

Hepatitis C Needs Assessment Final Report

June 2006

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Funded by:



Public Health Agence de santé
Agency of Canada publique du Canada

Canada

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ACKNOWLEDGEMENTS

The Social Planning and Research Council of Hamilton and the Hamilton Hepatitis C Network gratefully acknowledge the financial support of the Public Health Agency of Canada.

Thank you to the individuals living with Hepatitis C for braving the stigma and discrimination that surrounds HCV, for telling your stories and for bringing HCV out of the shadows and into the light.

Many thanks to the local service providers who participated in the needs assessment survey and focus groups. Your feedback has shed considerable light on HCV service priorities in Hamilton.

The following organizations and individuals were instrumental in recruiting individuals to participate in the focus groups:

John Street Clinic, Kim Gustafson, Sheila Martinez, Dr. Page
Public Health-Alcohol, Drug and Gambling Services, Karen Demaline, Debbie Christie
Salvation Army Booth Centre, Jackie Pilon
City of Hamilton Public Health, Suzanne Newmark

Thank you for your time, trust and commitment to HCV prevention and education.

Thanks to Ivy Morton, volunteer with the SPRC for her contributions of time and expertise in SPSS survey analysis.

Thanks also to Sally Quider for administrative support on this project.

Special thanks also to the members of the Hamilton Hepatitis C Network for their suggestions and support of this research. Members include:

Aboriginal Health Centre
Canadian Liver Foundation
City of Hamilton, Public Health, Alcohol, Drug and Gambling Services
City of Hamilton, Public Health, Infectious Diseases Team
Hamilton Urban Core Community Health Centre
Hepatitis C Society of Canada
Marie Stewart Cormier, Nurse
Shirley Alexander, representative from Dr. Witt-Sullivan's office
The AIDS Network
The VAN Needle Exchange
Wanda Green

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1.0 INTRODUCTION

1.1 Background on Hepatitis C

Hepatitis C is a liver disease caused by the hepatitis C virus (HCV). It is a complex disease to prevent, monitor and treat,¹ and presently there is no vaccine for HCV. Public awareness about HCV is lacking and stigma surrounds the disease in a climate where little public knowledge about transmission and prevention exists. In Canada an estimated 250,000 people are currently infected with HCV and one third of those with HCV do not know they have it.²

HCV is transmitted through blood to blood contact with infected individuals. Such contact most often occurs in the following situations: sharing of any blood contaminated equipment including those used for drug injection/snorting/smoking, and any equipment used for piercing, tattooing, nail care, electrolysis, shaving, acupuncture; receiving blood or blood products where HCV is present; sexual activities where blood is present; needle stick injuries and vertical transmission (during childbirth).³ "To avoid HCV infection, people must be aware of HCV and its routes of transmission; however, their ability to translate that knowledge into practice is strongly related to environmental and social factors (also known as determinants of health).⁴ Presently, injection drug use constitutes nearly two-thirds of new HCV infections;⁵ consequently prevention strategies from a harm reduction perspective are being and have been introduced to reduce the spread of HCV among the target population of people who use drugs.

HCV is a progressive disease that affects people differently. Many people with HCV have no symptoms and feel healthy; (one reason many people living with HCV can have it and not know). Others may feel extremely unwell and experience: abdominal and joint pain, jaundice, nausea and loss of appetite, unbearable itching, lassitude (fatigue/weakness caused by loss of energy) and difficulty with concentration and memory. Chronic hepatitis C may develop into cirrhosis, irreversible and potentially fatal scarring of the liver.⁶

While there is no treatment that will work for every single person, hepatitis C can be managed in a number of ways. A healthy lifestyle including: nutritious diet, exercise, and the incorporation of harm reduction principles (ideally avoiding if not reducing alcohol and/or drug intake) is promoted as the least invasive way to maintain health and minimize damage to the liver. It is also highly recommended that people with HCV get immunized against hepatitis A and B. Treatment using antiviral drugs exists and subsidies are available to mitigate high treatment costs. However, treatment can be difficult and stressful due to side effects such as nausea and depression. Decisions about undergoing treatment are complex and must take into account many factors. Generally treatment is not given to people that continue to drink alcohol in large amounts, and people that continue to use injection drugs.

¹ Canadian Public Health Agency, *Responding to the Epidemic: Recommendations for a Canadian Hepatitis C Strategy*. 5 (Ottawa: Health Canada: 2005) Available at www.hepc.cpha.ca

² Ibid 3

³ Ibid 4

⁴ Ibid 4

⁵ Alter MJ in Twerell et al. 2006. HCV Advocate Medical Writers Circle, *Stigma: Hepatitis C and Drug Abuse*. 1. Available at www.hcvadvocate.org

⁶ Canadian Liver Foundation, *Hepatitis C: A Liver Disease*. Pamphlet (Toronto: 2003)

1.2 Needs Assessment Background

In 2001-2002 with funding from Health Canada the Social Planning and Research Council of Hamilton conducted a needs assessment to learn about the service issues and needs of people infected and affected (friends and family) by hepatitis C in Hamilton. The findings of that research indicated a lack of targeted prevention strategies to curtail HCV in Hamilton and a significant lack of training and information about HCV among the general public and service providers, including health care workers. The Hamilton Hepatitis C Network was borne from the recommendation that a multi-stakeholder community-based network be established to enhance Hamilton's capacity to provide a sustainable response to the challenges posed by HCV in its communities.

Since 2002, the Hamilton Hepatitis C Network has been involved in a number of prevention and awareness raising activities; from leading public forums about HCV to creating and disseminating educative pamphlets to local organizations, to initiating the development of peer run HCV support groups.

The needs assessment was updated in 2006 to determine the service needs, (informational, supportive, medical) of people living with hepatitis C in Hamilton in order to help the network prioritize future actions and activities accordingly. The purpose of this report is to make those findings available to: Hamilton Hepatitis C Network members, community services providers who work with HCV target populations, and to everyone interested in HCV prevention and education.

2.0 INVENTORY OF HCV SERVICES IN HAMILTON

Presently there is no single point from which to access information about HCV services in Hamilton. As such HCV services (from informational to medical) are somewhat fragmented as is awareness of such services. The following list was developed as a resource in effort to consolidate HCV services located in Hamilton and to demonstrate what services currently exist.

