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

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### **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

**Introduction**

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 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.

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, & McGuinness, 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 e-mail 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 minutes and were audio-recorded and transcribed.

**Data Analysis:** NVivo 9<sup>TM</sup> 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 (GP), 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 blood-work 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 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 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 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 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, 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, & Stooove, 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 an 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 behaviour and lifestyle may be scrutinized, especially for those with a history 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 post-test discussion, to guide standards for diagnosis care, which can address the inequalities women face when diagnosed with HCV.

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. 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).

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 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)

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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