do not take care of themselves.

> *Hep C I think, hep C and HIV I think are both, there is a stereotype about it that says, you can get it, its mostly junkies that get it, prostitutes, drug addicts. Drug addicts, junkies or prostitutes. People who don't take care of themselves, homeless people. (08)*

Almost all participants described the experience of others treating them differently upon discovering their hepatitis C status. Several were fearful of telling others about their diagnosis as a result. Many explained that they have only told a few people about their diagnosis, some had told nobody, and others had experienced a poor reaction to disclosing and now do not tell anyone.

> *I don't know, it was, a little rough because, I just thought that when I told people that I had that, it seemed like they just treated me differently, and I had a hard time wrapping my mind around that. (04)*
>
> *I don't tell too many people because it's, I don't know, cause you kind of get shunned. People won't smoke after you, they kinda look at you like its dirty kinda thing. (07)*

> *After I told a few people and I saw the reaction, that they were a little leery about touching stuff that I touched and that kind of thing, it got me to the point where I didn't really want to tell anyone that I had it. (04)*

This secrecy, shame, and sometimes resentment over being treated differently meant that several of the individuals interviewed had become isolated, both physically and emotionally. Some felt as though they did not want to burden their friends or family with their diagnosis, having already made them deal with their addiction, trouble with the law, or children's services. Others worried that their friends or family would be scared if they knew about their diagnosis.

> *I am just scared of the reaction if they [family] knew that I had hep C… I am always cautious around them right, but its just, if they knew I think they would be scared or something. (02)*

Another participant described the stigma associated with hepatitis C treatment in particular. She explained that she did not want treatment because doing so would identify her as hepatitis C positive and she did not want others to know that she had hepatitis. She discusses not wanting 'the whole thing', that is treatment and the association with hepatitis C, around her:

> *I just don't, I don't, I don't want that. The whole thing around you. (07)*

5.3 Having and Getting Information

During the interviews, participants discussed and reflected upon their knowledge of hepatitis C and its treatment. Overall, the predominant sub-theme here was the relationship between lack of knowledge and experience of stigma. Many participants suggested that a lack of information stemmed from the stigma associated with hepatitis C. Lack of knowledge and lack of access to knowledge seemed to have started before their diagnosis, but persisted throughout their lives.

Upon initial diagnosis, many indicated that they knew very little, or nothing at all, about hepatitis C. Participants discussed being extremely scared when they first heard their diagnosis because they did not know what HCV was, immediately thought of HIV/AIDS, and assumed they had been issued a 'death sentence'.

> *I mean like, when you first find out, you think you are gonna die. Really it was just like telling me I had AIDS really. And I still don't know much about it really. You know? (09)*
>
> *Um, when I first got it, I didn't think it was really a big deal. Because everybody, I had hepatitis B when I was younger and I had jaundice and I got better. But then when I found out I had hep C and that it wasn't going to get better, it just, at first it was like 'yeah whatever' right?(05)*

This trend demonstrates the impact of stigma; people who were at high risk for contracting HCV (i.e. those who were injecting drugs) had little or no idea about the risk. Many were not aware of, or confused about, the differences between HIV and HCV.

Several participants disclosed that they had cleared an acute infection before acquiring their current, chronic infection; many of these participants said that they still did not know much about the disease, even after their first diagnosis.

> *For a long while, I didn't know there was any treatment because it hadn't been offered and it hadn't been explained to me or anything. And I hadn't heard it from anyone else. I didn't even know it was there to be honest, I didn't even know (04) [speaking about after he was diagnosed the first time]*

It appeared that even after being diagnosed with an acute infection, individuals were not provided with enough information to protect themselves in the future. Many also said that they might not have avoided an infection, even with knowledge about hepatitis C, because when they where actively injecting they rarely thought about the consequences of sharing needles.

> *… when I was in active addiction, I didn't know a whole lot about it, I just knew that it was a, you know. And maybe if I had more education on it, I don't know. When I think about it though, I don't think it really would matter (02).*

None of the participants mentioned their primary care physician as a source of information on HCV and its treatment. Participants indicated that, in their experience, health care professionals were often reluctant to discuss hepatitis C with them; this was a conversation that participants, themselves, had to initiate with their physician.

> *I don't know if they really – the doctors here are so busy that we don't really have time to talk. Well, we do but – its like, I think that would be more of a family doctor thing. To have enough time to have a conversation. Because they are so busy here, it's kind of like you are in and out. So it's kind of up to you to bring it up, you know (02).*

Having a lack of information about hepatitis C began, for participants of this study, well before they were diagnosed with the disease, even though they were at high risk of contracting it. Participants believed that they had access to information through pamphlets and literature, but had difficulty getting information from their physician

5.4 Back on Track

Almost all of the participants discussed that being 'back on track' acted as a barrier to initiating HCV treatment. The most predominant theme here was that participants wanted to avoid being 'sick'. Many participants felt that they were currently at a stage in their lives where they were not dependant on drugs, did not feel withdrawal symptoms everyday and were taking steps toward healthy lives. Because the side effects of hepatitis C treatment are so toxic, many did not want treatment because they did not want to be sick.

Some participants felt that they had been sick for a long time, whether in terms of their addiction or their physical health, and they were just beginning to feel better. Participants discussed being 'dope sick' for much of their recent lives, always chasing the high and avoiding withdrawal symptoms. One participant in particular said that the reason he stopped using drugs was to stop feeling sick; to him, hepatitis C treatment would mean being sick again:

> *The sickness. I have been a heroin addict since I was 11 years old and I have seen my share of sickness and I can't take it no more. That's half the reason I am suicidal. I just can't, you know. I have been sick way too much in my life, and I don't, I don't wanna go be sick anymore. I am sick of being sick, that's why I gave up drugs. I am sick and tired of being sick and tired. That's my main reason for giving up drugs. When you are an opiate user, you get really sick. (07)*

Others participants discussed regaining control of their lives. This control was described both in terms of their physical and mental health, and also in terms of their day to day lives. As demonstrated below, one participant wanted to take some time to enjoy her newfound health:

> *I feel a little bit more empowered now, I feel like I am in control of my life now, I don't feel like people can knock me down, I don't feel like my sicknesses are as bad because I have taken care of myself. So, do I want to go through that [hepatitis C treatment] really right? I don't know, because I just got better. It's been a long road. Eventually, I do want to get better you know? It's just really hard. And so, right now, I want to take that for myself. I want to live a little. (03)*

Beyond physical and mental health, many participants discussed their day to day lives and some of the support and stability they have started to build. A common subtheme here was that some had recently gained stable employment, or were looking for stable employment, and did not want to risk this progress by being sick from HCV treatment. One participant explained that her life was starting to take shape again, and feared that hepatitis C treatment would interrupt that:

> *I have been in active addiction for so long and so irresponsible and now that I have a job and I am getting out, almost clean 3 years, and life is starting to get good. I don't really want to end up getting sick and not being able to work right (02).*

It was clear that participants had experienced many hardships and that day-to-day survival had been a challenge for most of their lives. Being in control of their lives was a positive thing, and hepatitis C seemed to act as a reminder of a past that they were trying to leave behind. Hepatitis C treatment was viewed as a step backward, with the potential to undo some of the process they have made towards healthy lives.

