# What Do We Know About Women's Experiences of Living With Hepatitis C?
# An Analysis of Canadian Women's Journey with Hepatitis C Care

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**This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes**

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## ABSTRACT

**Background:** The Hepatitis C virus (HCV) is a blood-borne infection affecting an estimated 170 million people worldwide including approximately 250,000 Canadians. Untreated HCV can contribute to significant morbidity and mortality. Despite the benefits of HCV care, there continues to be significant gaps in the uptake of services.

**Purpose:** This thesis explored Canadian women’s experiences of the journey with HCV care from the perspective of the women, in order to promote care engagement, improve patient-provider relationships and deliver services that meet women’s needs.

**Methods:** This study, inspired by grounded theory techniques, explored women’s experience of living with HCV and factors influencing their journey with care. Purposive and theoretical sampling across three Canadian provinces generated interviews with 25 women.

**Results:** Three concepts were central to understanding women’s journey with HCV care: 1) The **point of diagnosis** shaped women’s journey with care through a) their preparedness for a positive diagnosis, and b) the information/health education they received; 2) Women faced complex **barriers to care** - (a) information provision, b) family and caregiver responsibilities, c) relationship with healthcare provider, d) active substance use and e) stigma and discrimination - but often showed inventiveness and determination to overcome them; 3) Women saw their **decision**

**to attend for HCV care** as prompted by a) immediate crisis, b) gradual sequence of awareness, or c) medical intervention.

**Conclusion:** The development of effective interventions and integrated models of care requires an understanding of the complex factors that shape women's journey with HCV care. Improving women's journey with HCV care will enhance their access to the new treatment regimes.

**Recommendations:** A National HCV Strategy and comprehensive guidelines for care, treatment and prevention; HCV education throughout the healthcare system; and equitable and accessible healthcare for women living with HCV.

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Most importantly, I would like to acknowledge that this thesis would not have been possible without the women who agreed to participate in this research and share their stories with me. Thank you; I am truly humbled by your resilience.

Just because I was *using drugs at the time doesn’t mean*

*I’m not any better, or doesn’t mean I’m worse than anybody else,*

*I deserve the best care, I still deserve the same level of care that*

*everybody else gets and I felt that because of what I was doing*

*and because of what he (the doctor) had said I certainly wasn’t going to*

*get the same level of care because he was going to look at me in a*

*different light*

- Quote from Research Participant

## THESIS AUTHORSHIP ATTRIBUTION

Chapter Six of this thesis contains material published in the Canadian Journal of Nursing Research (Mitchell, Bungay, Day, & Mooney-Somers, 2016). Three people, including me, conducted the interviews for the National Non Attendance for Care Project. I, however, conceived the analysis for this thesis. I analysed and interpreted the data and I wrote this thesis.

*As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements are correct.*

Supervisors name Julie Mooney-Somers

Signature

Date 25/2/2017

# TABLE OF CONTENTS

## TABLES AND FIGURES

## GLOSSARY OF TERMS

**Acute HCV Syndrome** –The first six months after being exposed to HCV

**Chronic HCV** – When HCV remains active in the body 6 months of infection.

**HBV** – Hepatitis B Virus

**HCC** – Hepatocellular carcinoma

**HCV** – Hepatitis C Virus

**HCV Care** - The engagement with healthcare services for HCV testing, monitoring, symptom management, and/or treatment

**HIV** – Human Immunodeficiency Virus

**IDU** – Injecting drug use

**PWID** – People who inject drugs

**Relapse** - When HCV RNA decreases during treatment and is undetectable but becomes detectable when treatment is ceased.

**RNA** – Ribonucleic acid

**SVR** - Sustained virological response

**WWID** – Women who inject drugs

# CHAPTER 1 INTRODUCTION

## 1.1 Background Information

Hepatitis C virus (HCV) is a blood-borne infection that affects an estimated 170 million people worldwide, including approximately 250,000 Canadians (Borman & Swain, 2013; Myers et al., 2014). When untreated, HCV can contribute to significant morbidity and mortality usually associated with liver cirrhosis or liver cancer (Corey, Mendez-Navarro, Gorospe, Zheng, & Chung, 2010). Engagement with healthcare services for HCV testing, early diagnosis, monitoring, symptom management, and/or treatment are essential elements for the promotion of health and well-being, prevention of further transmission and decrease the likelihood of disease progression (Hung et al., 2006; Yoshida et al., 2002) of those with HCV. Despite the well-documented benefits for improving quality of life, increasing survival rates and decreasing the likelihood of cancer and cirrhosis (Khokhar & Lewis, 2007; Munoz-Plaza et al., 2008), low rates of attendance for these services remain a concern. Research literature has reported rates of attendance ranging from 20-72 percent (Groom et al., 2008; Gunn et al., 2005; Subiadur, Harris, & Rietmeijer, 2007). A Canadian study that tracked attendance over seven years reported up to 28 percent of those referred did not attend for care (Butt, 2009).

Although the overall reported cases of HCV in Canada are declining (Myers et al., 2014; Public Health Agency of Canada, 2011, 2016) incidents of new HCV infections are rising among young women aged 15–29 years (60 % of new Canadian HCV cases aged 15-29 years are women) and have exceeded the rates of men in this age category (Communicable Disease Prevention and Control Services, 2013). The exact reasons for the rise of HCV infections in women in this age range remain unknown. Women's experiences and concerns about living with HCV have been identified as an under-researched area (Olsen, Temple-Smith, & Banwell, 2013). Furthermore, it has been estimated that 21 percent of people infected with HCV in Canada remain unaware of their infection (Myers, Shah, Burak, Cooper, & Feld, 2015); however, it is unclear how women are represented in this data.

To date, there have been minimal investigations of women's journey with HCV care and the factors that shape this journey. There is growing evidence that some people living with HCV experience substantial misconceptions about the seriousness and the prognosis of the infection. Healthcare providers have provided misinformation regarding the need for ongoing monitoring of health status, and treatment, which adds to this confusion (Gidding et al., 2012; Khokhar & Lewis, 2007; Munoz-Plaza et al., 2008).

The research concerned with women and their experiences of living with HCV has emphasized the significant impact the condition has on their everyday lives stressing substantial individual, social and economic cost. In a qualitative study examining the impact of a HCV and Hepatitis B Virus (HBV) diagnosis, participants reported hepatitis impacted all aspects of the quality of their daily life (Teston, Silva, & Marcon, 2013). To improve the journey with care and ultimately health outcomes for these women living with HCV an understanding of the complex factors that shape their HCV journey with care could ensure that effective and appropriate interventions and integrated models of care are developed for these women.

## 1.2 Explanatory Framework used by this Research

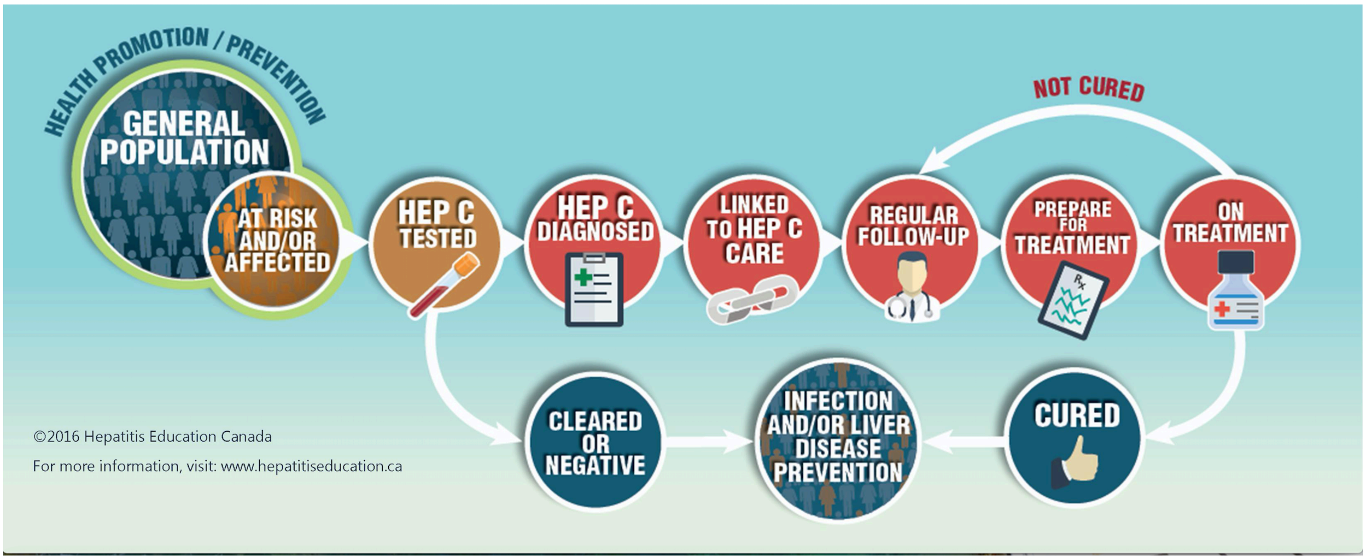
The HCV cascade of care was adapted and used as a framework for this research. I will begin by describing this model. Further details on how the HCV cascade of care model was used to identify barriers throughout the women's journey with HCV care will be provided in Chapter Seven.

### 1.2.1 Cascade of Care

The cascade of care is a framework, which is often used in the HIV literature to conceptualise the barriers to human immunodeficiency virus (HIV) care (Hallett & Eaton, 2013). This framework maps a person's journey over time identifying events, challenges, and gaps in the healthcare system that may prevent them from receiving treatment and care. The cascade of care is an effective tool to improve linkage and retention to care, initiate treatment, and ensure adherence to treatment (Baligh, Asher, Craig, & Vincent, 2014).

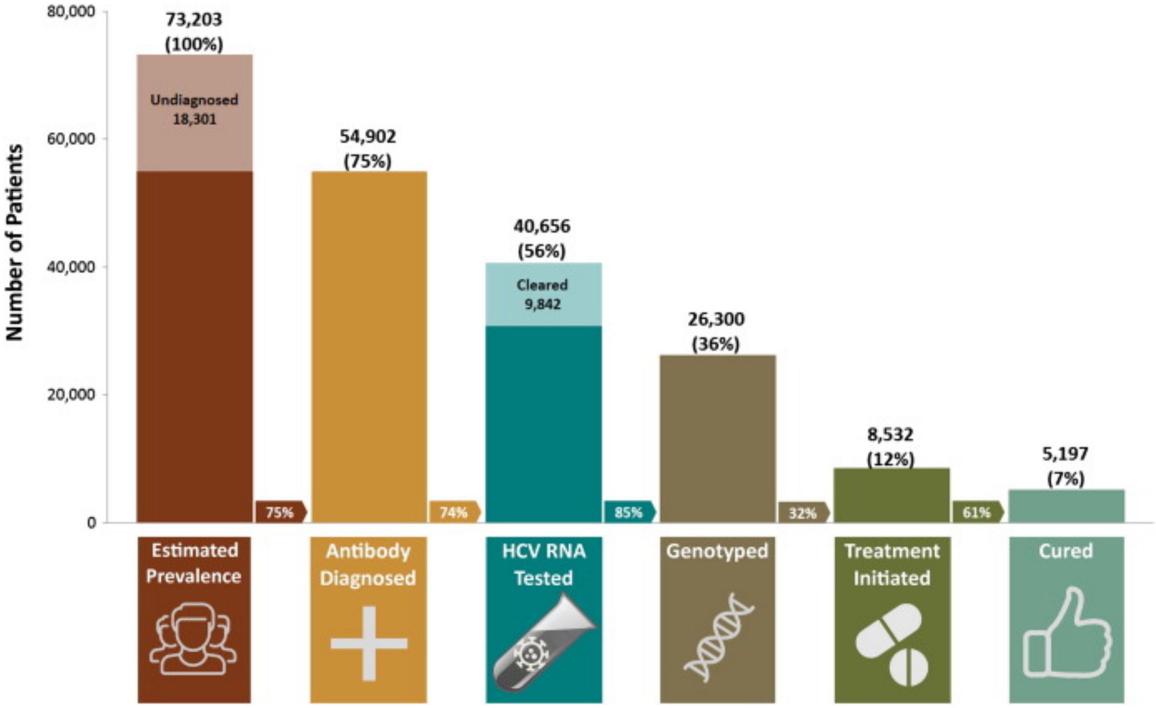
With the advancement in HCV treatment and HCV screening, there has been an increased interest to improve HCV care and follow-up after diagnosis (Linas et al., 2014). The HCV cascade of care has been adapted with six points along the continuum of care 1) HCV testing, 2) HCV diagnosis, 3) linkage into care, 4) receiving regular follow-up, 5) preparing for treatment if appropriate, 6) on treatment, 7) cured of HCV and 8) prevention of re-infection and/or liver disease (refer to Figure 1).

**Figure 1 – The HCV Cascade of Care (Hepatitis Education Canada, 2016)**



The framework suggests that to improve the health of people living with HCV, interventions and strategies must be developed at all points along the cascade of care. Using an adaption of this model as a framework Janjua et al. (2016) looked at population-level monitoring of HCV to identify gaps in access and engagement in care and treatment. They found the major gap in the cascade of care was low treatment initiation (refer to Figure 2) highlighting the importance of understanding the journey with care for people living with HCV, to improve attendance to care and HCV treatment uptake.

**Figure 2 - HCV Cascade of Care (Janjua et al., 2016)**



## 1.3 Rationale for this Study

Major advances in interferon-free HCV treatment have given new hope, promising less burdensome treatments of shorter duration that can effectively promote and protect the health of women living with HCV. However, these new treatments will be ineffective if people do not attend for care in the first instance. Missing the opportunity to access HCV care and treatment can have potentially devastating consequences for the health of individuals and communities and health system resources. A better understanding of the complexity of factors influencing the journey with care for women affected by HCV is therefore urgently needed. Without this understanding the design of more effective health policies and practices to promote HCV care may be seriously undermined.

## 1.4 Focus of this Thesis

This thesis explores Canadian women's journey with HCV care from the perspective of the women who participated. For the purpose of this thesis, HCV care was defined as engagement with healthcare services for HCV testing, monitoring, symptom management, and/or treatment. This research examined the barriers and motivators that women experienced along their journey with care. The results of this research are intended to inform healthcare providers and policy makers about the factors that influence women living with HCV and their journey with care in order to promote better engagement with care, improve patient-provider relationships and deliver healthcare services that better meet the needs of these women. Where possible, recommendations for practice and policy to reduce the negative experiences of women living with HCV will be made.

## 1.5 Research Question

The primary objective of this thesis is to investigate Canadian women's narratives of living with HCV in order to understand their journey with care.

## 1.6 Structure of this Thesis

Chapter Two of this thesis discusses the relevant literature on HCV infection, HCV treatment and HCV care in the Canadian healthcare system. The natural history, epidemiology, (both general and specific to Canada, where this research took place) and disease progression including specific issues for women are discussed. This chapter also provides an overview of the history of HCV treatment (combination therapy, response guided therapy, first generation protease inhibitors, second generation protease inhibitors, interferon-free therapies, and the most recent advancement in HCV treatments, the pan genotypic drugs). The chapter concludes with an insight into the Canadian Healthcare System and management of HCV within that system. Chapter Three comprises a summary of the relevant literature on the psychosocial issues and the barriers to accessing care associated with living with HCV, including specifically: the point of diagnosis, health literacy, relationship with healthcare provider, behavioural risks and stigma and discrimination related to drug use.

The research methods are detailed in Chapter Four including an overview of the Non-Attendance for Care Project (NACP) methodology and the National Advisory Committee. A reflection on my engagement with people living with HCV is also included. The chapter then focuses on my PhD Project – Women's Journey with Care including development of the research question, sample selection and demographics, analytic strategies and attending to narrative. The chapter concludes with a description of the methods used to ensure the quality of the research and its transferability.

Results of this research are presented in Chapters Five through Eight commencing with an overview of the sample characteristics. Chapter Six provides an analysis of Canadian women's experiences of receiving an HCV diagnosis and describes two interrelated themes: (1) how prepared the women were for their positive diagnosis, and (2) information and health education received at point of diagnosis. Chapter Seven identifies barriers throughout women's journey with HCV care focusing specifically on: (a) information provision, (b) family and caregiver responsibilities, (c) relationship with healthcare provider, (d) active substance use and (e) stigma and discrimination related to drug use. Finally, Chapter Eight presents an analysis of how women living with HCV make sense of their decision to attend for HCV care. I discuss three distinct stories that were evident in the women's narratives regarding events and their timing in their journey with care: (a) immediate crisis, (b) gradual sequence of awareness and (c) acquiring HCV through blood transfusions or vertical transmission.

Results are considered together in a detailed discussion in Chapter Nine. This final chapter concludes the thesis with a careful consideration of the implications the results may have for practice and policy and also the strengths and limitations of my research.

# CHAPTER 2 THE HEPATITIS C VIRUS

This chapter provides a summary of published literature relevant to HCV. There are eight sections: the discovery of hepatitis C, natural history of HCV, epidemiology of HCV, HCV in Canada, women and HCV risk, women and HCV disease progression, and a history of HCV treatment and HCV care in Canada.

## 2.1 The Discovery of Hepatitis C

HCV is an infectious blood-borne virus that primarily infects and replicates in the liver (Payne, Totten, & Archibald, 2014) and can lead to severe liver disease such as hepatic fibrosis, cirrhosis, end-stage liver disease and hepatocellular carcinoma (HCC) (Kong et al., 2014; Trubnikov, Yan, & Archibald, 2014). HCV was identified in 1989 as a small, single-stranded RNA virus. Following its discovery, HCV screening and diagnostic tests were developed and HCV became a reportable disease in Canada in 1990 (Ha, Totten, Pogany, Wu, & Gale-Rowe, 2016). Prior to HCV being identified, non-A non-B hepatitis was used to diagnosis a viral hepatitis occurring from a blood transfusion or intravenous drug use (IDU) and leading to a persistent infection and chronic liver disease, cirrhosis and HCC (Westbrook & Dusheiko, 2014). Subsequently, 70 to 90 percent of the non-A non-B hepatitis infections have been attributed to HCV (Alter, 1999).

## 2.2 Natural History

After exposure to HCV infected blood, acute HCV is generally asymptomatic, making diagnosis difficult, as many people are unaware they have been infected. Acute HCV syndrome occurs in approximately 20 to 30 percent of people, within 5 to

12 weeks of exposure and lasts 2 to 12 weeks (Chen & Morgan, 2006). Symptoms may include jaundice, nausea, abdominal pain, and flu-like symptoms.

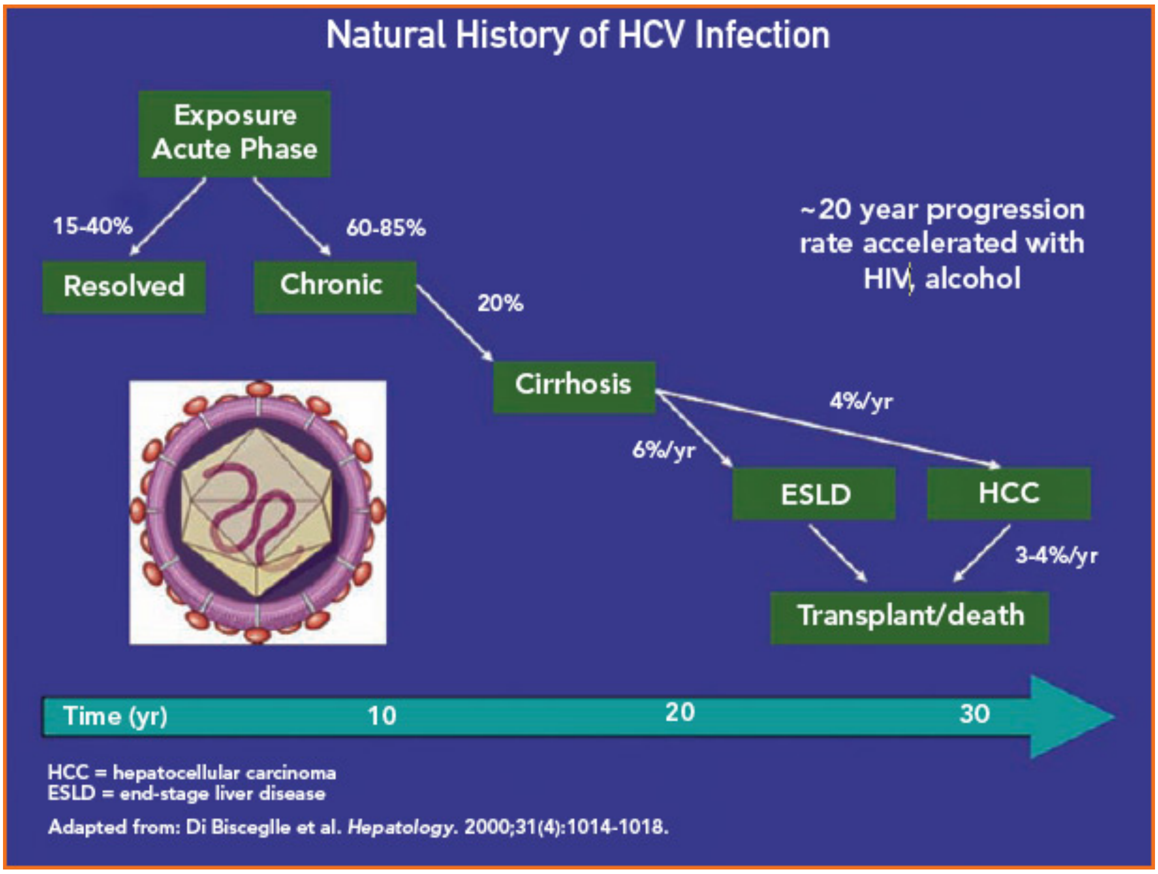
Approximately 15 to 50 percent of HCV infections will spontaneously resolve within six months of exposure (Public Health Agency of Canada, 2016); however, Hajarizadeh, Grebely, and Dore (2013) are more conservative on their estimate that 25 percent of individuals will experience spontaneous clearance (Figure 3). This variation in estimates can be related to the asymptomatic nature of HCV, which can make it difficult to identify new acute infections and study disease progression.

Age, gender and ethnicity have been shown to have an independent effect on spontaneous HCV clearance. A positive association between estrogen and spontaneous clearance has been shown indicating women in their reproductive years are more likely to have spontaneous clearance (McCombs et al., 2014; Poynard, Bedossa, & Opolon, 1997; Poynard et al., 2001). This will be discussed in further detail in Section 2.6.

A Canadian study found increased HCV clearance rates to be attributed to Aboriginal ethnicity and the female sex. Grebely et al. (2007) and Zhang et al. (2006) established clearance rates increased to approximately 45 percent among young women. This is consistent with Micallef, Kaldor, and Dore (2006) whose systematic review found women were twice as likely to clear HCV spontaneously (40%) compared to men (19%). More recently, Rao et al. (2012), reported on a cohort of Chinese plasma donors and, although they reported an overall lower clearance rate among their sample, they did find that spontaneous viral clearance in women was almost double that of men (26.3% vs 14.7%).

Chronic HCV infection damages the liver resulting in lethargy, nausea, pain, abdominal discomfort and jaundice (Webster, Klenerman, & Dusheiko, 2015). The risk of progression to severe liver disease such as hepatic fibrosis, cirrhosis, end-stage liver disease and HCC varies due to a number of host and environmental factors (Kong et al., 2014; Trubnikov et al., 2014). Factors that increase the risk of progressing to sever liver disease include mature age at infection, high levels of alcohol consumption, male gender, obesity, type 2 diabetes and co-infection with HIV or HBV (Hajarizadeh et al., 2013; Westbrook & Dusheiko, 2014). However, the presence of HBV appears to increase spontaneous clearance in the early stages of HCV infection (Kong et al., 2014), but exacerbate disease progression in chronic infection.

**Figure 3 – Natural History of HCV Infection**



HCC = hepatocellular carcinoma
ESLD = end-stage liver disease

Adapted from: Di Bisceglie et al. *Hepatology*. 2000;31(4):1014-1018.

## 2.3 Epidemiology of HCV Infection

HCV affects an estimated two to three percent of the world's population (Kong et al., 2014). Approximately four million people are newly infected with HCV annually and 170 million individuals are chronically infected with HCV worldwide (Myers et al., 2014). Since its discovery in 1989, HCV has been recognized as a major cause of chronic liver disease such as end-stage liver disease, HCC and other liver related deaths and is now considered to be one of the major causes of liver failure and transplantation in the developed world (Westbrook & Dusheiko, 2014). On estimate, over 350,000 people die each year from HCV-related liver diseases (Westbrook & Dusheiko, 2014; World Health Organization, 2012). In May 2016, the World Health Assembly endorsed the first-ever global hepatitis health sector strategy, acknowledging hepatitis as a health priority. The aim is to reduce new viral hepatitis infections by 90 percent and reduce viral hepatitis related deaths by 65 percent by 2030 (World Health Assembly, 2016).

HCV is genetically diverse; to date there are seven identified genotypes. The distribution of HCV genotypes varies by geographic region. Worldwide, it estimated that genotype 1 has a higher prevalence than any other HCV genotype at 83.4 million cases (46.2%) (Messina et al., 2015) with one-third being in East Asia. Genotype 3 is the next most common with estimates of 54.3 million (30.1%) cases globally. In most countries genotype 1 and 3 are dominant regardless of their economic status. However, in lower-income countries genotypes 4 and 5 are prominent. The remaining genotypes 2, 4, 5 and 6 are estimated to account for 16.5 million (9.1%), 15.0 million (8.3%), 1.4 million (<1%) and 9.8 million (5.4%) cases, respectively

(Messina et al., 2015). Globally, genotype 7 has only been reported once, in a Central African immigrant living in Canada (Messina et al., 2015).

## 2.4 HCV in Canada

It is estimated that 250,000 Canadians are infected with HCV (Borman & Swain, 2013; Myers et al., 2014) and, based on the most recent national surveillance data, 10,180 new HCV diagnoses were reported in 2012 (Payne et al., 2014). These rates are slightly higher than Remis' (2007) estimates of 7,900 new HCV infections in Canada each year. However, these Canadian HCV rates are thought to be an underestimate due to people remaining undiagnosed and because the affected populations are under-sampled (e.g., people who inject drugs (PWID), people on hemodialysis and immigrants who do not speak English or French) (Trubnikov et al., 2014). Due to the asymptomatic nature of HCV, people can remain undiagnosed for decades. There is wide variation in the estimates of the number of people who remain undiagnosed. Trubnikov et al. (2014) estimated that 44 percent of those living with chronic HCV were undiagnosed. However, this is almost double that of Krajden et al. (2010) who estimate that 20 percent of people with HCV remain undiagnosed. In 2011, 346 deaths in Canada were attributed to chronic HCV, however, this may also be an underestimate due to misclassification on death certificates when a more observable cause of death such as HCC or cirrhosis is the documented as cause of death (Ha et al., 2016).

HCV genotypes 1, 2 and 3 are the most common in Canada. Genotype 1 accounts for 65 percent of the cases, and genotypes 2 and 3 account for approximately 14 and 20 percent of cases, respectively. Genotypes 4, 5 and 6 are rare (<1% of all infections) in Canada (Myers et al., 2015).

It is estimated that 60 percent of all HCV cases in Canada are amongst PWID, 20 percent are amongst immigrants whom have been infected in their country of origin and 11 percent are amongst people who received contaminated blood products (Ha et al., 2016; Myers et al., 2015). Universal blood donor screening introduced in Canada in 1990 virtually eliminated new cases of HCV transmitted through blood transfusion (Chiavetta et al., 2003). The remaining nine percent of HCV infections in Canada are likely due to other risk factors, which include exposure to contaminated medical, dental or personal hygiene equipment, and vertical transmission from mother to child during pregnancy, or during delivery.

Despite increased knowledge and testing for HCV, medically acquired HCV continues to be a concern. For example, up to 270 people may have been exposed to HCV and HBV in Alberta between 2013 and 2015 when it was discovered that the steel instruments used in skin-invasive procedures had not been properly sterilized (Fitzpatrick, 2016). In 2011, the Ottawa Public Health Agency issued a warning, that over 6,800 people may have been exposed over a ten year period to HCV, HBV, or HIV while undergoing an undisclosed medical procedure (Spears, 2011). Given the chronic nature of HCV, these exposures from previous decades are a significant public health concern as they place a significant burden on the healthcare system, now and for years to come.

Although, between 2005 and 2013 the reported cases of HCV declined steadily in Canada (Myers et al., 2014; Public Health Agency of Canada, 2011, 2016) the number of existing cases that progress to serious liver disease continues to escalate. In Canada, 21.2 percent of liver transplants that occurred from 2003 to 2013 were in people that had a primary diagnosis of HCV (Canadian Institute for Health Information, 2014). HCV has also been ranked as one of the top most burdensome infections on the health of Canadians in terms of life years lost and reduced functioning (Kwong et al., 2010).

### 2.4.1 Populations at Risk in Canada

Specific groups suffering from extreme poverty, problematic substance use and social marginalization experience increased incidence and prevalence of HCV and ongoing barriers to care in Canada (Grebely et al., 2013a; Milne et al., 2015b). Using a combination of methods, Trubnikov et al. (2014) estimated the prevalence of chronic HCV and of undiagnosed people in Canada. They found former and current PWIDs and people who are homeless (approximately 1% of the total Canadian population), accounted for almost 44 percent of all chronic HCV-positive persons in Canada. These are populations that are often considered hard to reach and 'hidden' due to the associated stigma and illegal nature of the behaviour. People experiencing comorbidities such as chronic alcoholism, mental health issues, and high-risk behaviours have been identified as particularly vulnerable for HCV in Canada along with street youth, inmates in correctional facilities and Aboriginal Peoples (Dinner, Donaldson, Potts, Sirna, & Wong, 2005).

Although, men carry a disproportionate burden of infection (65% of all new Canadian HCV infections), the gender gap is narrowing, mainly due to the increasing incidents of new HCV infections in younger women (Communicable Disease

Prevention and Control Services, 2013; Ha et al., 2016). The Communicable Disease Prevention and Control Services (2013) reports that young women aged 15 to 29 years now exceed new infections compared to their male peers; women in this age category account for 60 percent of new Canadian HCV cases.

## 2.5 Women and HCV Risk

The issues that affect women living with HCV are multifaceted. This thesis will not examine participant's risk of acquiring HCV; however, information on the unique challenges that can potentially put women at an increased risk for acquiring HCV can enhance the understanding of women's journey with HCV care. Research clearly indicates that women are at a high risk of contracting HCV and other blood borne viruses. Few studies, however, have focused on the gender specific issues that increase women's vulnerability to acquiring HCV. Issues around IDU and the power relations between men and women are complex. Women are often on the bottom of the social hierarchy with fewer rights within injecting networks, limiting their ability to negotiate safer drug use and sexual practices (Bourgois, Prince, & Moss, 2004; Crockett & Gifford, 2004; Maher, 1997; Public Health Agency of Canada, 2009). A prospective study with more that 1500 PWID in Vancouver, Canada reported that women were more likely than men to require assistance to inject drugs which increased their risk or acquiring HIV and other bood borne virues (O'Connell et al., 2005). Women may be involved in at-risk behaviours such as shared injecting equipment and unprotected sex, to demonstrate trust and love to their partners (Bourgois et al., 2004; Martin, 2010). Research indicates that men and women have different access to drugs (Maher, 1997). Men often control the drug supply affording them power over women (Bourgois et al., 2004). This gendered power relationship along with violence within a relationship has been well documented as having negative impacts on women's health and their susceptibility to HCV (Bungay, Johnson, Varcoe, & Boyd, 2010; Evans & Mafubelu, 2009; Martin, 2010).

In Vancouver, Canada, Puri et al. (2014) undertook a prospective study on a cohort of 940 drug-using street-involved youth between 2005 and 2011 to examine gender-based differences in the risk factors of HCV. The rates of HCV seroconversions were measured six monthly to compare risk factors for HCV incidence between men and women street youth. Although the HCV transmission risk factors were similar for men and women, women had double the HCV incidence of men, thus emphasising the need to acknowledge the increased transmission risk for women and the differences in their journeys with HCV care.

Previous research has found women more likely to be involved in HCV risk behaviours such as shared injecting equipment and unprotected sex (Page et al., 2009; Wagner, Jackson Bloom, Hathazi, Sanders, & Lankenau, 2013). Batchelder, Masson, Sorensen, and Perlman (2015) examined gender differences in behavioural risks and if these differences relate to the high incidence of HCV among people living with severe mental illness. This study, conducted with people living with a mental illness in four sites in the USA, found women who inject drugs (WWID) had a higher prevalence of needle sharing, placing them at an increased risk of HCV compared to male PWID (Batchelder et al., 2015).

Puri et al. (2014) findings that men and women had similar HCV transmission risk factors were later validated by Batchelder et al. (2015) who undertook a randomized controlled trial on an adult population within two major cities in the

USA. Between 2008 and 2011, 489 participants from methadone maintenance treatment programs were recruited to analyse gender differences in PWID injecting risk behaviours. Similar to Puri et al. (2014), they found no significance difference in the risk behaviours between men and women. However, this could reflect parity in terms of risk behaviours or that the social stigma associated with these behaviours is more entrenched for women. Regardless of the similar risk factors these studies highlight that women are at high risk of acquiring HCV.

## 2.6 Women and HCV Disease Progression

HCV disease progression varies between men and women. Compared to men, women have higher rates of spontaneous clearance with acute HCV and lower rates of disease progression (Baden, Rockstroh, & Buti, 2014; Beste, Bondurant, & Ioannou, 2015).

Batches of anti-D immunoglobulin contaminated from a single HCV-infected donor and given to women in Ireland between 1977 and 1978 resulted in 704 women being infected with HCV (Kenny-Walsh, 1999). Of these 704 women, 390 continued to test positive for serum HCV RNA and all but 14 women continued to be followed. This study comprising of 376 women was the first to examine the natural progression of HCV liver disease over an extended length of time amongst a homogenous group. Their results found half of the women with chronic HCV had liver fibrosis, with 1.9 percent having cirrhosis. This study found a spontaneous HCV clearance rate of 45 percent amongst the exposed women compared to the 20 percent rate of the general population of men and women HCV-exposed population, indicating that women had higher rates of spontaneous clearance of HCV than men.

