

TORONTO COMMUNITY

HEP C PROGRAM

GUIDE BOOK



TABLE OF CONTENTS

FORWARD	2
INTRODUCTION & PURPOSE	5
Hepatitis C 101	6
Program History	8
Guiding Principles and Mandate	12
PROGRAM OVERVIEW	13
Client Profile	15
Team Composition/Staff Roles	16
Health Care Services	21
Psycho-Educational Support Group (“The Group”)	24
Art projects	29
Community Development	31
Patient Advisory Board	32
Community Support Worker (Peer) Training	33
Program Outcomes	35
Challenges	38
KEY COMPONENTS	39
CONCLUSION	42
REFERENCES	43
RESOURCES	43
APPENDICES/TOOLS	46
A: Group: Session Outlines	
B: Community Support Worker (Peer) Training: Session Outlines	



FORWARD

Ontario's Hepatitis C Teams Strategy

The Hepatitis C Secretariat of the Ontario Ministry of Health and Long-Term Care worked with stakeholders across Ontario to conduct a needs assessment, gathering evidence and community input to inform the key recommendations that address the gaps in hepatitis C service delivery.

Community consultations were held in thirteen communities across Ontario with stakeholder representation including Aboriginal health and social services, social service agencies, health care providers, correctional facilities and people living with/affected by the hepatitis C virus (HCV).

Subsequent to these meetings, each of the thirteen communities was asked to produce a local community strategy for addressing hepatitis C in their community. The thirteen local community strategies were submitted to the Hepatitis C Secretariat. Information acquired through both the local community consultations and the local community strategies were used to inform a Proposed Strategy to Address Hepatitis C in Ontario: 2009-2014 which was developed by the Ontario Hepatitis C Task Force, a ministerial advisory committee.

The Task Force's proposed strategy was presented to the Minister of Health and Long-Term Care in September 2009. A Proposed Strategy to Address Hepatitis C in Ontario: 2009-2014 focuses on 40 recommendations in five priority areas: treatment, prevention, education, support and research & surveillance. In response, the ministry received cabinet approval in February 2010 to put forward Ontario's Hepatitis C Strategy.

One of the key elements of the provincial strategy was the creation of 16 "HCV Teams" across the province to ensure a coordinated, comprehensive approach to treatment and support of those living with/at risk of acquiring hepatitis C. The HCV teams consist of HCV outreach workers and coordinators, additional HCV treatment nurses and access to other psychosocial supports.

Since 2007, community-based organizations have received funding for nursing support to increase treatment capacity and access, particularly in under-serviced communities with high rates of hepatitis C. The program has now expanded to create multidisciplinary HCV Teams. Additional organizations were approached to host HCV teams. The Hepatitis C Secretariat provided criteria for the development of the program plans.

These criteria state that the program must be developed locally, engage at least one treating physician, contain a peer component and must be within or near an adequately serviced community that has capacity to offer additional service for referrals, as necessary. The program is modeled on a community-based approach to service delivery. The intent is that the program be client-driven with built-in flexibility over time and between communities. Guidelines have been developed for the program to provide clarity and to recognize that local conditions will determine service provision.

The Toronto Hep C Program described in this guide was the pilot for the original HCV Teams model and remains one of its most fully developed.

Frank McGee
Manager, AIDS and Hepatitis C Programs
Ontario Ministry of Health and Long-Term Care
April 2013

Hepatitis C is often referred to as a time-bomb. In our community the timer had already gone off and yet traditional treatment avenues were closed to so many. Community members were sick, dying and at the same time told they were 'untreatable'. Quite simply, this was an unacceptable example of a health inequity that we felt we must and could do something about.

Community Health Centres are uniquely situated at the intersection of health promotion and health care provision. Our health promotion and harm reduction programs engage marginalized illicit drug users in low barrier services in order to reduce the harms associated with illicit drug use and to engage individuals in health care. One particular success we've had has been maintaining profoundly low rates of HIV and AIDS in the illicit drug using community and in achieving really incredible levels of community engagement. In all of our work we've built partnerships with community members, front line workers, primary care providers, researchers, specialists, and policy makers. This base of strong partnerships presented us with a unique opportunity to address the health needs of our community beyond our successes in HIV prevention and beyond the usual scope of primary health care.

The community-based program model described in this document is the result of partnership and collaboration between several agencies and between many individuals in Toronto, all of whom are committed to providing equitable health care and support to everyone in our community.