5.5 Other Things Come First

Linked to the theme of being "back on track", participants discussed the idea that other aspects of their lives had taken priority over hepatitis C treatment. As discussed above, the day-to-day challenges faced by the research participants, including finding housing, food, employment and taking care of children, were of more immediate concern. When one participant was asked why she was not interested in treatment, she responded:

> *Um, probably because I have a lot of other things wrong with me, that have had to come first. (03)*

Participants described other priorities in their lives, or things that they wanted to have under control or "sorted out" before they started treatment. One said that he rarely has enough food to eat, and that does not have enough social support to begin treatment.

> *And with the sickness, well. I need, I don't very rarely have, usually all I ever have in my fridge and freezer is a jug of water. That's all I ever have in my fridge. I never have food in my cupboards, never. Like if I eat, its usually I run to Sobeys and buy something to eat, bring it home and eat it, and its gone. Which is another thing that's bothered me in my life. I don't know why, even when I try, it just doesn't work out. But I have been, I have always had walls up on relationships too. So maybe if I was in a relationship, yeah I could probably pull off the treatment. (09)*

Another participant discussed several health issues that he wanted to have checked out and under control before he started treatment.

> *I want to be on my methadone, on a proper dose. I want to be, I want to find out what is going on with my bowels, I want to find out what's, everything that is going on with me before I start. I can only do one thing at a time. And that's just it pretty much (08).*

For many, being co-infected with HIV also meant focusing on bringing their HIV under control. One participant suggested that she has started to think more about hepatitis C treatment lately because her HIV has become manageable.

> *I have thought about it. I've been thinking about it a lot lately, probably because this is the first time my counts have been higher and HIV isn't such a prominent – because they treat the worser of the two first, and HIV has always been worse (03).*

Another participant was very clear that their HIV diagnosis has been the priority in terms of treatment; they said that they did not see the point in getting rid of their hepatitis C since they would never be able to get rid of the HIV.

> *I mean I have HIV, so why get rid of my hep C? If I can't get rid of HIV, I mean, its not gonna make me feel any better, its really not. (01)*

The participant went on to discuss the idea that HIV is seen as a 'dirty' disease, and that hepatitis C is not perceived to be as dirty as HIV. They attributed the lower degree of stigma associated with HCV to the fact that HCV can be contracted through 'clean' routes, such as transfusion, and that so many people have hepatitis C.

> *I have, when you say hep C and then you have HIV, immediately they tune into the HIV because HIV is almost like it's a dirty disease, that the feeling I get anyway from talking to people, that it's a dirty disease. And hep C, like so many people have gotten in from transfusions and stuff like that, that its not that, its not as bad as when you say you have HIV. HIV is much worse (01).*

A couple of participants explained that they did not feel the physical effects of hepatitis C, suggesting that they would wait until they really needed treatment.

> *If it got bad enough and I needed it, and I knew I needed it to save my life. Then definitely. I wouldn't even think twice about it. But right now I am pretty healthy. (05)*
>
> *I don't feel, I guess I am just waiting to get sick, then I don't know. Like what do you do? I was thinking about it last night and I mean, I live by myself and I just can't. Not at this point in my life, I can't. And I just don't, I don't, I don't want that. The whole thing around you. (06)*

Participants prioritized immediate concerns; because their hepatitis C was not 'acting up' or causing any immediate distress, it was pushed to the bottom of their list of priorities. The day to day struggle, and the parts of their lives that were in immediate jeopardy, took priority in participants current lives. Most participants suggested that when / if their hepatitis C became a 'life or death' situation that they would initiate treatment. This may also be a result of the stigma associated with HCV; for most other diseases (i.e. cancer, diabetes), individuals seek treatment right away, but, for HCV, there seems to be an accepted delay.

5.6 Summary

As discussed, five themes emerged from the interviews, which were connected to one another. The personal and emotional impact of living with hepatitis C began, for participants, upon being diagnosed and persisted throughout their lives. This emotional impact was further impacted by the stigmatization and discrimination participants experienced due to the associated with drugs, sex and poverty. The stigmatization of hepatitis C influenced participants' ability to access information as they knew very little about the disease before they were diagnosed, and they found access to information to be a challenge for them. For participants in this study, all of whom had been accessing methadone for at least 12 months, they were beginning to rebuild their lives in recovery and feared that hepatitis C treatment would interrupt and possibly hinder the progress they have made. Participants spoke of being back on track and also of having other immediate struggles and challenges that needed to be addressed before hepatitis C treatment could be initiated.

Chapter 6: Discussion

This research study explored the barriers to accessing hepatitis C treatment for people who have experience with injection drug use and who are currently accessing methadone for addiction treatment, using a mixed methods approach. Although interest in HCV treatment is often reported as high, there is a discrepancy between this interest and actual uptake of treatment, which remains low in many key populations. Research in the past has suggested that methadone programs offer a unique opportunity to treat HCV; this research addresses some of the barriers to accessing HCV treatment for methadone clients.

6.1 Discussion of Quantitative Findings

Demographic characteristics of the sample were generally in line with the literature on this population. The average age of participants was slightly older (42 years) than previous research (28) with people who inject drugs (35 to 37 years). Only a third of participants were stably housed, compared to half of participants in other studies (28-31), and participants reported similar high rates of poor mental health (approximately 40% reported poor or fair mental health) to other studies (28-31). Participants of this study had spent a longer amount of time accessing methadone (8 years) compared to clients in the tertiary Capital District Health Authority methadone program (approximately 3 years).

Fewer than 40% of participants indicated that they would be willing to initiate HCV treatment within the next six months, slightly below estimates from previous research. A study conducted in 2005 with 110 methadone clients in San Francisco found that 54% of participants were ‘definitely’ interested in treatment after discussing the risks and benefits with researchers (56). A 2001 study with 306 methadone clients found that 53% were definitely or probably interested in HCV treatment (55). One study, conducted with methadone clients in Australia, found interest rates as high as 70-80% (57). Discrepancies may be related to length of time in MMT; the studies cited do not report how long participants had been accessing methadone. As demonstrated in the results of this study, length of MMT may be related to willingness to initiate treatment; it might be that participants of this current study had been accessing methadone for a shorter period of time than those in the cited studies, resulting in lower levels of interest.

The main findings of the quantitative data suggest very few differences between participants who were willing to initiate HCV treatment and those who were not. Duration of MMT was one exception; those who were unwilling to initiate treatment had spent less time on methadone maintenance treatment than those who were willing to initiate treatment. Because methadone maintenance treatment is a form of addiction treatment, accessing methadone, for many individuals, marks the beginning of many changes in starting to build healthy lives. Use of methadone over a longer period of time, especially through an organization such as Direction 180 which provides a holistic program of care, may mean that individuals have had a chance to rebuild certain parts of their lives and are now able to start thinking about HCV treatment. For those who were unwilling to initiate HCV treatment, some had been on MMT for as short as a couple of weeks; in the early weeks and months of opioid recovery, HCV treatment may not be a priority.