Studies since then have validated this finding, showing women are three times more likely than men to spontaneously clear the virus (Grebely et al., 2007; Page et al., 2009).

Levine et al. (2006) conducted a retrospective-prospective study with 184 untreated women from the same cohort of infected Irish women, to provide further insight into the natural history of HCV. Baseline liver biopsy specimens taken in 1994 were assessed and compared to consecutive biopsy specimens for grade change and stage progression or regression. Their findings showed mixed results with a positive correlation between baseline and successive grade/stage scores. Variables such as alcohol, smoking, herbal supplements and paracetamol use were not found to influence the outcomes. In a follow-up study twenty-four years post-infection, almost half (49%) of the participants showed no change in fibrosis, 24 percent showed regression, and only 27 percent showed progression (Levine et al., 2006). Of the 27 percent of women who showed progression, only 2.1 percent displayed evidence of cirrhosis. Although other factors, such as alcohol and smoking, were not found to influence the outcomes, nearly one-third of the women had at least one other HCV transmission risk factor, thus the source and timing of their HCV exposure is not definitive. These finding were novel at the time and suggested that women living with HCV had low rates of progression to cirrhosis. However, given most of the women were in their fifties at the time of the study and the natural slow progression of HCV, the results may have been too premature to be conclusive and it is possible that these women could still advance to more severe liver disease.

Wiese et al. (2005) conducted a similar longitudinal study in Germany. A cohort of 2867 women infected peri-partum with contaminated batches of anti-D immunoglobulin between 1978 and 1979. Twenty-five years after infection, 1,980 women (69% of the cohort) were examined and only nine women (0.5%) had developed cirrhosis. In a follow-up study thirty-five years after infection, the rate of disease progression with evidence of cirrhosis had increased to 9.3 percent (Wiese et al., 2013).

A retrospective analysis on this cohort of women found that in women of reproductive age, HCV related liver disease progressed slowly, however, after menopause progression increased significantly (Villa et al., 2012). These results challenged the conclusions made by the Irish studies (Kenny-Walsh, 1999; Levine et al., 2006) and suggest that the low rates of cirrhosis in women is linked to their reproductive status and estrogen levels and therefore would change over time. These findings have been replicated in subsequent studies examining the association between female sex and reduced rates of disease progression, indicating that progression of liver disease is slow for women in their reproductive years but hastens post menopause (McCombs et al., 2014; Poynard et al., 1997; Poynard et al., 2001).

Further studies have contested the positive correlation between female sex and reduced rates of disease progression showing no association at all (Benhamou et al., 1999; Hisada, Chatterjee, Kalaylioglu, Battjes, & Goedert, 2005). Despite this small body of opposing evidence, the current consensus is that there is a correlation.

## 2.7 HCV Treatment

There have been major advancements in HCV treatments over the last three decades. Although this thesis does not explore women’s experience with HCV treatment specifically, it is important for context to acknowledge the advancements in HCV treatments over the last decades, starting with interferon alpha therapy to where we are today with Pan genotypic drugs. My study highlights important learning's on how these treatment advancements impacted the women's journey with care.

### 2.7.1 Background Information on HCV Treatment

Effective HCV treatments can alter the natural history of HCV, thereby reducing the impact of liver disease and its complications among people living with the virus. The goal of HCV therapy is to achieve a sustained virological response (SVR), defined as the absence of detectable virus in the blood 24 weeks after the end of therapy. Achieving an SVR is associated with a reduction in liver-related mortality from HCV.

For many years, standard treatment was a 48 weeks schedule comprised of a combination of Interferon injections and oral medications (Ribavirin); a therapy that was difficult to tolerate and frequently unsuccessful due to its significant toxicity (Liang & Ghany, 2013). Recently, HCV treatments have undergone dramatic advances such that it is now considered a curable disease (World Health Organization, 2012). However, given the high cost of these drugs and rigorous eligibility requirements, access to these new treatment remains limited in many parts of the world including Canada (World Health Organization, 2012).

### 2.7.2 Early HCV Treatment Options

The earliest HCV treatment study was undertaken before the HCV was isolated. It involved those diagnosed with non-A non-B hepatitis and evaluated various doses of interferon-alpha therapy for 48 weeks (Hoofnagle et al., 1986). This was the first study to suggest long-term, low-doses of interferon alpha therapy could be effective in reducing the disease activity in some patients with chronic non-A non-B hepatitis. Following this, there were a number of randomized controlled trials investigating chronic HCV treatment (Lindsay, 1997) and in 1997 the National Institute of Health Consensus Development Conference was held on the management of HCV. Guidelines for the diagnosis and management of chronic HCV were established recommending interferon alpha for 12 months as the standard of care treatment (Ahmed & Keeffe, 1999).

Efforts to find other therapies for the treatment of HCV led Reichard, Andersson, Schvarcz, and Weiland (1991) to conduct the first clinical trial of ribavirin which showed significant reductions in alanine aminotransferase (ALT) liver enzymes, a measurement of liver damage. Subsequent studies demonstrated that although ribavirin improved ALT levels, there was little impact on viral replication (Di Bisceglie et al., 1992; Dusheiko et al., 1996; Reichard et al., 1991).

### 2.7.3 Combination Therapy

During this time Brillanti et al. (1994) were also investigating the efficacy of interferon alpha in combination with ribavirin and demonstrated that up to 40 percent of participants achieved an SVR. Results were replicated in further trials (Fried et al., 2002; Hadziyannis et al., 2004; Manns et al., 2001; McHutchison et al., 1998; Poynard et al., 1998), resulting in interferon alpha and ribavirin combination therapy as the mainstay for HCV treatment. Despite these promising results, this combination treatment had significant side effects that many people found debilitating, leaving several unable to complete the treatment course (Webster et al., 2015).

### 2.7.4 Response Guided Therapy

As HCV treatments were evolving, HCV virologic testing became an important tool for the diagnosis and assessment of a person's response to treatment. Treatment began to be tailored based on the HCV genotyping and virologic response during therapy. HCV genotyping guided the duration of treatment, the dose of ribavirin and the virologic monitoring procedure required (Seeff & Hoofnagle, 2003). Virologic testing during treatment provided important indicators as to how the person would respond to therapy. Treatment could be discontinued early for individuals showing a low chance of achieving an SVR thereby limiting the toxicities and cost associated with the full duration of treatment (Dalgard & Mangia, 2006). Pegylated interferon was also approved during this time. Pegylated interferon monotherapy, which was dosed by the person's body weight, had SVR rates of 14 percent for genotype 1, and 47 percent for genotypes 2 and 3 (Fried et al., 2002).

### 2.7.5 First Generation Protease Inhibitors

In 2011, almost a decade after the combination therapy was approved, two new triple therapies emerged – telaprevir and boceprevir for the treatment of chronic HCV genotype 1 to be used in combination with interferon alpha and ribavirin (Giordano, 2012). These first generation protease inhibitors (PI) increased the treatment response rates in people with genotype 1. The boceprevir trial (Bruno et al., 2011; Poordad et al., 2011a), showed 67 percent of participants achieving SVR after only 28 weeks of treatment. Studies of telaprevir showed SVR rates as high as

92 and 88 percent with 24 and 48 weeks of treatment (Poordad et al., 2011b). Further studies demonstrated similar SVR rates of 29 to 33 percent in prior null responders and 83 to 88 percent in prior relapsers, people who became undetectable for HCV RNA during treatment, however when treatment ceased the HCV RNA became detectable (Jacobson et al., 2011; Zeuzem et al., 2011). Treatment with both these first generation PIs was complicated with significant adverse events and serious interactions with other medications (Giordano, 2012).

### 2.7.6 Second Generation Protease Inhibitors

Treatments for HCV changed rapidly as the second wave of PIs appeared that enabled once daily dosing and the possibility of shorten treatment time. In 2013, Simeprevir and Sofosbuvir were launched and used in combination together or in combination with interferon alpha and ribavirin. Results were favourable in those with genotype 1. In further trials, simeprevir was given for 12 weeks, with peginterferon and ribavirin for 24 weeks; 80 to 81 percent of participants achieved an SVR (Jacobson, Dore, & Foster, 2014; Manns, Marcellin, & Poordad, 2014). Sofosbuvir trials were expanded to participants with HCV genotypes 1, 2, 3 or 4, given with peginterferon and ribavirin for 12 weeks, SVRs were shown in 90 percent of genotype 1 and genotype 4 (Lawitz et al., 2013). In participants with genotype 2 and 3, for whom treatment with ribavirin was not an option, 78 percent of trial participants achieved SVR (Jacobson et al., 2013).

### 2.7.7 Interferon-Free Therapies

HCV treatments have continued to improve with the ultimate aim of all-oral interferon-free treatments, with reduced side effects, increased SVR rates and shortened treatment duration. Eliminating interferon will reduce the debilitating side effects many experience from the treatment.  In 2014, the first interferon-free once daily pill, Harvoni (ledipasvir/sofosbuvir) (Afdhal et al., 2014) was approved for the treatment of HCV genotype 1 infections, which had SVR rates of 99 percent in different subgroups for treatment naïve participants after 12 weeks of treatment (Afdhal et al., 2014). Soon after, Viekira Pak (ombitasvir/paritaprevir/ritonavir and dasabuvir) was approved as an oral combination therapy for genotype 1, including those with compensated cirrhosis (Webster et al., 2015). In trails this combination showed similar SVR rates to Harvoni of 95 to 100 percent (Deeks, 2015).

### 2.7.8 Pan Genotypic Drugs

In 2016, Epclusa (sofosbuvir/velpatasvir) was announced as the first all-oral, single tablet regimen for the treatment of adults with genotypes 1-6 (Younossi et al., 2016). Epclusa is the first single tablet ribavirin-free regimen for the treatment of people with HCV genotype 2 and 3. In trials, 98 percent SVR rates were achieved with 12 weeks of treatment and 94 percent SVR rates in people with decompensated cirrhosis (Younossi et al., 2016).

Until recently, many people lived with untreated HCV for decades, as they were ineligible for treatment or were unable to tolerate it. When I conducted this research in 2011, new treatments were starting to emerge, which were less toxic and more effective with cure rates of 95 percent. However, many of the women in my study spoke of their own experiences with the past interferon therapy and the barriers to access these treatments or stories they had heard from others. These experiences are important to acknowledge, as they were significant in the women's journey with care and can continue to affect their ongoing access to healthcare services in the future. Although these new HCV treatments have shifted the focus from living well with HCV to curing and even potentially eliminating HCV in the near future (Ha et al., 2016), until these new treatment's are accessible to all in Canada, access to treatment will continue to be a barrier and women will continue to live with untreated HCV.

## 2.8 HCV Care in the Canadian Healthcare System

Canada has a universal health insurance system that provides coverage for preventative care and medical services, without charge at the point of service to all Canadian citizens who hold proof of registration with a provincial healthcare system. This publicly funded medical coverage is administered by each provincial or territory government within federal government guidelines (Health Canada, 2011). Information on the Canadian Healthcare system helps to contextualize my study and adds to the understanding of factors influencing the women's journey with HCV care.

### 2.8.1 HCV Care in Canada

During the time when the participants in this study were on their journey with care, the majority of their HCV care and follow-up services were received at the first point of contact with healthcare services (e.g. primary health clinic, their GP or methadone doctor) (Zevin, 2007). HCV specialists were accessed for complex disease management of advanced disease and the provision of anti-viral therapy. Treatment was difficult to access as there were strict eligibility criteria, which included liver disease staging. Standard treatment was a combination of Interferon injections and oral medications (Ribavirin) given for up to 48 weeks; a therapy that was difficult to tolerate and frequently unsuccessful due to its significant toxicity (Liang & Ghany, 2013).

### 2.8.2 Access to HCV Treatment in Canada

Canada is the only developed country with a universal health insurance system that does not include universal coverage of prescription drugs (Morgan, Law, Daw, Abraham, & Martin, 2015). Each provincial government determines the medications that will be funded, resulting in an inconsistency in access to HCV treatment across Canada (Morgan et al., 2015). The only federally funded program that offers coverage for HCV mediation is Canada's Non-Insured Health Benefits (NIHB) Program. This program provides assistance with HCV medication coverage to First Nations and Inuit people who are not eligible for coverage by their provincial medical benefits. Dutt (2014) has argued that Canada’s lack of universal drug coverage is a serious weakness in the healthcare system. This contention is supported by the work of Morgan et al. (2015) whose findings reveal that due to the provincial variations in drug coverage, approximately 10 percent of Canadians cannot afford to take their prescribed medications due to the costs thereby creating barriers to accessing prescription drugs.

Women in this study were recruited from three provinces that have different drug coverage and therefore different access to care. In each province the eligibility criteria for HCV treatment are complex and depend on a person’s genotype, treatment experience and disease stage. In British Columbia, publically funded drug plans are provided through PharmaCare, the central agency responsible for regulating the coverage of prescription drugs and medical supplies. HCV medication coverage must be pre-approved for each person based upon specified criteria and evidence of their stage of liver disease. This process requires the person’s specialist to complete and send a Special Authority Request form for review to PharmaCare. When approved, the amount of coverage for HCV treatment will vary depending on the person’s income and their PharmaCare plan (BC Ministry of Health, 2016).

Ontario has two main provincially funded drug coverage benefit programs that may assist with covering the cost of HCV medication: the Ontario Drug Benefit Program (ODB) and the Trillium Drug Program (TDP). Approval for coverage of HCV medications must be received from the Exceptional Access Program (EAP) before they are paid for by one of the funded drug programs. The process requires a person’s HCV specialist to submit a request for HCV medication coverage to the EAP for review against specific eligibility criteria. If approved people will receive coverage for HCV medication for a specific length of time (Ontario Ministry of Health and Long Term Care, 2016).

There are four main publicly funded Pharmacare programs in Nova Scotia: the Department of Community Services – Pharmacare Benefits, Family Pharmacare Program, Seniors Pharmacare Program and Drug Assistance for Cancer Patients. The first three programs offer coverage for HCV medications. Before receiving coverage from the Pharmacare programs for HCV medication, approval must be obtained for Exceptional Status Drugs. HCV specialists must complete and submit the Standard Exception Drug Form to Pharmacare for review against the certain complex criteria for coverage. Approval will provide coverage for one full course of treatment (Department of Health and Wellness, 2013).

## 2.9 Conclusion

This chapter offered an overview of the natural history and epidemiology of HCV from both a global perspective and within Canada. It demonstrates how the asymptomatic nature of HCV means many people are unaware they are living with HCV. This is concerning as it masks the true extent of the burden of this disease.

The advancements in HCV treatment over the past three decades - the shift away from the interferon-based therapies, which have severe side-effect, long durations and low efficacy rates, to all oral interferon-free treatments and pan genotypic drugs – have dramatically increased the possibility of a cure for many.

Canada's lack a National Medicare program and the strict Provincial eligibility requirements for HCV treatment means women seeking HCV care through the Canadian Healthcare System face many barriers. There is considerable inequity across the country, when it comes to accessing the new treatments.

Women living with HCV have unique risk factors and disease progression. On the one hand estrogen has been shown to have a positive correlation with slower disease progression; younger women living with HCV may have a better prognosis. On the other hand, incidents of new HCV infections are rising among young women aged 15–29 years and their unique risk factors can potentially put women at an increased risk for acquiring HCV. This highlights how important it is to attend to the specific experience of women's journey with care.

# Chapter 3 What we know about Women Living with HCV and Healthcare

This chapter provides a summary of the literature on the multifaceted issues that affect women living with HCV. I will begin with an exploration of the research on the psychosocial issues that affect women living with HCV. Following that, I will explore research on the barriers to HCV care and provide an overview of five barriers to HCV care that can contribute to nonattendance to HCV care: the point of diagnosis; health literacy; relationship with healthcare provider; mental illness and active substance use; and stigma and discrimination related to drug use.

## 3.1 Women Living with HCV

Women's experiences and concerns about living with HCV have been identified as an under-researched area (Olsen et al., 2013). Women have unique challenges to consider such as the impact HCV will have on child-bearing with the potential for vertical transmission to their children (Beste et al., 2015) and the contraindications of HCV treatment during pregnancy and breast-feeding. As mentioned previously, (Chapter One) in Canada incidence of new HCV infections are rising among young women aged 15 to 29 years (Communicable Disease Prevention and Control Services, 2013; Public Health Agency of Canada, 2011). This increased diagnosis in young women has been associated in part with increased testing among the growing number of women accessing healthcare for reproductive issues and pregnancy care (Communicable Disease Prevention and Control Services, 2013; Public Health Agency of Canada, 2011), although the exact reasons remain unknown. There are well-documented gender differences for chronic blood-borne infections. These differences play a fundamental role in risk exposure, ability to access care, support and treatment (Bungay et al., 2010; Evans & Mafubelu, 2009; Zierler & Krieger, 1997). The available literature on the impact of gender on HCV disease progression indicates the gender stereotypes linked to domestic and occupational roles can reduce women’s access to key resources such as education, income and employment (Vogel & Bagshaw, 2016).

Australian research identified gender-related differences in response to living with HCV. Temple-Smith, Gifford, and Stoove (2004) found that women without symptoms sought out care for their HCV and were more willing to discuss their needs for information and social support than men. HCV featured strongly in the women’s everyday life, even when they were physically well. The women often described their social circumstances and judgement from healthcare providers related to their HCV. Comparable to this study, Crockett and Gifford (2004) identified key issues that women believe impacted negatively on their lived experience with HCV. The women in their study described feelings of shame and experiences of social exclusion, marginality, stigma and discrimination. Women with a recent diagnosis experienced parallel issues to the women diagnosed 8 to 10 years earlier (Crockett & Gifford, 2004). However, the study was limited to women who were currently or had a history of injecting drugs, so the stigma and discrimination associated with drug use may have influenced the care at diagnosis.

Nearly a decade after Crockett and Gifford (2004) and Temple-Smith et al. (2004) conclusions, Olsen et al. (2013) found the specific needs of women living with HCV remained under-researched. Olsen and colleagues’ (2013) qualitative research looked at 109 women living with HCV in two major Australian cities. Their study identified issues related to care and support for women around diagnosis and HCV management due to social positions and physiological differences. For example, HCV testing is offered as part of the prenatal check-up in Australia, however, as with the earlier studies, Olsen et al. (2013) found that women described feelings of being judged, receiving insensitive medical care and felt discriminated against by healthcare providers. Common in the women's narratives were issues related to poverty and homelessness, and worries related to their child's well-being and their ability to be a good mother in these circumstances. However, unlike Temple-Smith and colleagues' (2004) findings, women in the Olsen et al. (2013) study who had been diagnosed more recently reported they had received appropriate counselling and information, although they felt it was given insensitively and they also felt judged. The differences in the findings between these studies however, may be explained by the ten-year gap between studies. In early 2000 when Temple-Smith et al. (2004) interviewed participants, information and knowledge about HCV was limited. Olsen et al. (2013) findings are hopeful as they suggest that the information provided at the point of diagnosis in Australia has improved over the last decade.

## 3.2 Barriers to Care

Social exclusion and marginalisation coupled with stigma and discrimination have been well documented as creating a barrier and preventing people living with HCV from receiving adequate care (Iversen, Page, Madden, & Maher, 2015; Temple-Smith et al., 2007). Research undertaken over the past three decades during the interferon/ribavirin era of treatment, when treatment efficacy was low and toxicity high, identified these negative aspects of treatment were major barriers to care (McGowan et al., 2013). Since many of the participants in my study experienced treatment (personally or through witnessing others' experiences) during the interferon/ribavirin era, treatment will be considered as a potential barrier to attending to care in this thesis.  Regardless, if women living with HCV receive the new emerging treatments, which have far fewer, if any, side effects (Brennan & Shrank, 2014), the challenge remains: how to reduce the complex barriers to care and successfully treat those women living with HCV.

Literature on factors influencing attendance and nonattendance with HCV care is limited. What is available, however, is consistent with the research addressing other chronic diseases and involves the complex interplay between the patient, the provider, and the healthcare system (refer to Chapter Four - The Socio-Ecological Model) (Paterson, Charlton, & Richard, 2010). In Canada, we undertook the first study to explore the reasons for nonattendance for HCV care throughout the disease course (Butt, McGuinness, Buller-Taylor, & Mitchell, 2013) (The Non-Attendance for Care Project will be described in Chapter Four). In 2011, 84 patients and health and social care providers were interviewed across Canada via telephone interviews and focus groups. Nonattendance was defined as occasions when patients did not attend appointments, delayed or deferred care. Although patient and provider data was analysed separately, the findings were consistent with each other (Butt et al., 2013). Six themes were identified that contributed to nonattendance at various points along the disease course. The first four themes were centred around the patient and provider at the individual and interpersonal levels and involved patients' self-protection, a need to determine the benefits of HCV care; other competing priorities in their life (e.g. such as drug use), and HCV knowledge gaps. The final two themes were associated with the organisational and policy levels and included access to services and restrictive policies (Refer to the Socio-Ecological Model, Figure 4).

Butt and colleagues' (2013) results identified clinical practices and policy changes necessary to increase engagement and retention into care for people living with HCV. Participants indicated they would be more likely to attend to HCV care if they were treated in a respectful way by a knowledgeable healthcare provider. These findings highlight the importance of providing education and care to people living with HCV that addresses their individualised psychological and socio-cultural needs, as well as ensuring those healthcare providers who manage their care are educated and respectful. These results suggest that many of the reasons for nonattendance can be eliminated with improved models of care that include low barrier, nonjudgmental, and integrated services. This information is valuable as it can inform interventions aimed at engaging and retaining people living with HCV across the cascade of care (refer to Figure One).

In Scotland, Astell-Burt, Flowerdrew, Boyle, and Dillon (2012) conducted a quantitative study between 1991 and 2003, which explored if travel time was associated with increased non-attendance for people living with HCV. The information was collected from people living with HCV that were referred to and utilized a single HCV specialist clinic. A correlation between travel time and non-attendance was not found, although other factors were identified, which included a past or current IDU, a younger age, and those living in deprived areas.

### 3.2.1 The Point of Diagnosis

A woman's level of HCV knowledge can influence her HCV outcomes

(Glacken, Kernohan, & Coates, 2001). As information on HCV management and treatment was evolving, Treloar, Newland, Harris, Deacon, and Maher (2010b) examined the diagnosis experiences of 24 Australians diagnosed with HCV between 2006 and 2009. Overall, the HCV diagnosis experience was poor. Narratives were characterised by confusion in relation to tests that were performed and the implications of test results. Post-test discussions were inadequate, with a lack of information, support and referral provided to participants. The authors concluded that the impact of a negative diagnosis experience for patients is serious, potentially with long-term implications. Although this study was conducted when HCV knowledge was improving, the findings were similar to Hopwood and Treloar (2004) who examined people diagnosed with HCV over 10 years earlier between 1989 to 2001 in Australia. Findings from both studies highlight areas of suboptimal diagnosis experience, which then create barriers along the journey with HCV care as people are unaware of the need to attend to care (Hopwood & Treloar, 2004; Treloar et al., 2010b). The barriers potentially reduce HCV follow-up and management and increases fear of the disease and generate feelings of loss of control over one's health.

Studies on the experience of diagnosis within a specific population have had varied results. In a study on the impact of an HCV diagnosis on 17 homeless PWID (15 men and 2 women) in the north of England, Tompkins, Wright, and Jones (2005) showed similar results to Treloar et al. (2010b). Participants described feelings of shock, disbelief and anger when receiving a positive HCV diagnosis. Years after their initial diagnosis, participants continued to describe the lasting social, emotional, and psychological effects the result had for them.

More recently, however, an Australian study, that examined the link between identity and health, focusing on WWID living with HCV (Olsen, Banwell, & Dance, 2012) challenged the negative impact of an HCV diagnosis. Olsen et al. (2012) found only a small number of women had an unexpected and frightening experience of diagnosis. For the majority of women, an HCV diagnosis was perceived by them to be inevitable. It reinforced rather than challenged their identity as a PWIDs. Moreover, HCV was identified as 'insignificant' compared to the dangers of drug use, suggesting that HCV had become normalised amongst the PWID, a concept previously identified by Davis, Rhodes, and Martin (2004).

The difference in these finding (Olsen et al., 2012; Tompkins et al., 2005) might be explained by the time lapse between studies. The evolving knowledge and increased rates of HCV for WWID may have shaped this normalisation attitude. Another explanation could be related to the gender difference, as women were underrepresented in Tompkins et al. (2005) study. Nevertheless, these findings expanded the findings of previous research and demonstrate that the experience of HCV diagnosis cannot be generalised across populations.

### 3.2.2 Health Literacy

Health literacy, the degree to which a person is able to obtain, process, and understand basic healthcare, has a significant impact on healthcare outcomes (Remshardt, 2011). A few studies have explored the positive impact HCV knowledge can have on health outcomes and engagement into care for people living with HCV (Glacken et al., 2001). Between 2007 and 2009, Surjadi et al. (2011) conducted a study in San Francisco with 201 people living with HCV to assess the impact of formal

HCV education. Of the 201 participants who attended the HCV education sessions, 197 completed both the pre- and post-education questionnaires. The majority of participants were unemployed middle-aged men. Their findings indicated HCV education improved patient knowledge and attendance rates to liver clinics in a diverse population compared to those who were not offered the disease-specific education. Their results demonstrated the importance of HCV education for all people living with HCV as it can increase their readiness, willingness and acceptance of care and treatment. These findings were supported by Olsen et al. (2012), who demonstrated the positive impact of good HCV education for women living with HCV.

### 3.2.3 Relationship with Healthcare Provider

Research suggests that healthcare providers' attitudes can be a barrier and affect the willingness and acceptance of people living with HCV to attend for care (Butt et al., 2013; Temple-Smith et al., 2004; Trachtenberg, Dugan, & Hall, 2005). In an early Australian qualitative study on the experiences of 12 men and 20 women living with HCV, gender related differences were identified as influencing engagement and interactions with healthcare providers. Temple-Smith et al. (2004) showed healthcare providers' attitudes compromised the women's ongoing trust and engagement into healthcare services, which resulted in a barrier to, and future avoidance of, healthcare services.

Similarly, another Australian study found women reported higher rates of negative treatment related to their HCV and perceived discrimination from healthcare providers, than men (Temple-Smith et al., 2007). Conversely, some of the women in this study had well-established trusting therapeutic relationships with their healthcare provider, which positively influenced their ongoing care. These women, despite feeling discriminated against because of their HCV, persisted and were successful in finding a supportive healthcare provider. The results from both studies (Temple-Smith et al., 2004; Temple-Smith et al., 2007) reinforce the importance of therapeutic relationships, especially in the primary care environment, for people living with HCV.

Relationships with healthcare providers have a particular significance for women. Olsen and colleagues' (2013) research into the experience 109 women living with HCV found women encountered misunderstanding and confusion among healthcare providers around HCV, pregnancy and breastfeeding. This created a distrust of and lack of confidence in the healthcare provider and ultimately served as a barrier into HCV care. Despite these barriers, there was a determination within the women to look after themselves, attend to their healthcare needs and to get their life in order for their family and children.

### 3.2.4 Behavioural Risks

Mental illness and active substance use are complex barriers to HCV management and access to care. As mentioned earlier in Chapter Two, Batchelder et al. (2015) undertook the first study to examine gender differences in behavioural risks and if these differences relate to the high incidence of HCV among people living with severe mental illness. This study, conducted on people living with a mental illness in four sites in the USA, found WWID had a higher prevalence of needle sharing, placing them at an increased risk of HCV compared to male PWID

(Batchelder et al., 2015). Batchelder et al. (2015) also found the women to have higher prevalence of sexual risk behaviours, including unprotected sex in exchange for drugs, although this was not found to be an independent transmission risk for HCV in this study.

Other studies, however, have argued that sexual transmission of HCV amongst women is evident (Cilla, Perez-Trallero, Iturriza, Arrizabalga, & Iribarren, 1991; Hershow, Kalish, Sha, Till, & Cohen, 1998). An American study on HIV-infected or at-risk women in Chicago, found sexual risks, in combinations with a history of gonorrhoea or sex with a PWID, was associated with HCV (Hershow et al., 1998). Similarly, a study of men PWID, Cilla et al. (1991) found 10 percent of the men's non-injecting female partners were HCV positive. These studies were important as they introduced the risk of sexual transmission and HCV and the need for further investigation in this area.

### 3.2.5 Stigma and Discrimination Related to Drug Use

HCV is a highly stigmatised disease largely due to its close association with drug use (Anti-Discrimination Board of New South Wales, 2001; Day, Ross, & Dolan, 2003; Puplick, 2001). One of the first studies to define the levels of stigmatisation for people living with HCV was in the USA between 1998 and 2001. Zickmund, Ho, Masuda, Ippolito, and LaBrecque (2001) investigated 260 people diagnosed with HCV for the effects of stigmatisation on their quality of life. One hundred and forty-seven participants described a high prevalence of stigma related to its close association with injecting drug use, which had a negative impact on their quality of life. Similar findings were described by Butt, Patterson, and McGuiness (2008) in their Canadian study, which looked at the day-to-day life experiences, perceptions and responses of people living with HCV, confirming that the stigma, people with HCV experienced resulted from misconceptions about transmission and its association with drug use. These results highlighted a significant issue for people living with HCV. Although, differences if any, on how stigma is experienced by women and men was not considered in this study. Zickmund et al. (2001) did find, however, that women were more likely to report stigmatisation than men and urged for further research on the influence of gender on negative stereotyping.

Reid and Day (2015) have argued that women may be more adversely affected by such stigma given typical gender roles and social expectations of women who are typically the primary care givers to children. Iversen et al. (2015) also identified social norms and the role of women as primary caregivers resulted in WWID often experiencing additional, stigma and discrimination, and others have noted that this may occur from within drug using networks (El-Bassel, Wechsberg, & Shaw, 2012). This additional stigma towards WWID on multiple levels can result in isolation from peers and support for fear further stigmatisation, ultimately increasing vulnerability (El-Bassel et al., 2012). The unique needs of WWID therefore warrant further investigation.

A 2013 systematic literature review found HCV stigma was most commonly reported in healthcare settings and was closely linked to adverse health outcomes and poor, reduced and/or limited health access (Treloar, Rance, & Backmund, 2013), which has been supported in other research (Butt et al., 2013; Temple-Smith et al., 2004; Trachtenberg et al., 2005). Although these studies did not focus exclusively on women’s experiences, the findings highlight the urgent need to address the stigma experienced within healthcare settings. The fear of future experiences of stigma and discrimination from healthcare providers could prevent people living with HCV from seeking appropriate care and negatively impact future healthcare engagement.

## 3.3 Conclusion

The research available focusing on women and their experiences of living with HCV has emphasised the significant impact of the infection on their everyday lives demonstrating substantial individual and social costs (Olsen et al., 2012). There is an absence, however, of research on women’s life experiences along their journey with HCV care.

Women appear at greater risk of acquiring HCV, they are more likely than men to spontaneously clear the virus and, depending on their reproduction stage, may be less likely than men to progress to HCV-related liver disease (Iversen, Wand, Gonnermann, & Maher, 2010; Page et al., 2009). However, given the social positioning of women and the related HCV stigma, further research on the impact of gender on HCV remains necessary to ensure timely and appropriate gender-specific care and management (Olsen et al., 2013).

Major advances in interferon-free HCV treatment has given new hope for less burdensome treatments of shorter duration that can effectively promote and protect the health of women living with HCV and even potentially eliminate HCV in the near future (Ha et al., 2016). However, this requires that all people living with HCV attend for care in order to receive these treatments. Missing the opportunity to access HCV care and treatment can have potentially devastating consequences for the health of individuals, communities and health system resources. Therefore, there is an urgent need to better understand the complexity of factors influencing attendance for care among women affected by HCV, without which, the design of more effective health policies and practices to promote HCV care may be seriously undermined.

# CHAPTER 4 METHODS

## 4.1 Introduction

During 2011-2012, when the data for this thesis was collected, I was employed at the British Columbia Center for Disease Control (BCCDC) as a Nurse Educator with expertise in HCV care. As part of this role, I worked on a two-year qualitative NACP that explored the reasons why people attend, delay, defer or do not seek HCV care in Canada. The research design and specific methods of data collection, sampling and recruitment strategies for this thesis were conducted under the auspice of the NACP.

This chapter will detail the overall study methods and approaches of the NACP and explain how this dissertation fits within this larger project. This chapter is divided into two sections. The first section describes the methodological approach, the research setting, recruitment, sampling, analysis, informed consent and ethical considerations of the NACP and thus provides the context for the analysis presented in this thesis. The results for the NACP will not be discussed in this thesis however further details can be found in the NACP Report (Butt et al., 2013; Butt, McGuinness, Mitchell, & Peltonen, 2012). The second section describes the analytic strategy for the thesis, which focused on women living with HCV journey with care. The chapter concludes with a discussion of the transferability and reliability of the research.

## 4.2 The Non-Attendance for Care Project (NACP)

### 4.2.1 Context

The NACP was a two-year community-based project led by a research team at the BCCDC and sponsored by the Public Health Agency of Canada (2011-2013). The research team consisted of a Nurse Manager, an Anthropologist and myself a Nurse Educator. The study explored the reasons why people attend, delay, defer or do not seek HCV care in Canada. Using the socio-ecological model as a framework (refer to 4.2.2 for more details), the research study aimed to establish the personal and health system factors that contribute to non-attendance for HCV care (Butt et al., 2012). The findings would then be used by the project team at the BCCDC and the National Advisory Committee to determine the types of strategies and resources that could increase attendance for HCV care in Canada.

### 4.2.2 The Socio-Ecological Model

The social ecological model is a theoretical framework often used in health promotion to gain an understanding of factors that affect health and wellness at varying levels surrounding individual, groups and populations (Golden, McLeroy, Green, Earp, & Lieberman, 2015). A five level social ecological model was used as a framework for the NACP to better understand the reasons individuals with HCV do not attend for HCV care from the personal, interpersonal, and systems level. This model suggests that the relationships between individuals and societal systems are multifaceted and interactive and that people’s health and behaviours are shaped by multiple factors influenced by five different levels: individual, interpersonal, organizational, community, and public policy levels (Figure 1: (Bronfenbrenner, 1977).

*The Individual* - this is the first level, which identifies the biological and personal history factors that may affect people living with HCV. These factors include age, education, income, and/or substance use.