This inventory list was developed by using a variety of research strategies including: keyword searches of the "Inform Hamilton" database, key informant interviews with service providers, and by talking with people living with HCV. This list represents our best effort to include all existing HCV services in Hamilton.

There are a handful of organizations that are primarily mandated to provide hepatitis C services in Hamilton. A number of organizations are not mandated to provide HCV services but do so out of a response to clients needs. Here's what exists:

2.1 Public Awareness and Prevention Services

- Hamilton Hepatitis C Network: a partnership of community agencies and community members committed to developing the capacity of the local community to respond in a healthy manner to the many health and social issues faced by those living with, at risk of or affected by hepatitis C.
- Hepatitis C Society of Canada: a non-profit, national voluntary health organization that fights hepatitis C through prevention, early detection, support, appropriate treatment and comfort.
- The AIDS Network: Though not specifically mandated to do so the AIDS Network Serving Hamilton, Halton, Haldimand, Norfolk and Brant provides information and support services to individuals co-infected with HCV and HIV/AIDS.
- The VAN Needle Exchange Program: an HIV harm reduction program which offers free Hepatitis B Vaccine, HIV Anonymous testing, pregnancy testing, condoms, needles (for exchange) pregnancy tests, counselling and referrals. The City of Hamilton's Public Health Services works collaboratively with the Hamilton AIDS Network, Wesley Urban Ministries and a coalition of community based agencies to provide this service. The Van Needle Exchange Program has two components:
 - Mobile Van Program: a mobile van that operates Mon - Fri from 8:00pm - midnight;
 - Street Health Centre (fixed site): Sexual health information and related services are provided by a Public Health Nurse (e.g. Anonymous HIV testing, Hepatitis B vaccine, condoms, needle exchange); referrals. There is an addictions counsellor on staff Wednesday evening and Friday afternoon.

- City of Hamilton, Alcohol, Drug and Gambling Services: ADGS provides needle free needle exchange and distribution of condoms during regular office hours. This service is private and confidential. Harm reduction information is available.
- Mental Health/Outreach Team: There are 3 components to the Team. The first is a case management service that provides assistance to individuals who are living with a serious mental illness and focuses on increasing independence and participation in community life. The second is an outreach service where staff work to engage individuals living with a mental illnesses and who are homeless. The harm reduction service promotes harm reduction practices to individuals who are using injection drugs. All three components of the program assist their clients in accessing health, housing and social supports. The Team includes staff from diverse backgrounds such as nursing, social work, clergy, housing and harm reduction. The Team works closely with the staff from the Van Needle Exchange Program. Services are available Monday to Friday from 8:30 am to 9 pm and referrals are made through Intake at 905-528-0683.

2.2 Screening and Referral Services

- De dwa da dehs nye>s (Aboriginal Health Centre): Provides Aboriginal specific services including a full complement of primary care services which can include HCV screening, testing, diagnosis, referral, immunization and specific health promotion information.
 - Off-site services at the Living Rock: To assist street involved youth with screening, testing, diagnosis, referral and immunization services, (Wednesday and Thursday)*
- Methadone Maintenance Clinics: The Ontario College of Physicians and Surgeons has "Methadone Maintenance Guidelines" that recommend HCV testing among patients considered 'high risk' for HCV. Although these guidelines are not mandatory several methadone maintenance clinics in Hamilton routinely screen their client's blood for HCV and act as family doctors to people without primary health care. Acting in the capacity of family physician, doctors at some methadone clinics also make referrals, connecting people living with HCV to medical specialists (hepatologists, etc).
- City of Hamilton, Infectious Disease Program of Public Health Services: Perform surveillance role involving the collection of pertinent surveillance data for all reported cases of HCV, identification of common modes of exposure, and disseminate HCV data to community physicians in a monthly report with other reportable diseases data. Perform case management: ensuring clients are aware of diagnosis, notifying Canadian Blood Services of client blood transfusions/donation occurrences, promoting and supplying hepatitis A and B vaccines. The Infectious Diseases Program also provides education information to clients and the public and participates in community networks and other initiatives which support clients and assist in prevention.

2.3 Medical and Treatment Services

- Family Physicians: The family physician is often the first medical contact for someone newly diagnosed with HCV. Unless privy to specific training in the management of hepatitis treatment, (which is complex) family doctors are not qualified to provide treatment but can and do make referrals to specialists.
- Special Immunology Services, Hamilton Health Sciences, McMaster University Medical Centre: serves HIV positive patients and patients co-infected with HIV and Hepatitis C.
- Specialists: There is presently one hepatologists (liver specialist) in Hamilton who treats people living with HCV. However, Hamilton's HCV-positive population is also served by infectious disease specialists, internists and gastroenterologists from each of the major urban health care centres in Hamilton.

2.4 Support Services

At the time this research was conducted no HCV specific support services existed in Hamilton for people living with HCV and their loved ones.

METHODOLOGY 3.0

In order to learn more about the service needs of individuals living with Hepatitis C in the Hamilton area information was collected using a written survey and by conducting focus groups. Copies of the survey and accompanying letter can be found in Appendix A. The questioning routes used in service consumer and service provider focus groups are located in Appendix B and C respectively.

3.1 Survey

In order to compare baseline information about HCV-related service issues obtained in the 2001 needs assessment survey the 2001 survey was replicated for the 2006 needs assessment. The survey consists of 8 statement sets and required the respondent to use a likert scale of 1 to 5 indicating their level of agreement or disagreement with the statements made. At the end of the survey there is space and instructions inviting further comments about the needs for HCV services and/or support in Hamilton.

On Dec. 19th, 2005 a search was performed using the Inform Hamilton database in order to identify organizations that provide services to individuals living with HCV or at risk for HCV in Hamilton. A short list of search terms was developed in accordance with a strategy intended to identify organizations that provide services to target populations identified by the 2001-2002 needs assessment. The following search terms: "Hepatitis C", "Addiction", "Injection Drug Use", "IDU", "Disease Prevention", "Aboriginal", and "Shelter" were entered into the database and yielded descriptions of 104 service organizations. The list was scanned and narrowed to 53 organizations: by excluding duplicates (organizations found by more than one search term), and focusing on organizations that provide front-line services. A list of these organizations can be found in Appendix D.