Jason Altenberg

Director, Programs & Services

[South Riverdale Community Health Centre](#)

Most infectious diseases disproportionately impact marginalized populations; a fact that is especially true for the Hepatitis C Virus (HCV). During my medical training I was repeatedly struck by the fact that although good treatments existed for HCV, many individuals who were currently or had histories of using illicit substances were not able to either access or complete treatment. The fact that those at the highest need could not receive treatment drove me to question and examine how best to deliver HCV care to this group.

By listening to those with lived experience of HCV and to front-line care providers, I quickly realized that the traditional mechanism for the provision of HCV care – referral to a hospital-based specialist – was never going to work. Barriers such as housing, food security, mental health comorbidities, substance use and stigma were not being appropriately addressed in this traditional setting. After meeting with other care providers in the community, the idea for a community-based treatment program was developed and the Toronto Community Hepatitis C Program was born.

My experience with the Toronto Community Hepatitis C Program has taught me several things about health and its intersection with social marginalization and substance use. Reaching out to those with lived experience can teach you so much. Listening allows you to truly understand the magnitude of the problem and often leads you in the right direction towards unique solutions. Secondly, I learned that sometimes despite your best efforts you can't do things on your own. Combining individuals with different backgrounds and training often leads to synergy and unique approaches to complex problems like social marginalization. The unique approach of the TCHCP has allowed us to bridge the gap between availability and access to care. Even those clients previously considered 'untreatable' now have equitable access to high quality HCV care.

Dr. Jeff Powis

Infectious Disease Specialist

[Toronto East General Hospital](#)

The Toronto Community Hepatitis C Program (TCHCP) was designed to meet the health care needs of those who have had difficulty accessing the mainstream system, primarily people who use drugs and/or people with mental health issues and or HIV/HCV co-infection. Our program has been successful at offering care, treatment and support to people who have faced the greatest barriers to accessing treatment.

In 2004 I started my very first Hepatitis C psycho-educational support group in the basement of a small agency. It was created to address the needs of people who were being denied Hepatitis C care because of their substance use. It was education and information based with a harm reduction approach. What it was missing was access to health care and in 2006 this component was added and the groups expanded, moving into community health centres.

There were 10 people in that original group. Only 3 of those people are alive today. I truly believe a number of them would still be with us if they had had access to treatment, care and support when they were initially trying to access it. The main route of Hepatitis C transmission continues to be by injection drug use, accounting for 70% of new infections annually. At the same time, 80% of specialists in Canada who treat Hepatitis C feel uncomfortable treating people who use drugs. If we are to reduce the prevalence of Hepatitis C and deaths related to it, we need to be proactive, non-judgmental and inclusive of all people who are affected.

I owe an incredible amount of gratitude to those individuals I have supported over the years who taught me so much and allowed me to learn a great deal from them. It was their experiences that they would share and continue to share with me that have really pushed me to want to be an advocate and support for people living with or at risk for Hepatitis C.

My hope is that this manual will be used to address other health conditions in addition to Hepatitis C – hopefully readers can take some or all of it. The TCHCP didn't start with a huge team or program. We started small and we are continually looking for new ways to expand to meet the needs of people living with Hepatitis C through partnerships, allies and people dedicated to making programs like ours happen.

As a society we still have a lot of work to do but I feel very strongly that the Toronto Community Hepatitis C Program is one model of Hepatitis C care, treatment and support that really works for our community. Our program continues to grow, develop and expand to meet the needs of the people accessing it and it has been an honour to be part of this program since its inception.

Zoë Dodd
Hepatitis C Program Coordinator
South Riverdale Community Health Centre

The purpose of this document is to describe the work of the Toronto Community Hepatitis C Program (TCHCP) and to share what we have learned with the hope that it will provide others with a starting place from which to build other community-based Hepatitis C treatment programs. While this program has a specific focus on Hepatitis C, we feel that this model is well suited to the care and treatment of other complex health conditions for people who face barriers to mainstream health care.

This guide is based not only on our journey but on information from client chart review, focus groups with clients, interviews with staff, program documents, and current research in the field. It will detail who is served by the TCHCP, describe how services are provided, outline the scope of practice for individual team members, and discuss the program's outcomes. It will also provide an overview of key program components that have been critical to our success and which could be potentially transferable to other health conditions and populations.

