

Factors Affecting Attendance for Hepatitis C Care

REPORT OF STAGE ONE
OF THE ATTENDANCE FOR
HEPATITIS C CARE PROJECT



A special thanks to all project participants for your enthusiastic support of this research and for trusting us to tell your story. We are very grateful to our Advisory Committee whose commitment and contributions made this a truly national effort. And finally, we would like to acknowledge the role of the Public Health Agency of Canada in providing the funding that made this project possible.

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Shannon Taylor, North Island Liver Service



Liza McGuinness, Sandi Mitchell, Adrienne Peltonen



Dr. Gail Butt

Dr. Gail Butt, Principal Investigator

School of Nursing, University of British Columbia

Liza McGuinness, Research Manager

School of Nursing, University of British Columbia

Sandi Mitchell, Nurse Educator

BC Centre for Disease Control and Ph.D candidate

Adrienne Peltonen, Research Coordinator

University of British Columbia

Hepatitis C is a chronic, infectious disease that affects approximately 250,000 people across Canada. Although it is recommended that those affected receive regular care to monitor and manage their condition, reports from health care providers indicate high rates of non-attendance for hepatitis C care and a need for greater understanding of the issues behind non-attendance. Guided by a national advisory committee made up of people affected by hepatitis C and health and social care providers, this study aimed to explore why people attend, delay, defer or do not seek care for chronic hepatitis C. Information was gathered through 55 individual interviews (telephone and in-person) with those affected and group sessions with 29 health and social care providers from across Canada. Study findings were organized according to six interrelated themes:

- **Self-protection.** For some, non-attendance was a way to avoid possible negative impacts of the disclosure of their hepatitis C status or to protect themselves from negative care experiences.
- **Determining the benefits.** Participants described numerous issues that influence the decision to attend, delay, defer or not attend care, such as being told by a provider that follow-up care was not needed, feeling healthy or that care was pointless, past care experiences were not perceived as beneficial, or the personal costs of lifestyle changes or doing antiviral therapy were felt to be too high.
- **Competing priorities.** Many participants described priorities that needed to be managed in addition to hepatitis C, including other health conditions, life instability and/or responsibilities such as work or family.
- **Knowledge gaps and health literacy.** Both patient and provider participants reported knowledge gaps and misinformation about hepatitis C and its management and treatment. Difficulties understanding hepatitis C information and sorting through information from multiple sources, which in some cases conflicted, was also reported.
- **Access to services.** A number of participants reported care being unavailable, particularly in rural and remote areas, or difficult to access due to financial costs, wait times and the lack of integrated or culturally appropriate care.

- **Restrictive policies.** Clinic policies around making and keeping appointments were barriers to accessing care for some. Abstinence requirements of some providers, the necessity of a referral to see a specialist and provincial eligibility criteria for anti-viral therapy were other issues that contribute to non-attendance.

These findings show that the reasons for non-attendance are related to multiple interacting factors at the patient, provider and systems levels. In response to these factors, study participants recommended integrated health and social supports, improved education and standardized follow-up protocols for patients and providers.

About this Report:

This report provides a brief overview of a study conducted by a research team affiliated with the University of British Columbia and the British Columbia Centre for Disease Control and funded by the Public Health Agency of Canada. The aim of the study was to explore why some people living with hepatitis C attend, delay, defer or do not seek hepatitis C care. This research was conducted as the first stage of a two-year project which aims to develop and disseminate resources that will foster or support increased attendance for hepatitis C care.

Why is it Necessary to Attend for Health Care Services for Hepatitis C?

Approximately 250,000 individuals in Canada are chronically infected with hepatitis C. The highest rates of hepatitis C are among populations who are marginalized, such as those who use injection drugs and immigrant and Aboriginal populations.

For people living with chronic hepatitis C, only a small proportion are referred for specialist care and will qualify for treatment, leaving a large number of people to manage this disease long term. Those that do qualify for antiviral therapy will also require support and monitoring due to the possible side effects from the drugs and the added stressors of being on treatment. Despite the need for monitoring, support and treatment of people diagnosed with chronic hepatitis C, there are a large number of people who do not attend services or postpone care.

Researchers and service providers from across Canada identified non-attendance as a significant problem. The concern is that people who do not attend for hepatitis care may not be receiving the information and support they need to make decisions about their care, to prevent complications and live as well as possible.

The Study

The purpose of the study was to explore the personal and health system factors behind why people attend, delay, defer or do not seek hepatitis C care. Information was gathered through individual interviews (telephone and in-person) with those affected by hepatitis C and group sessions with health and social care providers. This project was guided by a national advisory committee made up of people affected by hepatitis C and health and social care providers.