The survey package, including self addressed postage paid envelopes were sent out by mail on December 29th, 2005 and respondents were asked to return the survey either by fax or mail by January 31st, 2006. 18 surveys were returned representing a response rate of 34%. SPSS software was used to analyze the data which is presented in the results section of the report.

3.2 Focus Groups with Consumers

From the time period of January 26th, 2006 to February 28th, 2006 4 focus groups were scheduled with people living with HCV. A total of 11 participants, 5 women and 6 men attended one focus group each held at one of the following locations: Wesley Centre Chapel, John St. Clinic (a methadone clinic), Public Health—Alcohol, Drug and Gambling Services, Salvation Army Booth Centre Men's Residence.

Focus groups were held at organizations in the community where some people living with HCV access services and at organizations where staff expressed an interest, willingness and ability to provide space and assist in the recruitment process by taping into pre-existing networks of established

trust between service providers and clients. Posters advertising the focus groups were posted within each hosting organization 2 weeks prior to the focus group events. Each participant was given 4 bus tickets as an incentive and in exchange for their time and contributions and nutritious refreshments were provided at each event. The moderator assured the participants of confidentiality and requested fellow participants to hold the contents of the discussion in confidence.

3.3 Focus Group with Service Providers

On March 3rd, 2006 a 2 hour focus group with service providers was held at the SPRC. 8 individuals representing 7 different stakeholder organizations attended. Types of organizations represented included: law enforcement—drug squad, sexual health clinic, public health, multi-service organization for men experiencing homelessness, outreach worker, shelter for women experiencing homelessness and a methadone clinic. An electronic flyer advertising and inviting participation in the service provider focus group was distributed through the Hamilton Hepatitis C Network contact list. Interested individuals were instructed to pre-register for the event by phone.

3.4 Research Limitations

The sample size used in these focus groups was small and was not totally representative of the heterogeneous population living with HCV. None of the participants in the focus groups with people living with HCV had received treatment for HCV thus the sample used in these focus groups does not reflect perspectives from people living with HCV who have had treatment. Similarly, due to time and resource constraints only one focus group was done with service providers, of whom all were women. While worth mention, it is impossible to determine the impact of this gender imbalance on research findings.

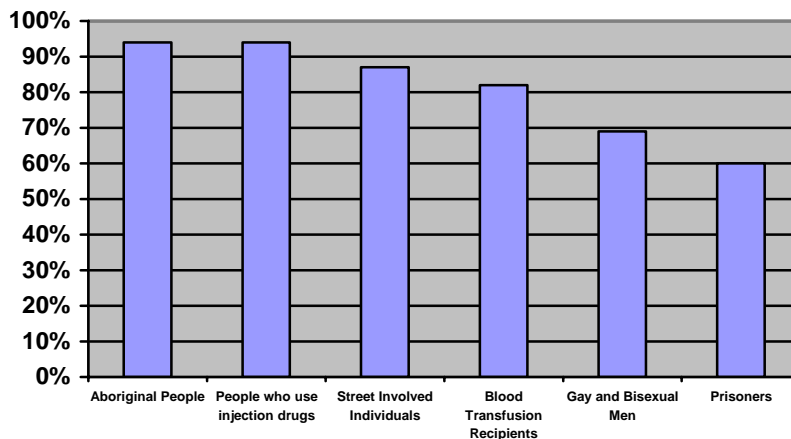
Efforts were made to connect with people who have undergone treatment by advertising the focus groups at places where people with HCV might access health care. Flyers were disseminated to: Special Immunology Services at McMaster University Medical Centre, North Hamilton Community Health Centre, Planned Parenthood Society of Hamilton Sexual Health Awareness Centre, Locke Street Walk In Clinic, Mountain Walk In and After Hours Clinic. The flyer invited participation in a focus group March 3rd and required interested persons to pre-register for the event by phone. No one responded to the request for participation. Due to time constraints no further focus groups were conducted.

RESULTS 4.0

4.1 Survey

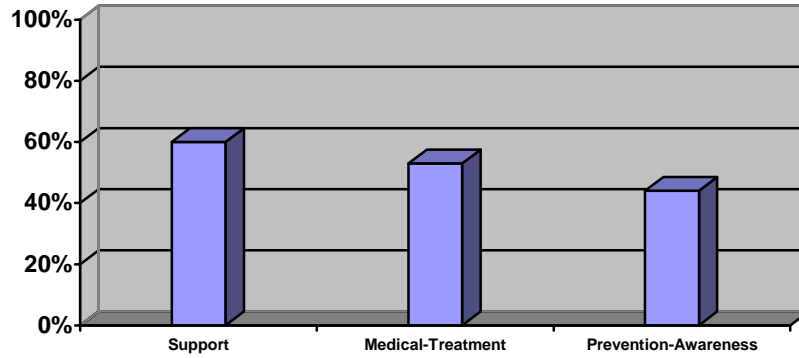
The Hamilton Hepatitis C Network community needs assessment survey was disseminated to 53 local social service organizations, 18 surveys were returned yielding a response rate of 34%. The findings of the survey are presented below and the survey tool itself can be found in Appendix A. Responses to the eight survey statement sets are listed below in the same sequential order as they appeared on the survey. Where possible, data is presented in chart form.

