THE STREET HEALTH REPORT 2007

ResearchBulletin#1

HOMELESSNESS & HEPATITIS C

NEARLY ONE QUARTER OF HOMELESS PEOPLE IN TORONTO HAVE HEPATITIS C AND FACE MAJOR BARRIERS TO HEALTH CARE

Hepatitis C rates among homeless people in Toronto are 29 times higher than in the Canadian population. In a survey by Street Health of 368 homeless adults in Toronto, nearly one quarter (23%) of homeless people reported having Hepatitis C, compared with 0.8% of the general population[1].

THE HEALTH OF HOMELESS PEOPLE LIVING WITH HEPATITIS C IS EXTREMELY POOR

While it is broadly known that homeless people have much poorer health than the general population, homeless people with Hepatitis C have an even bigger burden of illness.

Homeless people with Hepatitis C experience even higher levels of chronic pain and fatigue than homeless people without Hepatitis C

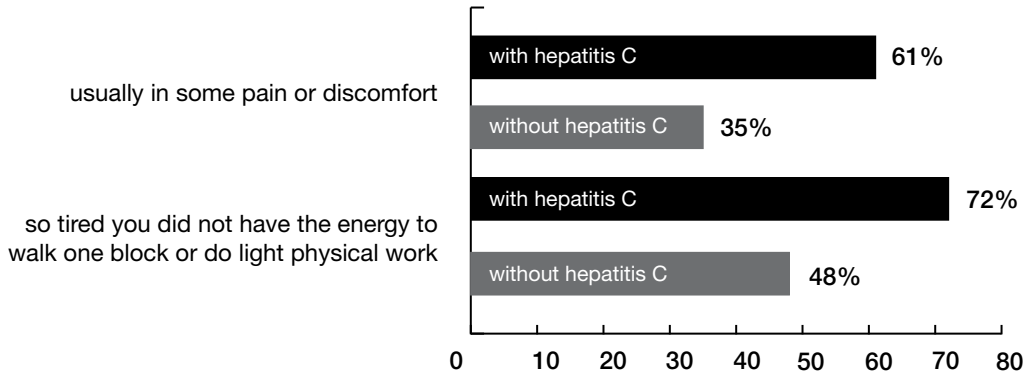
What is Hepatitis C?

Hepatitis C is a virus that attacks the liver and is transmitted through blood-to-blood contact. If not well managed, Hepatitis C can cause serious illness or death. It is the leading cause of liver disease, including cirrhosis and cancer. In Canada, it is estimated that at least 250,000 people are currently infected with Hepatitis C[2]. Currently, there is no vaccine.

While 23% of our sample reported having Hepatitis C, it is likely that this number is much higher. Hepatitis C progresses slowly and most people do not experience symptoms for many years, so they do not even know they are infected. It is estimated that one third of people living with Hepatitis C do not even know that they have the disease[3].

Experiences of chronic pain and fatigue

Homeless people with Hepatitis C compared with homeless people without Hepatitis C



[1] *Remis R, Hogg R, Krahn MD et al. 1998. Estimating the number of blood transfusion recipients infected by hepatitis C virus in Canada, 1960-85 and 1990-92. Ottawa: Health Canada.*

[2] *Public Health Agency of Canada (PHAC). 2008. About Hepatitis C: Virus Information. Ottawa: PHAC. Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/aboutvirus.html.*

[3] *Remis RS. 2004. A Study to Characterize The Epidemiology Of Hepatitis C Infection In Canada, 2002. Final Report. Ottawa: Health Canada.*

Pain and fatigue are symptoms of Hepatitis C, but because these experiences are also common for the general homeless population, many health care providers do not take these symptoms seriously. As a result, for many homeless people, Hepatitis C may not be diagnosed or adequately managed.

Homeless people with Hepatitis C report higher rates of many serious health issues

Key physical and mental health issues

Homeless people with Hepatitis C compared with homeless people without Hepatitis C

	Homeless People with Hepatitis C	Homeless People without Hepatitis C
Arthritis or Rheumatism	60%	38%
Cirrhosis	27%	4%
Suicide attempt in past year	23%	10%
Inactive or latent Tuberculosis	17%	4%
Hepatitis B	13%	1%

It is clear that homeless people with Hepatitis C carry a disproportionate burden of many serious health conditions, in addition to Hepatitis C itself, compared with homeless people without Hepatitis C.