*The Interpersonal Level* - is the second level, which considers relationships with peers, partners and family members that can influence an individual's behaviour and impact their journey with HCV care.

*The Organizational, Community and Public Policy Levels (Institutional)* - these remaining three levels explore the settings and institutional factors. They include healthcare clinics, models of care and health and social policies

The model allows for a multi-layer complex view of the range of factors that can influence people's overall journey with HCV care (Golden & Earp, 2012). It is important to acknowledge that the layers are complex and commonly interlinked.

**Figure 3 – The Socio-Ecological Model (Adapted from (Bronfenbrenner, 1977).**

### 4.2.3 National Advisory Committee

The NACP was guided by a National Advisory Committee that included those affected by HCV, health and social care providers working in urban, Aboriginal, rural and remote communities, public health, corrections, primary care, specialist clinics, and community support agencies. Members with lived experiences were represented on the Advisory Council through the Pacific Hepatitis C Network, British Columbia, which is an organisation representing people with lived experience in various settings throughout the Province (a list of members can be found in Appendix A). The National Advisory Committee brought lived experience perspectives to the research design and process. This added value and knowledge to the research and helped with getting an emotional commitment from participants (Slade et al., 2010).

Over the duration of the NACP, the research team held quarterly teleconference meetings with the National Advisory Committee to consult on all aspects of the research project. Feedback and further input was obtained during follow up one-on-one personal telephone calls to ensure everyone was comfortable voicing their opinion. This ensured that diverse issues and concerns were heard and represented in the research. The committee was fundamental in recognising the gaps for the people living with HCV. Members of the National Advisory Committee audited clinical data and their did not attend (DNA) for follow-up list collected by service providers and inquired about gaps in service provision at all levels within the organisations in which they worked. This helped to identify that women living with HCV were being under-represented in the clinical setting and over-represented in the DNA list and highlighted the need for further research focusing specifically on women and their journeys with care, which is the basis for this thesis.

### 4.2.4 Informed Consent and Ethics

Ethics approval was granted by the University of British Columbia and Health Canada's Human Research Ethics Committees (Appendix B & C). Prior to interviews, written and oral information was provided and reviewed with all the participants, who then signed informed consent forms (Appendix D). Participants were advised that no identifiable information would be included in the transcripts, data confidentiality would be maintained by using pseudonyms and codes in place of personal identifiers and that access to transcripts and data would be restricted to the research team**.**

### 4.2.5 Ethical Considerations

HCV is a stigmatised illness through its association with IDU. This stigma is often a barrier when recruiting participants for activities associated with HCV (Butt, 2008). An Australian study looking at women living with HCV, found almost half of the women had experienced negative treatment by a healthcare professional related to their HCV. These negative healthcare experiences then created a barrier to accessing and engaging with healthcare services and support (Gifford, O'Brien, Bammer, Banwell, & Stoove, 2003). When developing recruitment strategies for engaging this population, it was crucial to maximise confidentiality and anonymity and be cognisant of the stigma and potential barriers, to ensure this population was truly being represented. Telephone interviews were used as participants can be more willing to provide information about a stigmatised illness when they feel more anonymity than in a face-to-face (Bhandari & Wagner, 2006).

Although participants were not asked directly about their motivation for participating in the research, many described wanting to teach others about the issues and barriers that they faced as a result of having HCV. They hoped that by educating people it would ultimately reduce the stigma associated with HCV. Some participants reported after the interview that they had learnt a lot about HCV and planned to inquire more from their healthcare provider about ongoing management.

### 4.2.6 The NACP Research Question

The NACP used a qualitative descriptive design to answer the research question, what are the reasons individuals with HCV do not attend for HCV care from the personal, interpersonal, and systems level? Non-attendance was defined as instances when a person living with HCV did not attend appointments and instances when they delayed or deferred care.

### 4.2.7 Methodology

The NACP used a qualitative descriptive research design guided by the National Advisory Committee. A qualitative approach allowed for a rich understanding of the participants, their perceptions and experiences as it encouraged an exploration of their personal experiences and the realities and challenges of living with HCV, without imposing preconceptions or theoretical frameworks (Creswell, 2009). This flexible research design was appropriate to answer the NACP research question as it focused on the participant's narratives for the analysis, which were then used to understand and make sense of various life events described by the people who lived them (Chase, 2011; Creswell, 2009). How the participants chose to narrate their experiences or tell their story and what they included helped to construct meaningful realities of their experience (Chase, 2011).

Inspired by grounded theory, sampling strategies were employed to guide recruitment, data collection and analysis and facilitate an understanding of the process involved in attending for HCV care and the factors that influenced this process. That is, it supported the development of an understanding of the reasons people living with HCV did not attend, delayed or deferred care. Charmaz (2006) techniques guided data collection. Data was refined simultaneously with the analysis, which enabled analysis to inform data collection. Areas requiring further clarification or exploration in subsequent interviews were identified before data collection had ceased. For example, when it became clear deferring care due to difficulties in accessing income assistance was a salient issue, it was added to subsequent interviews.

### 4.2.8 Participant Selection

The NACP designed broad eligibility criteria to allow for the inclusion of participants with diverse backgrounds and experiences of non-attendance for HCV care. This enriched the complexity of the data and helped in gathering information on the reasons individuals with HCV do not attend for HCV care from the personal, interpersonal, and systems level (Refer to the socio-ecological model in Chapter Four). The eligibility criteria for participants in this research were that they be aged 19 years or older and have English language fluency. In Canada, the age for which a person is deemed legally competent to give informed consent, varies between provinces from 18 years to 19 years (Leadbeater, 2006). Nineteen years of age was chosen to ensure participants from all provinces would be covered by the age of majority. While the English language fluency would exclude individuals who do not speak or read English, there were insufficient funds and resources to allow for the provision of special assistance, including translation of consent forms and interpreters during the interviewer for languages other than English.

In addition to the eligibility criteria mentioned above participants were also required to self-report an HCV infection and have no conditions that impeded cognition and memory. Having participants self-report their HCV status reduced barriers of having to produce laboratory results (Schlicting, Johnson, Brems, & Wells, 2003). The self-reporting nature of the interviews relied on the cognitive process of recalling information (Bhandari & Wagner, 2006). A cognitive impairment may have influenced the participant’s memory and ability to recall and to understand and respond to the consent, interview process and questions. Prior to commencing the interviews, participant’s cognition and memory were assessed using standard demographic questions to determine participants recall ability and state of mind (For demographic and interview questions refer to Appendix E).

### 4.2.9 Methods of Sampling

The method of selecting participants by the NACP was a purposeful sampling strategy, as it is widely used to identify and select participants that are experienced and knowledgeable about the research question (Patton, 2002). A purposeful sampling strategy using a variety of recruitment techniques ensured participants could provide insight into the research question on the reasons individuals living with HCV attended or did not attend for care.

Snowball sampling was used as a recruitment tool. Participants, who knew people with similar characteristics of interest, recruited other participants with similar characteristics (Palinkas et al., 2015). Snowball sampling relied on the research team to encourage participants in the study to recruit other useful participants. Word-of-mouth recruitment occurred as study participants recruited others people living with HCV through their own social networks, by postings on their blogs or their online support groups.

While these strategies can introduce some bias into the research as they can reduce the variation across the study participants and limit the representation of a cross-section of the population when recruitment occurs within particular social groups (Hardon, Hodgkin, & Fresle, 2004), they also have benefits. HCV is a stigmatised illness given its association with IDU (Butt, 2008) which is often a barrier when recruiting participants for activities associated with HCV. These were effective tools to recruit participants who were not engaged into care and gain access to the harder to reach participants that may not have been recruited through healthcare services alone.

Once an initial sample was generated, grounded theory techniques were employed to guide recruitment, data collection and analysis and facilitate an understanding of the process involved in attending for HCV care and the factors that influenced this process. A theoretical sampling approach was then implemented that focused on recruiting participants that had experiences with and could expand on the ideas that emerged. For example, through regular meetings, the NACP research team identified early in the data collection that many participants' issues around non-attendance were linked with the long process required to obtain their medical benefits. Adjustments were made and theoretical sampling was used to ensure this issue could be investigated further. Inspired by Charmaz's process, recruitment ceased when saturation was reached. This occurred when it was evident from the analysis that no new concepts were being produced through data collection and theoretical sampling was exhausted (Charmaz, 2006).

### 4.2.10 Methods of Recruitment

To access a broad range of participants with HCV who had experiences seeking and not seeking care and delaying or deferring care, recruitment took place in multiple settings with a mixture of methods. Members of the National Advisory Committee identified sites for recruitment within their organisations, networks and clinics including community clinics, community support agencies, specialist clinics, public health, prison health, and street outreach services. Healthcare providers at these sites also targeted eligible individuals and asked if they would be willing to participate in a telephone interview about their experience of living with HCV.

Information pamphlets and flyers with a description of the research project were provided to these sites for distribution to potential participants. When participants expressed an interest they were referred to a toll-free telephone number to contact the research team indicating their willingness to participate and determine their eligibility. To facilitate participation for individuals without phones, community agencies provided a private space and telephone. During the initial call to the NACP team, participants were informed about the aims of the research and asked preliminary questions to ensure they met the selection criteria. Telephone numbers were exchanged with eligible participants and a suitable call back time to conduct the interview was arranged. Occasionally the interview occurred immediately.

During the initial call, the consent form was also read to the potential participants – this included detailed information about the study – and arrangements were made to obtain a written consent. Participants with computer access were emailed the consent form and asked to sign and scan it back. Participants that did not have access to a computer received the consent by mail with a self-addressed return envelope. This often caused a delay in the interview and some participants were lost as they did not call back or answer their phone at the arranged time. When this happened several attempts were made to contact them over the next two weeks but, given the sensitive nature of the research, messages were not left.

Telephone interviews were used to maximise confidentiality, increase accessibility and enhance disclosure. Confidentiality was essential for recruiting the less engaged participants' who did not want to be associated with having HCV and were reluctant to be seen attending a HCV service in case they were recognised. Accessibly was increased as telephone interviews enabled participants to be recruited from across Canada by a research team based in British Columbia. Telephone interviews have also been shown to enhance disclosure: participants are more likely to provide information about a stigmatised illness on a telephone interview where they feel more anonymity than in a face-to-face interview (Bhandari & Wagner, 2006).

Participants received a $40 (Canadian dollars) reimbursement for their time and incidental costs**.** In Canada, an honorarium for research participants has become a standard practice (Bell & Salmon, 2012). Several members of the National Advisory Committee advised us that it would be difficult to recruit for the study if an honorarium was not offered to cover the costs incurred from participating in the interview.

Due to the logistics of mailing cash across the country, participants were provided with a gift card of their choice. In a few circumstances, community clinics provided cash to the participants they had recruited and were then reimbursed by the research team with a bank cheque. Participants that lived close to BCCDC were also given the option to collect cash, which many of them choose to do. To ensure anonymity, an envelope with cash was left with the security guard in the lobby of BCCDC so participants were not required to interact with the research team.

### 4.2.11 Method of Data Collection

Semi-structured interviews were the sole source of data generation for the NACP. Interviews were a valuable method for eliciting the story of a participant's experiences and gathering in-depth information around the topic (McNamara, 1999). Stories can be useful for gathering personal information as the interviewer has the opportunity to probe and ask follow up questions. An interview guide (Appendix E), developed with input from the National Advisory Committee, contained standardised demographic and open-ended exploratory questions to assist with probing the issues and facilitated further exploration of perceptions, experiences and areas of interest contributing to non-attendance from the personal, interpersonal, and systems level (Smith, 1995). A toll-free line was used for conducting interviews.

At the beginning of the interview each participant was thanked for participating in the interview and provided information on the study purpose, the interview process and the right to refuse to answer questions. Participants were informed that confidentiality would be maintained using pseudonyms and codes to replace personal identifiers and by restricting data access to the research team.

The first part of the interview involved collecting data to assist in establishing generalised patterns common amongst individuals living with HCV. The structured questions touched on a wide range of subjects including demographics, education, housing, living situation, source of income, number of health concerns and engagement with health services. When these were complete, interviewers explained the remainder of the interview would be less structured; again emphasising that the questions can be very personal and they could refuse to answer them. Participants were encouraged to ask questions if they did not understand the relevance of the question being asked. This was followed by broad exploratory questions about individual's experience with HCV and the health services utilised. Participants were given the opportunity to tell their stories about living with HCV as well as explore how they made sense of their experiences. Story-telling is a human instinct that can help make sense of an experience and is a well-established approach in studies aimed at interrogating the complex and contextual nature of people's journey with healthcare (Sandelowski, 1991). Throughout the interview process the direction of questioning was led by the information the participant's provided.

At the end of each interview participants were thanked for taking the time to participate in the research. They were also informed that the result of the NACP would be written up in a final report and were asked if they would like a copy of the report to be emailed or posted to them for review to ensure that their issues had been captured accurately. All of the participants agreed to have a copy of the final report sent to them.

The interviews lasted 45 to 90 minutes and were audio-recorded. Prior to transcription of the data, participants were de-identified by the interviewer. One member of the research team transcribed all interviews verbatim. The three interviewers met with the person transcribing the interviews regularly to review the transcripts to ensure accuracy against the recordings and identify any information that was removed. Non-verbal behaviour, such as laughter, significant pauses and hesitations were documented as they helped to establish reliability, dependability, and trustworthiness of the study (Easton, McComish, & Greenberg, 2000). Notes were made throughout on the interview guide by each interviewer. For the purpose of this thesis quotes were edited.

#### 4.2.11.1 My Engagement with People with HCV

As one of the three interviewers for the NACP, I conducted 14 of the interviews. During these interviews, I was aware topics of a sensitive nature would be discussed with participants living with HCV and it would be crucial for me to establish a rapport very early in the interview. I only had the one opportunity to interview these participants so it was vital that they felt comfortable enough to discuss their personal and sensitive topics with me early in the interview. Participants are more likely to provide truthful data when they feel they can trust the researcher, which ultimately leads to more credible research (Minichiello, Aroni, Timewell, & Alexander, 1995).

For several years prior to the research, I was employed as an outreach nurse in Kings Cross, Sydney, Australia targeting vulnerable populations. This role provided me with the insight into the multi-layers of barriers that people with HCV can experience in relation to accessing healthcare. For me to be successful in that outreach role, it was necessary to develop skills to engage clients and establish a rapport immediately from cold contact. This required a non-judgmental, non-intrusive approach that conveyed trust and respect. My background and the skills I developed as an outreach nurse proved to be valuable for the interviews, as participants appeared to relax early in the interview and became comfortable enough to discuss personal issues and challenges. Gathering the demographic data at the start of each interview was helpful for establishing trust and building a rapport with individuals before diving into the deeper sensitive questions. Additionally, the telephone interviews, may have also helped to relax the participants and increase their willingness to disclose personal information (Bernard, 2002).

However, my nursing and education background also caused me much frustration during the interviews. Three members of the NACP research team conducted the interviews: a Nurse Manager, an Anthropologist and myself, a Nurse Educator. Despite two members of the interview team having clinical backgrounds, for the purpose of the research and to ensure consistency across the interviews, detailed and individualised health and HCV-specific information was not provided. However, interviewers provided referrals to clinics in the participant's area. During several interviews I was astounded by the misinformation participants had received in the past and had to refrain from intervening and providing correct information.

## 4.3 The PhD Project – Women's Journey with Care

As noted in the introduction, the research design and specific methods of sampling, recruitment and data collection were dictated by the NACP. Data generated by NACP was analysed by the research team and published (Butt et al., 2013; Butt et al., 2012). A sub-set of the data generated by NACP was separately analysed for this thesis concurrently to the analysis of the NACP data. This section outlines the analytic processes used for this work. As a PhD candidate at the University of Sydney, in addition to the ethics approval required for the NACP, the

University of Sydney ratified the approval granted from the University of Sydney Human Research Ethics Committee for this thesis (Appendix F).

### 4.3.1 Research Question

As noted in Section 4.2.2 the National Advisory Committee were significant in identifying that women living with HCV were being underrepresented in the clinical setting. The primary objective of this thesis is to investigate, women's narratives of living with HCV in order to understand their journey with care.

### 4.3.2 Sample Selection

To address the research question, a gender specific sub-set from the fifty-five participants generated by NACP was used. This comprised of twenty-five women from three Canadian provinces with self-reported HCV.

### 4.3.3 Analytic Strategies

As highlighted in Section 4.2 the methodology for this research was determined by the NACP. My analysis was inspired by Charmaz's grounded theory process (2006). This was well suited to address the research question and develop an understanding of the women's perspective of living with HCV and their journey with care as it allowed for a rich understanding of the participants being studied. Data was managed through NVivo 9 ™ software, which enabled data interrogation, refinement of the coding structure. NVivo 9 ™ software is a tool that assists with organising qualitative data and allows questions to be asked of the data to find insights in an effective and efficient way.

Drawing on tools for analysis inspired by Charmaz (2006), I read transcripts, developed an initial coding structure using open coding to identify concepts and categories in the data, which formed the components for my analysis. I coded for categories that fit successive and different situations that were grounded in the data. Once an initial coding structure was established my PhD committee simultaneously coded the same five randomly selected transcripts and compared coding similarities and differences among the four-team members. As new codes and issues were identified as being significant along the journey with care such as point of diagnosis, the narratives were reread and recoded with focused coding using the initial codes to synthesise and scrutinise the data. My PhD committee met regularly on teleconference or face-to-face when I was in Sydney to refine the coding structure and produce an inclusive list of codes through consensus that represented the range of women's experiences included in the narratives. Constant comparison was used to examine similarities and differences and ensure that the data continued to support the emerging categories. I kept memos to record my thoughts, interpretation and questions about the women's narratives and their interpretation as well as my emerging conceptual thoughts (Charmaz, 2006). Memoing while actively engaged in coding and analysing enabled me to continuously build theoretical sensitivity.

Inspired by Charmaz's grounded theory framework, conceptual mapping was then used to develop categories. I mapped out the various issues that shaped the women's attendance and non- attendance for care identified in the narratives and grouped them into categories. This provided a visual representation of the dynamic patterns and relationships between the various concepts for women living with HCV. Directional arrows, word links and simple lines were used to signify relationships or connections. The use of concept maps in data analysis offers a unique visual means to ground the theory within the data (Charmaz, 2006). For this thesis I focused on three conceptual categories (the diagnosis experience, turning point and receiving treatment) as they provided the most analytical insight and new knowledge for understanding women's journey with care. This concept map is provided in Appendix G to provide insight into my process and should not be read as an overall theory of journeys with care.

### 4.3.4 Attending to Narrative

Initially the research question for this thesis was what are the reasons women with HCV do not attend for HCV care? From my concept map (Charmaz, 2006) it became evident that for women living with HCV, the process of attendance/non-attendance with care was not a linear process. It was a metaphorical journey with many challenges along the way. This prompted me to redefine the research question slightly to focus more specifically on women's journey with care.

The narrative-focused analysis used for this thesis was an appropriate analytical approach for inquiry into women's experiences of living with HCV as it is interested in the meaning that is placed on an experience, especially in narratives of personal experience about life events. Using the "story" approach guided the exploration and analysis of women's life experiences of living with HCV from the perspective of the women. Through telling their stories, women were able to communicate their ideas and reflect on their experience of living with HCV and their journey with care.

During the analysis process, the stories in each interview were coded, summarised and conceptually grouped to help me develop an understanding and make sense of the various life events described by the women who lived them. A thematic analysis approach was used to identify patterns across the data (Riessman, 2008) that would help to answer the research question and develop a deeper understanding and empathy of women's journey with HCV care.  Attending to sense of narrative allowed points of decision or change to be identified, specifically the point of diagnosis and decision to go for care, that are described further in Chapter Six and Eight.

### 4.3.5 Attending to Demographics

Demographic data (for details on the questions refer to Appendix E) was collected during the interviews and used in the analysis to provide context for the interpretation of the data and when reporting specific quotes. In addition, I looked at time since diagnosis, age at diagnosis, education and income to see if it made a difference to women's journey with care, however, no pattern was evident.

### 4.3.6 Quality

#### 4.3.6.1 Interpretation

The interpretation of data relies on the interpretation of the researcher (Creswell, 2009). During the interviews, reframing and summarising the women's stories back to them helped validate the accuracy of my understanding of their narratives. This also helped to ensure that I had correctly interpreted the context of the narratives and the women's experiences while assessing the underlying intent and meaning. To ensure the accurateness of my understanding of the content in the interviews that I did not conduct, I met weekly with the other research team members who conducted interviews. During these meetings, we reviewed and discussed interpretation of the content for each interview, to ensure consistency and reduce the risk of perceived bias.

During the analysis, my PhD committee simultaneously coded randomly selected transcripts and compared for similarities and differences. When a difference in the random coding of transcripts was apparent amongst my PhD committee members, each person's interpretation of the codes were discussed and clarified to reduce the potential for misinterpretation of the narratives.

#### 4.3.6.2 Transferability and Reliability

This information is relevant for all healthcare practitioners across any setting where women living with HCV and/or a chronic illness are encountered. However, two caveats apply to the transferability and reliability of my findings. First, this is a purposeful sample. Recruitment was aimed at reaching those who do not attend, delayed, or deferred care for HCV. Attempts were made to obtain a diversity of views by using a national network of diverse stakeholders. However, the data should not be considered to be representative of the experiences of all women with HCV. The experiences of specific groups affected by HCV, for example, immigrants from areas with high HCV prevalence or Aboriginal and First Nation women, requires further investigation.

The second caveat relates to reliability due to participant recall bias. Many of the women in my study were diagnosed some time ago and were reflecting on a journey with care that may span a decade or more. The information they remembered may be limited and reframed to reflect how they see themselves today. My findings should be considered a starting point that partially maps women's journey with care.

### 4.3.7 Conclusion

Exploring the life experiences of the women and analysing their experiences along their journey with HCV care allowed for a deeper understanding and empathy for the life experience of the women living with HCV to develop (Schwandt, 2007) which can lead to provoking questions, changing the reader's point of view (Barone & Eisner, 2006) or motivating them to take action (Richardson, 2000). These methods were effective to recruit participants who were not engaged into care and gain access to the harder to reach participants that may not have been recruited through healthcare services alone. The description of the sample in the next chapter demonstrates that this sampling strategy was successful in obtaining the perspectives of a wide range of women, although no claims of generalisability to the wider population of women with HCV are made, given the small sample size.

# CHAPTER 5 OVERVIEW AND SAMPLE DETAIL

## 5.1 Overview of Results

Despite the benefits of HCV care, there is a significant gap in the uptake of services. The aim of my thesis was to explore the women's life experiences along their journey with HCV care from the perspective of the women. During the analysis, it became evident that the point of diagnosis was the starting point to understanding Canadian women's experiences of living with HCV and their journey with HCV care. Women in my study were diagnosed in a variety of settings, in which HCV awareness, knowledge, and expertise was not evenly distributed. Women's experience of diagnosis was shaped by varied circumstances, which contributed to receiving a HCV diagnosis and ultimately, their level of preparedness. Chapter Six illustrates how women's preparedness for a diagnosis shaped their diagnosis experience and the information and health education they received at diagnosis contributed to shaping their journey with HCV care. I explore how the diagnosis experiences were shaped by the context of diagnosis, what promoted testing, who did the testing, and the information and education received at the point of diagnosis. I then present an argument that the context of diagnosis often foreshadowed how prepared women were for their results, and the absence of accurate information magnified the psychological-distress that can follow a HCV diagnosis. A version of this chapter has been published in the Canadian Journal of Nursing Research (Mitchell et al., 2016).

From my analysis, it was evident that following an HCV diagnosis, the barriers women faced along the HCV cascade of care (refer to Chapter One) were important aspects of their journey with care. Women often saw these barriers as challenges to overcome along their journey with HCV care. These complex barriers were frequently interrelated and evident prior to diagnosis when woman contemplated getting tested for HCV and continued to the point of accessing healthcare. Previous research (Loveday, Treloar, Elek, Steele, & Hopwood, 2005; Treloar et al., 2013; Ward, Coleborne, & Fort, 2000), identified the well-established stigma associated with HCV as the most deeply rooted barrier to accessing HCV care. My results, which support these findings, show stigma, discrimination and judgmental attitudes from healthcare providers prevented women from accessing appropriate care, support and treatment. Chapter Seven presents five key issues: information provision, family and caregiver responsibilities, relationships with healthcare providers, active substance use and stigma and discrimination related to drug use, which acted as barriers for women along their journey with HCV care. In my analysis I found women simply were not defeated by the barriers, they often showed inventiveness and determination and saw these barriers as a challenge along their journey with care.

The final important aspect that was evident during my analysis was women's motivations and decision process to attend for care. Chapter Eight presents an argument that women's decisions to seek HCV care and treatment was either an event-driven sudden change in priorities or a slow process motived by various circumstances. In this chapter, I will illustrate how women came to understand the need to attend for care and the related contextual features that influenced this process. Two interrelated aspects will be highlighted that helped women make sense of their journey with care and its significance for their health - events that occurred in their lives that helped them to identify their health as a priority and the timing of these events within the context of their everyday lives.

## 5.2 Sample Characteristics

At the start of each interview, we asked participants standardised demographic questions, which included age, education, source of income, living arrangements, health status, years since HCV diagnosis, and antiviral therapy experience (refer to Appendix E for questionnaire). Demographic characteristics are presented in Table 1.

### 5.2.1 Geographic Regions Recruited From

The sample was geographically diverse with women from urban, suburban and rural areas. Women were recruited from three Canadian provinces, 17 from British Columbia, and four from both Ontario and Nova Scotia. The provinces all had high HCV rates; two higher than the national average and together account for 60 percent of all reported cases in Canada (Public Health Agency of Canada, 2011).

British Columbia has 21.5 percent of all reported HCV cases in Canada and the rates of reported HCV remain much higher, 54.9 per 100,000, compared to the national rate of 33.7 per 100,000. The majority of people newly diagnosed in this province reported a history of IDU (56%) or had immigrated from an area where HCV was endemic (33%) (British Columbia Centre for Disease Control & Ministry of Health, 2011) British Columbia is considered to be socio-cultural diverse with a number of community health and support services, needle/syringe programs and INSITE, the only supervised injection site in Canada when this research was conducted (Public Health Agency of Canada, 2011).

Ontario has 38.7 percent of all reported HCV cases in Canada with the reported HCV rates equal to the national rate of 33.7 per 100,000. The majority (54% - 56%) of new infections are current or former PWID with estimates of 11 to 13 percent being infected through blood transfusions, and 30 to 35 percent through unknown or other possible risk factors (Ontario Hepatitis C Task Force, 2009).

Nova Scotia has 7.8 percent of all the reported HCV cases in Canada, with a lower HCV rate of 29.7 per 100,000 compared to the national rates of 33.7 per 100,000 (Public Health Agency of Canada, 2011). The most commonly reported risk factor is IDU (70.9% of cases) (Nova Scotia Health and Wellness, 2012).

### 5.2.2 Age

The 25 women in the thesis sample were at various stages of the lifespan and HCV illness. The women's ages ranged from 29 to 62 years, with the majority of participants aged over 30 years (mean age of 43 years). As discussed in Chapter One, the age group in Canada that has the highest reported rate of HCV, is in women aged 15 to 29 years (Public Health Agency of Canada, 2011). Ten of my participants had received their diagnosis while they were between 25 to 29 years and the majority felt they had been exposed to HCV during that time in their life.

### 5.2.3 Education

Over half of the women reported having elementary or high school education. Two women reported having elementary school education, six women had some high school education and six reported completing a high school diploma. Eleven women reported completing post-secondary education. When compared to the 2011 general Canadian population data, a greater proportion of our sample had no high school certificate than the general Canadian population of adults (12.7% vs 8%). Similar proportions of the women sampled had received a high school diploma compared to the general Canadian population (24% vs 23.2%), and a slightly fewer (44% vs 53.7%) women in my sample had a university degree (Statistics Canada, 2013).

### 5.2.4 Source of Income

The majority of the women (76%) were receiving a disability pension or social assistance. Six women reported being employed: one woman full-time, three part-time and two as causal or seasonal workers. The level of unemployment for the women in our study was much higher than the 6.3 percent unemployment rate for women in the general Canadian population (Statistics Canada, 2013). This unemployment rate for women in Canada was obtained from the Labor Force Survey, which covers civilians and the non-institutionalized population 15 years of age and over. Although the Labor Force Survey attempts to be inclusive, vulnerable populations, who are homeless and without access to a phone are often missed.

### 5.2.5 Living Arrangement

At the start of each interview, women were asked how many people were living in their household. The majority of the women (60%) reported living with at least one other person. Five of the women reported living with their partner, seven of the women lived with their children and three lived with a roommate. Ten women reported they lived alone.

### 5.2.6 Health Status

Health concerns and comorbidities were common among participants. Twenty-two women reported two or more health concerns in addition to HCV. Common comorbidities included arthritis, chronic back pain, addictions, anxiety and depression; three participants reported HIV co-infection. Twenty participants reported taking two or more medications. Women were not asked if they were receiving methadone maintenance therapy[1]; however, six participants disclosed that they were receiving it as treatment for opiate addiction during their interview.

When asked as part of the standardised questions, all the women described experiences with health service utilisation and most were engaged with some type of health services at the time of interview. However, women also described periods along their journey with care where they did not attend to care. Non-attendance was defined as instances when a person living with HCV did not attend appointments and instances when they delayed or deferred care. When questioned about HCV support groups, fifteen women had never attended any form of a HCV support group, five were currently attending a HCV support group and five women stated they had previously attended a HCV support group. The definition of support group was not given to participants and was therefore dependent upon each women's own interpretation of what a support group meant for them.

### 5.2.7 Years since Diagnosis

The diagnosis data from this study covers a 26-year span. Twelve participants

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[1] Methadone maintenance therapy (MMT) is a treatment to address opioid dependence and its consequences. MMT is effective in reducing the use of opioids and other substances as well as injection-related risk behaviours that can transmit HCV and other blood-borne pathogens (Health Canada, 2002).

were diagnosed with HCV more than ten years ago; six between six to 10 years ago and the remaining seven within the past five years. Some women were only able to provide an approximate year of diagnosis. During the interviews women described being diagnosed by their family physician, methadone maintenance therapy prescriber, nurse practitioner, or by a doctor at a walk-in Primary Health Clinic.

On the advice of the National Advisory Committee, which included consumers, the decision was made not to directly ask the source of HCV transmission during the interview as it was felt this could be misinterpreted as an invasive question. However, all twenty-five participants disclosed their source of infection, and described the exact time in their life when they suspected they had become infected with HCV, which allowed for this to be explored during every interview in a non-stigmatising way. Literature has demonstrated that the source of HCV transmission can significantly affect access to care (Denniston et al., 2014). Women were also not asked directly about drug use, however, during the interview, twenty women disclosed current or a past history of IDU, which they believed was their source of HCV exposure. Two women discussed contracting HCV during a blood transfusion, one woman stated her exposure was from vertical transmission. The remaining two women described confusion and doubt about their exact source of exposure. As discussed in Chapter Two, on estimate, 60 percent of all HCV cases in Canada are amongst PWID (Ha et al., 2016; Myers et al., 2015).

### 5.2.8 Antiviral Therapy Experience

During the standardised questions, 11 women in our study replied that they had never engaged with HCV anti-viral treatment. Fourteen women had received

HCV antiviral therapy in the past: three women had undergone HCV treatment with the first generation protease inhibitors and one woman was on HCV treatment at the time of the interview. This is consistent with the research showing limited treatment uptake despite the well-documented benefits of antiviral treatments (e.g., interferon and ribavirin) for improving quality of life, increasing survival rates and decreasing the likelihood of cancer and cirrhosis (Khokhar & Lewis, 2007; Munoz-Plaza et al., 2008).

Of the 14 women who had undergone HCV treatment, nine achieved a SVR (refer to Chapter Two for more information on treatment responses); however, two of these women went through HCV treatment twice. Three of the women had no significant response to the HCV treatment; one woman went through treatment twice and continued to have no significant response. One woman had an HCV relapse after treatment had finished and one woman was unsure of her treatment outcome due to lack of follow-up.

## 5.3 Conclusion

The demographic information collected helped to provide an enhanced understanding and context of the sample of women who participated in the research. This generated an in-depth understanding of a women’s journey with HCV care and the transferability of the findings to other situations and populations. Given my sample was diverse and included women at various stages of the lifespan and HCV illness, the issues raised by these women may resonate for women living with HCV in Canada. However, all these issues may not be relevant for specific groups of women affected by HCV, for example, immigrants from areas with high HCV prevalence or Aboriginal and First Nation women

## Table 1. Participant demographics

| Characteristics | *n* | % |
|---|---|---|
| **Age** | | |
| 21-29 yrs | 1 | 4% |
| 30-39 yrs | 9 | 36% |
| 40-49 yrs | 4 | 16% |
| 50-62 yrs | 11 | 44% |
| **Years since diagnosis** | | |
| <1 yr | 1 | 4% |
| 1 - 5 yrs | 6 | 24% |
| 6 - 10 yrs | 6 | 24% |
| 11 – 15 yrs | 4 | 16% |
| 16 – 20 yrs | 6 | 24% |
| 21 – 28 yrs | 2 | 8% |
| **Antiviral therapy experience** | | |
| No treatment experience | 11 | 44% |
| Discontinued treatment | 1 | 4% |
| Unaware of treatment response | 3 | 12% |
| No response | 3 | 12% |
| Relapse | 1 | 4% |
| Achieved a sustained viral response (SVR) | 9 | 36% |
| **Health Status** | | |
| 1 Health concern | 3 | 12% |
| 2 – 5 Health concerns | 17 | 68% |
| 5 + Health concerns | 5 | 20% |
| **Education** | | |
| Elementary/high school | 14 | 56% |
| Post-secondary | 11 | 44% |
| **Source of income** | | |
| Disability/social assistance | 19 | 76% |
| Employed part time/casual | 6 | 24% |
| **Living arrangement** | | |
| Lives alone | 10 | 40% |
| Lives with 1 + person | 15 | 60% |
| **Provinces recruited from** | | |
| British Columbia | 17 | 68% |
| Ontario | 4 | 16% |
| Nova Scotia | 4 | 16% |

# CHAPTER 6 AN ANALYSIS OF CANADIAN WOMEN'S EXPERIENCES OF RECEIVING A HEPATITIS C DIAGNOSIS

## 6.1 Introduction

Early diagnosis of HCV in women is critical to facilitate timely, appropriate care and management, which has been shown to improve quality of life and liver function, decrease risk of liver cancer, and improve survival (Hung et al., 2006; Yoshida et al., 2002). Due to the large numbers affected and the relative shortage of specialists in Canada, HCV diagnosis and follow-up tends to be provided at first point of contact with healthcare services (Zevin, 2007). However, there are no national HCV testing guidelines for HCV diagnosis, including pre-and post-test discussion, to guide standards for diagnosis care, which could enhance the diagnosis experience for many women living with HCV along their journey with care.