INTRODUCTION

The Toronto Community Hepatitis C Program is an innovative, community-based, inter-professional, client-centred, collaborative care model of Hepatitis C (HCV) treatment, support and education. The program is a partnership between South Riverdale Community Health Centre, Regent Park Community Health Centre and Sherbourne Health Centre, with integrated specialist support from Toronto East General Hospital and the University Health Network.

The aim of the TCHCP is to improve access to Hepatitis C treatment and supports for individuals who have had difficulty accessing the mainstream health care system. TCHCP clients are often very low-income or homeless, with past or current use of alcohol or other drugs, who may also have serious mental or physical health issues. The program is based on a strong commitment to the principles of harm reduction, community development and the meaningful involvement of people with lived experience of HCV in program design and delivery.

The program is anchored on a weekly education and support group held at each

of the three partner sites. Primary care clinicians are available during the weekly group sessions with monthly on-site support from the HCV treatment and mental health specialists. Clients receive both HCV-specific and more general primary care. They may also access case management or other one-on-one supports and referrals through the group facilitators or other program staff.

Since 2007, the TCHCP has provided Hepatitis C treatment, support and education to individuals who otherwise would never have received this care. Our treatment success rates are comparable to clinical trials in mainstream health care settings. The program also has other important positive impacts for clients, including increased knowledge about HCV, improved ability to self-advocate within the health care system and self-manage their disease, improved sense of community-belonging and increased overall well-being. Further, the program has created a network of formal and informal peer educators who contribute to health promotion and disease prevention in the community.

HEPATITIS C 101

- Hepatitis C is a virus that attacks the liver.
- It is estimated that between 240,000 and 300,000 people are living with Hepatitis C in Canada.
- Hepatitis C disproportionately impacts people who use illicit drugs, the aboriginal population, people in prison, people who are homeless or low-income, and street involved youth.
- Hepatitis C is spread only through blood-to-blood contact. In North America, it is most commonly acquired through the sharing of equipment used to inject drugs.
- Other ways Hepatitis C may be transmitted include: unsafe tattooing, piercing, unprotected sex where blood is present, sharing of equipment used for smoking/snorting drugs, and unscreened blood transfusion or organ transplant.
- There is no vaccine for Hepatitis C.
- Some people (about 20%) spontaneously clear the Hepatitis C virus. The rest develop chronic Hepatitis C, which can lead to cirrhosis, liver cancer and other serious medical complications.
- Hepatitis C usually progresses slowly and affects people differently. There are often no symptoms for many years or symptoms may be very general and feel like other illnesses.
- If the liver becomes more damaged, symptoms sometimes include: feeling tired all the time, itchy skin, difficulty concentrating and remembering, jaundice, swelling of the stomach or ankle, or vomiting blood.
- Hepatitis C is treated with a combination of anti-viral drugs, including a weekly injection and multiple pills that must be taken daily.
- Treatment usually takes between 6 and 12 months.
- Hepatitis C treatment may produce debilitating side effects in some people, including: severe depression, anxiety, skin rash, fatigue, aches and pains and nausea.
- The length of treatment and likelihood of success depend mainly on the viral genotype and how damaged the liver is.
- There are 6 main types of the Hepatitis C virus. Genotypes 1, 2, and 3 are the most common in Canada.
- Someone is considered cured of Hepatitis C if the virus is no longer detectable in their blood six months after they have completed treatment. HCV anti-bodies will always be present.
- Once cured, an individual can no longer pass on the virus; however, it does not make them immune. Infection with Hepatitis C may occur again if someone is re-exposed.

Terms Used In This Guide

Harm Reduction: Harm reduction is a set of strategies and principles focused on reducing the health, social and economic harms related to substance use. Harm reduction programs are often focused on reducing the specific harms associated with substance use, such as HIV or HCV, through things like needle exchanges, crack pipe distribution, overdose prevention and bad drug alerts. More broadly, harm reduction is a pragmatic, non-judgmental approach to service provision that recognizes the human rights of all individuals regardless of substance use and does not require abstinence as a condition of service.

Interprofessional: Interprofessional health care refers to teams of health care providers who work in an integrated and collaborative manner. These teams include both regulated (doctors, nurses, nurse practitioners, social workers) and unregulated (case managers, mental health counsellors, housing workers) health care providers and peer workers.

Community-based health care: Community-based health care takes place outside of a hospital setting, often in community agencies such as community health centres or social service agencies.