To date, very little research has explored length of time on MMT as a factor for initiating HCV treatment, though there has been significant exploration of delivering HCV treatment through methadone programs. In 2005, Litwin and colleagues piloted a comprehensive HCV care, treatment and support program though a pre-existing methadone maintenance treatment program. They found that this type of care fostered adherence to medications and allowed for mitigation of adverse outcomes or complications. The authors demonstrated the success of the program through the description of two successfully treated complex patients (86). In 2009, Litwin published a retrospective study which looked at 73 MMT patients who were treated for HCV. Forty-five percent of patients cleared the virus, a similar rate to the average HCV response rates, despite high rates of ongoing drug use (49%), psychiatric co morbidities (67%) and HIV co-infection (32%) (87). The results of these two studies demonstrate the unique opportunity for delivering HCV care through methadone programs; these environments provide supportive, ongoing, and low threshold care. Further research may explore how length of MMT use influences an individual's decisions around HCV treatment; it might be that length of MMT use is a proxy for the time needed to establish relationships and support networks for enduring HCV treatment.

In terms of the association of willingness to initiate treatment with knowledge of HCV and its treatment, no statistically significant relationships were observed. Much research has found a relationship between these variables, suggesting that a lack of knowledge is correlated with a decreased interest in treatment. The small sample size may have contributed to the lack of statistical significance, although some interesting trends in knowledge were uncovered. The data is suggestive of higher knowledge being correlated with a lower willingness to initiate HCV treatment. This may be because being well informed of the risks associated with treatment (i.e. treatment toxicity, low efficacy rate, slow progression of the disease), may actually lower interest in treatment. However, these results were not confirmed by this data and further research is needed to explore this idea.

Similar trends in direction were noted for attitudes toward treatment. It appeared as though those who were unwilling to initiate HCV treatment had more negative attitudes towards treatment (i.e. concerns about efficacy, physical and mental side effects). The data also suggested that those who were unwilling to initiate treatment may have more responsibilities at home, such as children or other dependents that rely on them. These attitudes are very much in line with the literature, which suggests that concerns around the effectiveness of treatment (11), harsh side effects (66) and the effect on relationships (65) act as barriers to treatment. In addition, it appeared that those who were unwilling to initiate treatment might have been confident that they would be able to complete treatment successfully. This last finding is in line with the literature, which suggests that having a 'just get it done' attitude towards treatment acts as a facilitator to accessing HCV treatment (78).

The main finding from the quantitative data was the relationship between willingness to initiate treatment and duration of time on methadone. As compared to those who were willing to initiate treatment, those who were unwilling to initiate treatment were more likely to have spent less time in MMT. This is an important finding that could be explored further. Much of the recent literature suggests that MMT programs offer a unique opportunity to treat HCV, but this study in particular suggests that the longer a person is on methadone, the greater the willingness to initiate HCV treatment.

6.2 Discussion of Qualitative Findings

Five main themes emerged from the interview data. These themes included (1) self perceptions and emotional impact; (2) the stigma associated with drugs, sex and poverty; (3) getting and having information; (4) being back on track; and (5) other priorities. The influence and experience of stigmatization connects the five themes. Many participants reported experiencing stigma throughout their lives, ever since they were diagnosed.

Changes in self perception and the emotional impact of living with hepatitis C started, for many, upon diagnosis; many participants began their discussion of living with hepatitis C at the experience of diagnosis. Several participants had been diagnosed in prison, with most reporting a very negative experience, lacking any resources or emotional support. They spoke of hiding their diagnosis in prison for fear of being shunned by fellow prisoners. A few participants discussed being in denial after their diagnosis, rebelling, not taking care of their health and not addressing their disease. This initial reaction of fear and denial has been frequently reported in qualitative literature (88-90). This fear and denial may stem from the stigma associated with the disease; because of the stigma, HCV is not discussed openly in public, which creates a lack of knowledge of the disease among those who are at greatest risk. Being diagnosed with the disease brings about feelings of fear because there is such a lack of knowledge and awareness about the disease.

Upon acceptance of their disease, many still were fearful to tell others. Although some participants had told their close friends and families, there were many who still had not told their family, for fear of their reaction. A 2010 study, conducted with women living with HCV, reported that the women were fearful of telling their partners or friends of their diagnosis because they feared they would be rejected (89). For some participants who had told friends or family, experiences of judgement or rejection have led them to not disclose their diagnosis to others. It appears that these initial experiences of stigma upon diagnosis seemed to have shaped participants thoughts and feelings towards themselves and their disease, and have influenced how they reflect on the disease.

Almost all participants discussed feeling “dirty”, like “second class citizens” or like “junkies” because of others reactions to their diagnosis. This is a common theme in the literature. One study found that participants’ sense of self was tied into messages they had heard from others about their drug use. The authors found that participants made a distinction between injection drug use as ‘dirty’ and other forms of drug use (i.e. drinking, smoking) as ‘less dirty’ (75). In the current study, participants seemed to link HCV with drug use and recognized that the discrimination they experienced stemmed from the association of HCV with injection drug use specifically.

Half of the participants of this study disclosed that they were HIV positive during their interviews. Among those participants, many compared the experience of HIV with HCV. Most participants viewed HIV and HCV differently; because HCV was more common among their peers than HIV, it carried less stigmatization. For some participants who were co-infected with HIV, the experience of stigma was more pronounced in relation to HIV rather than HCV. This highlights an important aspect of co-infection, in that, stigma is experienced in varying degrees for both diseases’. Some qualitative research has reported participants citing the association of HCV with HIV as a source of stigma (89), while other research has reported that individuals minimize or normalize HCV as compared to HIV (79).

Lack of information, or difficulty getting information, was a common theme among many interviews. Many discussed being scared upon diagnosis because they did not know anything about the disease. Several participants reported that they had initially been infected with acute hepatitis C, which cleared spontaneously, and then were re-infected with chronic hepatitis C several years later. Participants discussed being unaware of the risk of HCV during their active drug use; this finding indicates a need for access to clean needles and safe injection facilities to reduce the risk of infection.

Many said that, upon diagnosis, they immediately thought of HIV/AIDS and worried that they had been ‘issued a death sentence’. This initial ‘jump’ to HIV has been previously documented in the literature (90). Once participants had moved past the initial shock of diagnosis, many said they found it easy to find pamphlets or other literature on hepatitis C. Many identified Direction 180 as a place where they can find information. On the other hand, many participants described difficulty in getting information directly from health care professionals and instead relied on friends. This theme has been identified in previous research, which found that HCV positive individuals often got information from typically less reliable sources such as peers (88) rather than their health care providers. Participants from this study indicated that they wait for their physician to initiate discussion about HCV, felt that there was not enough time during an appointment to bring it up, or were confused as to when and how information on their disease status was delivered to them (i.e. one participant wondered why he had never been offered treatment in the earlier years of his disease). When physicians do not discuss HCV with their patients, it’s possible that this creates a perception that HCV is not to be discussed; this further adds to the stigma, secrecy and lack of information for individuals living with HCV.