Who Participated?

All together, 84 people participated in the study from six provinces: British Columbia, Manitoba, Ontario, Quebec, Nova Scotia and New Brunswick. There were 55 participants who were affected by hepatitis C and 29 health and social care providers. Of the patient participants, 55% were men and all had lived with hepatitis C for at least one year. Providers all had experience working with people living with hepatitis C. They worked in community clinics, community support agencies, specialist clinics, public health, prison health, and street outreach.

What Were the Issues?

The study showed that there are many reasons why people living with hepatitis C decide to attend, defer, delay or not attend for care. We will discuss six interrelated issues that highlight the findings of the study: self-protection; determining the benefits; competing priorities; knowledge gaps/health literacy; access to services; and restrictive policies.

1. SELF-PROTECTION

“Like, she would not go to the hospital. I’d been to the hospital a couple times with her when we were drug addicts and the way she was treated, the one time I had to say something to the nurses, like, they were so rude, she left the hospital in tears. 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.”

Participants described experiences of self-protection through delaying, deferring or avoiding health care. For example some participants said that once they informed health care providers of their hepatitis C infection they were treated differently, unfairly judged or treated as a ‘drug user’. They described a

“go to the back of the line” experience or gave examples of providers making them feel that they were “not worthy of care.” These experiences were so damaging that many participants described avoiding health care services for several years and/or changing care providers.

“...just the way he looked at me and the way he talked to me you know it made me feel like dirt and it's not right like I just like I said I deserve the same level of care as everybody else in the world.”

Avoiding disclosure

“She didn't 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”

Participants described avoiding getting tested for hepatitis C even though they knew they had been exposed to it. For some, the stigma associated with hepatitis C caused them to feel shame and “...really dirty and icky and just like I wasn't good enough to deserve his care.” Reactions like this prevented participants from discussing hepatitis C with anyone, including their families. The negative effects from disclosure were also reported to be heightened in rural and remote areas.

Avoid negative health care experiences

“I have actually been asked to leave the emergency ward. I went out there, I couldn't walk there was something wrong... I went out to the hospital three times in an ambulance and three times I was asked to leave the emergency ward because they thought I was out scamming them for drugs.”

Many participants talked about negative experiences, particularly in emergency departments. Participants described behaviour by the service provider as “rude” and “judgmental” and that they were treated “like a dog” or “like dirt.” In some cases they were accused of drug seeking and/or discharged without an assessment. Some spoke of avoiding emergency departments even when they urgently required health care.

2. DETERMINING THE BENEFITS

"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."

Once diagnosed, some participants stated they were not offered follow-up care or treatment. Their doctors told them that they would be fine, not to worry and to have a good life. As a result, they often did not discover treatment was available until years later.

Contacts with providers

"I knew as much as him, I didn't see why I should go and use up that time."

Participants' experiences with health care services usually involved getting diagnosed, sporadic care and/or a referral to see a specialist. There was little mention of regular chronic hepatitis C follow-up or monitoring. Some participants felt that their health care providers did not provide them with the information they needed so did not attend for care. Experiences with specialists focused on treatment with anti-viral medications and, in a few instances, on monitoring end-stage liver disease when treatment was not an option.

Costs versus benefits

"It scared the crap out of me, I didn't 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?"

A large number of participants said decisions against attending for care were a result of one or more of the following: feeling healthy, seeing care as pointless and not being ready to make changes.

Participants said they "felt fine" and had no symptoms so did not feel they needed to go for care. Some who had recovered from addictions had increased feelings of well being and thought "my hepatitis C is better now." These beliefs were sometimes reinforced by providers when no information was provided or they had been told not to worry, they would be "fine."

On the other hand, a few participants believed that going for care was useless because they thought hepatitis C was a death sentence. Instead of seeing a health care provider, some said they went deeper into their addictions. Only after time passed and they realized they were not imminently dying did they seek care.

A few participants said they decided they were not ready to make changes, whether it involved sexual activities or drug and alcohol use. They also felt they were not able to go through the difficult and long course of anti-viral therapy.

Treatment

"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 doesn't make a lot of sense to me"

When asked about why they would attend for hepatitis C care, most participants spoke about treatment. The side-effects of treatment were often compared against their current state of health and their chance of success. For a number of participants, the personal costs of treatment were too high:

"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."

One person postponed treatment because it was hard to separate the treatment experience with other past experiences. Specifically, using needles that would make her feel unwell when previously they had made her feel better.

"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?"

3. COMPETING PRIORITIES

"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."