Client-centred: Client-centred (or patient-centred) care refers to a model of primary health care where a clients' needs and values drive goal-setting and shared decision-making. Health care is coordinated and integrated and clients are supported as they navigate between different health care systems, settings and phases. Care is comprehensive (where all health issues are addressed, not just one at a time) and includes emotional and educational support.



PROGRAM HISTORY

The Toronto Community Hepatitis C Program (TCHCP) grew out of a need to address a gap in the current health care system for the treatment of people with Hepatitis C. Despite the fact that injection drug use is the primary way that Hepatitis C is transmitted, studies have shown that only about 1% of Hepatitis C positive substance users receive treatment (Grebley, 2009).

Until 2007, people who used drugs were systemically excluded from receiving Hepatitis C treatment; national treatment guidelines recommended that drug and alcohol users and people with serious depression not be treated for Hepatitis C. A period of at least six months sobriety from all drugs and alcohol was recommended. In 2007, the guidelines were changed to recommend that the decision to treat be made on a case-by-case basis. This recommendation was maintained in the most recent 2012 HCV management guidelines (Myers, 2012). Still, a recent survey of Canadian hepatologists, general internists, and infectious disease specialists found that only 20% would likely provide HCV treatment to a current injection drug user (Myles, 2011).

Misperceptions and stigma surrounding substance use have contributed to concerns about adherence to treatment, efficacy of treatment, and the possibility of re-infection after treatment for people who continue to use drugs. While some of these concerns may be valid, most specialists and hospitals are not equipped or not willing to provide the supports needed to enable treatment for marginalized drug users who often face multiple and complex health and social issues. These issues may include: poverty,

mental health concerns, social isolation, and criminalization.

The treatment for Hepatitis C is demanding and requires stability and supports. The daily reality of poverty makes it difficult to follow even basic medical advice such as eating nutritious food. Without stable housing and an adequate income, it is hard to follow the strict schedule of daily medication, weekly injections and the monitoring that Hepatitis C treatment requires for at least six months. It is also difficult to deal with the side effects of treatment, which may be debilitating and include depression and nausea. Fear of treatment has been documented as a major reason why people living with Hepatitis C refuse or put off treatment (Mehta, 2008). Another barrier to treatment for this group is that a large number of people living with Hepatitis C don't know enough about the disease or are not aware that treatment is available (Grebley, 2008). Not having a family physician or distrust of the health care system based on past negative experiences are other major barriers to treatment. Lack of knowledge about HCV on the part of health care providers is also a barrier. Currently, there are no national pre/post testing guidelines for HCV in Canada. As such, many health and social service providers are not adequately informed about HCV and are unable to provide the advice and support that many people with HCV require. In addition, many low income people without employee health benefits must rely on and meet government funding criteria for treatment medications which often excludes people who are deemed to not be sick enough for treatment yet.

The TCHCP was created to both dispel these myths and remove many of these barriers. The individuals and agencies that started this program share deeply held values that access to health care is a human right and that everyone, regardless of income level or whether or not they use drugs, deserves information, choice and the right to treatment.

Inspired by the success of a handful of community-based Hepatitis C treatment programs elsewhere that were treating substance users¹, social service workers and health care providers in Toronto who were working with illicit substance users began to talk about developing a similar model here.

By 2004, outreach workers in the community had begun to notice both high rates of Hepatitis C and the significant barriers people faced when trying to access treatment or information. Most people who were living with HCV seemed to know very little about their illness, its prognosis or even how it was transmitted. Even health care providers did not seem to know much about HCV. Street Health, a community-based agency that provides outreach services to homeless and low-income individuals, responded to this lack of information by developing a Hepatitis C education and support group. This group provided weekly education and support for people living with Hepatitis C but did not have the capacity to offer treatment. Around the same time, staff at South Riverdale and Regent Park Community Health Centres were also starting to notice a high prevalence of HCV combined with a lack of access to treatment. They wondered if they might be able to provide treatment to their clients directly, in the

same way that HIV is now often managed in primary health care settings. In 2006, after finding an infectious disease specialist who was likewise concerned and willing to help train and mentor primary care clinicians, these agencies began working together; with Street Health providing the group support and education and the Health Centres providing the clinical care. In 2008, Sherbourne Health Centre joined the program.

Funding was initially project-based and scraped together from multiple sources. Individuals and agencies donated their time and provided staff and space in-kind. The program started small and continues to grow as needs are identified and as other health care providers hear about the program and want to become involved. The program is currently funded through the Hepatitis C Secretariat, AIDS and Hepatitis C Programs, Ministry of Health and Long-Term Care.