Lack of access to information regarding HCV has been attributed to stigma in much of the literature. Janke and colleagues (91) found that feelings of stigma isolated HCV patients away from social supports. Zickmund and colleagues (91) found that HCV patients of a hepatology clinic felt directly stigmatized by health care providers and thought that their disease was viewed with judgment (91). One study found that several participants reported experiencing stigma from a health care provider which caused them to leave care and not have their needs met (75). In general, research has suggested that individuals resort to secrecy to avoid judgment of their disease (92), which, in turn, can lead to social isolation and can prevent people from seeking medical care (77). Repeated experiences of stigma force individuals to withdraw from the public for fear of further discrimination, which manifests in a continued lack of understanding of the disease and puts individuals at further risk.

Some participants discussed the feeling that accessing hepatitis C related care would ‘expose’ them as being hepatitis C positive. Participants discussed that they thought others would know they had hepatitis C if they saw them sick from the treatment. Literature has shown similar trends, noting that accessing HCV specific care can often bring about feelings or experiences of stigma (79). This type of shame around accessing care does not exist at the same degree for other chronic diseases; this only further accentuates the deeply rooted fear of stigma that exists for individuals living with HCV.

One of the most prominent themes that emerged from this study was that many participants were beginning to put together healthy, stable lives and were unwilling to disrupt or risk the lives they were building in order to initiate HCV treatment. Participants spoke of gaining stable employment, developing important relationships and establishing routine in their lives. Participants also discussed their improved health, less reliance on alcohol or drugs, and not experiencing withdrawal sickness. To our knowledge, previous research has not focused on this factor, but has suggested that more stable lives create opportunity to initiate HCV treatment. In a study conducted in 2007 with HCV-infected veterans, the authors reported a connection between motivation for recovery from substance use and motivation to seek HCV treatment, with participants saying that they ignored HCV until they had their substance use was under control (88), at which time they began to consider HCV treatment. Another study, conducted with HCV/HIV co-infected individuals, found that gaining ‘sober time’ acted as a facilitator to initiating HCV treatment (78). These findings contradict what was discovered in this current research, which is that as participants have more stable lives and have their addiction in more control they are not willing to disrupt that to initiate HCV treatment. In addition, another study reported that participants of a residential substance use treatment program suggested that HCV treatment during addiction recovery offered a unique opportunity because of patients’ motivation for and readiness to change (80), but they also feared that HCV treatment side effects would sabotage their addiction recovery. It might be that participants of this current research do not have enough ‘sober time’ or are not far enough along in their addiction recovery to consider HCV treatment, or it might be that, for this population, addiction recovery does not necessarily translate to readiness for HCV treatment.

As mentioned, many participants did not want treatment for fear of being sick. Previous research has suggested this as well. One study, conducted in 2010 in Dublin, interviewed people who inject drugs and found that they considered HCV treatment to be more severe than the disease itself (80). The study reported participants discussing ‘war stories’ about treatment, similar to the ‘horror stories’ that participants from the current research study cited when discussing treatment. This may be a further effect of the experience of stigma, which manifests itself as withdrawing from the health care system and not accessing correct information about HCV treatment.

Finally, many participants discussed prioritizing other aspects of their lives over HCV treatment. For example, many discussed recent employment, housing or relationships that they did not want to jeopardize losing by going through HCV treatment. Participants also mentioned addiction recovery and methadone maintenance as immediate priorities. This idea of ‘competing priorities’ has been identified previously in the literature. In 2010, researchers interviewed 27 clients of an opiate substitution treatment program and found many participants indicated that competing priorities such as parental responsibilities, housing stability and physical health conditions, prevented them from initiating HCV treatment (93). In another study, conducted with HCV positive individuals not accessing addiction treatment of any kind found that participants were not willing to initiate HCV treatment because it meant that they would have to reduce or stop their drug use (11). Interestingly, both of these studies found that participants would prioritize HCV treatment if they were guaranteed to clear the virus (93, 11).

The qualitative data highlighted several barriers to accessing hepatitis C, all of which seemed to stem from the stigma that participants had experienced in relation to their hepatitis C. Initial experiences of stigma upon diagnosis, coupled with continued and repeated experiences of stigma throughout their lives, have affected how participants access information, who they tell about their diagnosis and how they think about HCV treatment. It is clear, from the qualitative data, that these experiences of stigma are deeply rooted both in participants' memories and within society.

6.3 Barriers to Hepatitis C Treatment

There were three overarching barriers to accessing hepatitis C treatment that emerged from this study; the two data sets complimented each other in the barriers they highlighted. The first barrier, which emerged primarily in the qualitative data, was the stigma associated with hepatitis C which prevents people from talking about hepatitis C, asking about treatment and accessing information. The second barrier was the toxicity of treatment itself and the disruption it causes among patients' lives. The final barrier was the overall challenge of participants' day-to-day lives, in which immediate survival concerns take priority over hepatitis C treatment.

6.3.1 Stigma

The first two themes of the qualitative interviews (emotional impact and self perceptions, and drugs, sex and poverty) demonstrate the effects of stigma on accessing hepatitis C treatment. The experience of stigma highlights the self perceptions individuals have and the emotional impact that their hepatitis C diagnosis has had on them. Many participants discussed their own experiences of stigma, especially in terms of telling others about their diagnosis. Participants said that they have felt 'dirty', like second class citizens, and like the public views them as a disease rather than a person. Many participants attributed this to the association of hepatitis C with sex work, drug use and poverty.

In turn, this well established experience of stigma may have contributed to some of the interesting trends in knowledge about hepatitis C and its treatment that emerged. Interview participants said that they did not have a hard time finding information on hepatitis C, but that they find information in pamphlets and from friends, rather than health care providers. It might be that the stigma of having hepatitis C prevents individuals from asking for information from their care providers, or discussing treatment with their physician. This is especially highlighted in the theme of waiting for health care professionals to initiate discussion about hepatitis C treatment; some participants did not know which genotype of hepatitis C they had for many years, while others were only made aware of the availability of treatment recently.

This gap in knowledge is highlighted in the quantitative data; although no statistical association between knowledge and willingness to initiate treatment was discovered, it was clear that gaps in knowledge existed for both groups of participants. With further research, it might be feasible to demonstrate that the experience of stigma influences how and when individuals access information.

It is clear that there is a long standing, well established stigma associated with hepatitis C which prevents individuals from talking about hepatitis C, asking about treatment and accessing appropriate and non-stigmatizing care, support and treatment. This is perhaps the most deeply rooted barrier to accessing hepatitis C treatment and weaves underneath many other issues related to hepatitis C.