There is evidence that the point of diagnosis is a critical time for accessing and engaging in HCV care and support (Treloar et al., 2010b). Diagnosis has been described as an overwhelmingly poor experience and has also been described as being trivialised by healthcare providers (Davis et al., 2004). Previous research has noted that people living with HCV have perceived clinicians as having "negative attitudes" toward them and reported being provided with neither information on HCV nor support at the point of diagnosis (Crockett & Gifford, 2004; Treloar et al., 2010b). It remains unclear whether the recent advancements in HCV knowledge and treatment are reflected in the diagnosis experience. For people living with HCV, their level of knowledge about the disease can influence health outcomes (Glacken et al., 2001). Lack of information and support during HCV diagnosis can potentially further reduce follow-up and HCV management (Treloar et al., 2010b), as fear of the disease increases and feelings of loss of control over one's health are generated (Hopwood & Treloar, 2004). Only a small portion of people will experience HCV-related symptoms, as symptoms are typically associated with disease progression and occur over decades (Sherman et al., 2007). When a person's diagnosis is delayed until they are suffering from advanced liver disease, their success with treatment is reduced (Ly et al., 2012)

This chapter examines a cohort of Canadian women's experiences of HCV diagnosis and explores the two interrelated themes that shaped the diagnosis experience: (1) how prepared the women were for their positive diagnosis, and (2) information and health education received at point of diagnosis. I will explore the factors that influenced the women's preparedness for a positive diagnosis and how the information and health education they received at diagnosis shaped their diagnosis experience and their journey with care. This information will be used as the basis for recommendations in the discussion (refer to Chapter Nine) to improve care at the time of diagnosis that will, in turn, enhance women's access to new treatments and improve their journey with care.

## 6.2 Results

### 6.2.1 Testing Circumstances and the Women's Level of Preparedness

During the analysis it was evident that the women's experience of diagnosis was shaped by varied circumstances, which contributed to receiving a HCV diagnosis and, ultimately, their level of preparedness. Three different contexts for testing contributed to how well prepared the women felt for a positive diagnosis: testing when feeling unwell; routine testing; and seeking testing for HCV.

#### 6.2.1.1 Testing when Feeling Unwell

The first of these three contexts of testing circumstances was reported by eight women who described HCV testing in the context of seeking healthcare for "feeling unwell" or as Deb explains "knowing something was wrong."

> *I was accessing a place…for girls working on the street or who have worked on the street. And they have a doctor there that would care for the girls and stuff and that's how I got diagnosed. I wasn't feeling well, I mean I didn't feel well most of the time anyway, but I knew there was something going on and something was different. I wasn't healing and I was really, sore, like tired muscles and…the symptoms are unique to anything else I've ever experienced [diagnosed 2006].*

In these narratives women often described experiencing symptoms, as Val explains "like nausea and fatigue and lack of appetite and headache, and then my skin was yellow, my eyes were yellow" and severe abdominal pain for weeks before going to see a doctor. The women, however, did not necessarily attribute their symptoms to HCV due to having limited or no HCV knowledge and its symptoms.

> *I was very jaundiced and I didn't know anything about it (HCV) then and my ex-husband told me I think I gave you hep C, he says you're all yellow and that's when I went to the hospital cuz I was, I was really sick, I was keeled over with stomach pains and yeah, it was weird. So they hospitalised me, I was quarantined for ten days [Val, diagnosed in 1986]*

Although the healthcare provider initiated the HCV testing, often the women received limited or no information about HCV during their pre-test discussion, if this discussion occurred at all. This is evident in Jodi's description of feeling unwell, which prompted a visit to her GP who tested her for HCV.

> *I ended up turning really jaundice for like a week or two…and I was having pains in my stomach, like my liver was inflamed and stuff. I went to my doctor and she said 'okay, we gotta test you for hepatitis, have you used any needles?' And I told her about the one time and, yeah, so a week went by and I found out (I was HCV positive) [diagnosed in 2002].*

Consequently, when diagnosed, women were often ill prepared, as they had limited knowledge and many had not considered the possibility of an HCV infection prior to being tested. They reported being puzzled and questioned their exposure source, which were often many years prior to the diagnosis as evident in the Eve's description below.

> *I went into shock for six months. Trying to figure out, where in the hell would I have got that [diagnosed in 2002].*

Although women were feeling unwell, many were unaware of HCV and what they were being tested for, therefore were not expecting positive results and they reported feeling unprepared, shocked and bewildered when they were diagnosed. Women were left feeling scared with many unanswered questions. The example below highlights the various feeling and questions experienced at diagnoses for many of the women.

> *I went to my doctor (when I felt sick)…And so a week went by and they told me that I was diagnosed, you know, positive with it (HCV) and so asked if I had any questions or if my mom did and when she told me I was really scared and my mom was really scared and, you know, like my dad started telling me*

> *that, you're gonna die and stuff like that, my mom asked the most silliest question in the world but I guess, you know, to her it was relevant, like, whether she can eat off the same silver plates as me and stuff, like just silly things, eh? It was really scary and heartbreaking for me…I mean it was really devastating at first and then, you know, I had to find a way to live with it [Nicola diagnosed 2002].*

#### 6.2.1.2 Routine Testing

In the second context of testing, 11 women described being tested during a routine examination for a health insurance application, in follow-up blood tests for abnormal liver enzymes, screening prenatally or after blood donations. As the screen was done as a matter of routine and at a range of locations, no risk assessment was completed. The example below describes a HCV diagnosis following a prenatal screen.

> *I found out, when I had to do the blood work for having a baby, during my prenatal kind of screen. It was a bit surprising…I didn't know what I was being tested for [Tia diagnosed 2007].*

Often these women were unaware they were being tested for HCV and reported feeling unprepared, shocked (as they felt well), and bewildered when told of their HCV diagnosis. The absence of information prior to diagnosis created enormous confusion for the women as they had little knowledge about HCV and its transmission routes. The following narrative highlights the bewilderment women experienced at diagnosis and the negative impact it had on their lives.

> *I didn't know much about it at the time but I had heard a couple stories of people um getting really sick and dying from it, and I knew people on the street that were, you know, pretty, in pretty rough shape and they told me they had hep C. I have kids and I have grandkids and (pause), I just felt so dirty and it was horrible, like, I just felt like oh my god, I'm gonna pass this on to my family, my daughter had just had my first grandson and when I told her she didn't even want me holding him or anything cause we didn't know, right. It was really devastating, it was horrible. I didn't cope with it very well, I was using and feeling pretty disgusting and feeling sorry for myself and stuff [Kathy, diagnosed, 2006].*

Confusion during the diagnosis experience can be exacerbated by a breach of confidentially. The example below highlights both an unacceptable breach of confidentiality in a small community hospital and how a lack of information and a pre-test discussion resulted in further unnecessary confusion.

> *My insurance agent called me between that Christmas and New Years to tell me that I was turned down, and I said, "oh why, was my blood pressure too high?" My sister-in-law had just gone to the hospital that day and she said, "no, don't you know that you have hep C?"...Needless to say, I did not take it seriously. "You're joking", you know, because I was still under the idea that it was mostly drug addicts who got it [Katie diagnosed 2002].*

#### 6.2.1.3 Seeking Testing for HCV

In the final of the three testing contexts, the narratives involved women who were aware of HCV and sought testing. The context for some women was the presence of known risk factors, which included past or current drug use, blood transfusion, and mother-child transmission. This prompted women or their health-provider to seek HCV testing at a drug treatment program or primary health clinic. Generally, these women were cognisant of an exposure event or that their practices put them at risk. As Jackie explains, a HCV diagnosis felt inevitable

> *The nurse that took my blood work, she gave me the results. I didn't know for sure but I figured I had it anyways because I knew what I was doing, right? So I knew I used dirty needles so it wasn't really that much of a shock to me cuz I had already known, it's still depressing though, right? You still have that hope that maybe you didn't get it, right? [Jackie, diagnosed, 2005]*

Thus, the women were anticipating a positive diagnosis and, after the initial shock, accepted it. The women who had a history of IDU often explained it in terms of their drug use. While in detoxification, Kerri describes asking to be tested for HCV, as she wanted to know if her past behaviours would always haunt her.

> *I was cleaning up after an eight year stint in addiction, I had a cocaine addiction and I was cleaning up and I thought I needed to get tested for everything…I was doing a complete turnaround at the that time and I said okay, I'm getting out of addiction, I'm changing my lifestyle but I wanna make sure, did I get out scot-free? [Kerri, diagnosed 2005]*

However, in other situations when women sought testing because of risk-exposures, they were unprepared for the positive diagnosis. For example, between 1986 and 1990 a number of Canadians were infected with HCV via blood products during hospital procedures (Norris, 2008). Following media reports of tainted blood, two participants made the decision to get tested. In these two cases, the decision to be tested was the result of a risk exposure.

> *It was all just coming out, it was something new I guess, so many people were diagnosed at one time…our public health nurse contacted me and they told me I had a blood transfusion in '87, I wasn't aware I had the blood transfusion because, well, I signed the paper but they didn't tell me after my surgery that I was given blood…So I got tested and it was more or less all new to me. The public health nurse is the one who told me I did have it (HCV). [Katie diagnosed 1999].*

These women, who sought testing after being informed about the possibility of exposure from tainted blood, response to a positive result was similar to those who had routine testing: unprepared for and surprised by the diagnosis. They were in shock and questioned how they had been exposed to HCV during a medical procedure and were often uninformed about their prognosis.

Similarly, a third participant who was tested due to a risk exposure, response to the HCV diagnosis was consistent to those who had routine testing. Tanya was tested because both parents were HCV positive. She described getting diagnosed at an early age when the child protection agency became involved. When she received her results she had no knowledge of HCV.

> *The Ministry had got involved and I had to do blood work, I can't remember what, I was really young, but yeah, the blood work came back and said I was positive and I hadn't had any sexual partners or anything like that or done any drugs so that kind of leaves only one reason, you know? Both my parents*

> *were hep C positive…So, yeah, that's when I got that diagnosis, I didn't really know what it means [Tanya diagnosed 2000].*

### 6.2.2 Information and Health Education Received at Point of Diagnosis

An HCV diagnosis can create distress and confusion for women when considering how this diagnosis will impact their health in the future. This distress and confusion can be exacerbated if women receive limited information or misinformation about prognosis from their healthcare provider (Hopwood & Treloar, 2004). The women in this study described varying experiences of information provision ranging from none to limited or inadequate, to appropriate and adequate information for health management.

#### 6.2.2.1 None to Limited or Inadequate Information

Irrespective of time since diagnosis (that is, from more than 10 years before interview to within the past five years), women described receiving limited information at diagnosis. The women who described not receiving HCV-related information, being uninformed about the need for follow-up, or not being told how to manage their HCV at the point of diagnosis described the experience as confusing and distressing. They were left wondering about the consequences of HCV. When women did receive information at diagnosis, most reported simply receiving advice about transmission and lifestyle modifications on alcohol use. One respondent was informed about her HCV diagnosis via a voice message, which gave her no opportunity to inquire about what this meant. Another respondent, diagnosed by a GP in jail, was provided with a pamphlet however received no information on follow-up, treatment or how to manage her HCV:

> *I found out in jail they just gave me a pamphlet and I went back to my cell crying, I thought it was like, next thing to AIDS, yeah, no education. Just here's a pamphlet. You have it… I just figured my life was over [Anna, diagnosed, 1995].*

Although the narrative below describes a diagnosis experience that occurred prior to the discovery of HCV in 1989, when certain viral hepatitis (refer to Section 2.1) were being diagnosed as non-A non-B hepatitis, it is important to acknowledge the negative impact of this experience and the misinformation that some women have lived with for decades. Due to the lack of information, Val was unaware of the need for ongoing HCV care and received no follow-up.

> *I wasn't given anything, they quarantined me for ten days, and here I'm thinking like what the heck is going on cuz I didn't know what it was, they quarantined me, fed me off styrofoam, like I was contagious with something. After ten days they let me go, they told me I was to go home so I'm thinking okay, so I'm fine now, I'm all better like, you know no follow-up, no nothing, I left there and thought I was okay because I wasn't yellow anymore [Val, diagnosed, 1986]*

For many women, their HCV diagnosis raised significant concerns about current and future health-status. Some described believing they were going to die soon after diagnosis and so they had no reason to inquire further about HCV or make changes in their lives. Others had no sense of the seriousness of HCV. One participant was given no information:

> *When I was diagnosed with hep C I was barely a woman (diagnosed at the age of 17) and told that I'm goanna die. That's exactly what they said like,*

> *don't expect to live very long because twenty years from now you're going to be really sick and then you're goanna die [Joe, diagnosed 2000].*

As a result of not receiving information Joe was unaware of the need for on-going liver monitoring and she received no follow-up. It was not until years later when, following abnormal blood-work results during a routine physical exam, further investigations were performed and appropriate medical-care was provided. This example highlights the multiple points of diagnosis in a woman's journey with care where pre-and post-diagnosis information can be provided as new knowledge around HCV develops.

Regardless of the circumstance that prompted the HCV test, information provided by healthcare providers at the time of diagnosis shaped women's subsequent health and healthcare experiences. Living for years with incorrect information about prognosis left Joe feeling she could have done things differently and made changes sooner *"if only I'd been told"* earlier about the consequences and need for follow-up. Some women attributed the lack of information to inadequate knowledge of their healthcare provider, others to the lack of information existing at the time. For example:

> *Well, in the beginning when I got the diagnosis the doctor that I saw basically gave me a pamphlet and said, "you know we don't really know much about this but maybe you might have two years to live," kind of thing... The doctor said that as long as I didn't have any symptoms that I would be ok. [Kerri, diagnosed 1992]*

Women who had received their diagnosis within the last decade, when new knowledge about HCV and new treatments were available, did not appear to have experienced improved information provision. Some participants diagnosed within the last decade reported being informed by a healthcare provider that the information they had received at diagnosis (by another healthcare provider) was incorrect. One participant, diagnosed in 2007 by her GP, was provided with no information on follow-up or management of HCV.

> *I said, "I have no energy and I'm sleeping so much", so I asked him if he could check my blood out and then he told me that I had hep C. He told me, "maybe that's why you're getting so tired" and that's it, I couldn't believe it, he didn't really say anything about it… He didn't say anything about what you should do [Becky, diagnosed 2007].*

#### 6.2.2.2 Appropriate and Adequate Information

A small number of the women diagnosed in the last decade reported receiving what they characterised as sufficient information about HCV. Being provided with information "…about the care needed now that I'm living with HCV and the treatment available to me" helped Kate to no longer feel afraid of her diagnosis. These women said they felt they had been provided with enough current information, enabling them to make informed decisions about their healthcare needs. Most of these women were diagnosed by a healthcare provider with whom they knew and had a long established relationship. They described feeling empowered and motivated to make lifestyle changes:

> *[When I was diagnosed]…they, were supportive of me and they, you know, they told me in terms I could understand, to begin to educate me a bit about it. I was able to kind of figure it out a bit… Every time I got tested from the*

> *beginning they told me about the treatment, it actually gave me, incentive to get my life together. It took a few years but I had something to work towards, you know, kind of like take control of my health [Lisa, diagnosed 2005].*

## 6.3 Discussion

The way in which the women chose to narrate their experiences of diagnosis or tell their story and what they included helped to construct meaningful realities of their experience (Chase, 2011). Negative experience and inadequate information at diagnosis continues to be a problem affecting women living with HCV, resulting in further disengagement from care and long-term consequences to their understanding of HCV and its management (Hopwood & Treloar, 2004; Treloar et al., 2010). Women in my sample described not knowing what to do post-diagnosis, or being told there was nothing they could do. This finding contrasts strongly with the sense of empowerment described by the few women who felt they received good information.

From my analysis it was evident that the absence of accurate information at the point of diagnosis magnified the psychological distress, which can follow a HCV diagnosis when little or no reliable information about prognosis is provided (Castera, Constant, Bernard, de Ledinghen, & Couzigou, 2006). The diagnosis experience for women can have significant implications on social functioning. The perceived stigma associated with HCV can produce anxiety and amplify fears of transmission, which may lead to social isolation and limited intimacy in relationships (Miller, McNally, Wallace, & Schlichthorst, 2012). The two important findings stemming from my analysis, that the diagnosis experience was shaped by varied circumstances, which contributed to women’s level of preparedness, reinforces claims that the process of diagnosis has major implications for HCV care. These findings contribute to the knowledge base and should inform the continuing development of recommendations and strategies aimed at improving the HCV diagnosis experience, which will ultimately positively impact their journey with care.

This analysis of women’s accounts of diagnosis can provide insights into current practice, which can inform and direct nursing clinical practice and programs to ensure women are receiving the information and support they require at this critical point in their life. Although my research on the experience of diagnosis was undertaken prior to the recent major advances of interferon-free HCV treatment, which have given new hope of speedy and less burdensome treatment, these new treatments alone will not solve the burden of HCV. The roles of healthcare providers in HCV care are expanding from specialty clinics into general practice, thus highlighting the need for these issues of diagnosis and clinical pathways into care to be refined.

### 6.3.1 Testing Circumstances and the Women’s Level of Preparedness

Women are diagnosed with HCV in a range of settings and after a variety of prompts. This study found the context of the diagnosis often foreshadowed how prepared women were for a positive diagnosis. Women who received limited information pre-diagnosis were less prepared and therefore shocked by the results. On the other hand, the few women who were well informed about HCV prior to diagnosis – generally those who had sought testing or were tested following risky practices – had a base from which to ask questions. For example, women who were diagnosed during routine blood-work or for insurance purposes were neither prepared for nor anticipating a positive result. Moreover, these women were more likely to be diagnosed in a setting where their healthcare provider was less informed about HCV. Being unprepared for a HCV diagnosis can trigger feelings of shock and devastation, potentially leading to long-term emotional, psychosocial, and physical-effects and maybe a barrier to accessing care (Miller et al., 2012).

### 6.3.2 Information and Health Education

Health education and effective communication of management plans can influence patients' emotional and physiologic status and significantly impact health-outcomes (Stewart, 1995). Communication interventions and patient health-outcomes are correlated; effective communication can positively influence the patient's emotional health, symptom management and physiologic status (Stewart, 1995). The women in my study were generally provided with inadequate or incorrect information at diagnosis leaving them confused and unsure about follow-up and management. Some were told there was no reason for follow-up while others were not provided with recommendations or guidance on the need for ongoing management and monitoring of HCV related liver disease progression. These experiences negatively impacted relationships with healthcare providers, which can create a barrier and avoidance of future healthcare (Miller et al., 2012). To improve the experience of diagnosis, post-test discussions are the ideal time to review health issues, assess support mechanisms, make immediate referral to support agencies and discuss HCV knowledge and prevention issues.

These results raise concerns about whether women are being educated, as they should be, to make informed decisions about their HCV care. Discussing the meaning of a positive result can help women understand their diagnosis and take control of their subsequent health behaviours (Gifford, O'Brien, Bammer, Banwell, & Stoove, 2003). My results highlight the importance for healthcare providers to have suitable training to equip them with the knowledge and skills to provide appropriate information and holistic care for women living with HCV along the HCV cascade of care. The findings also emphasise the significance of inquiring about each woman's prior knowledge of HCV and not assuming adequate information has been provided to her at her first diagnosis. As the knowledge base around HCV treatment and management is rapidly increasing, each healthcare interaction can be considered a point of diagnosis. Even though women may have been diagnosed previously, as it is evident in my results, they may have been diagnosis with non-A non-B hepatitis and never informed about HCV care or management. Each blood test needs to be considered a point of diagnosis and an opportunity to educate women about HCV and recommend follow-up management. Each interaction is a crucial opportunity for healthcare providers to correct or update information that may lead to better care and increase women's sense of control over their healthcare experiences and future health outcomes (Hibbard & Peters, 2003).

HCV is a stigmatised condition due to the association with IDU. A negative experience at diagnosis can lead to disengagement and create a barrier to, and avoidance of, healthcare, which will damage future relationships with healthcare providers (Treloar et al., 2010) and potentially negatively impact treatment and interventions. This potential outcome is important for all people diagnosed with

HCV, but especially pertinent to women as they often feel judged by healthcare providers (refer to Section 3.2.5 for more information) and that their behaviour and lifestyle is being scrutinised. Therefore, it is crucial that healthcare providers caring for women with HCV have a sound understanding of HCV to ensure appropriate care is provided.

This chapter has identified that women are diagnosed in a variety of settings, but HCV awareness, knowledge, and expertise are not evenly distributed across these diverse settings. Although pre-and post-test guidelines for HCV have been identified as important for prevention and care (Watson & Kosky, 1999), they are currently lacking in a number of settings, including in Canada, which was the site of this research. Countries that do have testing guidelines in place, for example, Australia implemented a National HCV Testing Policy to provide guidance for the management of diagnosis and pre-and post-test discussion for both HIV and HCV, have found them effective for ensuring minimum standards of care are met (Fethers, Andrews, McCoy, Harvey, & Spencer, 2008; Treloar et al., 2010b). Without consistent HCV pre-and post-test guidelines, nurses and other healthcare providers will continue to provide variable information during pre-test and post-test discussions, if any is delivered at all (Munoz-Plaza, Strauss, Astone, Des Jarlais, & Hagan, 2005). Implementing National Testing Guidelines and Policies in Canada is the first step towards improving the diagnosis experience for women living with HCV.

The point of diagnosis is an important window of opportunity for education and engagement into care and treatment. It is concerning that so few women diagnosed within the last decade received what they judged to be adequate information about HCV from their healthcare provider in an era when treatment was (theoretically) available. It is unsurprising however, given the lack of diagnosis and management guidelines. Although guidelines cannot guarantee appropriate care at diagnosis, they can be effective in articulating minimum standards of care. Implementation of a national HCV strategy and pre-and post-test guidelines would facilitate referral into care and treatment at the point of diagnosis and possibly reduce barriers to care, which otherwise could lead to unnecessary disease progression and, ultimately, reduce the overall burden of the disease in Canada (Krajden et al., 2010; Yu, Spinelli, Cook, Buxton, & Krajden, 2013).

It is essential that adequate and appropriate information about prognosis, treatment options and the ongoing need for healthcare is provided at the point of diagnosis to ensure those affected have the necessary knowledge and access to care. This chapter has demonstrated how the lack of information about HCV prognosis, the lack of preparation for a HCV diagnosis and follow-up during the diagnosis experience can all negatively influence their ongoing relationship with healthcare providers and ultimately negatively impact the ongoing journey with care for Canadian women living with HCV. It has highlighted the need for a proactive response from healthcare providers, which will improve women's experiences of HCV diagnosis and, in turn, enhance women's access to HCV care and other healthcare services.

# CHAPTER 7 BARRIERS THROUGHOUT WOMEN'S JOURNEY WITH HCV CARE

## 7.1 Introduction

Issues of social exclusion and marginalisation coupled with stigma and discrimination have been well documented as creating a barrier and preventing women living with HCV from attending to care (Iversen et al., 2015; Temple-Smith et al., 2007). Women have reported that feelings of shame, fear, and an altered sense of self (Crockett & Gifford, 2004) have all been barriers to attending for HCV care and have had a significant impact on their journey with care. Among parenting women, the link between poverty, HCV infection and feelings of mothering inadequacy have also been noted as barriers to attending to care (Hopwood & Treloar, 2003; Olsen et al., 2012; Treloar et al., 2013). Not attending to care can have potentially devastating consequences for the health of the individuals, communities and health system resources.

As highlighted in Chapter Six, for women living with HCV their level of knowledge about the disease can be a barrier to HCV care and influence health outcomes (Glacken et al., 2001). The lack of information and support from healthcare providers at the different stages along the HCV cascade of care (refer to Chapter One) can potentially further reduce HCV follow-up and management (Treloar, Harris, Deacon, & Maher, 2010a), as it increases fear of the disease and generates feelings of loss of control over one's health (Hopwood & Treloar, 2004). Prior studies have shown HCV education to be an important healthcare need for people living with HCV as it increased their readiness, willingness and acceptance of management and treatment (Surjadi et al., 2011).

Research undertaken when HCV standard treatment had considerable side effects with low efficacy rates demonstrated that the negative consequences of treatment were often a major barrier to care (McGowan et al., 2013). There is an urgent need to better understand the various factors and barriers along the HCV cascade of care that influence the journey with care among women living with HCV. As the new treatments with a short duration and fewer, if any, side effects (Brennan & Shrank, 2014) become universally publicly available, there is a much greater chance of cure for all those affected. However, for this to become a reality, the challenge will remain: how to address these complex barriers to care and successfully treat women living with HCV.

In this chapter I will describe five key issues that can have a positive or negative impact on women's journey with HCV care using the HCV cascade of care as a framework: information provision, family and caregiver responsibilities, poor relationships with healthcare provider, active substance use and stigma and discrimination related to drug use. I will describe how these five key issues were barriers for women attending to care and then explain how some of the women then saw these barriers as challenges they needed to overcome along their journey with HCV care. For the purpose of this thesis HCV care has been defined as engagement with healthcare services for HCV testing, monitoring, symptom management, and/or treatment. Understanding these barriers and acknowledging the challenges and achievements of these women living with HCV along their journey with care can help healthcare providers and policymakers implement services that start to address the health disparities among women living with HCV.

## 7.2 Results

### 7.2.1 Information Provision on Living with HCV

The women in this study described experiences of varying information provision along the HCV cascade of care that acted as barriers on their journey with HCV care. Common in the narratives were concerns about a lack of information provision at three points on the HCV cascade of care: ongoing follow-up, health promotion/prevention strategies and treatment. Becky's description below highlights the complex issues many of the women were challenged with, which often overshadowed their concerns around HCV.

> *Nobody has talked to me about it (HCV) so I don't really know like, how to treat it or anything… I know I have it but I don't know what it does to me so, cuz I got so much things wrong with me, like it's my arthritis or whatever, I completely forgot I had hep C… I don't know how to treat it [diagnosed 2007].*

For Becky, receiving limited information about HCV treatment and how to manage her HCV was confusing and distressing; she was left feeling that she "*didn't really know anything about HCV or treatment. It's, like I said, it's just a word to me*" and wondering about the consequences of HCV. This also highlights the missed opportunities to educate Becky and engage her into care.

Health literacy, the degree to which a person is able to obtain, process, and understand basic healthcare, has a significant impact on healthcare outcomes (Remshardt, 2011). In the narratives there were varying examples of barriers due to health literacy. This ranged from not understanding the information presented by the healthcare providers as evident in phrases such as *"like they won't really break* *things down and explain things in a way that people can understand"* to a limited understanding of what they read online. Below, Joan describes how receiving no information from her healthcare provider motivated her to seek out information herself but she was unable to understand the material available to her.

> *…because I don't have no information. I try to read it online, I read some but I couldn't understand it, but if somebody could explain it to me maybe I'd understand better [diagnosed 2007].*

When the women in my study were challenged by the barrier of receiving limited or no education about the disease they were living with, many were not discouraged by this. They described a desire to "*fight for something better*" and *"look for a solution*" so that they could live a fulfilling life. These women saw the need to become more knowledgeable about HCV to improve their health as they did not want to "*be one of those people who were gonna fail"*. This frequently involved seeking-out information to learn about living with HCV and ongoing care. In the following quote Sarah illustrates her motivation and desire to gain knowledge about HCV by researching information on the Internet:

> *Well I started to read a lot, a lot. No, I didn't know anything, I had heard of, you know, like hep A, B, C, you know, just as a cursory thing but not anything I paid attention to until then. And then I got on the internet and started to research it [diagnosed 2001].*

In the narratives, seeking medical information at various points along the HCV cascade of care provided women with a sense of power and confidence to question their healthcare providers about the management and treatment of HCV.

For example, Jena described her journey that included discovering HCV treatment was available and having the confidence to question her Doctor about her options:

> *I didn't know there was treatment. So now when we go back I'm gonna ask the doctor and I'm gonna talk to my husband after this phone conversation about, let's talk to the doctor about getting some treatment [diagnosed 1994].*

#### 7.2.1.1 Breastfeeding, Motherhood and Family

The issue of having limited or no information, which they were able to understand about HCV significance for their ability to breastfeed, motherhood and their family, were predominant in the women's health narratives. The women in my study described a misunderstanding and confusion by healthcare providers around HCV and breastfeeding. Women reported receiving incorrect information and being advised by their healthcare providers not to breastfeed because of their HCV status. Below, Jackie described her experience in hospital with her new baby. Although Jackie's example describes a negative experience with healthcare services after giving birth, it highlights the healthcare provider's inaccurate knowledge about the transmission risks of HCV.

> *…some of the nurses were scared, wouldn't let me breastfeed and stuff but as soon as they found out I was on methadone and have hep C, they just treated me like a* straight out junkie*, they wouldn't let me breastfeed, they wouldn't let me do anything [diagnosed 2005].*

This experience was confusing and distressing for Jackie. As she further explains, the lack of awareness by a healthcare provider created a negative experience that prevented her from returning to that hospital.

> *Well, I didn't breastfeed, I couldn't because they told me I wasn't allowed, cause they weren't experienced enough with the hep C and the methadone together so they decided that it shouldn't be done which it wasn't a problem, I did with my other kids... I mean, as soon as they find out you have hep C and you're on methadone they just treat you like a straight out junkie and, you know, very bad experience at that hospital, and that has kind of stopped me from going back [to that hospital] [diagnosed 2005].*

For Jackie, receiving incorrect information about HCV and breastfeeding from the healthcare providers was a negative experience, which left her feeling discouraged and questioning the other information she had received. This resulted in a disengagement from healthcare services and an ongoing avoidance to healthcare.

The women were concerned about the impact HCV would have on their ability to care for their current and future children and were worried about infecting their family. Below Emma describes how her lack of knowledge on HCV transmission impacted bonding with her new grandson:

> *I have kids and I have grand kids, and (pause), I just felt so dirty, it was horrible, I just felt like oh my god, I'm gonna pass this on to my family, my daughter had just had my first grandson and when I told her she didn't even want me holding him or anything cause we didn't know, right, it was really devastating, it was horrible [diagnosed 2006].*

For Emma, having limited information and “not knowing” about HCV and the transmission risks had a negative impact on her self- esteem and on her relationship with her family as she felt “dirty”.

When the women in my study were challenged by the barrier of receiving limited or no education about transmission risks and the impact HCV would have on breastfeeding, motherhood, and family some were not discouraged by this. These women saw this as a challenge to become more knowledgeable about HCV. This frequently involved seeking-out information to learn about living with HCV and ongoing care, which provided women with a sense of empowerment and confidence. In the following quote Sarah illustrates her motivation and desire to gain knowledge about HCV so she can live a fulfilling life with their family:

> *I knew nothing about hep C. After the initial shock (of being diagnosed) I started educating myself and my kids um…but then I had to, actually get an incentive to get my life together. It took a few years…I had something to work towards, you know, kind of like take control of my health, I wanted to do it, but then the more I learned about it and the more I knew I had to be clean and I had to have a stable life and everything so that was good incentive for me [diagnosed 2008].*

### 7.2.2 Family and Caregiver Responsibilities

Women often described a commitment to their family, caring for others and having to organize their lives around relational commitments, as a barrier towards maintaining their own health. Women frequently described delaying their journey with care for several years while their family was the priority. Below, Patsy describes delaying attending to her own healthcare needs while she looked after her sick husband at home, which took up all of her time so everything else including her own healthcare, 'just went by the wayside'.

> *He (my husband) was, he was my number one thing to look after and my life and my health took a back seat to his because he was very sick and when he came home from the hospital he needed more aftercare…and he took up a lot of my time, you know and it, it just went by the wayside…like I say my husband was sick and so he took the front seat, you know, he was number one on my list of things to do, yeah, I wasn't dying, I knew I wasn't gonna die you know so, like I say, it (HCV) kind of went to the back of my mind, it's not like you forget about it (HCV), it just went to the back of my mind and I looked after him [diagnosed 2006].*

As discussed in Chapter Two, until recently HCV treatment often had severe side effects. Women in the study with limited or no knowledge about the recent advancements in treatment, often described not attending to their own healthcare needs, which included HCV treatment, as their relationship with their family and loved ones was their priority. As Sam explains, she did not want to put her family through the consequences of the lengthy treatment.

> *Well, nausea, drowsiness, cranky, you know, I hear you just become irritable and take things out on everybody around you and I didn't want to do that to people I care about, I don't wanna be sick like that and then be cranky to people who care, my family is my priority you know [diagnosed 2011].*

Other women described not attending to and delaying their own healthcare needs, as the ability to care for their children was their priority. As Judy explains below she put her own healthcare on “hold right now” to focus on getting their kids back:

> *Well because I’m trying to get my kids back and I don’t want to be sick at all…I get tired and stuff but … my life’s kind of on hold right now…cause I’m trying to get my kids back and I’m not gonna take them back if I’m gonna be sick [from the treatment] [diagnosed 2005].*

For others their relational identities and caretaking roles shaped their motivation to go for care. Caring for themselves was considered a way to care for others. Women expressed wanting to ‘*live longer…and be around for my daughter and my grandchildren’.* As Tammy describes below, engaging with care and receiving HCV treatment was a means to look after her son and live longer.