From 2006 to 2012, the program was known as the **East Toronto Hepatitis C Program**. The program name was changed in 2012 to reflect the fact that the program is open to clients who live anywhere in Toronto and our future plans to expand the program to other community-based health centres across the City.

*Artwork by Robert McKay,
Hep C Community Support Worker*



¹ These programs include: the Pender Clinic in Vancouver, British Columbia, the OASIS program in Oakland, California, and others in New York City and Australia.

Mainstream Hepatitis C Care & Treatment

In order to access Hepatitis C treatment through the mainstream health care system, individuals are typically referred by their family physician to a hospital-based specialist, usually a hepatologist, internal medicine specialist, gastroenterologist, or infectious disease specialist. The wait time for a first appointment can often take a long time. Different medical tests and assessments are required before treatment can be started and this will often require visiting other health care centres or hospital departments. Clients are given a list of assessments and specialist appointments that are often inflexible and that they must conduct on their own. If clients cannot complete all of the assessments during this time period, they often must wait another six months before seeing someone on the HCV team again. Most mainstream programs require a six-month period of abstinence from drugs and alcohol before treatment can begin, which is sometimes monitored by urine testing.

Treatment injections are generally self-administered by individuals at home, with weekly to monthly visits to the hospital-based specialist, resident or nurse. Clients are responsible for picking up and storing their own treatment medications. Health education is one-on-one, often very minimal and generally offered in the form of printed materials that individuals take home to read. There is very little practical or emotional support and individuals receive health care and advice related only to their Hepatitis C. Mental health supports are usually available only by referral to a psychiatrist in severe cases and are often limited to pre-treatment assessment.

Of the TCHCP clients who had been referred to specialists for HCV treatment in the past, many were seen only once and then had no further care. Most were not encouraged to pursue treatment, had negative experiences or were denied treatment because of their substance use. Others came to us after finding that the mainstream system did not meet their needs in terms of informational, mental health or personal support.



Marty's STORY

My journey started in Calgary where I was diagnosed with Hepatitis C 10 years ago. I was told that in order to get treatment, I had to abstain from drugs for six months. I tried detox and a treatment centre but failed at sobriety and just gave up on my health for some time. Eventually, I ended up in Winnipeg where a dentist referred me to a clinic for my Hep C. Blood work revealed that it was getting worse. This troubled me and I set upon getting treatment for it but, like before, I was told I needed six months of sobriety. I tried detox and a twenty-one day treatment program. After I failed at this again, I felt like I just didn't care anymore and started using drugs all the time ... which probably wasn't the best thing I could be doing, health-wise. I decided I needed to see my son and daughter again, just in case I might die. I left for Ontario and stayed with friends near Kitchener. I went to another clinic – more blood work and more rejection. Eventually, I saw my ex and my kids but this ended up in disaster and then more depression and more drugs.

I next ended up in Toronto and caught a ray of hope as far as my health was concerned. I had my own stigma against the health care system but this time I guess I just figured what the hell? Let's see if there is anything they can do here. Not having much faith in the health care system, I thought to myself that this would probably be just another rejection followed by more depression. But in the end I figured it was worth a try, since I was already at the bottom and could only go six feet more.

The first couple of weeks of the TCHCP I just watched and didn't say much. But after that I started to open up and realized that these people were real and they listened to us and were actually trying to motivate us. But then disaster struck again – of the worst kind. I was told that I also had HIV. I was co-infected. It wasn't bad though because they were all there for me and kept me on track even though I was still just an addicted, homeless, co-infected person. I was on an HIV cocktail for about a year before they even could consider putting me on HCV treatment. Thanks to my group, I stuck with it. Three years after starting my first group, I completed treatment and I cleared Hep C!

This group and the whole team of doctors and nurses saved my life. Sure, I had to endure the brunt of it but they were there every step of the way and made sure that all the supports were there for me when I needed them. Since joining the TCHCP, I've acquired housing, employment, help with my disability benefits, become a member of the Patient Advisory Board and its co-chair, done public speaking, participated in the Hep C Alliance, graduated from a public speaking skills workshop, completed the 16 week training program and have been hired as an HCV Community Support Worker for the program.

But the most important thing is that I'm no longer sick – yeah! My HIV is undetectable and I've gained some dignity and belonging back in my life.