6.3.2 Toxicity of Treatment

The second major barrier that emerged from the qualitative data and highlighted by the quantitative data was the toxicity of treatment and the disruption it causes in daily lives. Many interview participants discussed that their reasons for not initiating treatment stems from not wanting to be sick from treatment and not wanting their lives interrupted due to treatment. For many participants, recent years have meant a re-establishment of healthy lives, employment, stable housing and the development of important relationships. Treatment, and being ill for up to one year, could result in undoing the progress they have made and are proud of. Toxicity of treatment and treatment side effects have been identified previously as barriers to accessing hepatitis C treatment (5, 11, 12, 58, 64), but this current research explores the reasons behind why being sick from treatment is such a prominent barrier.

This finding emerged in two ways in the quantitative data. The data suggests that individuals who were unwilling to initiate treatment were more likely to be employed; this relationship approached significance, suggesting that further research is needed to confirm this correlation. This potential relationship suggests that participants did not want to disrupt or jeopardize their employment to undertake treatment. Secondly, the opinion and attitude data suggest that individuals who were unwilling to initiate treatment may be more concerned about potential harsh side effects and effects on mental and physical health; although differences between groups were not tested, trends in the data suggest that further research should be conducted to further analyze how opinions and attitudes towards treatment affect willingness.

Again, these findings suggest that the toxicity of treatment is a barrier to accessing HCV treatment in that it disrupts lives that have, often, just recently been re-established and brought back on track.

6.3.3 Day to Day Survival

The third major barrier that emerged from this study was the general day-to-day chaos and challenges experienced by this community, in which hepatitis C and its treatment are not a priority. With several other immediate concerns, such as accessing methadone, seeking or maintaining employment, nurturing relationships, and securing money, housing and food, participants did not prioritize treatment as it was not part of their day to day survival. Previous research has also shown that other priorities often come before hepatitis C treatment; a 2010 study highlighted parental responsibilities, housing stability and mental / physical health concerns as taking priority over HCV treatment (65).

Many participants suggested that they would access treatment if it was ‘life or death’, suggesting that treatment would become a priority if their health deteriorated and treatment was the only option. Previous research has also highlighted that lack of symptoms often influences decisions around treatment (10, 12, 63). Those who were willing to initiate treatment had been accessing methadone longer, suggesting that they have had the chance to establish stability and have other aspects of their lives in order.

Some of the other variables that approached significant relationships with decreased willingness included shorter HCV length, less stable housing, moving more frequently in the past 5 years and spending longer in jail; these factors suggest that individuals who are unwilling to initiate treatment are in the process of re-establishing their lives and dealing with immediate challenges.

Overall, these three major barriers emerged from both the qualitative and quantitative data; the overlap between barriers suggests that making decisions around treatment is often a complicated process, influenced by many factors. As mentioned, stigma remains at the root of many barriers to accessing care, as it often pushes hepatitis C and its treatment to the background.

6.4 Limitations and Strengths

There are several limitations and strengths associated with this study, both in the quantitative and qualitative components, and overall.

In terms of the quantitative component, the sample size was small. Every attempt was made to capture a maximum number of Direction 180 clients, though only 60 of the estimated 90 HCV positive clients participated. The low sample size made it difficult to attain statistically significant results. Although a few clients declined to participate, there were several groups of clients that were missed. The first group is the population of clients who were incarcerated during the time of the study; it was impossible to access these clients in prison. Another group is the population of clients who are not daily visitors to the clinic; these individuals live in the community and attend the clinic only to see the physician. An attempt was made to conduct questionnaires on physician days, but it is likely that a significant portion of these clients were missed due to timing. Unfortunately, the questionnaire itself did not ask whether participants were daily or community clients, and therefore information on this factor is unavailable. It is possible that these two groups of individuals, those who were incarcerated and those who were ‘community’ clients, would have shifted the results of the questionnaire had they been full captured.

Another limitation was the questionnaire itself. The questionnaire was developed specifically for this study, and therefore was not systematically validated prior to use. It was, however, developed through consultation with stakeholders and pre-tested with individuals at risk of contracting hepatitis C. The questions may also have been interpreted differently by participants. For example, one question asked whether or not a participant had been diagnosed with any physical illnesses. Many participants responded ’no’, although they all had been diagnosed with hepatitis C. Some participants may have considered hepatitis C a physical illness, while others did not. A future study would ask the same question, but ask participants to consider physical illnesses besides hepatitis C. The wording in the knowledge section of the questionnaire could also be improved. Although done with consideration of the population in mind, some participants asked for the statement to be reworded to better understand. The knowledge statements could also be frustrating for some participants who did not know the answer to many questions; they may have felt embarrassed or frustrated, which led to responding “don’t know” to statement for which they knew the correct response. Finally, it was observed during the administration of the survey that participants were less engaged by the last section on attitudes and opinions. Participants often appeared confused or frustrated by the questions. The responses to this section may not provide relevant results beyond a general description of how participants felt about treatment. A future study would involve rewording this section and also randomizing the order in which the sections are administered to each participant.

Another limitation lies in the fact that this was an interview administered, self report questionnaire. Self report data is, by nature, somewhat unreliable, as participants may answer in a way that they deem socially acceptable. Data obtained through interviewer administered questionnaires may also be somewhat unreliable, in that participants are not anonymous at the time of the interview. These concerns were addressed by giving participants the option to fill out the questionnaire on their own, or having the questionnaire read to them; only a handful of participants filled the questionnaire out on their own. One participant remarked that they were happy to share the answers to any questions asked, and another corrected themselves when they provided an untrue answer.

The limitations of the questionnaire are countered by the strengths of the mixed methods approach. The findings from the survey data (i.e. employment being a barrier to accessing HCV treatment) were further explored during the interview component. Although conclusive quantitative results were hampered due to small numbers, the qualitative results served to triangulate the findings and lend validity to the conclusions.

As with most qualitative research, it is difficult to eliminate pre-conceived ideas and opinions among researchers during data collection and analysis. Through the literature review and administration and analysis of the questionnaire, I developed a perspective on barriers to HCV treatment, which I certainly brought to the interviews. It is likely that this perspective guided my questions and the direction of the interview.

Another limitation of the qualitative component is my own learning curve and relatively limited experience in qualitative research collection and analysis. Interviews were conducted and analyzed in groups of two. The first two interviews were conducted and reviewed thoroughly before continuing to the next interviews, with adjustments made to interview approach. I participated in qualitative analysis training at the Centre for Addiction Research of BC in Victoria in the Fall of 2010; this training was led by Dr. Bernie Pauly and brought me through the stages of analysis from open coding to narrative development. Careful consideration during the qualitative stage of this research study increased the reliability of the results.

Participants of the qualitative interviews were all hepatitis C positive, had indicated to Direction 180 staff that they were not interested in HCV treatment and had been accessing methadone for at least 12 months. It is possible that this sub group of clients do not represent all individuals who are not interested in treatment, and the barriers that they face may not be the same as those experienced by others. Because participants had been accessing methadone for at least 12 months, it is possible that they have had several discussions about treatment and the time to consider treatment. It is possible that their reasons for not initiating treatment have been well thought out; individuals who have been accessing methadone for a shorter period of time may have different reasons for not wanting treatment. Approximately half of the participants disclosed during the interview that they were HIV-HCV co-infected; it is therefore possible that the barriers and stigma experienced by this sub-group were much different from those mono-infected. Many co-infected participants prioritized HIV both medically and socially, which may mean that they have not considered HCV treatment for a variety of unexplored reasons.