- HCV is a priority for their organizations:**
 - 70% of respondents agreed or strongly agreed that HCV is a priority for the organizations they represent.
- In my organization, we provide services that:**
 - 70% agreed that their organization provides support services
 - 53% disagreed or strongly disagreed that their organization provides medical services
 - 53% disagreed or strongly disagreed that their organization provides services that address the awareness/prevention in the community
- Where HCV is concerned, my organization regularly provides services to:**

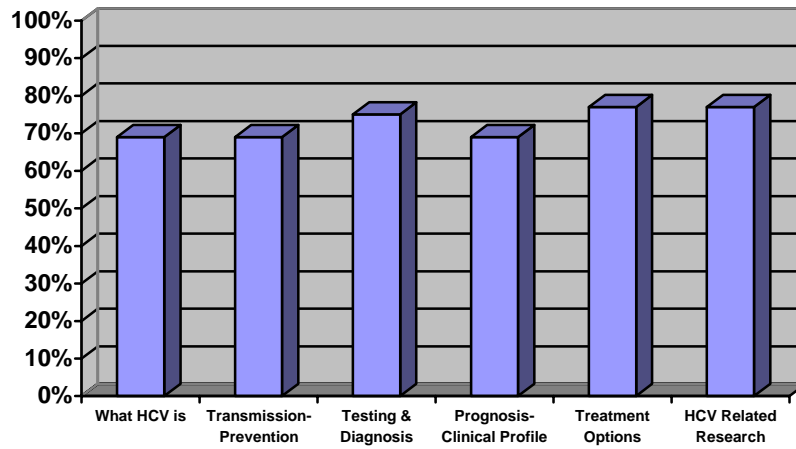


- In Hamilton I am familiar with:**
 - 72% agreed they are familiar with support services that address the impact of HCV on individuals
 - 67% agreed that they are familiar with education/prevention services related to HCV
 - 53% disagreed that they are familiar with medical/clinical services that specifically address HCV

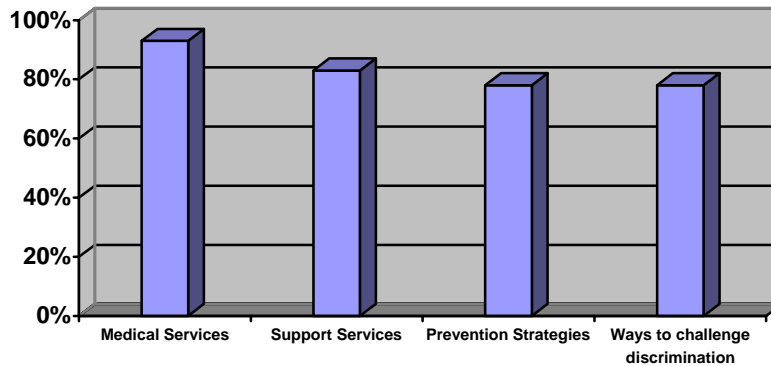
5. In the Hamilton area, there are adequate services to meet _____ needs:



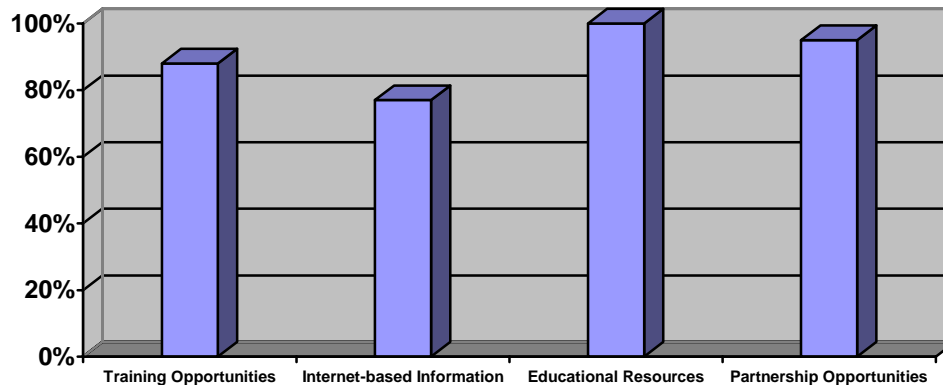
6. I would benefit from learning more about:



7. In the Hamilton area, I need more information about:



8. To improve HCV-related services in my organization, I would take advantage of:



4.2 Survey Key Findings

The questionnaire survey tool revealed some patterns regarding HCV service provision in Hamilton. Hepatitis C is a priority for the majority of organizations surveyed. Respondents to the survey indicated that there is a lack of services in Hamilton to respond to the informational, medical and support needs of people living with HCV. The survey also found that service providers are familiar with HCV support, education and prevention services available locally but are less familiar with medical or clinical services. The majority of respondents identified "Medical Services" as the topic they require more information about and identified HCV treatment, testing and research as areas they would benefit from learning more about. The clear indication was that service providers lack knowledge and want to learn more about treatment options for HCV. These findings seem to suggest a disconnect between hospital based medical services and social services highlighting the need for increased awareness and collaboration between these two stakeholder groups.

More than half of those surveyed indicated that there are inadequate services to meet the support needs of people living with HCV. A large percentage of respondents agreed that they provide support services to people living with HCV, and that they are familiar with support services that address the impact of HCV on individuals yet there is no organization that provides HCV-specific support services in Hamilton. Though difficult to draw definitive conclusions, these findings suggest that individuals living with HCV are getting their support needs met by local social service and community based organizations that are not specifically mandated to do so but may be responding to clients needs.

4.3 Focus Groups

The following section identifies themes that emerged repeatedly throughout the focus groups with service providers and consumers. Themes are identified under two broad categories, 1.) Using services, and 2.) Providing services. The themes are in bold print with the number of times a theme was mentioned in parentheses and are presented from highest to lowest in terms of frequency. Examples from the focus groups are included for clarity and a summary of the responses are in paragraph form below.

4.4 Focus Groups Using Services

4.4.1 Stigma and Discrimination (31)

- "people think if you're putting needles in your arm you deserve it"
- "the public perception of HCV is that there are 2 groups who get it, addicts and people who've received blood transfusions prior to 1991"
- people are reluctant to access hospital emergency and health care because they "get treated like dirt"

Stigma and discrimination were the most prevalent topics discussed in each of the focus groups. Participants spoke about society's fear and ignorance of HCV and the public perception of HCV as an "addicts" disease. Stigma impacts HCV infected people regardless of how they actually contracted the virus; as the assumption is that unless contracted via tainted blood and blood products the individual living with HCV is to blame for contracting the disease and has done so because of some poor choice of their own. People living with HCV who use drugs are discriminated against doubly, on the basis of their drug use and their HCV status. The stigma(s) of living with HCV can also be compounded by racism and classism. The stigmas that surround HCV and drug use are barriers that prevent some people living with HCV from accessing services such as health care and needle exchange programs.