GUIDING PRINCIPLES & MANDATE

The Toronto Community Hepatitis C Program is dedicated to improving the quality of life for people infected with HCV (or at risk of HCV) through client-centred, inter-professional, collaborative care and education.

Our program is grounded by the following principles and frameworks:

- Community-based
- Meaningful involvement of people with lived experience of Hepatitis C
- Harm Reduction
- Advocacy and Community Development
- Partnership and Collaboration
- Anti-oppression, addressing stigma and discrimination
- Research, Evaluation and Education
- Quality Improvement

We aim to improve people's quality of life by: reducing the barriers and stigma for people living with Hepatitis C, providing equitable access to comprehensive care and services, strengthening the capacity of people with lived experience of HCV to self-advocate, creating a sustainable program, and building a healthy community through prevention, education and support.



PROGRAM OVERVIEW

The Toronto Community Hepatitis C Program is anchored on a weekly education and support group held at each of the three partner sites. All three health centres are located in Toronto's east end in neighbourhoods that are culturally diverse, home to a range of income earners and have significant homeless populations. Up to 20 people at each site attend the 2-hour weekly group meetings which focus on a different educational topic related to HCV each week. The program recently expanded to include two drop-in groups; one for people who are post-treatment and one for women/transwomen, both of which take place once a week at one site. For more details about the structure and specifics of the groups, please see page 23.

Primary care clinicians (physicians, nurse specialists and nurse practitioners) are available every week during the group sessions. Clients leave the group to meet with health care providers on an as needed basis (determined by either the client or the clinical team) and then return to the group afterwards. The specialists (infectious disease and psychiatry) visit the health centres on a monthly basis to see clients during group time. They are also available to the primary care team for advice by phone or email at any time between visits.

Program clients are able to receive both HCV-specific and more general primary care. Many clients who come to our

program do not have a family physician and the program often becomes a path for clients to access primary care. For clients who already have a family physician, the program will communicate and coordinate any primary care needs with this provider. As much as possible, all blood work and other assessments take place on-site. If a client is receiving treatment for HCV, injections are usually administered during group time by a member of the primary health care team. Clients may access case management or one-on-one support through the group facilitators or other program staff. Clients can also use the range of other clinical services and health promotion programs available at each of the health centres. Additional programs and services may include: drop-in programs, community kitchens, services for people who identify as lesbian/gay/bisexual/trans/queer, diabetes education, chiropody, yoga, group programming, as well as comprehensive harm reduction services and programs.

Referrals to the program come largely by word-of-mouth from past or current participants and from other community-based agencies or health care providers. The majority of participants self-refer. Referrals are made in-person or by phone, in discussion with the Program Coordinator, Case Manager, or Hepatitis C Treatment Nurse who explains the program and group model. The program does not have any geographic boundaries within the City



TCHCP Program Model

of Toronto and there is no strict inclusion/exclusion criteria – clients must be HCV positive and unlikely to be able to access, or succeed within, the mainstream health care system. Clients are only required to have an interest in learning more about HCV and its treatment. Potential clients are invited to participate in the next available group cycle. As much as possible, clients can choose which site they would like to attend.

At each site, a small number of people receive HCV treatment and care but do not attend the weekly group. All clients are encouraged to give the group a try but a group model may not be appropriate for everyone. Many clients have had past

negative experiences with group programs or settings, especially people who have been in prison or forced to participate in group programming elsewhere. Some people may be triggered in group settings from past trauma, personality factors and/or interpersonal difficulties. The program also occasionally offers group support to clients who are receiving their HCV treatment in the mainstream system. These may be clients who are involved in clinical trials or who have severe liver damage. These clients attend the weekly support group and receive support from the community workers but are not usually monitored for their HCV by a member of the TCHCP health care team.

CLIENT PROFILE

Almost all TCHCP clients live on very low incomes and face housing and food insecurity. Nearly three quarters have some history of incarceration and many have a history of mental health issues, including depression and serious trauma. Crack cocaine (which can be smoked or injected) is the most commonly used illicit drug (other than marijuana) by our clients, some of whom continue to use while on treatment. Chronic pain is extremely common and clients often have other serious physical health conditions.

Below are some program demographics based on a group of 129 clients who participated in the TCHCP between March 2007 and July 2010 ². Unless otherwise indicated, this information refers to circumstances at the time of intake.