This study is not generalizable to the larger population of people who use drugs, or people who are living with hepatitis C. Direction 180 clients may not represent the population of hepatitis C positive methadone maintenance patients as a whole. Direction 180 does not serve every methadone maintenance patient who is hepatitis C positive in Halifax; some individuals may be seeking methadone from tertiary health settings or their family physician and could potentially have different barriers to treatment. Direction 180 offers a low threshold approach to medical care; clients accessing care may not necessarily be abstinent from drugs and alcohol, whereas they may be expected to be abstinent if their care was being managed through tertiary care settings. The sample does not include individuals at high risk for infection, and therefore conclusions can not be drawn about methadone patients in general or injection drug users in general. The results of this study do, however, describe the population of individuals accessing care from Direction 180. The study was not necessarily intended to be generalized to a larger population, but to describe the barriers experienced among Direction 180 clients in order to identify ways to increase access to and uptake of hepatitis C treatment at the clinic. This study, therefore, is immediately beneficial for Direction 180. Direction 180 staff will be able to use the information to develop treatment uptake programs and target their population in a more individualized approach. The clients themselves will benefit from this individualized approach, which is already implemented at the clinic, but will be reinforced and complimented by this research.

A further strength of this study is the utilization of community based research principles. The research question itself was identified by Direction 180 as an area of interest and need. The specific objective, methods and measures were all developed in collaboration with Direction 180 staff and clients, which lends credibility to the need to conduct this research. In addition, this collaborative process insures that the results of the study are useable within the community and represent the target population.

Chapter 7: Conclusion

This study explored the barriers to accessing hepatitis C treatment for individuals who have experience with injection drug use and who are accessing methadone maintenance treatment. The mixed methods approach allowed for a deeper exploration of the barriers experienced by this population than previous research, and began to unlock the relationship between knowledge and stigma as barriers to accessing care.

From the two sets of data, three main barriers to accessing hepatitis C treatment emerged. Perhaps the most deeply rooted barrier was the stigma associated with hepatitis C which stems from its association with drug use, sex work and poverty. This stigma, in turn, results in a patchwork of hepatitis C knowledge among people living with the disease. The toxicity of treatment acts as a barrier by acting as a threat of disruption to the lives that individuals have established, with the side effects of treatment (i.e. sickness) threatening to undo the progress individuals have made in their lives. Finally, the unique challenges of individuals day-to-day lives puts hepatitis C and its treatment at the bottom of their priorities.

There are several key messages to take away from this research. The first is that the underlying issues of stigma and discrimination still exist for this population in a very concrete manner. All participants discussed experiences of stigma, and all of them explained how these experiences had shaped their lives. The stigma from the public creates a perception that hepatitis C is a dirty disease and that ‘junkies’ are not worth treating. The public places blame on those living with hepatitis C, which, in turn, results in a lack of willingness to care for and treat the disease. The stigma experienced by participants has pushed their disease to the bottom of their priorities; hepatitis C is not a priority for society, and in turn, has become less of a priority for those living with the disease.

The second message is the need for continued support for individuals who are actively using drugs. This research suggests that the lack of information about hepatitis C has effects on individuals long before they are diagnosed; many indicated that they did not know about hepatitis C before they were diagnosed, and many had been initially confused about the difference between it and HIV. Some participants indicated that, even if they had known about the risk of hepatitis C, they may not have acted any differently during their active addiction; this highlights the need for increased access to needle exchange programs, safe injection facilities and other support services.

The third message from this research is that MMT programs are an ideal place to offer hepatitis C treatment. With high rates of hepatitis C infection among MMT clients and the holistic care provided by most MMT programs, this environment provides the necessary support and care needed to treat hepatitis C. The results of this study suggest that time spent on methadone supports an increased willingness to initiate HCV treatment. Within the qualitative data, some of the barriers identified (i.e. lack of information, lack of support networks, other immediate struggles) can be addressed through methadone programs which offer holistic care.

There are some areas of future research which follow from this study. The questionnaire itself could be further studied and validated through a more rigorous process; it could then be used in a larger population to obtain more statistically significant results. The barriers that emerged from both sets of data (i.e. stigma, toxicity of treatment, challenge of day to day lives) could be further explored through additional qualitative research with more Direction 180 clients or individuals living with hepatitis C on a broader scale. In particular, individuals who have participated in HCV treatment could be interviewed to determine whether or not these perceived barriers were experienced during treatment.

The overarching goal of this research, and other research on the barriers to HCV treatment, is to increase interest and uptake of treatment. From this study, it is clear that simply providing information and increasing knowledge of the disease and its treatment, which has been suggested in the past, will not work. This research suggests that knowledge may not be the key barrier to accessing hepatitis C treatment, but that other aspects of individuals' lives may pose more immediate barriers; it is necessary to support individuals as they make changes in their lives (i.e. find stable housing, establish reliable child care) which are necessary before they can start treatment.

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Appendix 1: Survey

SURVEY

Barriers to accessing hepatitis C treatment for individuals who have experience with injection drug use and who are accessing methadone maintenance treatment.

SECTION 1

Background Characteristics

The first part of this survey is made up of a number of questions that will address different aspects of your life – like smoking and alcohol history, your general health and well-being, and your health as it is related to hepatitis C. You do not have to answer any question that you don't feel comfortable answering and you may stop the survey at any point. Your name will not be linked to any of the answers you provide, and all answers will be kept anonymous once the survey is complete. Answering questions on this survey will in no way change the type of care you receive at Direction 180.

Put a check mark in the box next to your answers.

Smoking History

The first few questions are about smoking.

1. In your lifetime, have you smoked a total of 100 cigarettes or more? (about 4 packs)		
0		Yes
1		No **(skip to question 5)**

2. At what age did you smoke your first whole cigarette?	Age:

3. At the present time, do you smoke cigarettes daily, occasionally, or not at all?		
0		Daily
1		Occasionally **(end section)**
2		Not at all **(end section)**

4. How many cigarettes do you smoke each day now?	Cigarettes:

Alcohol History

The next few questions are about alcohol. When we use the word 'drink', it means:

- *one bottle or can of beer or a glass of draft*
- *one glass of wine or wine cooler*
- *one straight or mixed drink with one ounce and a half of hard liquor*

5. In your lifetime, have you ever had a drink?		
0		Yes
1		No **(end section)**

6. How often do you drink?		
0		Daily
1		At least 5 times a week
2		At least once a week
3		Once a month
4		Very rarely

7. When you drink, how many drinks do you have?		
0		1
1		Between 2 and 5
2		More than 5
3		More than 10

Employment

Now I will ask you some questions on your employment history.