> *Well my son, he’s just come back into my life in the last five years like he was with my ex-husband and then my ex-husband put him in foster care and everything. When I got out of jail, I got clean and sober and everything…And I was going for custody of him and I knew that if I didn’t get the [HCV] treatment that it could progress to something worse. I wanted to get it done and taken care of so I could look after him [diagnosed 2005].*

### 7.2.3 Relationship with Healthcare Provider

For some of the women in my study, a previous negative experience(s) had created a dislike and distrust of healthcare providers, which resulted in a barrier to engagement with healthcare services at various stages along the HCV cascade of care. This is displayed in Monica’s description of an interaction she had with her doctor when she was feeling unwell. Her doctor dismissed her concerns of having a potential illness and suggested her complaints were due to the demands of a young family rather than investigating further into her ailments. The lack of acknowledgment and attention to her concerns made her feel disrespected and that she was not important, which can negatively impact any ongoing and future relationships with this healthcare provider:

> *They just said that's arthritis and the demands of a young family and a shitty husband is what my doctors told me, you know, of course you're feeling this way, look at your life, you know? They thought it was causational but no, I felt that, all of these things they were blaming on something else instead of looking for an answer. And, you know, a lot of the time unfortunately male doctors dismiss when women say shit [diagnosed 2005].*

Women expressed a lack of confidence in healthcare providers in general. They doubted their knowledge and expertise in HCV with phrases such as: *"considering my family doctor doesn't know anything about HCV"* and *"my GP didn't know a lot"* were common. Trina explains that she did not trust the doctor's knowledge about HCV and so she did not recognise the importance of attending ongoing appointments, thus creating a barrier to care.

> *I didn't go, I didn't make an appointment because by that time, I'm researching everything and I know about this new medication that's on its way. So I knew as much as him. I didn't see why I should go and use up that time [diagnosed 2002].*

Conversely, some of the women in our study already had well-established relationships with a healthcare provider. In Jenna's narrative below, she acknowledges that her doctor had limited knowledge about HCV. However, she has established a trusting relationship with him and felt confident that he would listen to her ideas regarding her healthcare management plans.

> *Well, because I knew I had HCV and I wanted to get rid of it, I wanted to go in and see if I was able to, it was just all my doing…. he was a new doctor right, so he was just finding everything out about me but I came in knowing what I wanted to do [diagnosed 2005].*

Other participants, despite experiencing negative interactions with their healthcare provider, used the negative experience as a motivator to seek out and eventually find a supportive healthcare provider whom they felt happier with. This is reflected in Trudy's narrative, who after seeing several other doctors returned to her long-term trusted GP, despite the geographical distance.

> *I saw 14 different doctors and then I ended up calling my doctor back here and asking if he would take me back if I would come and see him every month so I'd take the bus up every month for an appointment to see him…it's worth the travel… and helps to have a relationship with your doctor, him knowing you [diagnosed 2006].*

### 7.2.4 Active Substance Use

The majority of the women in my study identified three issues related to their active substance use that presented complex barriers to HCV management and care: 1) engagement with drugs so not attending to their health, 2) response from healthcare providers, and 3) children and family.

#### 7.2.4.1 Focused on their Engagement with Drugs

While some of the study participants were actively using drugs, accessing HCV care and attending to their healthcare needs was not a high priority. Comments describing not thinking about their HCV and the need for follow-up were shared:

> *I was leading a different lifestyle then…I knew I was sick, but for some reason, it didn't enter my mind to go to the doctor… I never did go see a doctor about anything… It had a lot to do with my lifestyle, you know? If you walked a mile in my shoes in the lifestyle that I led you would understand a little bit better um, you know, at that time my lifestyle was concerned with getting as much drugs into me as I possibly could…yeah, it [going for care] wasn't number one on the list of things to do [Carmen, diagnosed 2005].*

Women explained that while they were using drugs, their time was consumed by drug activity preventing them for attending to their own care. As Deb describes, her days were filled with activities to make money to buy drugs.

> *It was pretty much the money aspect, I knew I needed my prescription for my antidepressants and instead of using my money to get the prescription for antidepressants I'd use it for my other drugs that I would want and uh, yeah, my day were filled with just trying to find drugs for myself, not doing anything else but making money and finding drugs [diagnosed 2011].*

#### 7.2.4.2 Response from Healthcare Providers

While they were actively using drugs, participants stated they were persistently unwell and when they did express concerns to their healthcare provider, they were dismissed and belittled. Women described being negatively judged or treated differently by healthcare providers when they sought care, which often resulted in an emotional trauma for them. As a result women described periods of up to several years in which they did not attend to care as a way of avoiding further negative treatment. As Trudy explains below, incorrect assumptions made by her healthcare providers resulted in a negative healthcare experience:

> *I was sick all the time, but he (my doctor) thought I was in there scamming him for drugs. Now the drugs you get from the doctor all take you down, right? ...My drug of choice would speed you up, right? So there's no way I was in there scamming him for dope…like, that's not my gig and I don't do that, I've never done it and never will but he thought I was in there telling him stories and trying to lie to him just in order to get drugs from him… he was totally under the wrong impression [diagnosed 2006].*

#### 7.2.4.3 Family and Children

Family and children often played a significant role in the women's motivation to overcome the barrier created by their addiction, statements such as "…*wanting to be healthy enough to regain custody so I can become a caregiver again, or to start a family*" were common. Women spoke about wanting to be healthy enough to start a family, protect family members from the risk of transmission and prevent worse outcomes. There was a determination to look after themselves which, involved attending to their healthcare needs to maintain their own health and wellness for their family and children. Women discussed the need to take time out to realign life plans which was felt to be necessary in order to access HCV care and treatment. There was a common misunderstanding that it was necessary to be free from active substance use in order to access HCV treatment. Below, Jodie describes how her journey with care was fuelled by her desire to overcome her addiction for her children. Her determination to look after herself and attend to her healthcare needs which involved treating her HCV and her active substance use was driven by her desire to care for her children:

> *I want to get my life together and getting rid of the hep C would be very good for me because I have young children and I don't want something to happen all of a sudden or whatever right, I just want to be clean from drugs and be able to be talk to them, or be able to take care of my kids and deal with my hep C [diagnosed 2004].*

### 7.2.5 Stigma and Discrimination Related to Drug Use

In my study, the majority of the women had experienced varying forms of discrimination from healthcare providers, which was largely linked to their history of drug use. Self-stigma, defined as the stigmatising beliefs of others that individuals learned to internalise, accept and personalise (Oakley, Kanter, Taylor, & Duguid, 2012) and discrimination were very prominent in the narratives as a barrier to attending for care as they did not feel worthy of the care or were fearful of further experiences of stigma and discrimination. Many of the women described feeling 'dirty' because they had HCV. Below Nancy's describes her desire to rid her HCV and the stigma related to it:

> *It's the stigma, the self-stigma. I did not want that and if there was a way to make myself healthier I was going to do it. It doesn't matter how hard it was,*

> *doesn't matter how agonising, you know, that too would pass but the hep C and the stigma wouldn't unless I did it, you know? [diagnosed 2006]*

The women in my study also reported varying experiences of stigma and discrimination from within the healthcare setting. Below, Trudy describes her experience of being denied access to ongoing healthcare by her GP as a result of her drug use. This experience of discrimination negatively influenced her seeking care in the future for fear of rejection.

> *My doctor fired me because I was an IV drug user… he requested that I don't come see him anymore, that I find a new physician because I was an IV drug user and he didn't like to have IV drug users as patients… I'm not going to argue with the doctor, you know, cuz I find once they, they take a negative look on you it just stays with you [diagnosed 2006].*

Healthcare related stigma and discrimination was often reported by the women as occurring when healthcare providers made assumptions and/or judgements that automatically linked their HCV diagnosis to drug use. As outlined in the literature review (Chapter Two) HCV is a highly stigmatised disease largely due to its close connection with drug use and associated risk behaviours. In the following quote, Pam discusses her feelings of being judged by healthcare providers and how this has negatively affected the care she receives.

> *I don't think they should be so judgmental, healthcare providers and stuff like that, I run into nurses sometimes or doctors that find out I have hep C they automatically assume that I use drugs, right? So I mean that makes things a little frustrating because then I don't get the right service I need, you know? [diagnosed 2002]*

These assumptions made by the healthcare providers resulted in inadequate care and a frustration for Pam with healthcare providers. This negative experience acted as a barrier and may have triggered an avoidance of future interactions with healthcare providers to escape additional experiences of stigma.

Stigma was also prominent in the narratives as a motivator for change. HCV infection was described as a constant reminder of their past life and stigma of IDU. Treating their HCV had the effect of symbolically eliminating this past identity as a drug user and the guilt and shame associated with their past behaviours. As Diana said*, "I just want to get rid of everything and start making a life for myself, a positive life for myself and my kids"*. Women felt getting rid of the HCV was essential to erase their past.

## 7.3 Discussion

The past two and half decades have seen much progress in the understanding and management of HCV. Nevertheless, women continue to be faced with barriers along their ongoing journey with HCV care. Inadequate information on sexual and reproductive health, negative experiences with healthcare providers, addiction and stigma, result in further disengagement from care at all points along the HCV cascade of care and long-term consequences to their understanding of HCV and its management (Hopwood & Treloar, 2004; Treloar et al., 2010b). An understanding of the barriers women are challenged with on their journey with care and their motivators to cope with these challenges can guide the development of educational resources and inform clinical practice, policies and models of care (Chapter Nine).

This chapter highlighted the barriers and challenges these women faced along the HCV cascade of care during their journey with care. Women responded to barriers by identifying motivators to overcome these challenges, which included establishing self-reliance, making decision about their healthcare needs, and seeking education, information and support.

### 7.3.1 Health Literacy

Health literacy, the degree to which a person is able to obtain, process, and understand basic healthcare, has a significant impact on healthcare outcomes (Remshardt, 2011). For people living with HCV, health literacy education and knowledge about the disease has a crucial role in improved attendance to care and an increased uptake in treatment (Beste et al., 2009; Surjadi et al., 2011). This chapter raises concerns about the information and education women are being provided with to make informed decisions about their HCV care. Each healthcare interaction is a crucial opportunity to provide updated information that can lead to better care, empower women and increase their sense of control over the healthcare experience which can make a vital difference in their future health outcomes (Hibbard & Peters, 2003).

The women in my study were generally provided with limited or inadequate information throughout their journey with care, leaving them confused and unsure about follow-up and management. They described a misunderstanding and confusion by healthcare providers around HCV, pregnancy and breastfeeding, which was similar to the results reported by Olsen et al. (2013) results. Pregnancy is a particularly vulnerable time for women because they often feel judged and their behaviour and lifestyle may be scrutinised, especially those women with a history IDU (Olsen, Temple-Smith, & Banwell, 2013). Situations like this can adversely affect their relationships with healthcare providers, which Miller, McNally, Wallace, and Schlichthorst (2012) suggest can create a barrier and avoidance of future healthcare. Gender-sensitive health education and effective communication of management plans can influence patients' emotional and physiological status and positively impact health-outcomes (M. Stewart, 1995). Communication interventions and patient health-outcomes are correlated. Effective communication can positively influence the patient's emotional health, symptom management, physiological status and pain control (M. Stewart, 1995).

### 7.3.2 Relationship with Healthcare Provider

As evident in my results, the women in my study experienced various negative and positive experiences with healthcare providers. Throughout the narratives, women prioritised having a positive non-judgemental therapeutic relationship with a healthcare provider. They often engaged several different healthcare providers before they found one, which they were confident, would understand and follow-up with their challenging healthcare needs in an empathetic manner. This is supported by previous research which noted that people living with HCV perceived clinicians as having "negative attitudes" toward them and reported being provided with neither information nor support (Crockett & Gifford, 2004; Treloar et al., 2010b) which can be a barrier and affect the willingness and acceptance of people living with HCV to attend for ongoing care (Trachtenberg et al., 2005). In an Australian study, Temple-Smith et al. (2007) found women reported higher rates of negative treatment related to their HCV and perceived discrimination from healthcare providers, than men. Similar to my results, Temple-Smith et al. (2004) showed women's sensitivity to healthcare providers' attitudes compromised their ongoing trust and engagement into healthcare services.

Treloar et al. (2013) has highlighted the importance of establishing trust between the client and the healthcare provider if therapeutic interactions are to be positive. This can influence the client’s attendance to care, quality of therapeutic interactions and behavioural change. Often, therapeutic relationships were built on an established trust in the healthcare provider’s knowledge. The women in my study experienced various levels of accurate information about living with HCV. This echoes Cox et al. (2011) results which found gaps in healthcare provider’s knowledge on the progression and transmission risk of HCV. The lack of accurate information from healthcare providers has damaged therapeutic relationships and acted as a barrier along their journey with care. As highlighted previously, implementation of HCV education for all healthcare providers will ensure healthcare providers are knowledgeable and able to provide accurate information along the HCV cascade of care, which will ultimately improve the therapeutic relationships and reduce this barrier along their journey with care.

### 7.3.3 Active Substance Use

As highlighted in this chapter, for PWID, accessing HCV care was limited as it may not be a high priority for them (Swan et al., 2010) and HCV treatment uptake is low, especially among women (Iversen et al., 2015). Within the PWID community, research has shown HCV to be minimalised and normalised. Limited knowledge, combined with the asymptomatic nature of the HCV has resulted in a perception that HCV does not to require ongoing medical attention and the seriousness of HCV being underestimated (Grebely, Oser, Taylor, & Dore, 2013b; Swan et al., 2010).

WWID have an increased exposure risk to HCV with higher rates of receptive sharing of needles compared to men (Iversen et al., 2015). To improve the journey with HCV care for WWID, HCV education and awareness programs are needed in the various healthcare services. Misconceptions about HCV transmission risks must be addressed to reduce the stigma that has been established within this target population.

### 7.3.4 Stigma and Discrimination Related to Drug Use

As highlighted in this chapter, HCV is a stigmatised condition due to the association with IDU and the magnified assessments of transmission risks. The majority of the women in my study identified active substance use as a complex barrier to HCV management and care. Research has shown women may be more adversely affected by such stigma given typical gender roles and social expectations of women being the primary care givers (Iversen et al., 2015; Reid & Day, 2015). Due to HCV association with IDU, stigma is often magnified when children are involved as it is assumed that the women who are the primary care givers will neglect the child’s care due to drug related activities.

The majority of the women in my study had experienced increased experiences of discrimination related to their drug use by healthcare providers.

Research has shown health related stigma to be closely linked to adverse health outcomes and poor/reduced/limited health access (Treloar et al., 2013) as it often leads to further disengagement from and avoidance of healthcare interactions (Treloar et al., 2010b). For therapeutic relationships to develop, it is crucial for healthcare providers to be aware of these past experiences of stigma and discrimination and how it has been translated into their behaviours and ongoing interactions. Implementation of HCV stigma education and awareness programs will help to ensure that healthcare providers are mindful of past damaging interactions that may have created barriers. This will ultimately lead towards clinical practices that allow for supportive interactions and prevent further harmful interactions.

This chapter has highlighted the barriers to care that women living with HCV are challenged with and their motivators to overcome these challenge to maintain their health along the HCV cascade of care. Inadequate health information, combined with negative experiences with healthcare providers, can result in further disengagement from care and long-term consequences to their understanding of HCV and its management (Hopwood & Treloar, 2004; Treloar et al., 2010b). An understanding of these barriers that women are challenged with and their motivators for change along their journey with care can guide the development of educational resources and inform clinical practice and integrated models of care that may ultimately improve the journey with care for women living with HCV. Using the HCV cascade of care as a framework will help identify gaps in services along the journey with care. The next chapter will continue on the journey and investigate the decision making process these women go through when choosing to attend for HCV management and treatment.

# CHAPTER 8 "I DIDN'T GET CLEAN TO DIE": HOW DO WOMEN LIVING WITH HCV MAKE SENSE OF THEIR DECISION TO ATTEND FOR HCV CARE?

## 8.1 Introduction

To date, there have been minimal investigations concerned with women's attendance for HCV care and the related influential issues along the HCV care continuum. Numerous studies show the influence of a sense of responsibility on health beliefs and behaviours (Bolam, Hodgetts, Chamberlain, Murphy, & Gleeson, 2003; Olsen et al., 2012). However, little is known about the decision process and what contributes to behavioural changes for women living with HCV. There is growing evidence that some people affected with HCV, experience substantial misconceptions about the seriousness of the infection as they feel healthy and do not understand the liver damage HCV causes. Due to the asymptomatic nature of HCV, the efficacy of healthcare interventions including health education, monitoring of health status and treatment is not recognised (Gidding et al., 2012; Khokhar & Lewis, 2007; Munoz-Plaza et al., 2008). As described in Chapter Two, there is an urgent need to better understand the complexity of factors influencing attendance for care among women affected by HCV.

In this chapter I argue that understanding women's experiences of living with HCV and how they make sense of deciding to attend for HCV care is crucial in their journey with care. I was interested in the related influential personal, social and structural factors associated with their decisions to seek healthcare concerning HCV. The emphasis on the contextual features of women's narratives was intentional in light of the growing empirical evidence illustrating the significant social and economic effects of HCV and the influence of other life circumstances (e.g., mental illness, drug use, unstable housing, poverty, discrimination) on attendance for care (Butt et al., 2008; Olsen et al., 2012; Olsen et al., 2013; Rance & Treloar, 2014; Temple-Smith et al., 2007; Treloar, Newland, Rance, & M, 2010c). My analysis investigates the following questions: (1) how do women living with HCV make sense of their decision to attend for HCV care; and (2) what contextual factors – personal, social and structural – influenced their decision and journey with care?

## 8.2 Results

Women's journeys with care were distinctly different and reflected their unique experiences. However, from my analysis it was apparent that for the women in my study, key motivators shaped their narratives around their decision to present for care. My analysis illustrates differences in access to healthcare related to mode of HCV infection, which can ultimately affect women's journey with care.

Women's attendance for HCV care was situated within an overarching desire to remain alive. Moreover, each of their narratives reflected two interrelated factors that helped them make sense of their journey with care and its significance for their health - events that occurred in their lives that helped them to identify their health as a priority and the timing of these events within the context of their everyday lives.

Three distinct stories were evident in the women's narratives regarding events and their timing in their journey with care: (a) immediate crisis, (b) gradual sequence of awareness and (c) acquiring HCV through blood transfusions or vertical transmission. The majority of women's accounts were reflected in these first two stories, with three participants' narratives of attendance for care falling into the third story type. As described in Chapter Five, mode of transmission was not directly asked during the interviews, but was volunteered by all twenty-five of the women and thus fully explored through the interview process and used in the analysis.

### 8.2.1 Narrative One: The Immediate or Crisis Event

Several women's narratives reflected a journey with care that was associated with an immediate and sometimes life altering event that provoked them to take steps to fulfil their desire to remain alive. These life-altering events shared suddenness in their timing. They were narrated as contributing to a desire to change and "fight for something better" so that women could live a fulfilling life. However, the nature of the actual event and the meaning women ascribed varied. Most of the women represented in this immediate or crisis narratives were aged 40 years and older and had been diagnosed with HCV for six or more years.

#### 8.2.1.1 Diagnosis: - "The wakeup call to start changing my life"

Some women made sense of their journey with care by identifying that receiving a HCV diagnosis was the immediate event associated with prioritising their desire to live. These women described their diagnosis experience as unexpected and frightening. For many this shock was explained in relation to having limited knowledge and understanding about HCV. As discussed in Chapter Six, at diagnosis many of the women reported that they received little or no information from their healthcare providers other than that there is no cure for HCV. At the time these women were diagnosed, HCV treatment was difficult to tolerate with low efficacy rates.

After the initial shock of diagnosis, the women often saw the need to make a change and improve their health; this frequently involved attending for care to learn about living with a 'chronic disease'. Their diagnosis revelation became an opportunity to make a significant shift in their journey. The shock of their diagnosis was a 'wake-up call' that caused participants to question the direction of their life (King et al., 2003). The importance of life was central in these diagnosis narratives and the desire to live longer was the motivator to make changes that could improve their health. For example, as Jen described:

> *If it weren't for the hep C I wouldn't have had the wakeup call and changed my life…I mean, I know it's a life threatening illness, but it was a mixed blessing, if I hadn't have come down with that I wouldn't have had the wakeup call to start changing my life and striving for healthy and happy, or healthier I suppose…a wake-up call [diagnosed 2005].*

However not all experiences of diagnosis caused a disruption that prompted a turning point. Some viewed their HCV diagnosis as a death sentence. These women often had limited knowledge about HCV and described feelings of hopelessness and that their life was over. In these narratives, there was no motivator for a positive change in care seeking behaviour. Sue provides a good example of this:

> *When I found out I had hep C I just figured my life was over so my big thing was just getting my time in and going back to using and just staying that way because I just figured that life is gonna be over, you know, quick and I didn't know how quick cuz it didn't say in the pamphlet but um, I didn't have any desire or knowledge of staying clean, I figured I'd die out there, I really did [diagnosed 1994].*

The specific experience of a loss of future identities and meaning is palpable in this extract from Amy:

> *So I just went hard into my drugs and just said, what do I have to look forward to? I'm never going to be a mum and if I am a mum I'm gonna die and not raise my children. I'm never going to be a wife because I'll die and I'll never have a career because I'll die and so, why even live right? … So I became a, a raging drug addict, stick really bad needles into you, I had no reason to quit [diagnosed 1999].*

For others, a HCV diagnosis was expected and what they described as an inevitable part of their life course. They described HCV as common and acceptable in their social network sometimes stating that they were surprised that they had not been diagnosed years earlier. When these women received a HCV diagnosis, they rationalised that it was self-inflicted and they deserved it. For example, Carolyn stated:

> *…Everybody has it [HCV] (laughs) lot of places I went there was a lot of people with it, like that have found out that they have it or whatever, and I think at that point my, my partner knew he had it first so, you know, eventually I would have gotten it anyway. But, yeah, so it, I mean it was a little bit of a shock but I did it to myself, right? [diagnosed 2005]*

#### 8.2.1.2 Seeing your Future Played out Though Another: "Looking in the mirror"

For some women the crisis that prompted engagement with care was a result of a shock from somewhere else. Women described being confronted by the reality of their life through seeing their life in others. This experience forced the women to realise, as Strauss (1992) describes it, that "I am not the same as I was, as I used to be (p.149).” By looking at someone else’s life, some women saw what their future might be. This created a desire to change to avoid an undesirable future. As Trish described:

> *I remember it was the day after my birthday that I stopped, that night of my birthday I went to the drug house to pick up. I had money and then I just seen one of my old ex-boyfriends and he was wandering around all sketched out and weird and it just brought me back. And I told the guy, I said I’ve changed my mind I don’t want anything and I left with money still in my pocket and went home and went to sleep and that was the last time I ever used [diagnosed 1999].*

For some women, observing the illness or death of friends or family members that shared similar life circumstances (e.g. drug use, psychosis) provoked a sudden awareness of the reality of their own life and salience around their own mortality. By looking at someone else’s life, and seeing what their own future might be, women experienced a desire to change in order to avoid an undesirable future. In Bec’s case, this impetus for making change promoted her to attend for care and seek treatment to eliminate HCV from her body.

> *My one friend came in there one day and I look across the street and, “oh my god, he’s dying”…yeah, about two weeks after that he was gone and it just, that one really caught me, you know. And it reminded me cuz his stomach was bloated and that’s exactly what was happening when I was 15 or 16…so that scared the hell out of me, it really did…So I decided to go on treatment and try to get rid of the hep C [diagnosed 1994].*

### 8.2.2 Narrative Two: Gradual Sequence of Awareness

In the second type of narrative, the women described a gradual shift from a sense of apathy and hopelessness around their life to developing a new desire to look after themselves and a passion to live. The participants describing this gradual sequence of awareness narrative were younger (aged 21-49 years), had been infected with HCV six or more years ago and, in contrast to the women adopting the sudden crisis narrative, had no experience with HCV anti-viral treatment suggesting that they were not linked into any healthcare services.

Gradual awareness narratives featured a long journey with a series of events or insights, and *"stops and starts along the way",* that produced an on-going change in women's lives. For these women, attendance for care that included assessment, management and HCV treatment was often an end point of a long journey. Phrases such as *"I didn't want to sober-up and then later die from it"* and *"I didn't get clean to die"* were common. For example, Mary described her journey that included stopping IDU as having taken place over a few years:

> *I was using and feeling pretty disgusting and feeling sorry for myself and stuff, but then after the initial shock I started educating myself and my kids …but then I had to (laughs), ah actually get an incentive to get my life together. It took a few years but it's been some, I had something to work towards, you know, kind of like take control of my health, well, I wanted to do it, but then the more I learned about it (HCV) and the more I knew I had to be clean and I had to have a stable life and everything so that was good incentive for me [diagnosed 2006].*

Three motivators appeared repeatedly: self-care, shame and grief.

#### 8.2.2.1 Self-Care: "I had to learn to take care of me first before I could take care of everybody else"

The ability to provide care and support for others was prevalent within this narrative type. Children often played a significant role in the decisions to seek care, for example, being healthy enough to regain custody so they could become a mother again, or to start a family. Women also described seeking care so they could protect family members or future sexual partners from the risk of transmission. A gradual awareness was described of the need to look after their own healthcare and get their life in order before they could care for others. These women all described wanting to embrace the future with their children and family. Mary highlights this below:

> *I'd never taken the time for me before and now that I've taken time for me I'm actually being able to do more for my children, I had to learn to take care of me first before I could take care of everybody else [diagnosed 2005].*

#### 8.2.2.2 Stigma and Shame: "I felt dirty, having a disease made me feel dirty"

Stigma and shame was evident throughout the narratives. At diagnosis, this was seen due to the lack knowledge around the transmission routes of HCV.

> *At first I was embarrassed to have hep C, it was like I was ignorant of the fact that you can get it in a lot of different ways, I just always thought that hep C was for people who were IDU or, you know, prostitutes or something, I didn't know anything about it (Betty, diagnosed 2001).*

In other narratives, stigma and shame and the desire to rid HCV from their body and their life were strong motivators leading to a gradual awareness of the need to attend for care. HCV infection was described as a constant reminder of their past life and stigma of IDU. Treating their HCV was seen as a way to erase a past identity. As Diana said,

> *I didn't want to sober up and then later die from it. I wanted to clean out my system and get rid of the past, basically of what I had done to myself [diagnosed 2008].*

#### 8.2.2.3 Loss and Grief: "I lost everything in my life"

In several narratives, women described realising they had to make a change when they felt that they had "*hit rock bottom*". The meaning of "rock bottom" differed, for some it was when their children were removed by child protection services, for others it was when they were homeless and living on the street. For some "*hitting rock bottom*" may have created a sudden change (refer to 8.2.1); however for these women it was gradual. The sense of loss and grief associated with these significant and meaningful gradual losses, provided the motivation to make a change, access HCV care and, for some, cease drug use. Jayne provides a good example of this:

> *I've been addicted to opiates for over ten years and uh…I lost everything in my life, it started with my job, then it was (pause) my kids, my apartment and I ended up having nothing at all but the clothes I had. I knew it was time to change, I want my children back, it's really hard on me still and so I knew I had to make changes and (pause) start uh, start my life over [diagnosed 2006].*

For these women change was a gradual process that was instigated after thoughtful reflection and evaluation of what they thought their future would look like now that they had an HCV diagnosis.

### 8.2.3 Narrative Three: A Journey Driven by Medical Authority Intervention

Two women who had been infected with HCV through blood transfusion prior to universal HCV screening of donor blood, described a very different experience of accessing treatment and care to those presented above. In these narratives, an identifiable change or reflection point in their journey with care was absent. Once diagnosed these women who acquired HCV iatrogenically received support and immediate access to healthcare, monitoring, treatment and follow-up. Their journey with care was driven by a medical intervention rather than a personal shock or personal reflection. We see this in Shari's description of her diagnosis:

> *When I first found out I that had hep C, my family doctor had made the arrangements for me to start going there (to a specialist clinic) and they're the ones who put me on the medication right away [diagnosed 2001].*

## 8.3 Discussion

This chapter explored women's narratives to provide insights into the experiences of women living with HCV and their motivation in relation to attending for HCV care management and treatment along the HCV cascade of care. Numerous studies show the influence of a sense of responsibility on health beliefs and behaviours (Bolam et al., 2003; Olsen et al., 2012). However, little is known about the decision process for women living with HCV and the motivators that shaped their journey with care.

The factors that ignite women's motivation to attend for care were complex. Learning from the women's experiences will help healthcare providers to engage more meaningfully in clinical practice and research.

### 8.3.1 The Importance of Diagnosis Delivery

A crisis can be experienced as an opportunity or a hazard, which a person may or may not have control over (Cohler, 1987; King et al., 2003; Turner & Avison, 1992). According to Clausen (1990) at least 85 percent of people can describe a crisis or turning point in their life. These life changing events can come as a sudden shock and/or enlightenment or an accumulation of events which results in the person wanting to make an abrupt change or a gradual shift (Denzin, 1989; King et al., 2003). Specifically, diagnosis of chronic illness can create what Bury (1982) has termed a "biographical disruption": a drastic shock in the person's life. These shocks may be ideal times for healthcare providers to intervene (Lambert & McKevitt, 2002). A HCV diagnosis could produce a sudden crisis that changed how women subsequently dealt with HCV. For many women, their HCV diagnosis raised significant concerns about current and future health status. As evident in my study and the work of others (King et al., 2003), this is the time when risk taking practices can be altered and a person may be open to working towards behaviour change. Recognising diagnosis as a potential sudden crisis that can be a motivator for some women or as a death sentence for others is only the first step. Information provision is critical to support these women towards behaviour change. Also, once women receive their diagnosis, ideally there would be immediate referrals and entry points into care.

### 8.3.2 Enhancing Self-Worth and Prioritising Meaningful Relationships

Women described a process of reflecting on a series of events or experiences and gaining insight about the important things such as their own survival or their children. This reflection produced a gradual shift in awareness and perspective and then action for the women. These narratives were very future focused, with a desire to "*leave the past behind*" to start a new life with and for their children and were significant motivators for attending for care. For other women, relationships with their family and children acted as a barrier to attending to their own healthcare. Being aware of what provides women a sense of meaning and future can support healthcare providers to develop interventions that promote better health outcomes for women living with a chronic illness (B. Stewart, Mikocka-Walus, Harley, & Andrews, 2011).

Many of the women that went through a reflection process associated with slow change described feeling they had been beaten down over time from negative experiences and they wanted to change, to move on. This struggle to emerge from a sense of oppression and shame arising from one's diagnosis towards a sense of self-worth and satisfaction with their identity was a long complicated journey. In the grief and loss context, this process is often described as transforming an initial loss into an ultimate gain (Brandtstädter, 1999; King et al., 2003). Healthcare providers can facilitate this transformation journey with respectful, supportive, environments that help women develop a sense of self-esteem and move towards prioritising self-care and identifying potentially meaningful motivators.  This model of patient-centred practice has been shown to improve patients' health status and increase efficiency of care (Stewart et al., 2000). Many of the women described long journeys with many challenges along the way, requiring perseverance and ‘fighting’ to overcome these challenges, which are consistent with personal resistance to perceived oppression being a form of empowerment (Mancini, 2007). In these narratives a common thread was their motivator for change and a desire for life.

### 8.3.3 Healthcare Access and Equity

Although HCV source was not directly asked, all participants volunteered and discussed their exposure source and thus it was fully explored through the interview process. From this it was clear that the mode of HCV infection was associated with differences in journeys with HCV healthcare. Women who acquired HCV iatrogenically had support, access to healthcare follow-up and information; there was no sense of a personal process towards care for these women, it simply happened. Their journeys were very different – one was about medicine and the other one a social consequence.

In Canada, the introduction of anti-HCV screening for blood donors ultimately decreased the incidence of iatrogenic HCV. However, valuable lessons can be learned from this experience and the women’s narratives. The seamless access to healthcare appeared to short-circuit the struggle and long complex journey with care described by other women and may provide insight into how the journey can be better managed for others. Bindman et al. (1995) found populations with perceived poor access to healthcare had higher rates of hospitalisations for chronic conditions. Nurse practitioners and public health nurses are often key points of entry for women into the healthcare system. Developing better clinical pathways into care at first point of contact may reduce hospital admissions rates for women living with HCV and ensure accessible and equitable healthcare, as was the case for those women with iatrogenic-acquired infection.

Barriers to healthcare from all levels including government, policy and community clinic practices must be examined to increase engagement into care and ultimately reduce the long-term co-morbidities associated with HCV. National testing strategies that engage women living with HCV into care and treatment will ultimately reduce the progression onto liver cancer and the burden of this disease. Having Government, policy makers and communities come together with a united voice would strengthen the strategies and interventions, which would assist in transforming HCV into a curable, manageable chronic disease.

Continuing on from the previous two chapters, the impact of diagnosis and gender specific barrier when living with HCV, this chapter has identified key motivators that changed the journey for a sample of Canadian women. As new interferon-free treatments become standard care therapy, understanding the factors that mediate women's journeys with care is crucial to support the success of these new treatments. The information from these three chapters on the lived experience of women with HCV will help to increase the depth and quality of knowledge in this area and provide insight into what it is like to live with HCV and the factors that have acted as barriers and impacted decisions along their journeys of living with HCV.

# CHAPTER 9 DISCUSSION

*We can feel isolated and powerless when living with chronic illness, but what if your story begins to bridge the barrier or open a way for someone to connect? What if your story offers a glimmer of hope to someone standing at the edge of desolation? ...What if your story starts the conversation?*

— Cindee Snider Re, Author of Discovering Hope:
Beginning the Journey Toward Hope in Chronic Illness (2016)

The journey with HCV care for the majority of the women in my study was complicated and chaotic. Barriers and complex challenges were prominent throughout many of the women’s narratives, which were often interrelated. However, for a few women the seamless access to healthcare as described in 8.2.3, prevented the struggle and long complex journey with care. Valuable lessons can be learnt from this experience and the narratives contained in this thesis.

My analysis illustrated that challenges and barriers began prior to diagnosis when women sought care and healthcare providers recognised HCV risk factors. My findings demonstrate that although each journey was unique, the difficulties along the way for many woman were caused by a mix of personal circumstances, mode of transmission, stigma, and a below par (and sometimes simply bad) diagnosis experience, follow up and healthcare access. It highlights the importance of using each healthcare interaction as an opportunity to provide updated information that can increase their sense of control over the healthcare experience and ultimately lead to better health outcomes.

In an era with new highly effective, simpler, safer, and shorter course antivirals therapy available, the scale-up of HCV treatment, using integrated models of care for women living with HCV is crucial. An understanding of these barriers women face and the motivators they embrace on their journey with care must be acknowledged and used to inform clinical practice and identify gaps in the HCV cascade of care. Only then will the uptake of these new treatments be improved and the journey with care for women living with HCV may ultimately be improved.