A number of participants said their care was deferred or interrupted because other priorities took over their time, such as work or family obligations, dealing with day-to-day concerns and/or managing symptoms or other health conditions.

“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 just went by the wayside.”

Some participants said they did not attend for care because they were heavy into their addiction and their health issues were often ignored during this time. One participant mentioned that she actively put her hepatitis C in the background, choosing to ignore it. She said she did not want to think about it everyday and let it take over her identity.

4. KNOWLEDGE GAPS AND HEALTH LITERACY

“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... but if somebody could explain it to me maybe I'd understand better.”

During the interviews with both the patient participants and providers it became obvious that there were many gaps in the information about hepatitis C regarding the disease process, the need for monitoring and follow-up and about eligibility for treatment. A number of health care providers stated that during their first few appointments with clients, a large amount of time was spent providing information and/or correcting misinformation.

“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.”

Participants described experiences of being given a hepatitis C diagnosis with no other information regarding follow-up. For example, a person would receive a positive result and no pre-or post-test counselling was provided.

Several participants believed they could not get treatment if they were using illicit drugs or alcohol. One person said that they were not even aware that there was treatment available for hepatitis C.

Health literacy

Interviews with participants showed difficulties with understanding the information that was available. The language and abbreviations used by health care providers was often not understood. Nearly all of the people who spontaneously cleared the virus, described their hepatitis as “dormant” or “resolved” and said they were unsure what that meant.

“I’m pretty intelligent and I knew that sometimes hep C can be a death sentence, you know, it can eventually sometimes take your life, I know that but I um, I made a few enquiries, I did some reading and so on and so forth on my own and um, I just kind of carried on life that way, right?”

Discussions about where people got their information showed that their personal networks and the internet were as, or more, important than information from a health care provider. Participants compared what providers told them with information from the internet and with what their own networks told them. They said they had difficulty deciding what information to believe.

5. ACCESS TO SERVICES

“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.”

“It hurt, you know, like, I need a doctor because there’s so much wrong with me and it really it made me feel like I was dirt on the bottom of his shoe you know? 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.”

A number of participants talked about when they were refused care. In some cases it was for missed appointments and in other situations it was because of an injection drug use history that was disclosed once they received their hepatitis C diagnosis. Talking about these experiences was difficult for participants who said they felt as though they were judged as undeserving of care.

Participants described services as being unavailable or difficult to access. Many of these issues were heightened in rural and remote areas. In rural settings people said walk-in clinics were not available, leaving the hospital emergency department as their only option, which some would not attend. In other cases, services were available but had long wait times for appointments. These long wait times could be discouraging and made it difficult for participants to plan.

Financial barriers were described by both participants living with hepatitis C and providers as a major issue for access to services. People did not have funds for transport to appointments, parking, phone minutes, and child care. Financial costs for travel from rural and remote areas for specialist care were a barrier, particularly if the person was ill and needed to be accompanied.

“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.”

According to some participants, hepatitis C services should be comprehensive and provided by local community-based agencies in a timely way, for example, by having mental health services, addictions counseling, housing, and social services workers in a one-stop shop. A lack of culturally appropriate services, it was argued, means individuals from youth, Aboriginal and immigrant populations are less likely to attend services because they face language barriers and do not identify with the services.

6. RESTRICTIVE POLICIES

“The methadone program, the way it is set up in this province does not make somebody’s life more liveable 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?”

Participants identified a number of service policies that limited access to care. For example, requirements to make or confirm appointments could be challenging for participants without easy access to a phone. Some participants also spoke about clinics having a 'three strikes and you're out' policy meaning if you have missed three appointments you were no longer able to access that service.

To be considered for treatment with anti-viral therapy a person must get a doctor's referral to see a specialist. In areas where there is a shortage of family doctors, this requirement made it difficult to access care. In some provinces, treatment eligibility criteria also acted as a barrier to treatment. Some providers were reported to insist on abstinence from drug or alcohol use or participation in a methadone program prior to starting treatment. Many participants reported long waits for access to methadone and difficulties normalizing their life while complying with the program regulations.

Participants in this study described reasons for non-attendance which involved multiple interacting factors at the patient, provider and system levels. To address these issues, participants recommended comprehensive services which integrate both health and social supports, improved education that keeps providers and patients up to date with the frequent changes in hepatitis C knowledge and treatment, and standardized protocols for primary care providers for following-up patients with chronic hepatitis C.

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If you would like more information...

Contact Dr. Butt by e-mail at gail.butt@bccdc.ca or by phone toll-free at **1-866-660-1676**.

More information about this project is available on the attendance project page at www.bccdc.ca including a PowerPoint presentation of the study findings.