Hepatitis C & HIV: Co-infection

Liver disease is a leading cause of death among people living with both Hepatitis C and HIV/AIDS[4]. Eleven percent (11%) of people with Hepatitis C in our study also reported having HIV/AIDS. Each disease makes the other worse and it is more difficult to treat both simultaneously.

HOMELESS PEOPLE WITH HEPATITIS C FACE MAJOR BARRIERS TO HEALTH CARE

"The hardest part is not having your own place so you can take proper care of yourself."
– Survey Respondent with Hepatitis C

Hepatitis C can be effectively managed and treated. However, homeless people with Hepatitis C face major barriers when attempting to access health care. Even when they are able to access care, the daily reality of homelessness often makes it difficult to follow general medical advice such as getting plenty of rest and eating nutritious food.

Hepatitis C requires careful daily management and lifestyle choices. The treatment for Hepatitis C is demanding and it requires stability and supports. Without stable housing and an adequate income, it can be hard to follow the strict schedule of daily medication, weekly injections and monitoring that Hepatitis C treatment requires for at least six months. It can also be difficult to deal with the side effects of treatment, which can be debilitating and include severe depression, flu-like symptoms and nausea. Many health care providers are unwilling or unable to provide the extensive support that homeless people need.

"As soon as a doctor sees that I am a drug user they discriminate automatically - you can just see the look on their face change."
– Survey Respondent with Hepatitis C

Some of the barriers that homeless people with Hepatitis C face when attempting to access health care include:

- 57% of homeless people with Hepatitis C do not have a family doctor (compared with only 9% of the general population of Toronto[5])
- 33% did not have an Ontario Health Card at the time they were interviewed
- 40% had been refused health care in the past year because they did not have a health card
- 61% said they had been judged unfairly or treated with disrespect by a health care provider in the past year. The most common reasons respondents felt they were discriminated against were because they were homeless (cited by 46%) and because of their use of alcohol or drugs (cited by 45%)

[4] *Salmon-Ceron D et al. Liver disease as a major cause of death among HIV infected patients: role of hepatitis C and B viruses and alcohol. Journal of Hepatology 42(6): 799-805. June 2005.*

[5] *Source: Statistics Canada. Canadian Community Health Survey (CCHS) Cycle 3.1 (2005).*

Management and treatment of Hepatitis C requires adequate housing, income and supports and yet:

- 39% of homeless people with Hepatitis C said they were unable to follow their health care provider's treatment plan at least once in the past 12 months. Of those:
  - 74% said it was because their living situation would not allow it or that it was too difficult to do
  - 25% said the advice or treatment plan cost too much
  - 16% said they had no one to help them carry out the treatment
- Only 29% of people with Hepatitis C were receiving Ontario Disability Support Plan (ODSP) benefits, even though the remaining 71% all felt they should be receiving them

"Sometimes you're stuck eating slop. You don't get vegetables, iron, calcium and stuff. Some of the drop-ins … you don't want to eat their food. Eighty percent of the time my diet consists of hot dog stands. That's gonna catch up with me one of these days."
– Survey Respondent with Hepatitis C

Poor nutrition and lack of sleep exacerbate the effects of Hepatitis C and yet:

- 40% of people with Hepatitis C said they were hungry at least a couple of days per week
- 46% said they get 6 or less hours of sleep each night
- 48% said they had slept outside at some point in the last month

Holistic Hepatitis C Care and Treatment Models in Toronto

With adequate support many homeless people with Hepatitis C can successfully undergo treatment. *The East Toronto Hepatitis C Project* is an innovative, community-based treatment program that has enabled street involved substance users to access Hepatitis C treatment and support.

The East Toronto Hepatitis C Project is a collaboration between South Riverdale Community Health Centre, Regent Park Community Health Centre and Street Health. The project was developed to address the barriers street involved people with Hepatitis C face when trying to access health care. Harm reduction principles guide the project, which consists of weekly group sessions that provide peer support for street-involved people with Hepatitis C as well as access to medical clinics run by interdisciplinary teams of health care providers. In less than two years this small project has helped over 50 street-involved people to access Hepatitis C care and treatment.