8. Are you currently employed (either part time or full time)?		
0		Yes
1		No

9. Which of the following have you spent most of your time doing, during the past 12 months doing?		
0		Working at a job or business
1		Looking for work **(end section)**
2		A student **(end section)**
3		Retired **(end section)**
4		At home with children / elderly **(end section)**
5		Other **(end section)**
6		Prefer not to answer **(end section)**

10. What kind of business, industry or service is/was it that you work/worked for?	

Housing

The next questions will address housing.

12. Where do you live now?		
0		Own apartment
1		Own house
2		Parent(s) house / place
3		Other relative’s house / place
4		Friend’s place
5		Hotel / motel room
6		Rooming / Boarding house
7		Shelter / hostel
8		Transition house / halfway house
9		Recovery house / detox
10		Street
11		Squats
12		Jail / prison / corrections
13		Psychiatric institution
14		Prefer not to answer

13. Do you think your current housing situation will change in the next 6 months?		
0		Yes
1		No
2		Don’t know
3		Prefer not to answer

14. In the past 6 months, in what types of places have you lived?		
0		Own apartment
1		Own house
2		Parent(s) house / place
3		Other relative’s house / place
4		Friend’s place
5		Hotel / motel room
6		Rooming / Boarding house
7		Shelter / hostel
8		Transition house / halfway house
9		Recovery house / detox
10		Street
11		Squats
12		Jail / prison / corrections
13		Psychiatric institution
14		Prefer not to answer

15. How many times have you moved in the past five years?	

Incarceration

And now, a few questions on jail time.

16. Have you ever spent any time in municipal, provincial or federal jail?		
0		Yes
1		No **(end section)**
2		Prefer not to answer **(end section)**

17. Including all the times you've been in prison, how many years in total have you spent incarcerated?		
0		Less than 1 year
1		1 year or longer
2		Prefer not to answer

Drug Use

Now I am going to ask you some questions about drug use. Just to remind you – the responses you provide will not be linked to your name and will not influence the care you receive at Direction 180.

18. Have you ever injected drugs?		
0		Yes
1		No **(skip to question 23)**
2		Prefer not to answer **(skip to question 23)**

19. How old were you when you first started injecting drugs?	

20. For how many years did you inject drugs?			
0		Less than 1 year	
1		More than 1 year	Years:
2		Prefer not to answer	

21. How long has it been since you last injected?		
0		Within the past 30 days
1		More than 30 days ago but within the past 12 months
2		More than 12 months ago
3		Prefer not to answer

22. Have you ever shared needles or syringes? [4]		
0		Yes
1		No
2		Prefer not to answer

23: Please indicate what your experience is with each of the following drugs:

	Ever used or tried	Age when you first used or tried drug	In the past 12 months, have you used…	Number of days drug was used in the past month
Cannabis	Yes No		Yes No	
Magic Mushrooms	Yes No		Yes No	
Ecstasy	Yes No		Yes No	
LSD (acid)	Yes No		Yes No	
Cocaine (powder)	Yes No		Yes No	
Crack (rock)	Yes No		Yes No	
Amphetamine (speed)	Yes No		Yes No	
Crystal Meth	Yes No		Yes No	
Ketamine (Special K)	Yes No		Yes No	
Heroin	Yes No		Yes No	
Pain Medications (i.e. morphine, dilaudid, Tylenol)	Yes No		Yes No	
Sleeping Pills (i.e. valium, clonazepam, ativan)	Yes No		Yes No	

24. Have you ever shared any other drug paraphernalia? (i.e. crack pipes) [4]		
0		Yes
1		No
2		Prefer not to answer

Health History

The next section asks questions about your mental and physical health – including some questions about HIV, hepatitis A, B and C.

25. In general, would you say your physical health is…?		
0		…excellent?
1		…very good?
2		…good?
3		…fair?
4		…poor?

26. In general, would you say your mental health is…?		
0		…excellent?
1		…very good?
2		…good?
3		…fair?
4		…poor?

27. Have you ever been diagnosed by a health professional with any mental health conditions? (i.e. anxiety, mood disorder, etc…)	

28. Have you ever been diagnosed by a health professional with any physical health or chronic condition? (i.e. diabetes, asthma, heart disease)	

Now some questions on HIV.

29. Have you ever been tested for HIV?		
0		Yes
1		No **(skip to question 31)**
2		Don't know **(skip to question 31)**
3		Prefer not to answer **(skip to question 31)**

30. What was the result of your most recent HIV test? [5]		
0		HIV positive
1		HIV negative
2		Indeterminate
3		Don't Know
4		Prefer not to answer

And now some questions on hepatitis A and B.

31. Have you ever been tested for hepatitis A?		
0		Yes
1		No
2		Don’t know
3		Prefer not to answer

32. Have you ever been tested for hepatitis B?		
0		Yes
1		No
2		Don’t know
3		Prefer not to answer

33. Have you ever been vaccinated for hepatitis A and B?		
0		Yes
1		No
2		Don’t know
3		Prefer not to answer

And now some questions on hepatitis C.

34. How long have you had hepatitis C?	Months / Years:

35. How do you think you were infected with hepatitis C?		
0		Injecting drugs / sharing needles
1		Piercing
2		Smoking / snoring crack
3		Blood transfusion
4		Sex with an infected partner
5		Drug paraphernalia
6		Don’t know
7		Other:
8		Prefer not to answer

36. Where was your most recent hepatitis C testing done?		
0		Family physician
1		Hospital (i.e Emergency Department)
2		Research
3		Direction 180 / methadone program
4		Prison
5		Walk in Clinic
6		Other
7		Prefer not to say

37. Have you ever been approached about HCV treatment?		
0		Yes
1		No
2		Don't know
3		Prefer not to answer

38. Have you ever been treated for hepatitis C?		
0		Yes
1		No
2		Don't know
3		Prefer not to answer

Methadone Maintenance Treatment (MMT)

And a few questions on methadone maintenance treatment.

39. How long have you been on methadone maintenance therapy?[4]	Months: (or) Years:

40. Prior to your current methadone maintenance therapy, have you ever been on methadone before?		
0		Yes
1		No (end section)
2		Prefer not to answer

42. How many times have you been on methadone maintenance therapy?	Times:

Socio-Demographic Information

For the next section of this survey I am going to ask some more personal questions.

