

Will the moment of Hepatitis C diagnosis
undermine the promise of new treatments?
An analysis of Canadian women's experiences

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Hepatitis C – In Canada

- ▶ An estimated 242,500 (of **35.8 million**) **Canadians** are infected with hepatitis C
- ▶ ~ 21% are undiagnosed (Public Health Agency of Canada, 2011)
- ▶ The majority of new hepatitis C cases are among people who inject drugs
- ▶ Associated with 61% of infections (Public Health Agency of Canada, 2011)

Why Study Diagnosis?



- ▶ *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, “it’s a lot to take in I know but go home and read this pamphlet”... The doctor said that as long as I didn’t have any symptoms that I would be ok.*

(diagnosed 1992)

What we did:

- ▶ A qualitative study employing narrative methodology explore women's experiences of HCV diagnosis and factors contributing to non-attendance for HCV care.
- ▶ Guided by advisory committee
- ▶ Data collected through open-ended interviews and a demographic questionnaire
 - Recorded, transcribed, and coded

Who Participated?

- ▶ 25 women living with hepatitis C for more than a year, the majority were drug dependent.
 - ▶ Recruited from 3 provinces, British Columbia, Ontario and Nova Scotia.
 - ▶ Participants were drawn from community clinics, community support agencies, specialist clinics, public health, prison health, and street outreach
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Participants

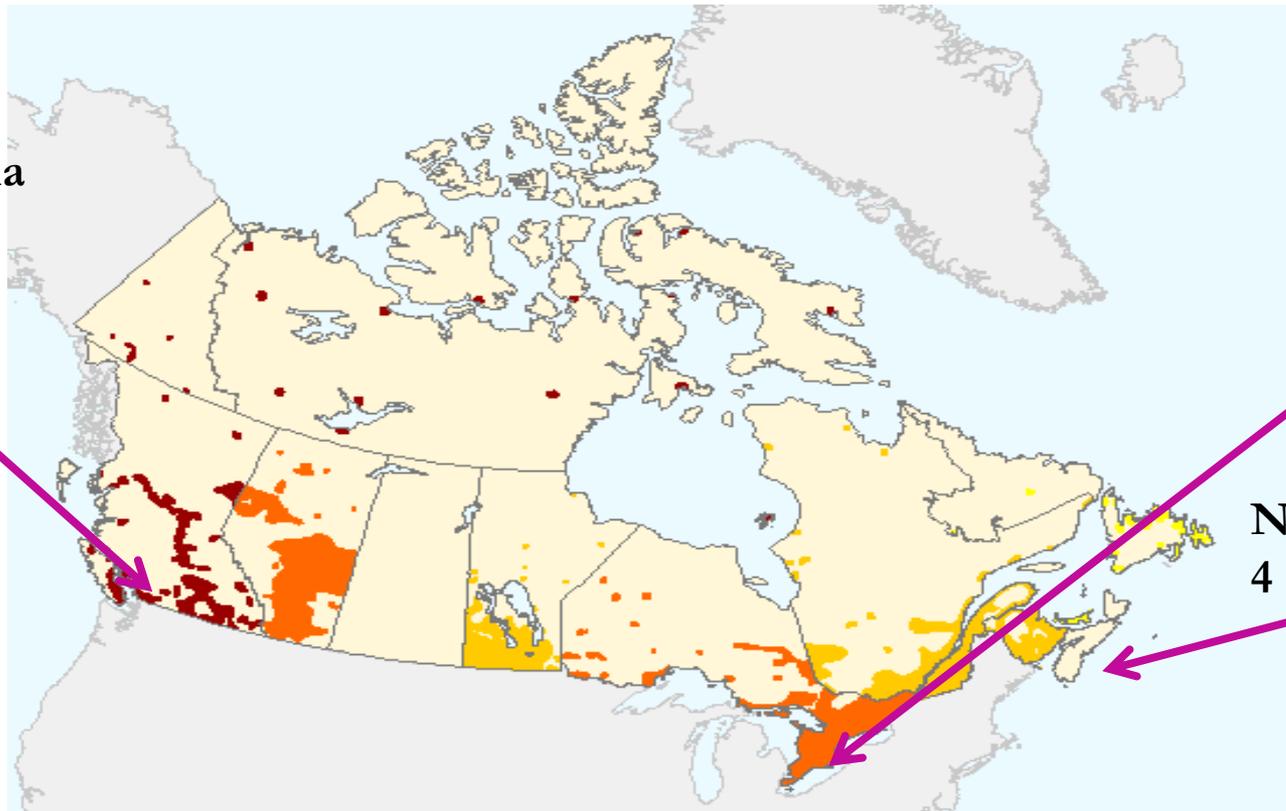
- ▶ 25 females

Hepatitis C Females, All Ages 2004

British Columbia
17 (68%)

Ontario
4 (16%)

Nova Scotia
4 (16%)