Male	71%
Average age	48 years
Caucasian/White	83%
Homeless or under-housed	35%
Unemployed [receiving welfare: 48%; disability: 47%; EI: 1%]	96%
History of incarceration	74%
HIV co-infection	6%
Past hospitalization for mental health reasons	25%
Suicide attempt in lifetime	25%
Methadone substitution therapy	13%
Past history of crack use	85%
Past history of injection drug use	87%
Crack use in past month	45%
Injection drug use in past month	8%
Daily or binge (>1 week) alcohol use	34%

² Charlebois A, et al. Factors associated with HCV antiviral treatment uptake among participants of a community based HCV program for marginalized patients. J. Viral Hepatitis. December 2012.

TEAM COMPOSITION & STAFF ROLES

The TCHCP team includes primary care providers (physicians, nurses, nurse practitioners), specialists (infectious disease, psychiatry), a program coordinator, community support workers, a case manager, a mental health counsellor, and an outreach worker. Some positions are shared between sites and some are specific to certain sites. Each site has its own primary health care team and the specialists visit and consult at all three sites. A director at one of the Community Health Centres provides leadership and administrative support (funding, reporting) for the program. The program also has a full-time research and evaluation coordinator.

The program employs a complimentary, shared-care approach to HCV education, support and treatment. Roles are flexible and often overlap. TCHCP physicians are either salaried or otherwise remunerated using alternative payment models. The program also has dedicated resources from the Hepatitis C Secretariat to pay specialists an hourly rate, which allows for more collaborative work than a fee-for-service or referral-based model of health care. The specialists will often see clients with another health care provider or one of the group facilitators. The emphasis is on joint work and learning together with both the client and other team members to provide the best care and support possible. The clinical teams meet weekly at each site to review current client care and to develop or update care plans. Physicians and nurses/nurse practitioners block off a half day during the same time

as the group to see clients who are being treated or who are doing pre-treatment work-up. All partnership members, including the specialists, meet bi-monthly for educational rounds and updates, knowledge sharing and partnership meetings.

Hepatitis C Program Coordinator

The Hepatitis C Program Coordinator plays a pivotal role in the TCHCP. As a co-facilitator of the groups, the Program Coordinator plans the group cycle educational content and leads most of the group discussions. The Program Coordinator also provides some individual client support and Hepatitis C counselling. The Program Coordinator conducts outreach to encourage referrals to the program and is often the first point of contact for new clients. The Program Coordinator also provides support to the Patient Advisory Committee, which meets monthly to provide input and feedback on all aspects of the TCHCP. For more information about the PAB, please see page 31.

Another important part of the Coordinator role includes community development, public education and advocacy. The Program Coordinator represents the program at a number of HCV related committees and coalitions, participates in research and represents the program at conferences, develops and conducts educational workshops and does numerous HCV-related presentations for other agencies, health care providers, front line workers, researchers and policy makers. The Program Coordinator is

responsible for program development and identifies and conducts advocacy to address systemic issues related to HCV and works to engage clients and other community stakeholders in these efforts.

Primary Health Care Team

The TCHCP has a dedicated **Hepatitis C Treatment Nurse** position. This is the only primary health care provider who is focused exclusively on the Hepatitis C Program. The HCV Treatment Nurse is primarily responsible for clinical intake and for overall coordination of the clinical pieces of the pre-treatment and treatment process, including preparation of the Exceptional Access Program application. The HCV Treatment Nurse is able to see clients during and outside of group time for intake or treatment work-up. The HCV Treatment Nurse also plays an important educational role both with the program clients and the rest of the team by providing specialized knowledge regarding HCV. The HCV Treatment Nurse advocates for clients on an individual level and does outreach and education with other external health care providers.

At each site, **Family Physicians, Nurse Practitioners** and the **Hepatitis C Treatment Nurse** work in close consultation with one another and with the specialists to provide care and treatment for clients. With input from the specialists, the physicians will order the treatment drugs and establish the duration of treatment. Through any member of the Primary Care Team, clients are able to access: HCV viral load and genotype testing, referral for liver biopsy (if needed), on-site consultations with specialists (see below), HCV anti-viral treatment and monitoring and management of treatment side-effects. As much as possible, all of the services are provided on-site during group time. Through the program, clients are also able to receive

treatment and support for other primary health care issues that often surface during HCV assessment or treatment. For clients who have family physicians outside of the program, close communication is maintained throughout treatment by the TCHCP team.