As discussed in the literature review, due to the asymptomatic nature of HCV the need for testing and diagnosis is often not apparent therefore many people remain undiagnosed. The cascade of care model (Chapter One) recognises the need for early HCV identification, linkage to care and treatment, which can improve the quality of care for women living with HCV. It acknowledges that education and information on HCV transmission risks, harm reduction initiatives and the need for diagnostic testing can be the starting point in a woman's journey with care. This is a comprehensive framework that should be applied to HCV strategies to ensure all aspects of care are considered.

Women in my study were diagnosed in a variety of settings, in which HCV awareness, knowledge, and expertise was not evenly distributed. Women's experience of diagnosis was a key point along the journey with HCV care, where education and adequate information could have positively influenced the women's journey with HCV care. My findings validate previous research that found the majority of people living with HCV received minimal or inaccurate information at the point of diagnosis (Gifford et al., 2003; Hopwood & Treloar, 2003, 2004). From my analysis it was evident that the absence of accurate information at the point of diagnosis magnified the psychological-distress, which can follow a HCV diagnosis when little or no reliable information about prognosis is provided (Castera, Constant, Bernard, de Ledinghen, & Couzigou, 2006). In the era of new antivirals therapy and increased access to treatment and a cure, it is important for healthcare providers to be aware of past negative diagnosis experiences and explore the ongoing impact and implications with their patients.

This is an exciting time as new information about HCV treatment and management is discovered, however, it is essential to ensure this new information is provided to the women living with HCV. National standards of care are essential to ensure that standardised information is provided during each healthcare interaction, which can help women make informed choices and improve their journey with care.

It was evident from my analysis that the continued lack of/inadequate information provision about monitoring and HCV follow-up, combined with negative experiences with healthcare providers could impact the individual and result in further disengagement from care and long-term consequences to their understanding of HCV and its management (Hopwood & Treloar, 2004; Treloar et al., 2010b). Therefore, each healthcare interaction is a crucial opportunity to provide women living with HCV the care and information they need to improve health outcomes. Healthcare providers can use these interactions as opportunities to assess women's knowledge and correct any misconceptions they may have developed about HCV or misinformation they may have received along their journey with care. This can lead to better care by empowering women and increasing their sense of control over the healthcare experience and future health outcomes (Hibbard & Peters, 2003).

My research finding's adds to the current body of knowledge and have implications for clinical practice, policy and future research. Acknowledging and identifying these opportunities and barriers along the journey with care for a sample of Canadian women can offer insights into current practices and issues and direct clinical practice and programs. The new highly effective, simpler, safer, and shorter course antivirals therapy has led to a substantial expansion and the scale-up of HCV treatment among people who are recognised to be at high risk of disease progression, transmission and death. Despite this, HCV treatment uptake among marginalised populations remains low due to limited engagement in care. Understanding the motivators that contribute to behaviour change can facilitate attending for HCV care and may help healthcare providers learn from these women's experiences and engage more meaningfully in clinical practice and research. This could ensure that women receive the information and support they require along their journey with HCV care. This is the first step towards improving health outcomes and reducing HCV-related morbidity and mortality for the growing number of women living with HCV and has significant potential to decrease HCV incidence and thus reduce HCV prevalence.

## 9.1 Implications for Practice and/or Policy

Canada lacks a national HCV strategy and comprehensive guidelines for care, treatment and prevention of HCV, which is unacceptable for a country that prides itself on a universal healthcare system. Australia, a country with a similar universal healthcare system and similar HCV rates, recently implemented their Fourth National Hepatitis C Strategy (Commonwealth of Australia, 2014) highlighting HCV as an urgent health concern that requires immediate attention to prevent new infections and improve health outcomes for people living with HCV. The Australian strategy sets priority actions to promote increased testing, improve care at diagnosis, expand treatment to primary care settings and develop evidence-based public health responses.

An effective Canadian national strategy would require the collaborative efforts of all government, affected communities and healthcare providers to engage people living with HCV into care and treatment, which may ultimately reduce the progression to liver cancer and the burden of the disease. A national strategy could provide recommendations for healthcare policies and practices, with a comprehensive understanding of the complexity of factors influencing women's journey with care. This may assist with aligning all healthcare providers involved in the prevention and management of HCV towards ensuring that the journey with care for women living with HCV is improved. Having government, policy makers and communities come together with a united voice, could strengthen the strategies and interventions, which would assist in transforming HCV into a curable, manageable chronic disease.

**RECOMMENDATION ONE:**

**A national HCV strategy and comprehensive guidelines for care, treatment and prevention of HCV is essential to improve health outcomes for women living with HCV.**

### 9.1.1 Point of Diagnosis

My research has demonstrated the significant impact the quality of information provided at diagnosis can have for a sample of Canadian women living with HCV. Emphasising the need for a proactive response from healthcare providers to improve women's experiences of HCV diagnosis and, in turn, enhance women's access to HCV care and other healthcare services. Women in my study were diagnosed in a variety of settings, by healthcare providers with inconsistent HCV awareness, knowledge, and expertise. Effective HCV diagnosis depends on a collaborative approach amongst healthcare providers. Strategies to improve the education for healthcare providers that are involved at the point of diagnosis must become a priority. National standards with HCV testing and diagnosis guidelines would guide minimal standards for HCV care, which could enhance the journey with care for many women living with HCV.

As HCV treatment and care becomes less burdensome and requiring less specialised care, generalist healthcare providers may have more involvement in HCV care and diagnosis, which can be a critical time to facilitate appropriate education and management. As discussed in Chapter Three, Surjadi and colleagues' (2011) assessment of the impact of formal HCV education results demonstrated the importance of HCV education for all people living with HCV as it can increase their readiness, willingness and acceptance of care and treatment. These finding are significant as they highlight the importance of expanding HCV education across all healthcare providers to ensure people living with HCV are offered information at all points along their journey with care.

My findings provide a clear and compelling case for a national HCV testing and management guidelines. National HCV diagnosis guidelines, including pre- and post-test discussion can inform clinical practice and ensure healthcare providers deliver relevant and current information during these important windows of opportunities and apply interventions to facilitate behavioural change at this crucial time, which can ultimately reduce the negative impact of diagnosis. National HCV management guidelines could inform healthcare providers of recommended management and follow-up standards and ultimately prevent the progression to serious liver disease.

**RECOMMENDATION TWO:**

**National HCV management guidelines could inform healthcare providers of standardised management and follow-up care and ultimately prevent the progression to serious liver disease**.

### 9.1.2 Stigma and Discrimination

While new antiviral treatments provide a cure for HCV, this alone is not enough. The stigma and discrimination associated with HCV needs to be addressed. HCV-related stigma and discrimination is a well-documented finding and clearly a significant issue for women living with HCV. The work of Crockett and Gifford (2004) findings suggest that when stigma is experienced at the point of diagnosis, it can affect participants' thoughts and feelings towards themselves and influence how they reflect on HCV in the future. The stigma and discrimination associated with HCV can therefore have an ongoing negative impact for women living with HCV.

My findings related to stigma and discrimination are similar to that of studies undertaken in the 2000s (Loveday et al., 2005; Treloar et al., 2013; Ward et al., 2000). Participants' experiences have not changed, they continue to experience HCV-related stigma, discrimination and judgmental attitudes by healthcare providers, irrespective of when they were diagnosed, which continues throughout their journey with care. This is unacceptable, the stigma and discrimination within the healthcare setting needs to be addressed. This clearly highlights the need for new innovative strategies to combat institutional stigma and discrimination in health care settings. Healthcare providers are the first point of contact for support and advice in regards to health concerns. If women living with HCV are reluctant to access care from healthcare providers out of fear of judgement – which may or may not be based on direct personal experience - the individual health and wellbeing of these women will be seriously compromised.

HCV treatments have now advanced such that we are on the precipice of being able to combat this disease, possibly eliminate it, but we cannot achieve this without healthcare service and worker buy in. One explanation for healthcare providers' negative attitudes and discriminatory behaviour could be due to a lack of training and education on HCV-related issues (Ward et al., 2000). My data clearly validates stigma and discrimination related to the association of HCV with drug use. This reinforces my recommendation below, regarding the need for increased HCV education throughout the healthcare system. Improved training and education on HCV-related issues and societal stigma related to drug use is the first step towards raising healthcare providers' awareness and potentially dispel HCV's association with drug use, which may underpin their judgmental attitudes and discriminatory behaviour. This may ultimately lead towards clinical practices that enable supportive interactions and prevent further harmful communications. At a government level, policy makers need to implement and enforce anti-discrimination laws that are in place to prevent this discriminatory behaviour. These policies need to be reinforced, to ensure that all healthcare providers, as well as the broader community are aware of and adhere to them.

**RECOMMENDATION THREE:**

**Develop and implement HCV education throughout the healthcare system. Improved training can raise healthcare providers' awareness and potentially dispel judgmental attitudes and discriminatory behaviour.**

### 9.1.3 Models of Care

If the burden of HCV-related liver disease is to be lifted, facilitating supportive linkages and easy access into care must become a priority. An equity-based multidisciplinary integrated approach, which includes experienced physicians, nurses and allied healthcare professionals is essential for successful comprehensive HCV care (Myers et al., 2015). A key challenge for the future will be to ensure the public health sector is well prepared and knowledgeable as HCV care extends from HCV specialist clinic to the broader public healthcare sector. Improving HCV knowledge and awareness across all healthcare providers and strengthening the strategies and interventions that engage women with HCV care and treatment may address the lack of information provision and barriers to accessing care that were revealed in my analysis; thus will ultimately improve the experience of living with HCV.

In the Canadian context, research has shown a comprehensive integrated multidisciplinary team approach has been effective in diminishing commonly experienced barriers to testing, management and treatment for specific population's living with HCV (Milne et al., 2015a). In-house primary healthcare in low-threshold settings, which are culturally appropriate and where trusting relationships between people living with HCV and healthcare providers are fostered, could help with the uptake of the new HCV treatments.

Equitable and accessible healthcare for women living with HCV and other chronic conditions is an essential public policy measure that must be examined. The most recent update of the Canadian Consensus Guidelines from the Canadian Association for the Study of the Liver (CASL) recommends that all patients with chronic HCV be considered for antiviral therapy, particularly those with evidence of liver fibrosis (Myers et al., 2015). As mentioned earlier, the goal of HCV treatment is to achieve an SVR at least 24 weeks after treatment completion. The decision to initiate treatment should be based on the person's preference and the potential risks versus the benefits of treatment. For people living with HCV who are genotype 1 and treatment-naive or treatment-experienced, the CASL treatment guidelines recommend that the new all-oral interferon-free regimens be used as first-line therapy (Myers et al., 2015). However, these treatments are not publically available in every province across Canada, and the current high cost of the treatment adds to the disparity of access to HCV treatment. Only when HCV treatments are made publically available to patients across Canada and successful treatment models enhanced and expanded (Bruggmann & Litwin, 2013; Grebely & Dore, 2014) will the potential for cure become a reality for all Canadians with HCV. However, the challenge will remain: how to reach and successfully treat HCV in the various priority populations across Canada.

In Canada, the introduction of anti-HCV screening for blood donors ultimately decreased the incidence of iatrogenic HCV. However, lessons can be learnt from this experience. The seamless access to healthcare as described in Section 8.2.3, can improve the complex journey with care. Bindman et al. (1995) showed populations with perceived poor access to healthcare had higher rates of hospitalisations for chronic conditions. Developing seamless pathways into care can ensure accessible and equitable healthcare for women living with HCV. Providing low threshold healthcare services that address the stigma and social barriers associated HCV could increase engagement throughout the journey with care (Milne et al., 2015b). Barriers to healthcare from all levels including government, policy and community clinic practices must be examined to increase engagement into care and ultimately reduce the long-term co-morbidities associated with HCV and transform HCV into a curable, manageable chronic disease.

**RECOMMENDATION FOUR:**

**Equitable and accessible healthcare for women living with HCV and other chronic conditions is an essential public policy measure that must be examined.**

### 9.1.4 Ongoing Research

This study has highlighted the barriers and motivators for women living with HCV. However, to date there has been little research evaluating current services and initiatives for women living with HCV. Further research is needed to explore current clinical practices, cascades of care and organisational policies that impact women's journey with care. This could provide insight into the practices and care, which can best facilitate a supportive environment to engage women into care and treatment.

From my analysis it is evident that healthcare interactions are a vital opportunity to provide updated information. It is important to acknowledge this and ensure that healthcare providers are knowledgeable about HCV along the journey with care. Further research is needed on healthcare providers' readiness and attitudes towards their responsibility for providing HCV care at all points on the HCV cascade of care. This could highlight gaps where healthcare providers are missing these fundamental opportunities to provide updated HCV information.

Further study is required to capture other factors that interplay from the perspective of other specific populations. To improve the health outcome for these women living with HCV and the barriers to HCV education, care and management must be addressed at the system, provider, and patient levels. Accessible, stigma-free, integrated healthcare services that address the barriers to care must be considered. This is critical if we hope to eliminate the current HCV epidemic.

**RECOMMENDATION FIVE:**

**Accessible, stigma-free, integrated healthcare services that address the barriers to HCV care must be implemented.**

## 9.2 Strengths

Conducting the research for this thesis simultaneously with the NACP at the BCCDC had several benefits. Situating the research for this thesis, within a bigger research project at a well-recognised and respected organisation throughout Canada gave me access to the well-established National Advisory Committee. This committee was fundamental in recognising the gaps for the women living with HCV and identifying the need for further research focusing specifically on women and their journeys with care, which is the bases of this research.

The use of qualitative inquiry and the purposeful sampling of participants to gain insight into the journey with HCV care from the client perspective adds rigor to the research. As outlined above, I hope that the findings from this research will contribute to current knowledge as well as improve clinical practice and reduce stigma and discrimination for women living with HCV.

## 9.3 Limitations

This information is relevant for all healthcare practitioners across any setting where women living with HCV and/or a chronic illness are encountered. I have identified key barriers and motivators that changed the journey for a sample of Canadian women. Understanding and recognising these factors, which can create barriers or ignite behaviour change for women along their journeys with HCV care is crucial to support the success of the new treatments and ultimately reduce the burden of disease.

However, caveats apply to the transferability and reliability of the findings. First, although identified by the National Advisory Committee as a potential barrier to open communication, the lack of data collection about the use of methadone maintenance therapy may be considered cofounding factors impacting the interpretation of the findings.

The second caveat relates to the sampling and recruitment of those who do not attend, or who delay or defer HCV care.  Attempts were made to obtain a diversity of views by using a national network of diverse stakeholders, but some voices are missing. The experiences of specific groups affected by HCV, for example, immigrants from areas with high HCV prevalence or Aboriginal and First Nation women, requires further investigation. While there are likely to be many similar issues, there are also differences specific to each group that would be better teased out in a dedicated piece of research. English language fluency was necessary for participation in this research. While this excluded individuals who do not speak or read English, resources for translation services were limited. This could have excluded the immigrant population which accounts for 20 percent of the HCV cases in Canada (Myers et al., 2015). Given that some of these women may be more likely to have come from endemic countries where the population prevalence is higher and not as closely associated with IDU, perhaps they had a smoother or less stigmatising journey? Perhaps their barriers and pressures are very different and associated more to low health literacy. This is an important area of research that is yet to be fully explored.

The third caveat relates to the reliability and the participant’s recall. Many of the women in our study were diagnosed some time ago and were reflecting on their journey that may have spanned a decade or more. For many of the women it was a long journey that started prior to diagnosis. Over time the most significant and memorable issues may be recalled, however women may also have forgotten (perhaps consciously so) negative experiences, and their current sense of themselves may shape their memory of past selves.

Participants received a $40 (CAN) reimbursement for their time and incidental costs**.** In Canada, an honorarium for research participants has become a standard practice (Bell & Salmon, 2012), however, this is controversial. Some would consider it a limitation of the study as it is seen as a motivator, however, other researchers (Jeal & Salisbury, 2004; Neale, 2008) argue it is an appropriate way to reach participants that may otherwise be hard-to-reach. Several members of the National Advisory Committee felt that it would be difficult to recruit for the study if compensation was not offered to cover the costs incurred from participating in the interview. Interviews typically lasted between 45 and 90 minutes, therefore it was felt to be reasonable to offer reimbursement for their time.

## 9.4 Conclusion

In conclusion, my findings are significant for improving the journey with care for women living with HCV. I have provided insights into what it is like for the women to live with HCV and the issues that negatively and positively influence their decisions along their journey with care. From my analysis, it was evident that for many women the road along their journey with care was chaotic. I have identified barriers and the motivators that ignited women’s decision to attend to care, which can guide clinical practice and the development of services with seamless access to care at the varying entry points along the cascade of care. I have highlighted each healthcare interaction as a crucial opportunity to provide women living with HCV the care and information they need to improve health outcomes. My research is only a starting point. Expanding on this knowledge of women’s experience on their journey with HCV care is crucial to ensure the success of the new treatments, which can ultimately reduce the burden of this disease.

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## APPENDIX A - The National Advisory Committee (NAC) Members

Canadian Aboriginal AIDS Network

Aboriginal Nurses Association

Aboriginal Health Nurse Practitioner

Canadian Liver Foundation

Thompson Rivers University, British Columbia

Interior Health Authority, British Columbia

Pacific Hepatitis C Network, British Columbia

North Island Liver Service, British Columbia

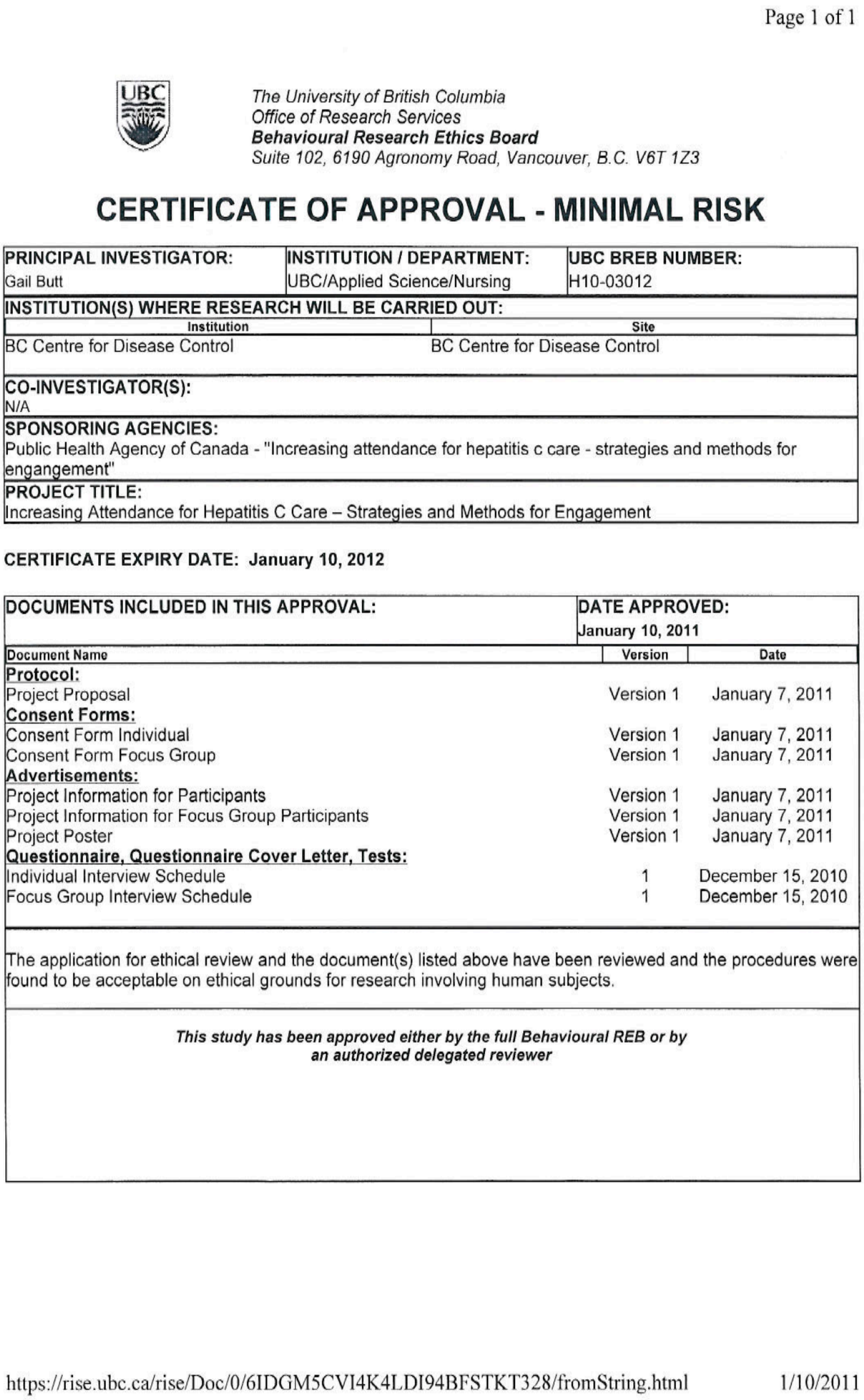
Stanley Mission Health Services, Saskatchewan

London Health Sciences Centre, Ontario

South Riverdale Community Health Centre, Toronto, Ontario

Capital District Health Authority, Nova Scotia

# APPENDIX B – University of British Columbia Ethics Approval



Page 1 of 1

*The University of British Columbia*
*Office of Research Services*
***Behavioural Research Ethics Board***
*Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3*

## CERTIFICATE OF APPROVAL - MINIMAL RISK

| **PRINCIPAL INVESTIGATOR:** | **INSTITUTION / DEPARTMENT:** | **UBC BREB NUMBER:** |
|---|---|---|
| Gail Butt | UBC/Applied Science/Nursing | H10-03012 |

**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:**

| Institution | Site |
|---|---|
| BC Centre for Disease Control | BC Centre for Disease Control |

**CO-INVESTIGATOR(S):**
N/A

**SPONSORING AGENCIES:**
Public Health Agency of Canada - "Increasing attendance for hepatitis c care - strategies and methods for engangement"

**PROJECT TITLE:**
Increasing Attendance for Hepatitis C Care – Strategies and Methods for Engagement

**CERTIFICATE EXPIRY DATE: January 10, 2012**

**DOCUMENTS INCLUDED IN THIS APPROVAL:**

**DATE APPROVED:**
**January 10, 2011**

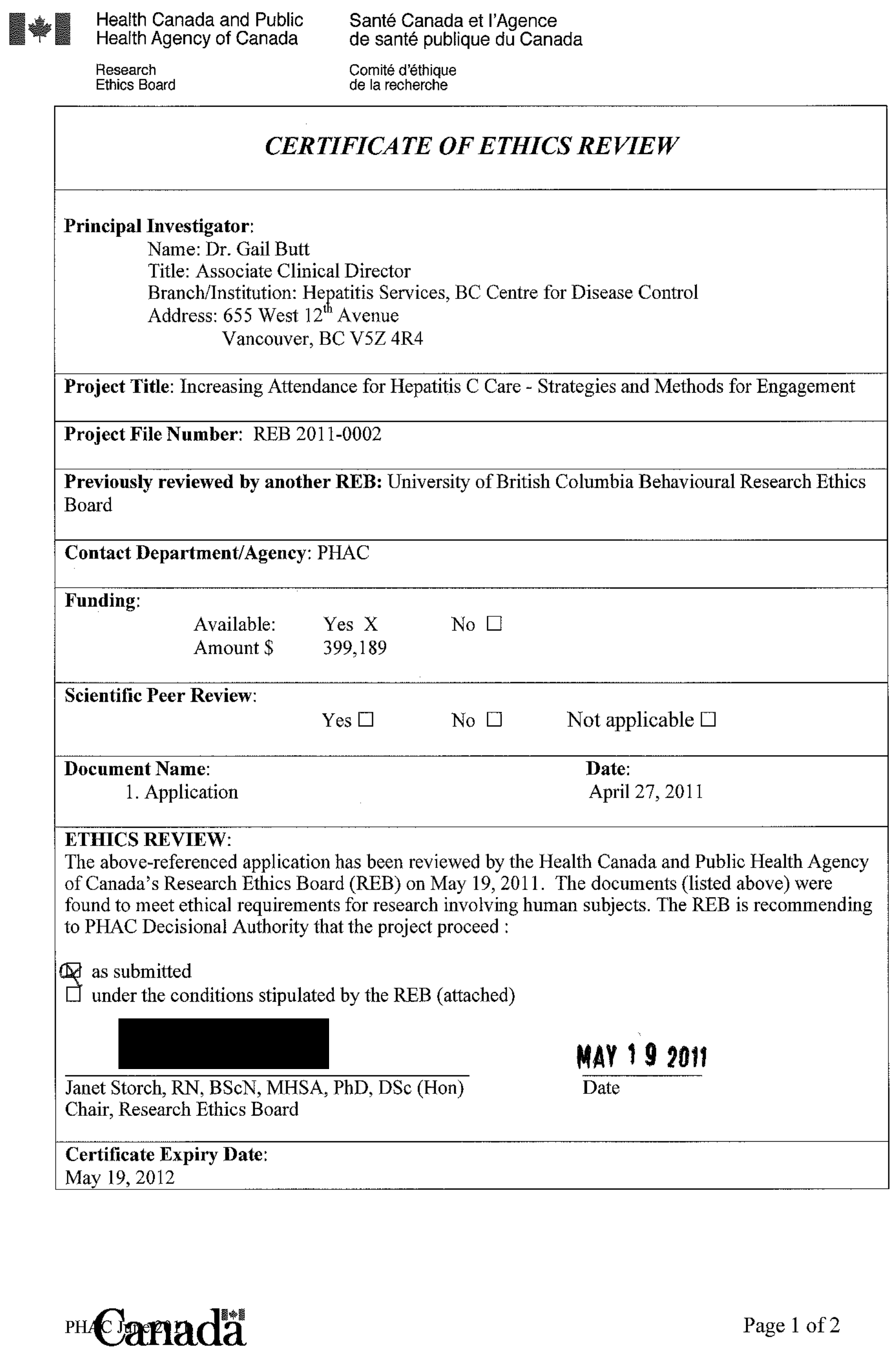
| Document Name | Version | Date |
|---|---|---|
| **Protocol:** | | |
| Project Proposal | Version 1 | January 7, 2011 |
| **Consent Forms:** | | |
| Consent Form Individual | Version 1 | January 7, 2011 |
| Consent Form Focus Group | Version 1 | January 7, 2011 |
| **Advertisements:** | | |
| Project Information for Participants | Version 1 | January 7, 2011 |
| Project Information for Focus Group Participants | Version 1 | January 7, 2011 |
| Project Poster | Version 1 | January 7, 2011 |
| **Questionnaire, Questionnaire Cover Letter, Tests:** | | |
| Individual Interview Schedule | 1 | December 15, 2010 |
| Focus Group Interview Schedule | 1 | December 15, 2010 |

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

***This study has been approved either by the full Behavioural REB or by an authorized delegated reviewer***

https://rise.ubc.ca/rise/Doc/0/6IDGM5CVI4K4LDI94BFSTKT328/fromString.html 1/10/2011

## APPENDIX C – Health Canada Ethics Approval



Health Canada and Public Health Agency of Canada
Research Ethics Board

Santé Canada et l'Agence de santé publique du Canada
Comité d'éthique de la recherche

### *CERTIFICATE OF ETHICS REVIEW*

**Principal Investigator**:
Name: Dr. Gail Butt
Title: Associate Clinical Director
Branch/Institution: Hepatitis Services, BC Centre for Disease Control
Address: 655 West 12th Avenue
Vancouver, BC V5Z 4R4

**Project Title**: Increasing Attendance for Hepatitis C Care - Strategies and Methods for Engagement

**Project File Number**: REB 2011-0002

**Previously reviewed by another REB:** University of British Columbia Behavioural Research Ethics Board

**Contact Department/Agency**: PHAC

**Funding**:
Available: Yes X No ☐
Amount $ 399,189

**Scientific Peer Review**:
Yes ☐ No ☐ Not applicable ☐

**Document Name**: 1. Application
**Date**: April 27, 2011

**ETHICS REVIEW**:
The above-referenced application has been reviewed by the Health Canada and Public Health Agency of Canada's Research Ethics Board (REB) on May 19, 2011. The documents (listed above) were found to meet ethical requirements for research involving human subjects. The REB is recommending to PHAC Decisional Authority that the project proceed :

☒ as submitted
☐ under the conditions stipulated by the REB (attached)

[redacted]

Janet Storch, RN, BScN, MHSA, PhD, DSc (Hon)
Chair, Research Ethics Board

MAY 19 2011
Date

**Certificate Expiry Date**:
May 19, 2012

PHAC June 2011

Page 1 of 2

## APPENDIX D - Consent Form: Individual Interview

THE UNIVERSITY OF BRITISH COLUMBIA

a place of mind

**School of Nursing**
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada
V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

**Title of Research Project: Attendance for Hepatitis C Care**

| | |
|---|---|
| **Principal Investigator:** | Dr. Gail Butt<br>Clinical Assistant Professor, School of Nursing<br>University of British Columbia<br>Telephone 604-707-2434 |
| **Sponsor:** | Hepatitis C Prevention, Support & Research Program,<br>Public Health Agency of Canada |

**Purpose:** You are invited to participate in a research study because you have been diagnosed with hepatitis C. The study will explore why people with hepatitis C go or do not go for hepatitis care. Study participation involves one interview that will be one and a half hours long at most.

You are invited to participate in this research because you have been diagnosed with hepatitis C, are 19 years of age or older, able to speak and write in English, and do not have a condition that makes thinking or remembering things about your life difficult for you.

**Study procedures:** If you agree to take part in the study, you will be interviewed by a researcher you do not know and who is not a member or volunteer with the agencies or organizations that might have provided you with information about the project. You will be asked to talk about your experience with the disease to date, as well as some information about yourself. The interviewer will begin by asking you some short-answer questions about yourself and your family (for example, “Tell me what living with hepatitis C has been like for you?”). The interviewer will write notes about your answers to these questions. All interviews will be taped and transcribed. You will receive a summary of the research findings with an invitation to provide feedback about the findings using a provided toll-free number. You are under no obligation to respond to the feedback invitation.

**Potential risks:** There are no known risks to this research.

**Potential benefits:** If you agree to participate, you will provide information that may be beneficial to other people living with hepatitis C. You will receive a written summary of the results of the research at the end of the study if you choose to provide your email or mailing address at the end of this form.

**Confidentiality:** Your identity will be kept strictly confidential. Your name and any identifying information will be removed from the transcript of your interview. Your interview tape and transcript will be identified only by a code number assigned to you by the project manager. Only the research team will have access to the tapes and transcriptions; the tapes and transcriptions will be stored in a locked filing cabinet to which only the Principal Investigator has a key. The tapes and transcriptions will be destroyed five years from the end of the study. The tapes will be erased and the transcriptions will be shredded and given to a confidential waste management company for disposal. Electronic files will be password protected and will be erased using appropriate file deletion software. The findings of the research may be published but your name will not appear in the publication.

**Compensation:** To help with the costs of participation, if you agree to participate, you will receive a $40.00 honorarium after your interview, which will be given in-person or mailed to you at the address you specify at the bottom of this form.

**Contact for information about the study:** Before you sign this form please ask any remaining questions you have about the study. If you have questions or would like more information, you may contact the Principal Investigator, Dr. Gail Butt, at 604-707-2434 or toll free at 1-866-660-1676 (and press 1) or by email at gail.butt@bccdc.ca. She will answer any questions you may have before, during, or after the study.

**Contact for concerns about the rights of research subjects:** If you have any questions or concerns about your rights or treatment as a research subject, contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance by email to RSIL@ors.ubc.ca

**Consent:** Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time and it will not affect the health and social care you receive or would like to receive.

By providing your oral consent or your signature, you give permission for the information provided in interviews to be used for publication in research articles/journals/books, and/or teaching materials. Additionally, your oral consent/signature indicates that you have received a copy of the consent form.

**Consent**
Name of person consenting (Please print): __________________________

Signature (if in-person): _______________________ Date: _____________

**Mailing Address (optional):**

House/Unit number & Street name: ___________________________________

City: _____________________________ Province: __________________________

Postal Code: _____________________

If you prefer to receive the results by email, please fill in your email address:

_______________________________

## APPENDIX E - Interview Schedule for Women Diagnosed with HCV

**Date:** ___________
**Data Collector:** _____________________ **Participant ID Code:** ________________

**Socio-demographic characteristics:**

1. Area participant lives in (check one) urban ☐ rural ☐ remote ☐

2. Others co-residing with participant:
#1. Age______ Gender: Male☐ Female☐
Relationship to participant __________________

#2. Age______ Gender: Male☐ Female☐
Relationship to participant __________________

#3. Age______ Gender: Male☐ Female☐
Relationship to participant __________________

#4. Age______ Gender: Male☐ Female☐
Relationship to participant __________________

3. Highest level of education completed?
elementary school ☐ high school ☐ college/technical ☐
university ☐ graduate ☐ post graduate ☐

4. Source of Income?
Employment/self-employ ☐ If yes: full-time ☐ part-time ☐

social assistance ☐ disability ☐ retired ☐ other ☐

If retired: Old age security ☐ Canada pension ☐ private pension ☐

5. Occupation? ______________________________________

**Participant Past History Data:**

1. Current Age (in years) _______ Gender: Male☐ Female☐ Transgender ☐

2. When did you find out you have hepatitis C? ____________

3. When do you think you got hepatitis C? _________

4. Participation in a HCV support group? Ever ☐ Present ☐

5. Ask participant to identify the health problems he/she experiences in order of significance in her/his life. Check appropriate box to indicate whether participant believes the problem is related to HCV or not.