4.4.2 Multiple Life Challenges (21)

- "I find it hard to hold onto money throughout the month, at the beginning I can eat healthy..."
- dual diagnosis: mental illness/mental health issues, lack the ability to follow through (with disease management, attending appointments)

All of the participants spoke about multiple life challenges that make living with HCV and managing the disease difficult. Homelessness, addiction, poverty, lack of food security, mental health issues, and concurrent health concerns pose additional challenges to living well with the disease and are often experienced interconnectedly. Multiple life challenges can prevent individuals from following through with health care appointments, from accessing health care in the first place and from having access to the fresh fruits and vegetables recommended to keep the liver healthy. Several participants also noted that when confronted with multiple life challenges HCV may take a back seat to more pressing issues or needs; this is particularly the case for individuals who are asymptomatic (not experiencing symptoms).

4.4.3 Inadequate Health Care (20)

- "there's not much anyone can do about it," but more doctors. Waiting lists presently 10 months to 1 year to see specialist
- my doctor told me I have Hep C, that's it nothing else...doctor hasn't talked about it since
- many women know they have HCV but have no doctor

Many participants in both provider and consumer focus groups mentioned a variety of factors that contribute to inadequate health care experienced by people living with HCV. One of the major concerns was that many family doctor's and general practitioner's lack knowledge about Hepatitis C and are thus unable to provide accurate disease management and treatment information to people living with the disease; yet many participants suggest that they perceive physicians as one of their few sources for information about the disease. A lack of understanding of addictions issues and HCV among health care providers was another factor felt to contribute to the experience of inadequate health care. The lack of specialists, lengthy waiting lists and referral process were other factors identified as hindering access to adequate health care.

4.4.4 Lack of general HCV information (20)

- "not too much; there's not too much that's available"
- "I hit brick walls when I go looking"
- "The only place I have is what my doctor knows"
- "I know how to research but I only get a little dab here and there"

The prevalent feeling was that there is a lack of general HCV information available in Hamilton. Many individuals who participated in the focus groups came to the focus groups looking for information about the disease. Several participants stated that they know of no sources of information related to Hepatitis C available in Hamilton. A few participants identified health care facilities (hospitals, doctor's offices, psychiatrist offices) as the venues where they expect general information about HCV to be made available. Pamphlets and posters were most often suggested as the mediums through which people wanted to receive information and several participants mentioned having seen advertisements on television for Hepatitis A and B vaccines suggesting that television may be an effective medium for disseminating information.

4.4.5 HCV Symptoms (13)

- fatigue is an issue—no house work gets done...tired, mood swings, depression, stress..."there is no life"
- symptoms motivated participant to go to doctor and use internet to find out Information about the disease

Many individuals living with HCV suffer from symptoms of the disease that make activities of daily living difficult. For many, fatigue is a significant issue that hinders the accomplishment of routine tasks, limits social interactions, and can limit one's capacity to effectively manage the disease. Each person's experiences with HCV symptoms are unique; some people live without symptoms for many years, others are plagued by symptoms from the onset of their disease. The presence of symptoms tends to be a factor that influences decisions to seek medical attention for HCV.

4.4.6 Inadequate Disease Management Information (12)

- I don't know what to eat, or about exercise, what medications not to take or mix together

- “all I know is not to drink alcohol—that’s all I know and I looked on the internet”

Many people living with HCV lack the information they need to effectively manage living with the disease; including information related to harm reduction, diet, nutrition, exercise and medication management. Aside from treatment many steps can be taken to promote feeling healthy and minimizing the effect of symptoms while living with the disease. Without access to this information people living with HCV are not empowered to make lifestyle decisions that can impact their health. Many participants wanted information about transmission and prevention and expressed a strong desire to want to protect others from getting HCV.

4.5 Focus Groups—Providing Service

4.5.1 Working Well (16)

- VAN will bring clean needles to your home
- good bedside manner from doctor, shows concern, gives honest perspective using simple terms
- the John St. Clinic makes referrals and acts as family physician to some clients who don't have doctors

Although they identified a lack of HCV specific services in Hamilton participants in each focus group identified several things that are working well with regard to service provision. The John Street Clinic (methadone maintenance) tests all of their clients for HCV as part of their intake process. They are not mandated to do this but do so because HCV is prevalent among many of their clients. They also act as family doctors to clients without doctors and perform the blood tests necessary to refer patients to HCV-specific specialists. One participant mentioned that testing for HCV is available at all methadone clinics in Hamilton. The VAN needle exchange anonymous testing and clean needle delivery exchange were also mentioned as services that some people living with HCV rely on and feel are working well.

Though few people spoke positively about their experiences accessing health care for HCV those that did expressed some common themes that made those experiences positive and are worth noting. Whereas doctors are well informed about Hepatitis C and/or addictions issues and ensure that their patient’s enzyme and blood levels are monitored regularly and their patients have access to all the information they need about the disease people feel empowered to effectively manage living with HCV.

4.5.2 Service Shortage (15)

- we wait until HCV becomes a crisis/huge issue before services are put in place
- need social/self help group, some kind of way (mechanism) to bring people together who have it
- lack of pre/post stabilization homes for addiction

Service providers and people living with HCV identified a lack of HCV services available in Hamilton. Although HCV is a priority for a range of local health and social service organizations, few of these organizations offer HCV specific services. Service providers need access to an HCV "expert" in the community that they can go to for HCV information when providers don't know the answers. HCV support groups and intervention programs for people who use drugs were other service areas identified by participants as lacking in Hamilton.

4.5.3 Lack of Professional Knowledge and Resources (13)

- need access to people in the community who are experts
- not enough education in the medical field, "you ask one doctor he might know something, you ask another..."
- concern with not being able to answer clients medical questions about the disease

Many service providers lack working knowledge about HCV and feel unable to support HCV positive clients effectively. Service providers are concerned about not being able to provide their clients with accurate information and referrals and feel that having access to a HCV expert in the community would be helpful. "User friendly" pamphlets—identified as those with accessible, street language and photos for individuals with lower literacy levels were suggested resources that providers would find useful to disseminate to their clients.

