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Canadian women's experiences receiving a hepatitis C diagnosis

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The rate of hepatitis C is on the rise among Canadian women, in particular among women aged 15 to 29 years old. Approximately 60% of new infections in this age group are in women.

Detecting hepatitis C early in women is key for accessing timely care, treatment and support to improve health outcomes and quality of life. Having a chronic illness can be especially difficult for women because of its social impact, particularly when the illness is as stigmatized as hepatitis C. This stigma can also create barriers to healthcare access.

Diagnosis is a critical opportunity for connecting people to hepatitis C care. However, some research has found that people often have a poor experience with the hepatitis C testing process. Some people with hepatitis C report that they perceive that healthcare workers have negative attitudes toward them. They also report that healthcare workers provide little support or information about hepatitis C. When people diagnosed with hepatitis C have limited information, it can result in reduced follow-up and access to hepatitis C care, increased fear about hepatitis C and feeling a lack of control over one's health.

A recent study aimed to better understand the experiences of Canadian women who receive a hepatitis C diagnosis and to provide recommendations about how to improve hepatitis C testing experiences.

Study participants

Twenty-five women from three Canadian provinces participated in interviews about their experience receiving a hepatitis C diagnosis. They were from urban, suburban and rural parts of Canada. The vast majority of participants were over 30 years of age.

Twelve of the participants were diagnosed with hepatitis C more than 10 years ago, and seven found out they had the virus five years ago. Most of the participants were diagnosed by their family doctor, a methadone prescriber or a doctor at a walk-in clinic. Just over half received hepatitis C treatment some time after diagnosis.

Being prepared for the diagnosis

The degree to which a woman felt ready to receive a positive hepatitis C diagnosis greatly impacted the experience of receiving the diagnosis.

Eight of the 25 study participants reported being unprepared for a positive hepatitis C diagnosis. Some were tested for hepatitis C when they went to a healthcare provider either because of a symptom, such as jaundice, or a generalized feeling that something was wrong. They reported that their healthcare provider decided to give them a hepatitis C test but in many cases did not tell them they were being tested. When they received a positive hepatitis C diagnosis, they said they were not ready for it and were confused about how they might have gotten the virus.

Eleven of the participants received a hepatitis C test for one of three reasons: as part of a routine exam for an insurance application, screening for a blood donation, or as a follow-up to a test showing abnormal liver enzymes. These women reported that they did not receive a risk assessment prior to the hepatitis C test and, in some cases, were not informed that they were being tested for hepatitis C. They were not expecting to find out they had hepatitis C and reported feeling unprepared, shocked and bewildered when they received the results. Not receiving a

risk assessment before receiving a diagnosis caused a lot of confusion for these women because they were not aware of how hepatitis C is transmitted.

Another small group of participants went for hepatitis C testing because of a suspected exposure to hepatitis C, such as through the Canadian blood supply prior to 1992. However, these women were unprepared for a positive hepatitis C test result due to having little or no information about what hepatitis C can do to the body.

Several women requested hepatitis C testing because they were aware of a reason why they might have been exposed to hepatitis C. These participants were ready to find out they had hepatitis C and despite experiencing some shock were able to accept the diagnosis.

Hepatitis C education during the testing process

Study participants received widely varying amounts of information about hepatitis C during the testing process, with some women reporting they received limited or no information and others reporting that they received an adequate amount of information. Other women reported receiving misinformation.

The information provided during the testing process impacted how the women in the study perceived having hepatitis C and their experiences with further healthcare.

Women who received no basic hepatitis C information or instruction about follow-up care described their testing experience as confusing and distressing. They were unclear about how hepatitis C would affect their bodies. For some women, this led to them disconnecting from care.

Some women came to believe that they would die soon from hepatitis C and that there was little they could do to change that, so they did not seek more information. Other participants did not understand that hepatitis C was a serious illness.

Some women who received additional healthcare at a later date discovered that the healthcare provider who diagnosed them had given them incorrect hepatitis C information.

The small number of participants who felt that they had received enough information about hepatitis C when they were diagnosed felt ready to make decisions about managing their health. Most of these women were diagnosed by a healthcare provider with whom they had an ongoing relationship. They reported feeling motivated and able to make changes in their life.

Moving forward with hepatitis C testing

Given that hepatitis C testing is done in a range of settings with providers who have differing levels of hepatitis C knowledge, testing experience and skills, the researchers recommend that the development of Canadian hepatitis C testing guidelines be developed, and that these guidelines encourage a minimum amount of hepatitis C information to be given during testing. They suggest that these guidelines specify the minimum amount of information to be given during testing and recommend topics to be covered during both pre- and post-test counselling. Moreover, to be effective, hepatitis C testing guidelines would need to be supported with relevant policies, strategies and frameworks.

As improved hepatitis C medications with fewer side effects become available across Canada, hepatitis C treatment will likely move away from specialist care into primary and community care. This is why it is critical for healthcare providers administering hepatitis C testing to be adequately trained in the appropriate information and skills to be able to deliver accurate education and care to women diagnosed with hepatitis C.

A key part of successful hepatitis C testing and care would involve asking women about their knowledge of hepatitis C, even if they have received hepatitis C testing or care previously, because they may have received inadequate or inaccurate information.

As people with hepatitis C often experience discrimination, it is important to provide testing and information in a non-judgmental way. This is especially important for pregnant women who often experience extra scrutiny of their behaviours, especially if they inject drugs. Negative experiences may deter people from seeking further hepatitis C care and treatment.

While some healthcare providers may downplay the importance of the hepatitis C testing process, it is a critical time for education and connection to care and treatment.

Resources

[Hepatitis C pre- and post-test counselling information](#)

[Diagnostic tests](#)

—*Scott Anderson*

REFERENCE:

Mitchell S, Bungay V, Day CA, Mooney-Somers J. Has the experience of hepatitis C diagnosis improved over the last decade? An analysis of Canadian women's experiences. *Canadian Journal of Nursing Research* 2016;48(1):21-28.

Produced By:



Canada's source for
HIV and hepatitis C
information

555 Richmond Street West, Suite 505, Box 1104
Toronto, Ontario M5V 3B1 Canada
Phone: 416.203.7122
Toll-free: 1.800.263.1638
Fax: 416.203.8284
www.catie.ca
Charitable registration number: 13225 8740 RR

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