Health problem #1__________________________
Related to HCV? Yes☐ No ☐

Health problem #2__________________________
Related to HCV? Yes☐ No ☐

Health problem #3__________________________
Related to HCV? Yes☐ No ☐

Health problem #4__________________________
Related to HCV? Yes☐ No ☐

Health problem #5__________________________
Related to HCV? Yes☐ No ☐

**History of HCV Care & Management**

1. Do you currently get healthcare for your hepatitis C? Yes ☐ No ☐

2. If yes, where do you receive hepatitis C care -

| | | | | | |
|---|---|---|---|---|---|
| Family doctor | ☐ | primary care clinic | ☐ | nurse practitioner | ☐ |
| Specialist physician | ☐ | methadone clinic | ☐ | other | ☐ ______________ |

3. If no, have you ever been for hepatitis C care since diagnosis? ☐ Yes No☐
If yes, specify from whom:
______________________________________________________________________
______________________________________________________________________

4. If you have not been to a specialist physician have you:
Ever been referred or self-referred for specialized assessment for hepatitis?
Yes ☐ No ☐

If yes, by what type of practitioner? (eg., nurse, GP, specialist)
___________________________________

Current Medications (indicate how often he/she is receiving)
____________________________
____________________________
____________________________
____________________________
____________________________

Have you ever received hepatitis C Antiviral therapy? Yes☐ No ☐

If yes, when?______________ For how long (months) _______ Don't Know ☐

Outcome? SVR ☐ Relapse ☐ No response ☐ Don't Know ☐

Alternative therapies other than medication (eg., massage; naturopath; acupuncture):

Present ☐ Ever ☐ No ☐

Specify: ________________ Specify: _________________
________________ _________________
________________ _________________

**Attendance for Hepatitis C Care**

1. **Tell me about what is has been like to live with hepatitis C?**
   Prompt for:
    - history with hepatitis c care providers – do they have a primary care physician (GP),
    - symptom perception;
    - perceived consequences (severity and impact of hepatitis C including complications);
    - perceived and desired control of hepatitis C
    - cause and course of hepatitis C;
    - stress of living with hepatitis C;

2. **Tell me about your sources of support and how you have coped with living with hepatitis C**
   Prompts
    - practical and emotional support received/not received from family, friends, care providers and others;
    - coping strategies;
    - evaluation of support;
    - evaluation of coping strategies

**3. What has it been like going for services or care for your hepatitis C?** (Note: tailor following questions according to answers from demographic section - If referred/attended)

Prompt for:

- whom/when referred
- what did they know about the service at referral,
- accessibility of the agency (hours open, cost, scheduling etc.)
- feelings/thoughts about agency at the time of referral;

- experience at agency if they attended (wait times, appointments, booking systems, attitudes, cultural relevance, practitioners recommendations or prescriptions
- what was prescribed course of care and did they follow and why
- feelings/thoughts about agency now

**4. Can you think of any times in the last month or so that you delayed or interrupted going for care or did not go at all? Any other times?**
Prompt to expand on response, e.g., if participant indicated they had not attended the agency because they thought they would be told by health care providers to change their lifestyle, the interviewer might ask,

- what changes do you think they would tell you to make? Why do you think they might do that? What would those changes mean to you?

Prompt for following topics:

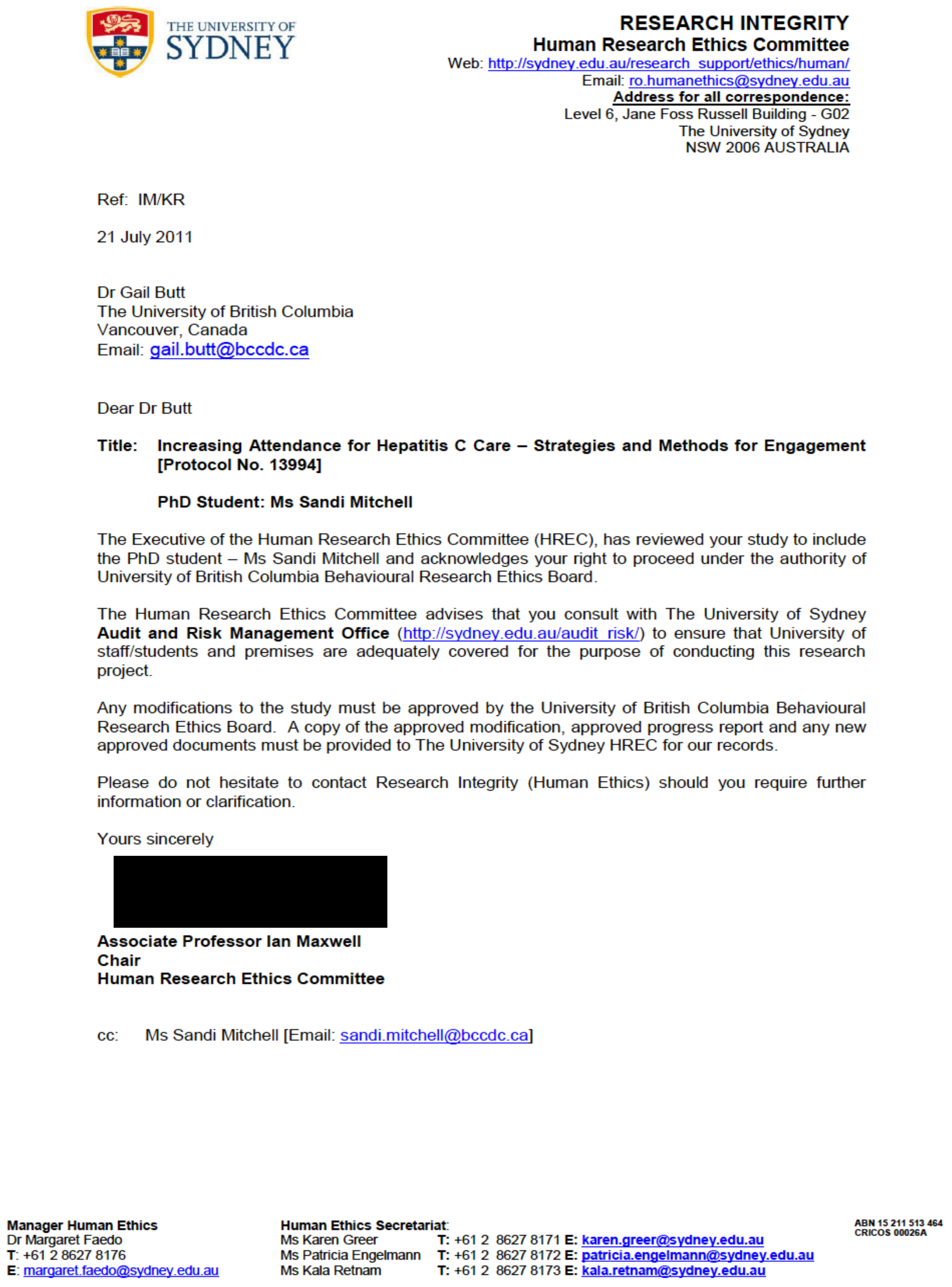
- Circumstances of attendance/non-attendance (when, how often, reasons, perceptions of seriousness and consequences),
- practitioners' response;
- personal impact of attendance/non-attendance on spiritual, emotional, physical and intellectual health;
- impact of attendance/non-attendance on the care they have received from practitioners;
- impact of attendance/non-attendance on significant others, community, practitioners; and other impacts of attendance or non-attendance.)
- what could have made it possible/more likely that you would have attended i.e., barriers and supports required

Prompts:
"What happened when you stayed away from the clinic?" "How did you feel at the time about not going to the clinic?" "What about now?" "What was the clinic staff's response when you didn't go?" "Did anyone talk to you about going to the clinic?" "Who?" "What did they say?" "Did it influence whether or not you went back to the clinic?"

**5. The interviewer will pose questions derived from themes** that arose in data of other interviews (e.g. "Some people have told us that ----. What is your response to that? Is that your experience?"

**6. At the end of the interview**, the interviewer will ask, "Is there anything else you would like to add?" or "Are there any recommendations you'd like to make to service providers about attendance for care" and at the conclusion, the interviewer will thank the participants for their contribution.

# Appendix F– University of Sydney Ratification of a Human Ethics Approval Certificate



THE UNIVERSITY OF SYDNEY

**RESEARCH INTEGRITY**
**Human Research Ethics Committee**
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Email: ro.humanethics@sydney.edu.au
**Address for all correspondence:**
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The University of Sydney
NSW 2006 AUSTRALIA

Ref: IM/KR

21 July 2011

Dr Gail Butt
The University of British Columbia
Vancouver, Canada
Email: gail.butt@bccdc.ca

Dear Dr Butt

**Title: Increasing Attendance for Hepatitis C Care – Strategies and Methods for Engagement [Protocol No. 13994]**

**PhD Student: Ms Sandi Mitchell**

The Executive of the Human Research Ethics Committee (HREC), has reviewed your study to include the PhD student – Ms Sandi Mitchell and acknowledges your right to proceed under the authority of University of British Columbia Behavioural Research Ethics Board.

The Human Research Ethics Committee advises that you consult with The University of Sydney **Audit and Risk Management Office** (http://sydney.edu.au/audit_risk/) to ensure that University of staff/students and premises are adequately covered for the purpose of conducting this research project.

Any modifications to the study must be approved by the University of British Columbia Behavioural Research Ethics Board. A copy of the approved modification, approved progress report and any new approved documents must be provided to The University of Sydney HREC for our records.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

[redacted]

**Associate Professor Ian Maxwell**
**Chair**
**Human Research Ethics Committee**

cc: Ms Sandi Mitchell [Email: sandi.mitchell@bccdc.ca]

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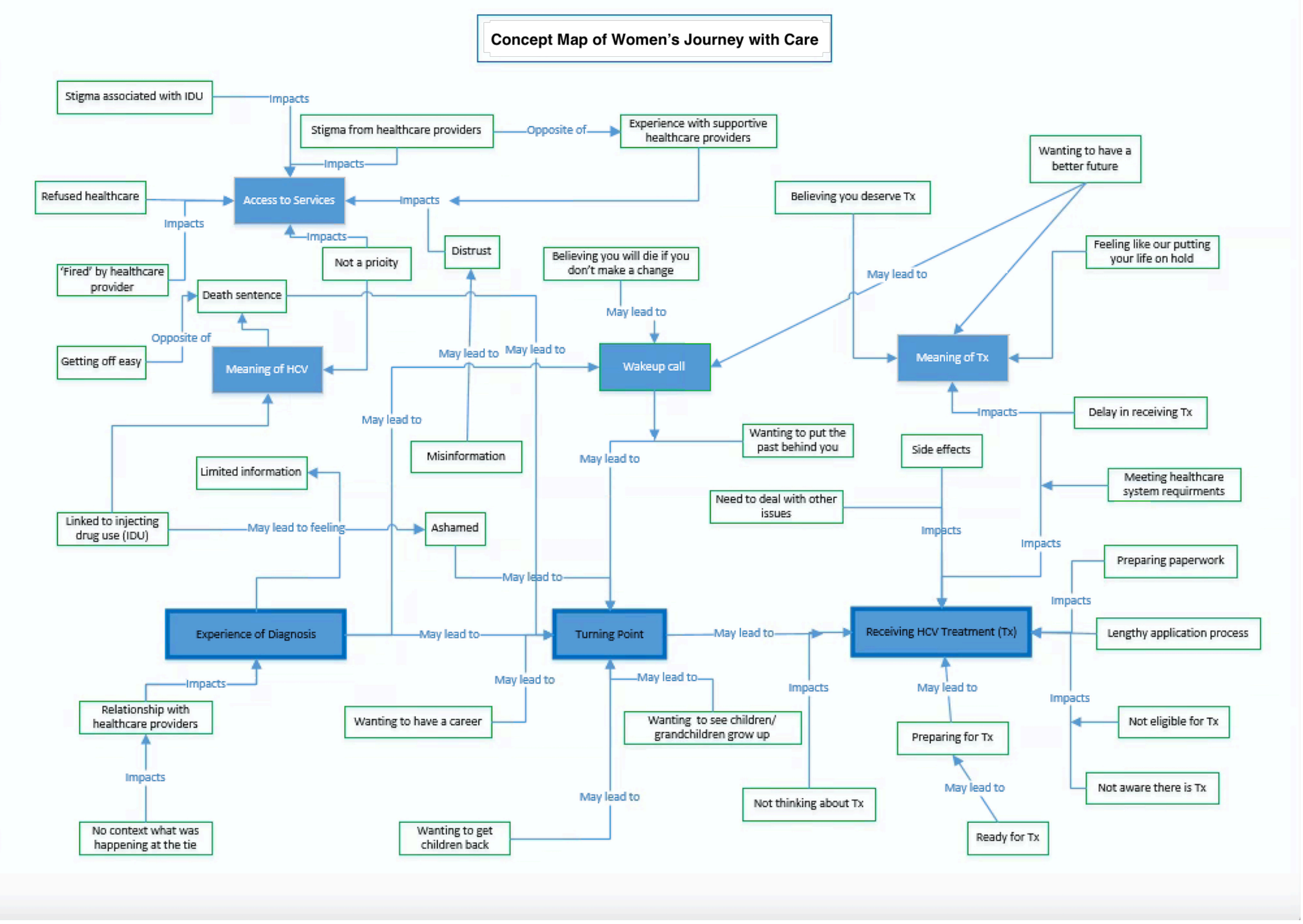
CRICOS 00026A

# Appendix G– Concept Map



**Concept Map of Women's Journey with Care**

# Appendix H– Reasons for Nonattendance across the Hepatitis C Disease Course

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*Research Article*

## Reasons for Nonattendance across the Hepatitis C Disease Course

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This descriptive qualitative study examined the patient, provider, and institutional factors contributing to nonattendance for hepatitis C (HCV) care throughout the disease course. Eighty-four patients and health and social care providers were interviewed. Thematic analysis of the data yielded 6 interrelated nonattendance themes: self-protection, determining the benefits, competing priorities, knowledge gaps, access to services, and restrictive policies. Factors within the themes varied with the disease course, type of provider/service, and patient context. Nonattendance could span months to years and most frequently began at diagnosis where providers either advised that followup was not necessary or did not recommend any followup. The way services were organized (low barrier access) and delivered (nonjudgmental approach) and higher HCV knowledge levels of patients and providers encouraged attendance. This is the first study to explore the reasons for nonattendance for HCV care throughout the disease course and validate them from multiple perspectives. There are missed opportunities for providers to encourage attendance throughout the disease course beginning at diagnosis. Interventions required include development of integrated health and social service delivery models; mechanisms to improve knowledge dissemination of the disease, its management, and treatment; and implementation of standardized followup protocols for liver disease monitoring in primary care.

## 1. Introduction

We report the findings from qualitative research to ascertain the patient, provider, and institutional factors that contribute to nonattendance for care for hepatitis C virus (HCV) infection at various points along the disease course.

HCV is a chronic infectious disease, spread through blood to blood contact that affects 170 million worldwide, including approximately 250,000 Canadians [1]. Because HCV has a heterogeneous presentation and a slow, unpredictable course of liver inflammation that spans decades, patients require long-term monitoring for signs of progressive liver disease and associated issues such as cirrhosis, end-stage liver disease, liver cancer, HIV coinfection, fatty liver disease, and alcohol overuse [2–8].

Patients receive diagnostic and most followup services in primary care due to the large number affected and the relative shortage of specialists [9]. Specialists provide complex disease management for those with advanced disease including the provision of a 24- to 48-week course of antiviral therapy for those eligible, consenting, and able to tolerate it. Treatment uptake has been historically low, even though antiviral therapy can permanently arrest viral replication (initially in 10% but presently in 70% of cases) [10], improve quality of life and liver function, decrease the likelihood of developing liver cancer, and improve survival [11, 12].

Disease management, whether in primary or specialist settings, can assist patients to manage symptoms and prevent liver disease acceleration [13]. Despite these benefits, patient nonattendance rates range from 28 to 80% [14–16], and little is known about the reasons for this. Nonattendance results in wasted clinician time and health care resources, but a more critical issue is the delay in presentation and lack of monitoring and management that can predispose the patient to complications unnecessarily.

Gaps in HCV care have been noted to result from patient and provider actions. Many patients begin HCV testing but do not return to obtain their results or complete the diagnostic testing process [16–18]. Other gaps occur when patients with a history of nonattendance in primary care are not offered a specialist referral by their provider [14, 19, 20]. Of those who are referred, many fail to attend the specialist appointment. A small study that looked at reasons why patients referred to a specialist clinic who did not attend found fear of the unknown precipitated nonattendance, for example, fear of being asked to undergo a liver biopsy, or being told that they had advanced disease or were going to die [21]. The research did not include factors such as whether patient preparation at the primary care level affects nonattendance for specialist assessment. For those under specialist care, studies have identified patient factors specific to the decision to decline or defer antiviral therapy which include concern over side effects, inconvenient time to start, belief that the disease is not serious enough to need intervention, disbelief in treatment efficacy, ongoing drug or alcohol use, and chaotic lifestyles [22–26].

Nonattendance has been noted as an outcome of HCV stigma from health care provider and institutional policies/practices. For example, policies that restrict eligibility for HCV treatment and agencies that give preference to patients with certain characteristics are viewed by patients as stigmatizing and result in nonattendance [27]. HCV stigma is thought to be rooted in a lack of knowledge of HCV and its association with injection drug use [27, 28].

HCV nonattendance research, although sparse, is consistent with findings from other chronic diseases which indicate that the factors affecting nonattendance are complex and involve the patient, the provider, and the health care system [29]. As a first step towards enhancing our understanding of the HCV nonattendance issues, we report the findings of descriptive research to identify, analyse, and describe patient, provider, and institutional factors contributing to nonattendance throughout the disease course [30]. The purpose of this paper is to describe the breadth of the nonattendance issue and identify areas for action.

## 2. Methods

A descriptive design was used to answer the research question, what are the reasons individuals with HCV do not attend for HCV care? Nonattendance was defined as instances when patients did not attend appointments and when patients delayed or deferred care. To extend our understanding of the perceived contributing factors, patients and HCV providers from multiple contexts were engaged in the research.

*2.1. Ethics.* Ethics approval was granted from two required review boards. Prior to interviews, written and oral information was given to all participants to ensure informed consent. To maximize confidentiality and accessibility, patient participants were interviewed by phone on a toll-free line with the exception of four patients who requested in-person interviews. To facilitate participation by patients without phones, community support agencies provided a private space and telephone. Data confidentiality was maintained using codes in place of personal identifiers and restricting transcript and data access to the research team. Participants received a $40 honorarium for their time and incidental costs.

*2.2. Data Collection, Management, and Analysis.* Purposeful sampling techniques were used to obtain a varied sample of “patient” and “provider” participants [31]. Patients were recruited through advertising by staff in health promotion, harm reduction, health, and social service programs and through snowballing, where participants recruit others directly or through postings on their blogs or online groups. Providers who were experienced in hepatitis C care were recruited through advertisements circulated by the research team and their provider networks.

Patient interviews lasted 45 to 90 minutes. Three trained interviewers used standard questions to collect demographic data followed by broad open-ended queries that led to more individual-focused questions to elicit the patient’s experiences with HCV care and specifically instances of nonattendance. An interview guide, based on our previous work and input from an expert advisory committee of patients and providers, was used to facilitate exploration and enrich the data [32]. Ninety-minute interviews were conducted in-person with groups of 6 to 9 providers by the principle investigator (PI) (GB) for consistency [31]. All interviews were audio-recorded, transcribed verbatim, and thematically analyzed. Analysis occurred concurrent with data collection to facilitate identification of new questions and areas for further exploration or clarification [30].

Data were managed through NVivo 9 software which enabled separation of patient and provider data, data interrogation, refinement of the coding structure, and themes. The first five transcripts were read, reread, and manually coded by the PI (GB). The other team members (LM, SM) subsequently read, reread, and coded the same transcripts. The team then produced an inclusive list of codes through consensus. The coding structure was refined at weekly team meetings. Notes were kept to record thoughts, interpretations, questions, and decisions, about the data and its interpretation. Thematic analysis allowed for the data to be interpreted and organized into themes through inductive coding and systematic classification. For example, codes that described the issues considered by patients when deciding whether to attend for care were grouped under the theme “determining the benefits.” Recruitment ceased shortly after no new codes or themes were identified.

*2.3. Sample Characteristics.* Participants included 55 patients with self-reported HCV and 29 HCV health and social care providers from 5 provinces: Nova Scotia, Quebec, Ontario, Manitoba, and British Columbia. Patient demographic data in Table 1 reveals that although patients tended to be over 40 years (73%) and well educated (69% had 12 or more years of formal education), most required income support (76%), a need they attributed to their poor health status. Patients reported difficulty determining which symptoms to ascribe to HCV as they had a mean of 4 other coexisting conditions (range 1 to 9) including arthritis, diabetes, digestive problems, chronic pain, addictions, anxiety, and depression. Their

TABLE 1: Characteristics of patient participants ($n = 55$).

| Variable | $N$ (%) |
|---|---|
| Gender | |
| Male | 30 (55) |
| Female | 25 (45) |
| Age | |
| 19–29 | 3 (5) |
| 30–39 | 12 (22) |
| 40–49 | 12 (22) |
| 50+ | 28 (51) |
| Province | |
| BC | 35 (64) |
| MB | 1 (2) |
| ON | 8 (15) |
| NS | 10 (18) |
| NB | 1 (2) |
| Education | |
| Elementary/some high school | 17 (31) |
| Completed high school | 12 (22) |
| Postsecondary | 26 (47) |
| Source of income | |
| Disability/social assistance | 42 (76) |
| Employed full or part time | 13 (24) |
| Living arrangements | |
| Live alone | 23 (42) |
| Live with family/others | 32 (58) |
| Years since diagnosis | |
| <1 | 1 (2) |
| 1–10 | 25 (45) |
| 11–19 | 21 (38) |
| 20+ | 8 (15) |

mean number of medications was 3 (range 0 to 15), with methadone, antidepressants, sleeping pills, analgesics, and antihypertensives being the most frequently reported.

Years since HCV diagnosis ranged from 1 to more than 20. Four (7%) had cleared the virus spontaneously. Of the 22 (40%) patients who had experienced antiviral therapy, 13 (59%) attained viral clearance, while 2 were currently on therapy.

The 29 providers represented a range of agencies including public health (8), prison health (3), street outreach (1), community clinics (4), community support agencies (7), and specialist clinics (6). Mean years experience working with HCV patients was 8.5 (range <1 to 15+ years; $n = 20/29$).

## 3. Results

Patient and provider data, although analysed separately, revealed the same six themes, evidencing congruence between patient perspectives and that of providers that specialize in working with HCV patients. The six themes were self-protection; determining the benefits; competing priorities; knowledge gaps; access to services; and restrictive policies. The first four themes center around the patient and provider at the individual and interpersonal levels, while the final two themes align with the institutional (system) level. The results are presented using examples where it enhances the explanation or description.

*3.1. Self-Protection.* This theme represents nonattendance as a self-protective response precipitated by the perception of being negatively judged or treated differently by providers on patient disclosure of HCV infection. Providers echoed the powerful and pervasive patient accounts. The participants perceived that negative provider behaviours were closely linked to a lack of HCV knowledge and the association of HCV with injection drug use. Patients described strong emotional responses to negative experiences in primary care, emergency care, and to a lesser extent specialty care. The emotional response and the need to prevent further negative events were so strong that many patients not only avoided disclosing their status to potential sources of support but also described periods of up to several years in which they did not attend care or changed providers.

In primary care settings, patients relayed that, beginning at HCV diagnosis, they felt that they were unfairly judged or treated as a "drug user." A few patients described delaying diagnostic testing to keep their HCV status a secret in order to protect themselves from anticipated negative experiences. Patients described many instances in which they felt obliged to disclose their HCV status resulting in a "go to the back of the line" experience or providers indicating, implicitly or explicitly, that they were "not worthy of care." Implications of disclosure were magnified in patient accounts from small, rural, and remote communities as confidentiality is difficult to maintain and there are few choices of where to receive services. Other difficulties arose if providers occupied additional roles such as cultural or religious leader. In one example, the patient's physician was also a religious leader, so the patient felt conflicted as disclosure of the behaviour that led to HCV infection was in opposition to religious norms. The possibility that diagnosis or disclosure could lead to service termination by the practitioner created a patient dilemma.

Many participants described care in emergency departments as "rude" and "judgmental." Patients described being treated "like a dog" or "like dirt." In some cases they were accused of drug seeking and/or discharged without assessment for their presenting problem. Many participants pointed out that women found emergency room experiences particularly difficult and that they refused to seek emergency services. One participant related that his partner delayed attending for so long she died within hours of entering hospital:

> *cuz they treated her like she was a dog . . . she'd go out and get dope, you know, four blocks from the hospital but she wouldn't go to the hospital, you know, and she basically they uh, one day the ambulance picked her up, took her to the hospital and she was dead by midnight.*

In contrast, walk-in clinics were frequented, and when explored further, it was perceived that the way clinics are run, for example, no appointments were required and approachable staff created a comfortable atmosphere. Patients explained that walk-in clinic staff had more experience working with people with HCV and were more knowledgeable about the disease.

Although disclosure avoidance was rarely mentioned in relation to specialist care, some patients expressed discomfort with sitting in waiting rooms because of judgments they perceived other patients might make about them. Providers recounted that patients delay or defer treatment because they fear that someone they know will guess their diagnosis if they are seen attending hepatitis clinics or have visible symptoms during treatment. One provider recounted a particular client who struggled with the decision to start treatment: "she did not want to go to be treated, because she said everybody knows me, I'm well known in this city . . . if I come here to visit you and to see you they'll know what I'm here for."

Patients who received intensive phone support during treatment were appreciative as it was easily accessed and more anonymous than an office visit. Providers also noted that flexibility and willingness to provide phone support could act as an attendance facilitator. Some questioned the effectiveness of strict requirements for frequent in-person visits during treatment citing clients' expressions of difficulty, especially when they were ill from the treatment effects.

Patients and providers expressed concern that an unintended consequence of disclosure avoidance is that few patients speak out about the issues they face or lobby for the type of services they need to improve their care. Examples of needed support services included peer and group support programs, volunteer driver programs, HCV chronic illness management education groups, and home support and volunteer visitor services for those on antiviral therapy.

*3.2. Determining the Benefits of Attendance.* Patients described a decision process of determining or weighing the benefits of attending for care. Patients readily identified benefits in primary care related to attending for diagnosis, acute episodic care, and obtaining a specialist referral. Specialty care was circumscribed with benefits focused on issues surrounding treatment with a course of antiviral therapy or, in a few instances, management of advanced liver disease when treatment was not an option.

Most patients did not report attendance for planned HCV monitoring in primary care. Those that reported planned care were being monitored for troublesome HCV symptoms or other conditions. For example, patients who reported regular laboratory monitoring of liver function in primary care relayed that these tests were required for methadone or HIV monitoring. Several explanations ensued regarding the absence of monitoring.

Early in the disease course patients did not attend largely because of the absence of provider guidance on the need for monitoring following diagnosis. Patients relayed being advised to "live healthy," eat a healthy diet, get exercise, and avoid alcohol. Provider participants confirmed this finding and said that youth were particularly at risk of not receiving any HCV followup. Providers explained that the lack of monitoring in primary care was linked to a knowledge gap and the paucity of detailed guidelines on long-term monitoring requirements in primary care.

Patients made assumptions regarding the lack of followup advice. Some assumed that because of their addiction experiences they were not offered followup:

> *I think that some of the physicians think because like I'm an ex drug addict, and I think they think that people that are drug addicts, I dunno, they figure that we're not going to pursue the treatment or you know we're not going to stick with it because we have addictions and everything and that's not the case . . . Like, maybe I wasn't told about it cuz maybe they saw it well like you know she has an addiction problem.*

Others assumed that followup was not advised because treatment was unavailable or they were ineligible. For example, a participant, diagnosed for four years, was surprised to learn about available treatments through the study.

Several patients said that they began to consider the need for monitoring when they learned more about HCV and observed HCV complications among their peers or experienced symptoms. In contrast, a few patients noted that, with increased knowledge, they were less likely to attend, "I knew as much as him, I did not see why I should go and use up that time."

Many patients reported that they did not attend for HCV care for years because they "felt fine" or had increased feelings of well-being after recovery from addictions. A few believed that the virus was "dormant" or not causing damage because they were taking care of themselves. However, others said they feared that the disease was a death sentence and thought that followup was futile: "it scared the crap out of me, I did not know anything about it. I thought that it was a disease that was gonna just progress so fast that, I actually thought I was gonna die from it, right?"

With respect to treatment, many patients relayed that they sought treatment after they considered information from their peers, pamphlets, or the internet. Most patients said that they had to initiate the request for referral for treatment and be very assertive and persistent to obtain treatment:

> *I've always known that it was my right to get healthcare even though I know certain nurses or doctors how they can treat you. You know I, I know that I have a right to healthcare just as much as anybody else you know whatever kind of coverage they have. I knew I had a right to it. So I, I never let that stop me.*

While some expressed a strong and urgent desire to undertake treatment, many spoke of weighing the risks and benefits. In preparation for therapy, fear of the risks from the required liver biopsy caused some to withdraw from care. One individual recalled how on three separate occasions he participated in the pretreatment workup until a liver biopsy was required:

> *I've been doing this for many years now where I get to the point where I go in, I get an ultrasound*

> *done, I do my blood tests, I get my ultrasound done and then I'm supposed to get a biopsy on my liver and I usually, every time, I've chickened out and that's when I've relapsed and then I have to wait again.*

Providers relayed that the liver biopsy requirement can also affect future treatment opportunities:

> *I have a case I remember, a patient is positive for hep C, has cancelled four times a liver biopsy, and that usually with our doctor we work for its strike three, strike four and that's it end of story.*

Other patients identified weighing the positive outcomes of antiviral therapy versus the difficult to tolerate side effects: "the point of treating something that's not bothering me at this point in time and make myself sick for the next six months, well, it does not make a lot of sense to me."

For those who had experience with injection drug use, there were additional considerations:

> *the other thing that scares me is being sick all the time because I, you know, being a, a junkie, when I was, or an addict or whatever, you know, you use that needle to make yourself better, you know, not to make yourself feel sick, right?*

Some decided to avoid experiencing treatment because the side effects would be "like going through withdrawal." Others said that knowledge of rigours of treatment caused them to reject treatment until they could establish a more stable lifestyle and stronger support system. Others decided that the antiviral therapy success rates were too low and the personal costs too high, preferring to wait for newer improved therapies to emerge:

> *some of the things I've seen people go through while on treatment and then come out at the end worse than they were when they started it, so that's one of the reasons I don't seek treatment until they get it right.*

Many expressed concerns about the mental and emotional impacts of antiviral therapy including the effects on their significant others. They were concerned that therapy would trigger a depression or volatile emotions that they often termed "ribo-rage." Many said that they delayed HCV treatment because of what they heard from others who had experienced treatment, including opinions that regardless of the success rate they would not attempt treatment again. A participant who had prior experience with cancer chemotherapy recounted:

> *I was very unwell . . . I went for chemotherapy for four years, I was in the palliative wing, I was very unwell and I survived that and I found this [HCV antiviral treatment] tougher. I found this tougher because it took away all of my fight, it took away because of the mental [impact], this was new territory for me. I've been near sick and dying before, I can do that—this was worse.*

A few said that they rejected treatment in the belief that "it is not a cure" or because they "felt pushed" by an emphasis on treatment at the specialist clinic.

*3.3. Competing Priorities.* The competing priorities theme illuminates the place that HCV is given when patients have multiple and sometimes conflicting priorities in the other aspects of their life such as other health, work, or social needs.

A number of patients described competing priorities of their work or family caregiver obligations. As one woman said, concern about HCV was supplanted by the needs of her sick husband:

> *he was my number one thing to look after and my life and my health took a back seat to his because he was very, very sick and when he came home from the hospital he needed more aftercare . . . and he took up a lot of my time, you know and it, it just went by the wayside.*

Several patients said that they did not attend for care when they were actively using drugs. They described addictions as a "black hole" that absorbed them. A provider described youth who were addicted to crack as especially hard to engage because their lives were so chaotic. Related to drug use were disruptions in attendance for care on admittance to or release from prison. For example, treatment begun in prison would be interrupted on release until the person could access alternate resources in the community. Many said that prison release led to nonattendance for care because of other obstacles such as resumption of drug use or unstable living conditions.

Social service providers identified that many of their clients with HCV have unstable income and living conditions, for various reasons, and those issues absorb their time and energy:

> *I don't even know that some of the people that we work with who are homeless, who are street involved, whose lives are pretty chaotic, that they're even at a point where they feel that they have a choice, you know, because there are so many things that need to kind of get into place before the choice of treatment even enters their thinking about hep C.*

Patients spoke of needing to give time and priority to managing other coexisting conditions. One said "I got so much things wrong with me I, just like, oh, like it's my arthritis or whatever, like, I completely forgot I had hep C." They also described not having the time to deal with HCV because the lack of an integrated approach required them to travel to a different provider for each condition, making their health management more complex.

Many examples dealt with taking time out to realign life plans that patients described as necessary before accessing HCV treatment. It was a common belief that it was necessary to be recovered from addictions in order to access therapy, but there were other associated goals. For example, a young woman who used illicit drugs said that she was motivated to "get clean," so she could access HCV treatment and be cured of the disease. She said her ultimate goal was to be healthy enough to "get her children back." Other patient goals identified were to be healthy enough to start a family, protect family members or future sexual partners from the risk of transmission, be free from stigma, and prevent worse outcomes.

For those with advanced liver disease, competing priorities were managing symptoms like fatigue and memory loss. Nonattendance resulted from not having enough energy to travel or simply forgetting about appointments.

*3.4. Knowledge Gaps.* Gaps in patient and provider knowledge represent a prevalent theme in participant interviews. Knowledge gaps arose from a lack of knowledge, lack of understanding of information, misinterpretation of information, misinformation, and difficulty appraising information.

Patients said that they obtained information through family, social and peer-networks, the internet, pamphlets, support groups, service providers, and community agencies such as drop-in centres. Information obtained focused on how HCV is acquired, prevention of transmission, and treatment with antiviral therapy. Patients described a lack of information that would help them sort out which of their symptoms were related to HCV, how often they should be monitored by a health care provider, what monitoring should involve, and how to most effectively self-manage their disease. This was especially relevant for those who did not or could not access antiviral therapy or for those who had not cleared their infection through therapy. Providers said that they were not aware of any standard recommendations for the type and frequency of monitoring for advancing liver disease in primary care, unlike specialty care where patient monitoring is individualized and based on specialist recommendations.