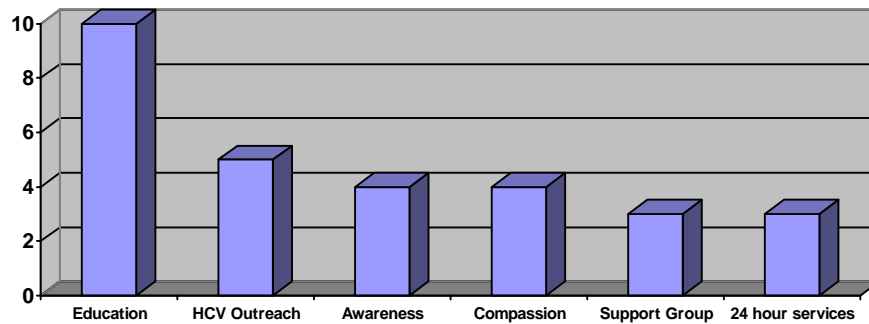
4.5.4 Inadequate Collaboration (7)

- miscommunication between agencies, limited flow of information is a barrier
- usually mental health/illness issues concurrent with addiction, "Why is there segregation between addiction services and mental health services?"

Some participants felt that the current level of community collaboration around HCV in Hamilton is inadequate and can be improved. Communication and limited information flow between stakeholders (people living with HCV, family doctors, community based organizations, mental health and addiction services, specialists) were identified as barriers to effective collaboration.

4.5.5 "What services would you set up?"

Participants in all of the focus groups were asked what services they would set up for people living with hepatitis C. Six themes emerged from the responses to this question and are presented below in chart form. The number of times a theme was mentioned is represented by bar height along the x-axis.



4.5.6 Summary of Suggestions from Focus Group Participants

The prevalent feeling among participants in all of the focus groups was that there needs to be more education about hepatitis c in Hamilton. In particular, there was a sense that youth require education about HCV as they are at high risk due to experimentation with drugs and/or body piercing. Participants felt that schools were the place where young people should be receiving education about HCV. Another common suggestion was that Hamilton needs a HCV outreach worker to help educate and support people living with HCV or at risk for HCV. Several participants commented on the need to raise public awareness about the disease. Participants felt that compassion and non-judgement were important aspects of service delivery that they would like to see more of. Several participants suggested that Hamilton needs a support group for people living with HCV to connect and share experiences. There was also an expressed need for 24 hour services; such as a 24- hour HCV anonymous information phone line and 24 hour VAN needle exchange.

5.0 ANALYSIS AND CONCLUSIONS

The findings of this needs assessment mirror the findings of the 2001-2002 hepatitis C needs assessment and shed light on other issues related to HCV service provision in Hamilton.

The 2001-2002 needs assessment key findings indicated that Hamilton lacks the targeted HCV strategies needed to raise awareness and prevent the spread of HCV in our communities. That research also found a general lack of awareness about HCV among the public and service providers. Other findings indicated that people at risk or infected with HCV have difficulty locating and accessing important information and services related to disease prevention, management and treatment. Stigma and discrimination were prevalent and had negative impacts on the lives of people with HCV and their loved ones. These same issues were identified by the 2006 needs assessment and are still challenges for people living with HCV in Hamilton today.

HCV is a complex disease to prevent, monitor and treat;⁷ in Hamilton it is also a complex disease to live with. The stigma that comes with HCV negatively impacts the quality of life of many people living with the disease and can serve as a barrier to accessing health, informational and support services. Regardless of the route of transmission the public perception about people living with HCV is that they have contracted the disease by some 'bad' behaviour or choice (most often assumed to be through injection drug use). People who use drugs experience double discrimination and are vilified as a result of their HCV status and drug use. One of the disturbing consequences of stigma from a public health, harm reduction perspective is that it can serve as a barrier discouraging people who use drugs from accessing services they need to stay safe, reduce harm and make positive life changes.

Hepatitis C is especially difficult to live well with for individuals with multiple life challenges such as poverty, homelessness, addiction, lack of food security, mental health issues and concurrent health concerns. When determinants of health go unmet an individuals' capacity to manage the disease, make healthy choices and access services such as medical treatment are hindered.

Many people with HCV receive inadequate health care attributed to a variety of factors. Many health care providers require a better understanding of addictions in the context of HCV in order to effectively meet the needs of their patients. People living with HCV expect that their family physicians are knowledgeable gatekeepers of HCV related information however many health care providers do not have accurate, up-to-date disease management and treatment information to share with their patients.

In Hamilton, there is a pervasive lack of awareness about HCV. Few venues exist for locating information about the disease and service providers and people living with HCV alike need greater access to information especially about medical and treatment services.

Although services such as the needle exchange and un-mandated hepatitis C testing in methadone clinics were identified as working well, the 2006 needs assessment also found that Hamilton presently lacks the HCV-specific services (supportive, informational and medical) needed by people

⁷ Canadian Public Health Agency, *Responding to the Epidemic: Recommendations for a Canadian Hepatitis C Strategy*.5 (Ottawa: Health Canada: 2005) Available at www.hepc.cpha.ca

living with HCV, the general public and by service providers. Though the community services inventory demonstrates that medical services are most abundant in Hamilton (compared to informational or support services) service providers indicated that they are unfamiliar with and require more information about medical services in Hamilton. This finding suggests a disconnect between hospital-based medical services and community based social services highlighting the need for increased collaboration. This disconnection is reinforced by the finding that inadequate collaboration exists among stakeholders (people living with HCV, family doctors, community based service providers, mental health and addiction services and specialists).

People living with HCV and service providers thoughtfully articulated their suggestions regarding what's needed to improve HCV awareness and services in Hamilton. Most common was the assertion that Hamilton's general public needs greater education about HCV including outreach to youth through the education system. Other needs uncovered by this research include: an HCV outreach worker, an awareness campaign, compassionate attitudes, a support group and more 24-hour HCV services.

This report reiterates the findings of the 2001-2002 needs assessment which found a great need for increased community collaboration, awareness, education and services to raise the profile of HCV and meet the service and informational needs of people at risk, infected or affected by hepatitis C in Hamilton.