43. In what year were you born?	Year:

44. Are you …?		
0		Male
1		Female
2		Transgender
3		Prefer not to answer

45. Are you…		
0		White
1		Chinese
2		South Asian
3		Black
4		Filipino
5		Latin American
6		Southeast Asian
7		Arab
8		West Indian
9		Korean
10		Japanese
11		Other: (please specify)

46. What is the highest level of schooling that you have completed?		
0		Never attended school
1		Kindergarden / preschool
2		Some elementary school
3		Completed elementary school
4		Some high school, but no diploma
5		Completed high school or G.E.D
6		Some trade school, vocational school, community college etc
7		Completed trade school, vocational school, community college etc
8		Some university
9		Completed university
10		Post-graduate work

47. Are you…		
0		Single (never married)
1		Living with a common law partner
2		Married (and not separated)
3		Separated
4		Divorced
5		Widowed
6		Prefer not to answer

48. Do you have any children and /or step children of school-age living with you?		
0		Doesn't apply – I don't have any children (end section)
1		Yes
2		No (end section)
3		Prefer not to answer (end section)

49. Are you the person who primarily takes care of your children and / or step children?		
0		Yes
1		No
2		Prefer not to answer

SECTION TWO
Willingness to Initiate Treatment

The purpose of this next section is to assess your intention to begin hepatitis C treatment within the next 6 months. Your answers here will not commit you to start treatment, nor will they diminish your opportunities to be treated in the future. Please answer honestly.

Given the opportunity, how willing would you be to start hepatitis C treatment within the next 6 months?		
0		Definitely willing
1		Somewhat willing
2		Neither willing nor unwilling
3		Somewhat unwilling
4		Definitely willing

Treatment involves weekly injections and daily pills. Knowing this, how willing would you be to start hepatitis C treatment within the next 6 months?		
0		Definitely willing
1		Somewhat willing
2		Neither willing nor unwilling
3		Somewhat unwilling
4		Definitely willing

Side effects of treatment may include persistent flu-like symptoms. Knowing this, how willing would you be to start hepatitis C treatment within the next 6 months?		
0		Definitely willing
1		Somewhat willing
2		Neither willing nor unwilling
3		Somewhat unwilling
4		Definitely willing

Treatment can take between 6 months to longer than a year. Knowing this, how willing would you be to start hepatitis C treatment within the next 6 months?		
0		Definitely willing
1		Somewhat willing
2		Neither willing nor unwilling
3		Somewhat unwilling
4		Definitely willing

We have now completed the first part of the survey. Do you have any questions about anything we discussed, or have anything additional to add?

SECTION 3
Knowledge of hepatitis C transmission, progression and treatment.

I am going to ask you a series of True or False questions. These will be questions about hepatitis C transmission, progression and treatment. For each question, please take a moment to think about the question and then respond with "true", "false" or "don't know". It is okay if you don't know the answers to these questions – we can go over the correct responses at the end.

The hepatitis C virus is spread through blood to blood contact.	True	False	Don't Know
Only those who have HIV can get hepatitis C.	True	False	Don't Know
Injection drug use is one of the main ways to get hepatitis C.	True	False	Don't Know
A person can have more than one kind of hepatitis C.	True	False	Don't Know
A mother will always pass hepatitis C to her child when giving birth.	True	False	Don't Know
A father will always pass hepatitis C on to his unborn child.	True	False	Don't Know
A mother with hepatitis C should never breastfeed	True	False	Don't Know
Unprotected sex between a man and a woman always spreads hepatitis C.	True	False	Don't Know
Even if you don't see blood, hepatitis C can still be present	True	False	Don't Know
Smoking crack can lead to hepatitis C infection	True	False	Don't Know
People can be vaccinated against hepatitis C	True	False	Don't Know
Long term hepatitis C infections cause liver damage.	True	False	Don't Know
Infection with hepatitis C can lead to liver cancer	True	False	Don't Know
Hepatitis C follows the same path in everyone	True	False	Don't Know
Hepatitis C infections in men progress faster than women.	True	False	Don't Know
Age does not effect the progress of hepatitis C	True	False	Don't Know
Drinking alcohol does not affect hepatitis C	True	False	Don't Know
Being infected with HIV speeds up liver damage from hepatitis C.	True	False	Don't Know
Eating healthy and maintaining a healthy weight is important for slowing progression.	True	False	Don't Know
Once a person gets rid of hepatitis C, they can never get it again.	True	False	Don't Know
There is no guaranteed cure for hepatitis C	True	False	Don't Know
There are medications that can get rid of the virus for some people.	False	Don't Know	Don't Know
Treatment involves a weekly needle and daily pills	True	False	Don't

			Know
Treatment lasts between 6 and 12 months, maybe longer.	True	False	Don't Know
Treatment works the same for all genotypes..	True	False	Don't Know
Missing several days of medication doesn't matter.	True	False	Don't Know
There are no side effects of treatment.	True	False	Don't Know
Hepatitis C medications in men or women do not cause birth defects in their children.	True	False	Don't Know

SECTION 4

Attitudes and Opinions around hepatitis C treatment.

I am now going to pose a series of statements around attitudes towards hepatitis C treatment, and ask that you indicate whether or not you personally agree with the statement by responding with one of the following: "Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree" for each statement.

a) Treatment is not effective enough

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

b) Treatment involves too much commitment

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

c) Treatment can affect my physical health too much

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

d) Treatment can affect my mental health too much.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

e) The side effects of treatment are too harsh.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

f) Treatment will affect my personal relationships too much.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

g) It would be too discouraging if treatment did not work.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

h) I don't care about the effects of hepatitis C.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

i) I am not ready for treatment because of school obligations.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

j) I am not ready for treatment because of work obligations

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

k) I have too many people depending on me right now; I can't be sick.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

l) I am not ready for treatment because I have children who need me to look after them.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

m) I am confident that I could complete treatment successfully.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree

Thank you for participating in this survey. Again, your responses will remain confidential and anonymous. If you have any questions regarding the survey or your participation in this survey, please do not hesitate to contact either myself or a member of the Direction 180 staff. Upon completion of the research study, we will provide the clinic with the results and provide opportunities for clients to learn the results.

<go over correct answers to the true / false section if the client desires>

Are there any further comments or questions you have? Are there any barriers to hepatitis C treatment that we did not talk about?

Appendix 2: Interview Guide

Interview Guide

Opener: *You have been approached to participate in a research study about the barriers to hepatitis C treatment. We are particularly interested in individuals who do not express interest in hepatitis C. The focus of these interviews will be on your own experiences with hepatitis C and the stigmatization and discrimination you may have experienced from others. These interviews will be audio recorded, but only I will listen to them. I will transcribe the interviews, after which all identifying information will be removed from the interview. The care you receive at Direction 180 will in no way be affected by your participation in this interview, nor the responses or thoughts you provide. Are there any questions you may have before we begin?*

Themes of Interview:

1. Life with hepatitis C
2. Relationships with family and friends
3. Experiences with services
4. Self perceptions

Probing Questions:

1. Life with hepatitis C
    - Tell me a bit about what it's been like living with hepatitis C
2. Relationships with friends / family
    - Have you told family / friends that you have hepatitis C?
    - How did they react? Have they been supportive?
    - If you haven't told them, why?
3. Experiences with services
    - What has been your experience with services been since you were diagnosed?
    - Do you feel like you have been treated differently because you have hepatitis C?
    - What have others said when you said you're not interested in treatment?
    - Have you found it easy to get help or advice about hepatitis C when you needed it?
4. Self perceptions
    - Do you think having hepatitis C has changed you? How?
    - How do you think people with hepatitis C are seen by the general public?
    - What doesn't the public understand about hepatitis C?