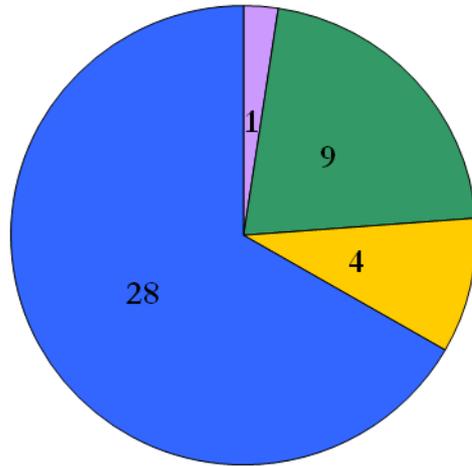


Rate per 100,000

■ 9.51 - < 20.76 ■ 20.76 - < 29.11 ■ 29.11 - < 49.03 ■ 49.03 - 72.47 7

25 Women with HCV at various stages of the lifespan and HCV illness

Age
Mean - 43



■ 21-29 ■ 30-39 ■ 40-49 ■ 50+

Years Since DX

- 1 (4%) - <1 yr
- 6 (24%) - 1-5 yrs
- 7 (28%) - 6-10 yrs
- 9 (36%) - 11-19 yrs
- 2 (8%) - 20+ yrs

Results:

- ▶ Significant variation was noted within participants' experiences which were influenced by:
 - the role of drug use
 - type of services delivered and
 - the context of women's lives.
 - ▶ The women's experience of diagnosis ranged from feeling fully supported to no support (diagnosis provided by letter).
 - ▶ The context of diagnosis often foreshadowed how prepared women were for their results,
 - ▶ The absence of accurate information post-diagnosis magnified the psychological distress that can follow a HCV diagnosis
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Understanding the women's experiences of diagnosis

- ▶ Two interrelated themes:
 - The context of diagnosis
 - Information and health education received at point of diagnosis.
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Context of Diagnosis



Seeking healthcare for “feeling unwell” or “knowing something was wrong.”

- ▶ *I ended up turning really jaundice ... and I was having like pains in my stomach, you know, like my liver was inflamed and stuff. And 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, and um, yeah, and so a week went by and I found out I was HCV positive (diagnosed in 2002)*

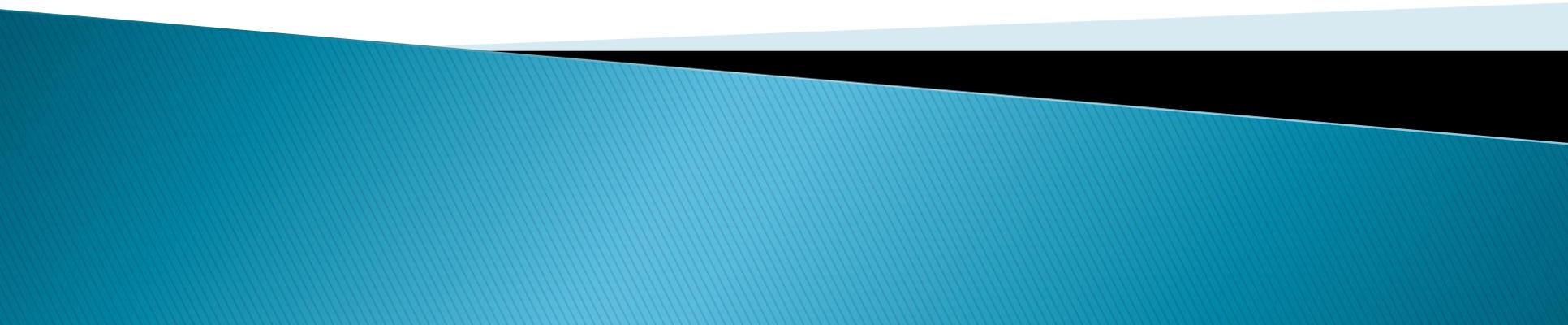
Tested during a routine examination for health insurance application or screening after blood-donations.

- ▶ *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. (diagnosed 2008)*

Women sought testing

- ▶ *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 scott free? (diagnosed 2005)*

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



Limited information given

- ▶ *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 (diagnosed 2007).*

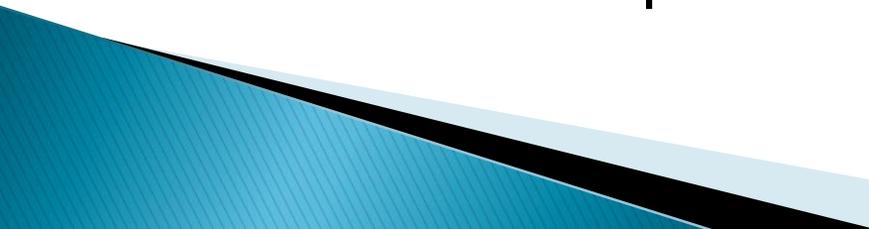
Happy with information

- ▶ *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 (diagnosed 2007).*

Recommendations

- ▶ National guidelines to address the inequalities women are challenged with when diagnosed with HCV
- ▶ Proactive Public Health response
 - *My family doctor being a bit better educated about hepatitis C would have been great because a couple of times when I went there for other, you know I had a cold or whatever and I knew my blood work had to go, too, and she couldn't read the forms but I could and know what they meant, where I was at. ...*

Conclusion

- ▶ Negative experience and inadequate information at diagnosis continues to be a problem affecting women living with HCV
 - ▶ Although our research was undertaken prior to the present major advances of interferon-free HCV treatment, these new treatments alone will not solve the burden of HCV.
 - ▶ Without National guidelines and a proactive public health response that focuses on providing front line management, support, care and referral for specialist treatment, the benefits of the new highly effective therapies will be missed.
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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 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

Any Questions