While there are many avenues relating to HCV service use and provision that deserve future exploration, the findings of this research—that none of the service user focus group participants had received treatment for their disease, suggest that future research should be directed towards understanding barriers to treatment for hepatitis C.

APPENDIX A

**Social Planning and Research Council of Hamilton
Hamilton Hep C Network - Needs Assessment Questionnaire 2006**

Social Planning and Research Council of Hamilton
Hamilton Hep C Network - Needs Assessment Questionnaire 2006

Please take the time to fill out the attached questionnaire. Your opinions and experiences are important in determining education, prevention and support strategies for people living with Hepatitis C, (HCV) affected by HCV or at risk of contracting HCV. If you are unable to complete the enclosed questionnaire, please forward it to the person in your organization who can best speak to needs and priorities regarding HCV services. The questionnaire should take no more than 10 minutes to complete. If you require additional space to respond to the questionnaire, please attach as many pages as necessary.

Background

In July 2001, with the support of Health Canada the Social Planning and Research Council of Hamilton facilitated the development of a local network to improve Hepatitis C support, prevention and education services in Hamilton. In 2001, a needs assessment was conducted to determine what such a network might do and how it might function. The needs assessment also identified information about the needs of local service providers and consumers for developing HCV (hepatitis C virus)-related support, prevention and education services.

The findings and recommendations from the 2001 needs assessment were used to shape the actions and priorities of what is now known as the **Hamilton Hepatitis C Network**. A multi-stakeholder network comprised of service providers, consumers and community members the Hamilton Hep C Network is committed to working towards two primary objectives:

- ♦ To increase the availability and use of HCV-related information for people living with HCV, service providers, and people at risk of contracting HCV especially from target groups in Hamilton.
- ♦ To increase the availability of support options for people living with HCV and their their caregivers in Hamilton.

To date the accomplishments of the Hamilton Hep C Network include: the establishment of a support group for HCV infected and affected individuals, the creation of educative materials aimed at target groups, the creation of the Hamilton Hep C Network web-site, the compilation of Hepatitis C resources—housed at The AIDS Network, and the delivery of educative workshops to over 500 service providers and consumers, including estheticians, street-involved youth, police officers, tattoo artists, nurses, and family physicians.

Presently the Hamilton Hep C Network is updating the 2001 needs assessment to ensure that our current goals and priorities meet the perceived needs of individuals living with HCV and individuals providing services to those infected, affected or at risk of contracting HCV in the City of Hamilton.

Please complete and return the questionnaire by Tuesday, Jan. 31st, 2006

Fax: 905-522-9124 Mail: SPRC, 162 King William St. Hamilton ON, L8R 3N9

**Please direct any inquiries to Shannon Lane—Hepatitis C Project Coordinator (905) 522-1148
ext. 315**

Social Planning and Research Council of Hamilton
Hamilton Hep C Network - 2006 Community Needs Assessment Questionnaire

**Please read each of the following statements and circle whether you:
 Strongly agree (SA) Agree (A) Disagree (D) Strongly disagree (SD)**

- | | | | | |
|---|----|---|---|----|
| 1. HCV is currently a priority for my organization: | SA | A | D | S |
| 2. In my organization, we provide services that: | | | | |
| a. address the medical needs of people living with HCV | SA | A | D | SD |
| b. address the support needs of people living with HCV | SA | A | D | SD |
| c. address HCV awareness/prevention in the community | SA | A | D | SD |
| 3. Where HCV is concerned, my organization regularly provides services to: | | | | |
| a. injection drug users | SA | A | D | SD |
| b. street-involved individuals, including youth | SA | A | D | SD |
| c. prisoners | SA | A | D | SD |
| d. gay and bisexual men | SA | A | D | SD |
| e. aboriginal people | SA | A | D | SD |
| f. people who have received blood transfusions | SA | A | D | SD |
| 4. In the Hamilton area, I am familiar with: | | | | |
| a. medical/clinical services that specifically address HCV | SA | A | D | SD |
| b. support services that address the impacts of HCV on individuals | SA | A | D | SD |
| c. education/prevention services related to HCV | SA | A | D | SD |
| 5. In the Hamilton area, there are adequate services to meet: | | | | |
| a. the medical/treatment needs of people living with HCV | SA | A | D | SD |
| b. the support needs of individuals infected or affected by HCV | SA | A | D | SD |
| c. needs related to understanding and preventing HCV infection | SA | A | D | SD |
| 6. I would benefit from learning more about: | | | | |
| a. what HCV is | SA | A | D | SD |
| b. transmission/prevention of HCV | SA | A | D | SD |
| c. testing and diagnosis for HCV | SA | A | D | SD |
| d. prognosis/clinical profile for HCV | SA | A | D | SD |
| e. treatment options for HCV | SA | A | D | SD |
| f. HCV-related research | SA | A | D | SD |
| 7. In the Hamilton area, I need more information about: | | | | |
| a. medical services for people living with HCV | SA | A | D | SD |
| b. support services for people infected or affected by HCV | SA | A | D | SD |
| c. targeted prevention strategies for groups at greatest risk for HCV | SA | A | D | SD |
| d. ways to challenge discrimination associated with HCV | SA | A | D | SD |

- 8. To improve HCV-related services in my organization, I would take advantage of:**
- | | | | | |
|--|----|---|---|----|
| a. training opportunities related to HCV prevention or support | SA | A | D | SD |
| b. internet-based information about HCV (e.g. listserv) | SA | A | D | SD |
| c. educational resources about HCV (e.g. pamphlets, posters) | SA | A | D | SD |
| d. partnership opportunities with local service organizations | SA | A | D | SD |

Please include any comments regarding needs for HCV prevention and support in the Hamilton area:

Thank you for completing this questionnaire!

Please return by January 31th, 2005. by fax: 905-522-9124 or mail: SPRC, 162 King William Street, Suite 103, Hamilton ON L8R 3N9

The Hamilton Hep C Network will be conducting discussion/focus groups for service providers who work with individuals living with HCV, affected by HCV or at risk of contracting HCV.