HOMELESS PEOPLE WITH HEPATITIS C HAVE POOR ACCESS TO THE HARM REDUCTION SUPPORTS THEY NEED AND WANT

One of the most common ways that Hepatitis C is transmitted is through the sharing of drug-use equipment such as needles, straws and pipes. Although injection drug users are a major risk group for acquiring Hepatitis C, efforts to control the virus have largely ignored this population[6,7].

91% of people with Hepatitis C in our survey reported using at least one illicit drug regularly (three or more times a week) at some point in the past year. Of those, 48% said they had injected drugs in the past year. Despite high rates of drug use and its role in transmission, 36% of regular drug users said they had needed a clean needle or safer crack use kit but had not been able to get one at some point in the past year.

[6] *Edlin BR, Carden MR. 2006. Injection Drug Users: The Overlooked Core of the Hepatitis C Epidemic. Clinical Infectious Diseases. 42(5): 673-676.*

[7] *Edlin BR, Kresina TF, Raymond DB, Carden MR, Gourevitch MN, Rich JD, Cheever LW, Cargill VA. 2005. Overcoming Barriers to Prevention, Care, and Treatment of Hepatitis C in Illicit Drug Users. Clinical Infectious Diseases. 40: S276-285.*

Drugs are often used to help people cope with stress or pain or to feel better about their lives. Ninety-four percent (94%) of homeless people with Hepatitis C said they had used substances in the past year for these reasons. Since many homeless people are unable to access health care and because illegal drugs are often easier for them to obtain than prescription medications, it is likely that many of the people with Hepatitis C in our study are 'self-medicating' themselves.

Harm reduction is a philosophy and model of service delivery aimed at reducing the spread of disease and other harms associated with drug use. This includes needle exchange programs or any other health or social service that does not deny someone access because of drug use. Many of the homeless people with Hepatitis C in our survey said they would be interested in harm reduction programs. Sixty-five percent (65%) of regular drug users said they would use a free harm reduction program and 72% said they would use a safe consumption site.

Robert's Story

Robert had been homeless on and off for fourteen years. Although he was first diagnosed with Hepatitis C in 1997, he did not receive any treatment or health advice for his condition for another ten years. This was partly because Robert's doctor did not communicate to him the urgency of the virus, merely referring to his condition as "dirty blood". It wasn't until his health began to dramatically deteriorate that he finally decided to seek help.

Robert first heard about the *East Toronto Hepatitis C Project* support group (described on page 3) through his family doctor at Regent Park Community Health Centre. It was through the group that he learned that there was help for Hepatitis C and that it could be treated without total abstinence from substance use. At the support group Robert also learned more about the disease, including information about transmission and dietary concerns. With the support of the group and access to non-judgmental health care services, Robert was able to complete a year-long course of treatment and has successfully cleared the virus.

A Silent Epidemic: A Crisis Without Support

Studies suggest that the mortality and health care costs from complications of chronic Hepatitis C will increase dramatically over the next 10 to 20 years[8,9] . Hepatitis C costs the healthcare system about $500 million annually to care for those currently infected and it has been estimated that this will soon double to $1 billion by 2010[10].

Despite these facts, Hepatitis C prevention, education, research and support programs in Canada are very limited. Funding for community-based programs aimed at reaching high-risk populations has been unstable and short-term.

[8] *Davis GL, Albright JE, Cook S, Rosenberg D. 1998. Projecting the future healthcare burden from hepatitis C in the United States. Hepatology. 28: Suppl:390A. Abstract.*

[9] *Wong JB, McQuillan GM, McHutchison JG, Poynard T. 2000. Estimating future hepatitis C morbidity, mortality, and costs in the United States. American Journal of Public Health. 90:1562-9.*

[10] *Canadian Hepatitis C Information Centre. 2005. Responding to the Epidemic: Recommendations for a Canadian Hepatitis C Strategy. Ottawa. Available at: www.hepc.cpha.ca.*

SOLUTIONS

"I would like to get help for Hep C and housing."

– Survey Respondent with Hepatitis C

Hepatitis C is a serious health issue that affects a disproportionate amount of homeless people. Research has found that Hepatitis C treatment for marginalized populations can be effective[11-12]. With access to quality health care, sufficient harm reduction programs, adequate housing and income, Hepatitis C can be successfully managed, treated and prevented.