Providers pointed out connections between the lack of monitoring and missed opportunities for patient education in primary care:

> *we get a lot of calls about people asking if it's too late for treatment, if they've missed their chance for treatment and they're just people who maybe had hep C often for just a few years. So I think that also is a sign of these missed opportunities for conversations and . . . I think that's a sign that monitoring is not there because if people were going for monitoring they'd know, they would hopefully have a better sense of whether treatment is an option for them at this time.*

In addition, gaps in provider knowledge resulted in missed opportunities for patients to access services like testing and treatment. One provider said, "on the helpline, I receive calls from people from all over . . . and the first information they receive is from a doctor who . . . says that it cannot be treated."

Participants relayed examples of omissions in diagnostic testing perceived to be related to inadequate provider knowledge. Two consecutive tests, a HCV antibody test followed by a HCV RNA test, are required to determine a chronic HCV infection, and yet many individuals have been told they had HCV, based solely on the antibody test, only to find out years later that this was not the case.

A number of patients believed that gaps in provider knowledge resulted from the low profile assigned to HCV in training and education programs. For example, one patient recounted, "there's this street nurse that we have in [our small] town, she knows a bit about hepatitis but not that much because they did not give them a lot of training."

There were other missed opportunities for education when patients were diagnosed that impacted decisions to attend care. One woman said, "I found out in jail. They just gave me a pamphlet and I went back to my cell crying, cuz like, no education, I thought it was like, next thing to AIDS, yeah, no education."

Patients relayed that many individuals make the decision not to attend for antiviral therapy based on misinformation or the absence of information. For example, a reason for treatment deferral was a common belief within the drug using community that one had to be "clean" or off drugs and alcohol for at least six months prior to requesting treatment. A patient deferred treatment because he believed that he could not manage the 48-week treatment course. Had he known his HCV genotype required a 24-week treatment course, he would not have delayed.

Many patients explained they frequently came across conflicting information requiring them to make decisions about which information to trust. Many privileged personal experience. For example, one patient said that the treatment information pamphlets did not correspond accurately with what he had seen friends endure. Nurse participants working in HCV treatment clinics said that they spend several sessions during the treatment preparation period assisting clients sort out "the myths and facts" and filling in knowledge gaps. They pointed out the dilemma of trying to establish a trusting relationship when patients disagree with or do not trust the accuracy of provider information. Providers identified the first few visits as critical to engaging patients and maintaining attendance for the duration of therapy.

Sometimes patients felt overwhelmed by the complexity of information:

> *I can't keep straight in my mind what tests I need to get from who and what blood work I need to get when. And what will happen to my body if I don't take these tests and get the blood works done. Also it would be good to know what the tests actually do and what they mean.*

Others had difficulties understanding HCV information such as the medical terms used by providers and were not comfortable exposing these difficulties. For example, many patients described their hepatitis as "dormant" or "resolved" but said that they were unsure what that meant. Others expressed problems wading through and understanding written information preferring to learn through other means:

> *I really don't know nothing about hep C, I really like, it's um, it's just a word to me . . . because I don't have no information. I try to read it online, I read some but I couldn't understand it, like I needed to,*

> *for me to read something like that um, I couldn't understand but if somebody could explain it to me maybe I'd understand better.*

*3.5. Access to Services.* This theme encompasses the institutional (system) contributors that lead to nonattendance because services were either difficult to access or inaccessible. Issues include poverty, provider shortages, long wait times, few integrated or culturally appropriate services, and difficulty scheduling appointments.

Poverty or limited financial resources were an important contributor to nonattendance. Participants provided detailed examples of deferred or delayed care because patients did not have the financial resources for such things as drugs, transportation (which for specialist appointments often required travel to a large centre with high parking fees), phone calls, and childcare. Travel from rural/remote areas for specialist care was particularly difficult if the person needed to pay for a caregiver to accompany them or a hotel stay.

Provider shortages in primary and specialist care and long wait times restricted access resulting in nonattendance. Those in rural settings without family doctors said walk-in clinics were unavailable, leaving the hospital emergency the only option, which many would not access because of past negative experiences. A lack of local providers precipitated decisions not to access treatment, because treatment requires a local provider for managing urgent issues when patients live far from specialist clinics. Participants noted that there was a general shortage of specialists and supports such as social work, mental health, and addictions services. Where services existed, there were long wait times, which patients said deterred attendance. A provider from a large urban centre explained that "up to 50% of people referred to HCV specialists do not attend, and most of those are no shows."

In contrast, availability of integrated and culturally appropriate services (youth, Aboriginal, and immigrant) positively impacted attendance. Participants and providers said that patients were more likely to attend appointments if services were fully integrated, colocated, or organized as a one-stop-shop through a case manager. The types of services frequently mentioned for inclusion in integrated approaches included primary care, hepatitis specialty services, mental health, addictions, housing, and social services:

> *they tried to do as much as they could for, for me in the appointment, right? And they had everybody in that one building so you know . . . the nurses and the psychiatrist and the doctors and, you know, um, yeah, that helped a lot, being able to just go to one spot.*

Providers confirmed that to improve attendance, patients need services based on the social determinants of health to "meet them where they are at." This approach would ensure attention to such things as the contextual and cultural needs for youth, Aboriginal, and immigrant populations.

The time it takes to attend appointments and the frequency of appointments contributed to nonattendance. For example, the time spent in waiting rooms, sometimes for more than two hours, was a deterrent. The frequency of appointments required in preparation for a course of antiviral therapy complicated patients' life plans prompting nonattendance. For example, several patients spoke of making changes in their life plans that they thought necessary in anticipation of the six months to one year on therapy. They explained that these plans were disrupted by a long pre-treatment preparation time which included several months of waiting for and attending for various tests and consultations with multiple specialists prior to treatment initiation:

> *. . . it's just been a long process and, and, and, you know, I wish when the doctor says you'd be starting it then that's when you start it, you don't get thrown all these other obstacles to get there which is, very, you know, cause you get all ready to do it and then you're like oh, now I have to do that and that's going to take three months, like that's wrong, right? You get yourself ready for it and then it's not happening.*

Providers confirmed that the time required for the pre-treatment evaluation is not widely communicated, even though it is essential to ensure the patient is fit to withstand the rigors of treatment.

*3.6. Restrictive Policies.* Restrictive policies, the other institutional (system) level theme identified, impacted patients' ability to attend and engage with HCV care. Policies that impacted attendance ranged from local office policies to provincial system level requirements including requirements for a doctor's referral to a specialist; abstinence before consideration for treatment at some clinics; treatment eligibility criteria in many provinces; frequency of required clinic visits for treatment monitoring; and practices that restricted how or when services could be accessed.

Policies at the agency level that deterred attendance included limited calling times for making appointments, financial penalties, or service withdrawal for missed appointments and segregated appointment times or waiting rooms for those who used illicit drugs. Some patients pointed out that because of restrictive policies they dropped out of care and received only episodic care through drop-in clinics.

Many spoke of system level policies that affected their ability to access treatment. The requirement for doctor's referral to a hepatitis specialist was difficult to meet especially in areas with family physician shortages. In some provinces, treatment eligibility policies such as the requirement to demonstrate liver damage through repeated lab tests or liver biopsy acted as a deterrent.

Participants reported that those with addictions who needed to be enrolled in a methadone program prior to HCV therapy reported difficulties normalizing their life while complying with the program regulations because of daily reporting requirements, restricted dispensing times, and drug effects. Obtaining "carries" such as a three-day methadone supply allowed some freedom, but that privilege depended on the degree of adherence, length of time in the program, and the methadone prescriber:

> *the methadone program the way it is set up in this province does not make somebody's life more livable because you gotta go to the pharmacy every couple of days, you gotta go to doctors appointments, you gotta go for mandated urine tests whether you're working or not, right, if you're out on a fishing boat you've gotta come in every three days to pick up your juice at the pharmacy, right?*

## 4. Discussion and Implications

This study explored the reasons for nonattendance for HCV care and identified factors affecting attendance at various points along the disease course: on diagnosis, postdiagnosis monitoring for disease progression, during preparation for and treatment with antiviral therapy once the disease had progressed, and in managing the disease when treatment was not an option. Analysis revealed nonattendance issues arise from the individual (patient or provider), patient/provider interactions, and institution (systemic) practices. The issues are contained within six interrelated themes: self-protection, competing priorities, determining the benefits, knowledge gaps, access to services, and restrictive policies. The findings from patients and HCV providers working in a variety of health and social service settings were congruent, confirming the work of Stewart who found concordance between patient, HCV specialist provider, and counsellor perspectives regarding HCV help-seeking and coping [33].

The study has several limitations. Participants were provided a small honorarium which may have influenced decisions to participate. In order to obtain a breadth and diversity of views, the participants were purposefully recruited, limiting the generalizeability of the findings. The results are based on participant recall which can be influenced by time and circumstances; for example, events in the present may be remembered with more clarity than distant events. However, the study's feedback loops during concurrent data collection and analysis provided opportunities to confirm, expand, or refute the points raised with subsequent participants.

The issues identified in the self-protection theme extend the HCV stigma literature by describing the impact on care engagement when patients anticipate or experience being negatively judged or treated poorly. It confirms the association of HCV with illicit drug use and describes issues arising from the lack of provider HCV knowledge [27, 28, 34]. In accordance with Paterson et al., emergency room care was a context that elicited particularly strong negative patient responses and in this study led to nonattendance even at great personal health risk [27]. Drop-in clinics and integrated service centres were contexts where patients were more likely to have positive experiences.

Determining the benefits of care, a recurrent theme throughout the disease course was of particular relevance on diagnosis as the absence of advice for monitoring or followup accounted for lengthy periods of nonattendance. Although there are specific guidelines for HCV assessment in primary care, they do not provide specifics for followup monitoring [35]. Closing the gap is crucial to improve secondary prevention of advanced liver disease and prevent premature deaths. As mortality studies have pointed out, interventions early in the course of the disease could prevent deaths from issues associated with HCV acquisition such as illicit drug use [36–38].

While the theme knowledge gaps confirmed previously identified HCV knowledge deficits among primary care providers, it clearly identifies consequences for patients [39]. In accordance with the findings of Holman and Lorig, participants identified needs for accurate information and self-care education to cope with and adjust to their chronic illness [40]. The findings revealed that patients rely on knowledge gained outside the health system to make care decisions but were limited in their ability to access comprehensive information, fully understand medical terminology, or appraise the accuracy of information. For example, active drug use was cited as a reason for patients not accessing treatment and for providers not discussing treatment options with patients even though evidence supports treatment provision both from a clinical and cost-effectiveness stand point [41, 42]. In addition, decisions to undergo treatment are often made in the absence of a discussion with a health care provider, and the patient literature is silent on pretreatment workup requirements, which for some took up to a year and precipitated nonattendance.

Competing priorities highlights the need to consider important aspects of lifestyle and other social determinants of health as well as disease specific aspects such as transmission and prevention, stages of illness, symptoms, prevention of progression, and options for antiviral therapy. This finding supports others who have identified the need for models of care that are patient-centered and integrate health and social care [9, 43]. Primary health care models that address complex health and social service needs similar to those of patients with chronic HCV have been shown to improve health outcomes [13, 44, 45].

The themes access to services and restrictive policies encompass multiple systemic obstacles faced by patients that impact care attendance such as lack of public transportation, provider shortages, long wait times, and the absence of culturally appropriate services. Restrictive policies were identified at single provider, agency, and provincial levels. These findings point to the need for system (policy) changes to improve service uptake such as: expanding specialist referral options to include self-referral and referral from allied health professionals; replicating approaches that improve access to specialists and reduce the need to travel to major centres by electronically linking medical specialists with generalist physicians in rural areas and nurse-led models of HCV prevention and care that include specialist consultation and have been shown to increase reach and access to care [18, 46, 47].

These results point to the need for clinical practice and system (policy) changes to increase engagement and retention in HCV care. Changes that would ensure patients are attended to in a respectful manner no matter what their background and that primary care providers have the knowledge and supports to provide patients with accurate and timely HCV information. Development and implementation of postdiagnosis monitoring protocols and mechanisms to improve knowledge dissemination in particular for nurses and physicians in primary care are recommended.

## 5. Conclusion

This is the first study to explore the reasons for nonattendance for HCV care throughout the disease course and validate the findings from multiple perspectives. It uncovered reasons for nonattendance, many of which are amenable through the provision of low barrier, nonjudgmental, and integrated services. It underscores the importance of provider and patient education that includes an emphasis on the psychological and sociocultural needs of the populations affected. This research can inform interventions, particularly in primary care, that are urgently required to engage and retain patients across the continuum of care, so that patients can realize the human and health system benefits of HCV care and emerging therapies that have the potential to cure 90–95% of those infected.

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# Appendix I – Has the Experience of Hepatitis C Diagnosis Improved over the Last Decade?

*Original Research Report*

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## Has the Experience of Hepatitis C Diagnosis Improved Over the Last Decade? An Analysis of Canadian Women's Experiences

**Sandi Mitchell[1], Vicky Bungay[2], Carolyn A. Day[3], and Julie Mooney-Somers[4]**

**Abstract**

**Background:** In Canada, incidents of new hepatitis C virus infections are rising among women aged 15–29 years and now comprise 60% of new infections among this age group. A negative diagnosis experience continues to be a problem affecting women living with hepatitis C virus. With new effective treatments, nurses will have more involvement in hepatitis C virus care and diagnosis, which is a critical time to facilitate appropriate education and management.

**Purpose:** This study explored Canadian women's experience of hepatitis C virus diagnosis in order to develop recommendations to improve care at the point of diagnosis.

**Methods:** Purposive sampling was used to recruit and interview 25 women. Using narrative inquiry, we examined Canadian women's experience of hepatitis C virus diagnosis.

**Results:** Women's diagnosis experiences were shaped by the context of diagnosis, factors prompting the testing, the testing provider, and information/education received. The context of diagnosis foreshadowed how prepared women were for their results, and the absence of accurate information magnified the psychological distress that can follow an hepatitis C virus diagnosis.

**Conclusion:** Our findings provide a compelling case for a proactive nursing response, which will improve women's experiences of hepatitis C virus diagnosis and, in turn, enhance women's access to hepatitis C virus care and other healthcare services.

**Keywords**

Hepatitis C, womens health, diagnosis, nurses, public health nursing

Hepatitis C virus (HCV) is a chronic blood-borne infection that affects an estimated 250,000 Canadians (Borman & Swain, 2013). The majority of new HCV cases are among people who inject drugs (Public Health Agency of Canada, 2009). Although men carry a disproportionate burden of illness with 65% of all new Canadian HCV cases in 2013 (Communicable Disease Prevention and Control Services, 2013), the gender gap is narrowing. Incidents of new HCV infections are rising among women aged 15–29 years and have exceeded the rates of men in this age category (Communicable Disease Prevention and Control Services, 2013). Generally, the social impact and access to care can be more burdensome for women with chronic illness, especially those with pronounced associated stigma such as with HCV (Butt, 2008).

Early diagnosis of HCV in women is critical to facilitate timely, appropriate care and management, which have been shown to improve quality of life and liver function, decrease risk of liver cancer, and improve

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survival (Hung et al., 2006; Yoshida et al., 2002). Due to the large numbers affected and the relative shortage of specialists in Canada, HCV diagnosis and follow-up tends to be provided at first point of contact with healthcare services (Zevin, 2007). However, there are no national HCV testing guidelines for HCV diagnosis, including pre-and posttest discussion, to guide standards for diagnosis care.

There is evidence that the point of diagnosis is a critical time for accessing and engaging in HCV care and support (Treloar, Harris, Deacon, & Maher, 2010). Diagnosis has been described as an overwhelmingly poor experience and has also been described as being trivialized by healthcare providers (Davis, Rhodes, & Martin, 2004). Previous research has noted that people living with HCV have perceived clinicians as having "negative attitudes" toward them and reported being provided with neither information nor support (Crockett & Gifford, 2004; Treloar et al., 2010).

For people living with HCV, their level of knowledge about the disease can influence health outcomes (Glacken, Kernohan, & Coates, 2001). Lack of information and support during HCV diagnosis can potentially further reduce follow-up and HCV management (Treloar et al., 2010), as fear of the disease increases and feelings of loss of control over one's health are generated (Hopwood & Treloar, 2004). HCV is a highly stigmatized disease that is closely associated with drug use (Butt, Patterson, & McGuiness, 2008), and women may be more adversely affected by such stigma given typical gender roles and social expectations. Therefore, a qualitative analysis of women's accounts of diagnosis can provide insights into current practice, which can inform and direct nursing clinical practice and programs to ensure women are receiving the information and support they require at this critical point in their life.

Although our research on the experience of diagnosis was undertaken prior to the present major advances of interferon-free HCV treatment, which have given new hope of speedy and less burdensome treatment, these new treatments alone will not solve the burden of HCV. The role of nurses in HCV care is expanding from specialty clinics into general practice, thus highlighting the need for these issues of diagnosis and clinical pathways into care to be refined. In this paper, we examine Canadian women's experiences of HCV diagnosis to develop recommendations to improve care at the time of diagnosis that will, in turn, enhance women's access to these new treatments and other services.

## Methods

The qualitative research design of narrative inquiry methodology was used in this study to allow for inquiry into women's experiences. This approach enabled an exploration of the women's life experiences using "story" to describe and analyze the experiences of living with HCV from the perspective of the women. Narratives were used to understand and make sense of various life events described by the women who lived them (Chase, 2011; Creswell, 2009). How the women chose to narrate their experiences or tell their story and what they included helped to construct meaningful identities and realities of their experience (Chase, 2011).

### Recruitment

Twenty-five women with self-reported HCV were recruited through community clinics and support agencies, specialist clinics, public health, prison health, and outreach services. Purposeful sampling using snowball and word-of-mouth sampling strategies were used to ensure participants were recruited that could provide insight into the research question. Information pamphlets and flyers were provided to these sites for distribution to potential participants. Healthcare providers at these sites also targeted eligible women and asked if they would be willing to participate in a telephone interview about their experience of living with HCV.

To maximize confidentiality and accessibility, participants were interviewed by phone on a toll-free line. When participants expressed an interest, they were referred to the toll-free telephone number to contact a member of the research team. To facilitate participation for women without phones, community agencies provided a private space and telephone. During the initial call, participants were informed about the aims of the research and asked preliminary questions to ensure they met the selection criteria: self-reported HCV infection, aged 19 years or older, English language fluency, and no conditions that significantly impeded cognition, memory, or the ability to give consent (e.g., dementia, psychosis, etc.).

Verbal consent was obtained during the initial contact with participants. Written consent was then obtained from all participants either via post or email prior to the full interview. Telephone numbers were exchanged with eligible participants and a suitable call back time to conduct the interview was arranged; occasionally, the interview occurred immediately.

### Data collection

An interview guide, based on input from an expert advisory committee comprised of healthcare providers and women living with HCV, was used to facilitate exploration and enrich the data (Smith, 1995). Women were interviewed by one of three trained interviewers who collected standardized demographic and open-ended exploratory questions that assisted with probing the issues and facilitated further exploration of perceptions, experiences, and areas of interest contributing to the women's experiences of living with HCV and health-service utilization. Interviews lasted 45–90 min and were audio recorded and transcribed.

### Data analysis

NVivo 9$^{TM}$ software was used as a tool to assist with organizing the qualitative data. This management system allowed the researchers to interrogate the data in an effective and efficient way. Transcripts were read and an initial coding structure was developed using open coding to identify concepts and categories in the data, which formed the components for the analysis. Once an initial coding structure was established, the research team simultaneously coded five randomly selected transcripts and compared coding similarities and differences among the team members. As new codes and issues were identified as being significant along the journey to care such as point of diagnosis, the narratives were reread and recoded with focused coding using the initial codes to synthesize and scrutinize the data. The coding structure was refined to produce an inclusive list of codes through consensus that represented the range of women's experiences included in the narratives. Constant comparison was used to examine similarities and differences and ensure that the data continued to support the emerging categories.

Memos were kept to record thoughts, interpretations, and questions about the data and their interpretation. The stories and events were the data and narrative inquiry was used to construct descriptive narratives that connected the stories in a meaningful way. This approach allowed for a deeper understanding and empathy for the life experience of the women living with HCV (Schwandt, 2007). Recruitment ceased shortly after data saturation was reached as no new codes or themes were identified.

### Ethical considerations

Ethics approval was granted by the University of British Columbia, the University of Sydney, and the Public Health Agency of Canada's Human Research Ethics Committees. Prior to interviews, written and oral information was provided and reviewed with all participants and signed consent forms were collected. Data confidentiality was maintained by using codes in place of personal identifiers and restricting transcript and data access to the research team. Participants received a $40 honorarium for their time and incidental costs. Pseudonyms were used throughout data collection and analysis to ensure participant confidentiality.

## Results

The sample comprised 25 women with self-reported HCV from three Canadian provinces. Two of these provinces together account for 60% of all reported cases in Canada (Public Health Agency of Canada, 2011). The sample was geographically diverse with women from urban, suburban, and rural areas. Women were at various stages of the lifespan and HCV illness. The majority (24/25) were aged 30 years or older. Twelve participants received their diagnosis more than 10 years ago and seven within the past five years. More than half the women had received HCV antiviral treatment. The majority of the women were diagnosed by their general practitioner, methadone maintenance therapy prescriber, or by a doctor at a walk-in primary health clinic.

Through our analysis, we found two interrelated themes in understanding the women's experiences of diagnosis: (1) how prepared the women were for their positive diagnosis and (2) information and health education received at point of diagnosis.

### Preparedness

The women's narratives illustrated that varied circumstances contributed to receiving a HCV diagnosis and, ultimately, their level of preparedness. The first of these circumstances was reported by eight women who described HCV testing in the context of seeking healthcare for "feeling unwell" or "knowing something was wrong." Symptoms often included jaundice and severe abdominal pain, which they did not necessarily attribute to HCV. Their health provider initiated testing for HCV and the women were often unaware they were being tested. Consequently, when diagnosed, women were often ill-prepared, as they had not considered the possibility of HCV infection. They reported being puzzled and questioned their exposure source, which was often many years prior to the diagnosis.

In the second circumstance, 11 women described being tested during a routine examination for a health insurance application, in follow-up blood tests for abnormal liver enzymes or screening after blood donations. As the screen was done as a matter of routine and at a range of locations, no risk assessment was completed. Again, some women were unaware they were being tested for HCV. Women were not expecting positive results and they reported feeling unprepared, shocked (as they felt well), and bewildered when told of their HCV diagnosis. The absence of a risk assessment prior to diagnosis created enormous confusion for the women as they had little knowledge about HCV and its transmission routes. The example below highlights both an unacceptable breach of confidentiality in small community hospital and how a lack of information and counseling results in further unnecessary confusion.

> My insurance agent called me between that Christmas and New Years to tell me that I was turned down, and I said, "oh why, was my blood pressure too high?" My sister-in-law had just gone to the hospital that day and she said, "no, don't you know that you have hep C?" ... Needless to say, I did not take it seriously. "You're joking", you know, because I was still under the idea that it was mostly drug addicts. (Kathy, diagnosed 2002)

The final set of circumstances involved women who sought HCV testing. The context for some women was the presence of known risk factors, which prompted women or their health provider to seek HCV testing at a drug treatment program or primary health clinic. Risk factors included past or current drug use, blood transfusion, and mother–child transmission. Generally, these women were aware of an exposure event or that their practices put them at risk. Thus, the women were prepared for a positive diagnosis and, after the initial shock, accepted it and were able to explain it in terms of their drug use.

For example:

> I was doing a complete turnaround at the that time and I said okay, I'm getting out of addiction, I'm changing my lifestyle but I wanna make sure, did I get out scott free? (Kerri, diagnosed 2005)

But in other situations when women sought testing because of risk-exposures, they were unprepared for the positive diagnosis. For example, between 1986 and 1990, a number of Canadians were infected with HCV via blood products during hospital procedures (Norris, 2008). Following media reports of tainted blood, two participants made the decision to get tested. Another participant was tested because both parents were HCV positive. In these three cases, the decision to be tested was the result of a risk exposure. However, the women's response to a positive result was similar to those who had routine testing: unprepared for and surprised by the diagnosis as they were unaware of their exposure source and uninformed about HCV prognosis. Tanya described getting diagnosed at an early age when the child protection agency became involved. When she received her results, she had no knowledge of HCV.

> The Ministry had got involved and, uh, I had to do blood work, I can't remember what, I was really young, but um, yeah, the blood work came back and said I was positive and I hadn't had any sexual partners or anything like that or done any drugs so that kind of leaves only one reason, you know? One reason. And both my parents were hep C positive ... So, yeah, that's when I got that diagnosis, I didn't really know what it means. (Tanya, diagnosed 2000)

### *Information and health education received at point of diagnosis*

An HCV diagnosis can create distress and confusion for women when considering how this diagnosis will impact their health in the future. This distress and confusion can be exacerbated if women receive limited information or misinformation about prognosis from their healthcare provider. The women in this study described varying experiences of information provision ranging from none, to limited or inadequate, to appropriate and adequate information for health management.

Irrespective of time since diagnosis (that is, from more than 10 years before interview to within the past five years), women described receiving limited information at diagnosis. The women who described not receiving HCV-related information, being uninformed about the need for follow-up or not being told how to manage their HCV at the point of diagnosis described the experience as confusing and distressing; they were left wondering about the consequences of HCV. For some of the women in our study, a negative experience and inadequate information at diagnosis resulted in further disengagement from care.

For many women, their HCV diagnosis raised significant concerns about current and future health status. Some described believing they were going to die soon after diagnosis and so they had no reason to inquire further about HCV or make changes in their lives. Others had no sense of the seriousness of HCV. One participant was given no information:

> When I was diagnosed with hepatitis C I was barely a woman right and told that I'm goanna die. That's exactly what they said like you're, don't expect to live very long because twenty years from now you're going to be really sick and then you're goanna die. (Jackie, diagnosed 2000)

As a result, Jackie was unaware of the need for on-going liver monitoring and she received no follow-up. It was not until years later when, following abnormal bloodwork results during a routine physical exam, further investigations were performed and appropriate medical care was provided.

Regardless of the circumstance that prompted the HCV test, information provided by healthcare providers at the time of diagnosis shaped women's subsequent health and healthcare experiences. Living for years with incorrect information about prognosis left Jackie feeling she could have done things differently and made changes sooner "if only I'd been told" earlier about the consequences and need for follow-up. Some women attributed the lack of information to inadequate knowledge of their healthcare provider, others to the lack of information existing at the time. For example:

> Well, in the beginning when I got the diagnosis the doctor that I saw basically gave me a pamphlet and said, "you know we don't really know much about this but maybe you know you might have two years to live," kind of thing" . . . The doctor said that as long as I didn't have any symptoms that I would be ok. (Kerri, diagnosed 1992)

A more recent diagnosis did not appear to improve information provision. Some participants diagnosed within the last decade reported being informed by their healthcare provider that the information they had received at diagnosis (by another healthcare provider) was incorrect. One participant, diagnosed in 2007 by her general practitioner, was provided with no information on follow-up or management of HCV.

> I said, "I have no energy and I'm sleeping so much", so I asked him if he could take, check my blood out and then he told me that I had hep C. He told me, he said, "maybe that's why you're getting so tired" and that's it, I couldn't believe it, he didn't really say anything about it . . . He didn't say anything about what you should do. (Becky, diagnosed 2007)

A small number of the women diagnosed in the last decade reported receiving what they characterized as sufficient information about HCV. These women said they felt prepared to make informed decisions about their healthcare management. Most of these women were diagnosed by a healthcare provider with whom they had an established relationship. They described feeling empowered and motivated to make lifestyle changes:

> [When I was diagnosed] . . . they, were supportive of me and they, you know, they told me in terms I could understand, like to begin to educate me a bit about it. Um, and um, yeah, I was able to kind of figure it out a bit . . . ah; it kind of, it actually gave me, incentive to get my life together. It took a few years but it's been some, it's, I had something to work towards to, you know, kind of like take control of my health. (Lisa, diagnosed 2005)

## Discussion

The past two-and-half decades have seen much progress in the understanding of management and treatment of HCV. Nevertheless, negative experience and inadequate information at diagnosis continues to be a problem affecting women living with HCV, resulting in further disengagement from care and long-term consequences to their understanding of HCV and its management (Hopwood & Treloar, 2004; Treloar et al., 2010). Women in our sample described not knowing what to do post-diagnosis or being told there was nothing they could do. This finding contrasts strongly with the sense of empowerment described by the few women who felt they received good information.

A HCV diagnosis can cause major psychological distress, which may be more troubling when little or no reliable information about prognosis is provided (Castera, Constant, Bernard, de Ledinghen, & Couzigou, 2006). The diagnosis experience for women can have significant implications on social functioning. The perceived stigma associated with HCV can produce anxiety and amplify fears of transmission, which may lead to social isolation and limited intimacy in relationships (Miller, McNally, Wallace, & Schlichthorst, 2012). Two important findings stemming from our analysis reinforce claims that the process of diagnosis has major implications for HCV care. These findings contribute to the knowledge base and should inform the continuing development of strategies aimed at improving the HCV diagnosis experience.

### Preparedness

Women are diagnosed with HCV in a range of settings and after a variety of prompts. In our study, the context of the diagnosis often foreshadowed how prepared they were for the results. Women who received limited information on pre-diagnosis were less prepared and shocked by the results. On the other hand, the few women who were well informed about HCV prior to diagnosis—generally those who had sought testing or where tested following risky practices—had a base from which to ask questions. For example, women who were diagnosed during routine blood-work or for insurance purposes were neither prepared for nor anticipating a positive result. Moreover, these women were more likely to be diagnosed in a setting where their healthcare provider was less informed about HCV. Being unprepared for a HCV diagnosis can trigger feelings of shock and devastation, which can lead to long-term emotional, psychosocial, and physical-effects and be a barrier to accessing care (Miller et al., 2012).

### Information and health education

Health education and effective communication of management plans can influence patients' emotional and physiologic status and significantly impact health-outcomes (Stewart, 1995). Communication interventions and patient health-outcomes are correlated; effective communication can positively influence the patient's emotional health, symptom management, and physiologic status (Stewart, 1995). The women in our study were generally provided with inadequate or incorrect information at diagnosis leaving them confused and unsure about follow-up and management. This situation negatively impacts relationships with healthcare providers, which can create a barrier and avoidance of future healthcare (Miller et al., 2012).

Our study raises concerns about how often women are being educated to make informed decisions about their HCV care. Discussing the meaning of a positive result can help women understand their diagnosis and take control of their subsequent health behaviors (Gifford, O'Brien, Bammer, Banwell, & Stoove, 2003). Our results highlight the importance for nurses to have suitable training to equip them with the knowledge and skills to provide appropriate information and holistic care for women living with HCV. The findings also emphasize the significance of inquiring about each woman's prior knowledge of HCV and not assuming adequate information has been provided to her at diagnosis. Each interaction is a crucial opportunity for nurses to correct or update information that may lead to better care and increase women's sense of control over their healthcare experiences and future health outcomes (Hibbard & Peters, 2003).

HCV is a stigmatized condition due to the association with injection drug use. A negative experience at diagnosis can lead to disengagement and create a barrier to, and avoidance of, healthcare, which will damage future relationships with healthcare providers (Treloar et al., 2010) and potentially negatively impact treatment and interventions. This potential outcome is important for all people diagnosed with HCV, but it is especially pertinent to women who may undergo testing while pregnant. Pregnancy is a particularly vulnerable time for women because they often feel judged and their behavior and lifestyle may be scrutinized, especially for those with a history of illicit drug injection (Olsen, Temple-Smith, & Banwell, 2013). Therefore, given the role of nurses and midwives in the care of women at this time, a sound understanding of HCV is crucial for appropriate care.

### Implications for practice and/or policy

Understanding women's experience at HCV diagnosis has implications for nursing practice, policy, and future research, especially as new highly effective treatments become more available, thus expanding the role of nurses in this area. Improving this experience can be the first step towards improving health outcomes and reducing the burden of the disease for the growing number of women living with HCV. As found in our research, women are diagnosed in a variety of settings, but HCV awareness, knowledge, and expertise are not evenly distributed across these diverse settings. Our findings provide a clear and compelling case for a national HCV testing guideline for HCV diagnosis, including pre- and posttest discussion, to guide standards for diagnosis care, which can address the inequalities women face when diagnosed with HCV. Although pre- and posttest guidelines for HCV have been identified as important for prevention and care (Watson & Kosky, 1999), they are currently lacking in a number of settings, including in Canada, which was the site of this research. Without consistent HCV pre- and posttest guidelines, nurses and other healthcare providers will continue to provide variable information during pre-test and posttest discussions, if any is delivered at all (Munoz-Plaza, Strauss, Astone, Des Jarlais, & Hagan, 2005).

The HCV diagnosis process is described as being trivialized by healthcare providers (Davis et al., 2004), yet the point of diagnosis is an important window of opportunity for education and engagement into care and treatment. Though it is concerning that so few women diagnosed within the last decade received what they judged to be adequate information about HCV from their healthcare provider in an era when treatment was theoretically available, it is perhaps unsurprising given the lack of diagnosis and management guidelines. Although guidelines cannot guarantee appropriate care at diagnosis, they can be effective in ensuring minimum standards of care are met.

Effective HCV diagnosis depends on policies, strategies, frameworks, and standards that focus on education for nurses and all healthcare providers around the point of diagnosis. Implementation of pre- and posttest guidelines would facilitate referral into care and treatment at the point of diagnosis and possibly reduce barriers to care, which otherwise could lead to unnecessary disease progression and, ultimately, reduce the overall burden of the disease in Canada (Krajden et al., 2010; Yu, Spinelli, Cook, Buxton, & Krajden, 2013).

As the new highly effective HCV treatments with greater tolerability and much lower toxicity become accessible across Canada, HCV care and treatment is likely to move away from the specialist clinic and out to the broader public healthcare sector. It is therefore essential that adequate and appropriate information about prognosis, treatment options, and the ongoing need for healthcare is provided at the point of diagnosis to ensure those affected have the necessary knowledge and access to care. Our research has demonstrated the impact the diagnosis experience has on Canadian women living with HCV and highlights the need for a proactive response from healthcare providers which will improve women's experiences of HCV diagnosis and, in turn, enhance women's access to HCV care and other healthcare services.

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