If you are interested in participating in this process please email: www.hepc@sprc.hamilton.on.ca or call Project Coordinator, Shannon Lane at (905) 522-1148, ext. 315.

APPENDIX B

Focus Group Questions for People Living with HCV:

Focus Group Questions for People Living with HCV

- 1.) What is the main concern for you living with Hepatitis C?

Prompts—What about living with HCV concerns you? What thoughts are on your mind related to living with Hep C?

[Intent: Encourage general reflection on what the concerns and realities are for people with hepatitis c]

- 2.) Where have you received Hepatitis C information or services?

Prompts—How do you get information/services related to the HCV? Are there organizations you visit? What's the availability of info /services like?

[Intent: Determine where needs are being met/not met to identify gaps, locate potential community allies]

- 3a) What is working well with respect to services in Hamilton?

Prompts—What do you want to see more of?

- 3b) What is not working well with respect to services in Hamilton?

Prompt—What do you want to see less of?

[Intent: Identify where needs are being met/not being met]

- 4a) Think back to a time when you have sought out Hepatitis C information or services...What made your experience positive?

Prompts—What encouraged you?

- 4b) What made your experience negative?

Prompt-- What discouraged you?

[Intent: Understand what factors act as barriers and what factors are positive reinforcers]

- 5.) What services would you set up for people with Hep C?

Prompts—If there was nothing holding you back what services would you set up for people living with HCV?

[Intent: Explore other means of meeting the needs of this population; creative strategies to improve access to information/services]

6.) Is there anything that we've missed?

APPENDIX C

Focus Group Questions for Service Providers

Focus Group Questions for Service Providers

- 1.) What do you think are the main issues for people living with HCV?

Prompts—Education about transmission / prevention?
Health management / treatment options?
Income maintenance? Poverty?
Discrimination?
Lack of support?

[Intent: Encourage general reflection and determine priority areas according to service provider experience]

- 2.) Which populations are in greatest need of HCV services in Hamilton?

Prompts—Which populations are at greatest risk?
Which populations are currently being served? Where?
Populations being missed? Why?
Specific services needed for different populations?

[Intent: Identify priority populations, develop strategies to meet target population needs].

- 3a) What is working well with respect to services in Hamilton? What is not?

Prompts—Are there things that work well? Are there gaps in service provision? Are there barriers that prevent people from accessing services?

[Intent: Establish clear understanding of where to direct future Network priorities, what to stick with and what needs help]

- 4.) What services would you set up for people living with Hep C?

Prompts—Feel free to let your imagination run wild...

[Intent: Elicit creative strategies or ideas people may have, other priority needs may be identified]

- 5.) Where should the money come from to fund Hepatitis C services?

- 6.) Is there anything we've missed?

APPENDIX D

List of Organizations to Receive HCV Survey

List of Organizations to Receive HCV Survey

- Alternative for Youth
- Catholic Family Services of Hamilton
- Centre for Addiction and Mental Health, Hamilton Policy, Education and Health Promotions Office
- Cocaine Anonymous, YMCA
- Come Walk a Mile
- De Dwa Da Dehs Nye>s (Aboriginal Health Centre)
- Elizabeth Fry Society, Hamilton Branch
- Elizabeth Fry Society, Hamilton Branch, Sex Trade Awareness and Resources Service, Drop In Centre
- General Hospital, STD Clinic
- Good Shepherd Youth Services, Notre Dame House
- Good Shepherd Women's Services, Martha House
- Hamilton Community Care Access Centre
- Hamilton Health Sciences, McMaster University Medical Centre Men's Withdrawal Management Centre
- Hamilton Health Sciences, Special Immunology Services
- Hamilton Public Health and Community Services Department
- Hamilton Public Health and Community Services Department, Employment, Housing and Long Term Care Division, Community Programs Branch, Alcohol and Gambling Services
- Hamilton Public Health and Community Services, Public Health and Children's Services Division, Healthy Lifestyles and Youth Branch, Chronic Disease Prevention
- Hamilton Public Health and Community Services Department, Employment, Housing and Long Term Care Division, Community Programs Branch, Alcohol and Gambling Services, Older Wiser Lifestyle
- Hamilton Public Health and Community Services, Health Protection Branch, Infectious Disease Control Program
- Hamilton Public Health and Community Services, Public Health and Children's Services Division, Healthy Lifestyles and Youth Branch
- Hamilton Public Health and Community Services, Community Programs, Nursing Service, Community Mental Health Outreach Program, Street Health Centre
- Hamilton Public Health and Community Services Department, VAN Needle Exchange Program
- Hamilton Regional Indian Centre
- Hamilton Urban Core Community Health Centre
- Hamilton Wentworth Chapter of Native Women Incorporated
- Hemophilia Ontario
- Hepatitis C Society of Canada
- Interval House of Hamilton

- John Howard Society of Hamilton Burlington and Area, Adult and Administrative Programs, Community Services Program
- John Street Clinic (formerly First Step Hamilton)
- Living Rock Ministries
- Mary's Place
- Metis Nation of Ontario Aboriginal Healing and Wellness Strategy
- Mission Services of Hamilton Incorporated, Men's Residence and Discovery House
- Mission Services of Hamilton Incorporated, Women's Services Inasmuch House for Women in Crisis
- Narcotics Anonymous
- North Hamilton Community Health Centre, Murray St. Site
- Ontario Ministry of Community Safety and Correctional Services, Operations Division, Hamilton Wentworth Detention Centre
- Planned Parenthood Society of Hamilton Sexual Health Awareness Centre
- Settlement and Integration Services Organization
- St. Leonard's Society of Hamilton, Emerald St. Treatment Centre
- Sexual Assault Centre of Hamilton and Area
- The AIDS Network
- The Bridge from Prison to Community—Family and Ex-Offenders Support Group
- The Salvation Army
- The Salvation Army, Correctional and Justice Services, Ellen Osler Home
- The Salvation Army—Gracehaven, New Choices
- Wesley Urban Ministries Incorporated
- Wesley Urban Ministries Incorporated, Transitional Youth Outreach Program
- Wayside House of Hamilton
- Womankind Addiction Services
- Women for Sobriety
- Women's Centre of Hamilton

Total: 53 organizations