The Federal Government of Canada has a stewardship role to play in ensuring that a comprehensive strategy is developed and adequate resources are allocated to prevent and address Hepatitis C among homeless and street-involved people.

IMPROVE ACCESS TO AND QUALITY OF HEPATITIS C TREATMENT AND CARE

Testing

Currently, no guidelines exist for counselling people who are going through testing for Hepatitis C. Many people only receive a single preliminary antibody screening test for Hepatitis C which does not provide adequate information for a diagnosis or treatment options. The only way to accurately determine active Hepatitis C infection and fully understand the disease prognosis for each individual is through a more sensitive, second stage RNA test. RNA tests detect the actual presence of the Hepatitis C virus in the blood, not just the presence of Hepatitis C antibodies. Proper testing and counselling are essential to ensuring that people have an accurate understanding of their condition and treatment options.

Recommendation 1: Ontario Ministry of Health and Long-Term Care should develop better guidelines for health care providers to ensure that everyone who is at high risk for Hepatitis C receives adequate screening, second stage testing and counselling about their condition and treatment options. These efforts must be specifically targeted to marginalized groups like homeless people.

Recommendation 2: Toronto Public Health should expand the number of Hepatitis C testing sites it offers for homeless and street-involved individuals and expand these services to offer second stage testing.

Treatment and Care

All people with Hepatitis C, regardless of income, need access to a full spectrum of health services, from specialist care to nutrition advice to pain management. However, high rates of substance use and discrimination by health care providers on the basis of substance use among homeless people with Hepatitis C indicates the need for harm reduction models of health care. Homeless people with Hepatitis C also have multiple health issues. Treatment for homeless and street-involved people with Hepatitis C needs to be holistic and flexible so that it can address a myriad of health issues, as well as underlying social determinants, such as inadequate income and housing. Many homeless people find it difficult to replace and maintain their identification and often have competing survival priorities that make it difficult to follow strict appointment schedules. For these reasons, if health care models are to be accessible to homeless people, they must have minimal health card and identification requirements, as well as unscheduled walk-in hours.

[11] *Backmund M, Meyer K, von Zielonka M, Eichenlaub D. 2001. Treatment of hepatitis C infection in injection drug users. Hepatology. 34(1):188-193.*

[12] *Sylvestre D, Loftis J, Hauser P, Genser S, Cesari H, Borek N et al. 2004. Co-occurring hepatitis C, substance use, and psychiatric illness: Treatment issues and developing integrated models of care. Journal of Urban Health. 81(4):719-734.*

Recommendation 3: Ontario Ministry of Health and Long-Term Care and Ontario Local Health Integration Networks should adequately fund and expand comprehensive, multidisciplinary, low-barrier models of health care, such as Community Health Centres, where homeless people are able to access Hepatitis C focused specialists, physicians, nurses, dentists, nutritionists, psychiatrists, social workers, harm reduction workers and receive referrals to other services.

Community-based supports

Community-based agencies are often better positioned to connect with 'hard to reach' groups than health care providers in hospitals or office-based family physicians. Many are already working with populations at risk for Hepatitis C. Beyond testing and medical care, homeless people with Hepatitis C often need counselling and other social supports. Community-based support workers can provide counselling, education and case management to people living with Hepatitis C and those at risk, if adequately resourced.

Recommendation 4: Ontario Ministry of Health and Long-Term Care and Ontario Local Health Integration Networks should fund community-based agencies that outreach to homeless and street-involved populations to support people living with Hepatitis C and those at risk to deliver education, support and prevention services.

Education and training for health care and social service providers

Most health care and social service providers are not adequately informed about Hepatitis C and are unable to provide the advice, support and information that people diagnosed with this serious infectious disease require. Sensitizing service providers regarding the stigma around Hepatitis C and substance use would eliminate a significant barrier to treatment.

Recommendation 5: Public Health Agency of Canada, Ontario Ministry of Health and Long-Term Care and Ontario Local Health Integration Networks should ensure mandatory Hepatitis C education and training for health care and other service providers. This includes not only physicians but also nurses, people working in addictions and mental health, corrections staff, and health care and social service providers at community-based organizations.

Recommendation 6: Ontario Ministry of Health and Long-Term Care should develop a system of Hepatitis C clinical mentorship programs for health care providers, consisting of practical training and consultation, similar to those that already exist for HIV.

EXPAND HEPATITIS C PREVENTION STRATEGIES

Hepatitis C is 100% preventable but current prevention efforts need to be increased, especially among high risk groups. To ensure accessibility, prevention strategies need to be based on harm reduction principles and involve peer support and education in their design and delivery. Many harm reduction programs, such as needle exchanges, are unable to provide adequate resources or service hours due to lack of funding. There is also a shortage of addiction treatment options, such as detox and residential treatment programs, available in Toronto.

Recommendation 7: Public health authorities at all levels of government, Ontario Ministry of Health and Long-Term Care and Ontario Local Health Integration Networks should expand community-based harm reduction programs so that they are adequately resourced to provide safer drug use supplies and information about Hepatitis C transmission, through outreach and support. This should include specific funding for the involvement of peers in the development and delivery of Hepatitis C education and harm reduction programs.

Recommendation 8: Public Health Agency of Canada and Ontario Ministry of Health and Long-Term Care should collaborate with correctional service authorities at both levels of government to ensure that harm reduction programs are available in all correctional facilities.

Recommendation 9: Ontario Ministry of Health and Long-Term Care and Ontario Local Health Integration Networks should provide funding for more detox beds and residential treatment programs to support people with addictions.

INCREASE THE AVAILABILITY OF AFFORDABLE AND SUPPORTIVE HOUSING

People need adequate and affordable housing in order to stabilize their lives, manage their Hepatitis C, undergo treatment, prevent re-infection and stay healthy.

Recommendation 10: All levels of government should provide adequate funding with sufficient flexibility for municipalities to administer and fund community-based, non-profit housing and to develop comprehensive supportive housing strategies. This includes housing designed to accommodate individuals with physical and mental health needs, as well as harm reduction housing which supports people with alcohol and other substance use issues.

IMPROVE ACCESS TO ONTARIO DISABILITY SUPPORT PROGRAM (ODSP) BENEFITS AND INCREASE RATES

People need adequate incomes in order to manage their Hepatitis C, undergo treatment and remain healthy. Currently, Ontario Disability Support Program (ODSP) benefits provide enough income for most people to maintain some form of stable housing, yet homeless people face many barriers to accessing these benefits[13]. In addition, ODSP benefits are far from adequate in that they do not reflect the real cost of living.

Recommendation 11: The Ontario Disability Support Program should recognize that people with Hepatitis C are eligible and should be fast-tracked for ODSP when: a) they are undergoing treatment and/or b) the disease progression has led to debilitating complications. In addition, the ODSP decision-making process should be streamlined to further reduce wait times and improve quality of service, and community-based supports should be provided to assist ODSP applicants in navigating the application process.

Recommendation 12: Ontario Ministry of Community and Social Services should raise benefit levels for ODSP to reflect a minimum standard of living, and index and adjust rates annually to meet this minimum standard.

[13] *Street Health. 2006. Failing the Homeless: Barriers to the Ontario Disability Support Program for Homeless People with Disabilities. Toronto: Street Health. Available at: www.streethealth.ca.*

The Street Health Report 2007

The findings in this bulletin are from a research study conducted in the winter of 2006/2007 by Street Health on the health status and access to health care of homeless people in Toronto.

A representative, random sample of 368 homeless adults were surveyed about their health and access to health care at 26 different shelters and meal programs across downtown Toronto.

The *Street Health Report 2007* provides a comprehensive overview of the physical and mental health, well-being, access to health care, and daily realities of homeless people in Toronto. The study found that the health and access to health care of homeless people is very poor and has gotten worse over the past fifteen years.

This study was conducted by Street Health in partnership with the Wellesley Institute.

A copy of the *Street Health Report 2007* is available at www.streethealth.ca.

About Survey Respondents

In total, we surveyed 83 people who reported having Hepatitis C. The average age of people was 43 years with an age range of 23 to 58 years.

- 71% identified as male
- 27% identified as female
- 1% identified as transgender

Homeless people with Hepatitis C had been homeless an average of 8 years, compared with 3.8 years for homeless people without Hepatitis C.

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Who Is Street Health?

Street Health is an innovative, community-based health care organization providing services to address a wide range of physical, mental, and emotional needs in those who are homeless, poor and socially marginalized in Toronto.

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Copies of this bulletin and related documents can be downloaded from our website.

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