Specialist Support

Providing consultation and mentorship for the Primary Health Care Team, as well as some direct client care, are an Infectious Disease Specialist and Psychiatrist. The **Infectious Disease Specialist** and **Psychiatrist** see clients who are interested in treatment and are available to the rest of the team as expert resources, anytime, to make recommendations and help with problems if they arise. Both specialists are available to meet clients at the health centres once a month and almost all group members see the specialists at some point during their time with the program.

The Infectious Disease Specialist recommends tests that are required before starting treatment, provides advice regarding if/when treatment initiation is appropriate, and advises on treatment dose, duration, as well as side-effect management. The specialist also provides expertise in Hepatitis B and HIV co-infection and management. The Psychiatrist provides support regarding mental health and psychiatric illness. Part of this role includes conducting risk assessments, recommending medications to stabilize depression, anxiety or other mental health issues as well as problem-solving related to specific clients. Additionally, each specialist leads one group discussion each cycle on HCV treatment or mental health in the context of liver disease, respectively. Over time, the specialist role has evolved from weekly in-person meetings with members of the primary health care

team and direct care provision for clients to monthly consultations and indirect care in the form of telephone or email support. This evolution is a result of the education and capacity-building provided to the rest of the team by these specialists in each of their fields of expertise.

HCV Case Manager

The HCV Case Manager position provides three key roles: acting as co-facilitator of the groups, providing one-on-one support to clients during and outside of group time, and supporting the involvement of people with lived experience of HCV in program delivery.

As co-facilitator of the group, the Case Manager attends group each week and sometimes leads the group discussion. The Case Manager also coordinates the health care visits that take place during group and attends the weekly clinical team meeting. Beyond the group, the Case Manager role includes: accompanying clients to medical, legal or other appointments, helping clients to find or maintain housing, connecting clients to other community resources and/or coordinating services with other existing supports/workers. The Case Manager also meets with clients one-on-one outside of the weekly group sessions to provide informal counselling or support. Advocating for clients on an individual and systemic level is also

part of this role as is public education about HCV through activities such as speaking at conferences and participating in community workshops. In addition, the Case Manager coordinates the peer-training component of the program and is the primary supervisor for the Hepatitis C Community Support Workers (described below). For more information about the Community Support Worker (peer) training program, please see page 32.

Hepatitis C Mental Health Counsellor

The Hepatitis C Mental Health Counsellor works with clients on an individual basis and uses an eclectic approach of trauma-informed, psychotherapeutic models of support that encourage skills development and building on each person's strengths. This role also involves client education to help people cope with the symptoms of having the virus, any side effects of being on treatment or both. Ongoing and long term goal structuring is also a part of counselling for people on treatment or who choose not to pursue treatment or who are post-treatment. Outside of clinical time, this role involves engaging stakeholders and other providers about the program and working with the rest of the team to help manage continuity of care for people accessing the program.

Hepatitis C Outreach Worker

The Hepatitis C Outreach Worker's primary role is to provide support and education for clients and community members who are living with or who are at risk of Hepatitis C. This includes facilitating the group as well as case-management. The outreach worker actively encourages program referrals by spending time and making presentations at drop-ins and other places in the community that are likely to be frequented by at risk community members or people living with Hepatitis C. The Outreach Worker co-facilitates the weekly treatment group and the Women's Group, runs a yoga class for people living with or at risk of HCV, supports the post-treatment group and the program's client involvement initiatives like the Patient Advisory and Community Support Worker training. Program development, public

education, as well as advocacy at both an individual and systemic level are also part of the Outreach Coordinator's role.

Hepatitis C Community Support Worker

The program has recently added six casual Hepatitis C Community Support Worker positions. These positions were filled by former or current program clients who have graduated from the TCHCP Community Support Worker Training Program (see page 32 for details). The work of these new positions varies at each site and will evolve over time but currently includes such responsibilities as: outreach, client accompaniment to appointments, post-treatment support, Hepatitis C education and information, public speaking and advocacy.

The P Word?

The TCHCP has decided to move away from using the word 'peer' to describe people who are formally employed in the TCHCP as a result of their lived experience with Hepatitis C and/or use of alcohol or drugs. Referring to someone as a 'peer worker' often has negative social and financial implications that should be considered. Peer workers tend to be paid less than other workers who have similar responsibilities and may not have their skills and experiences valued in other ways. The peer label often limits professional growth opportunities if employers cannot see beyond the 'peer' aspect of the job. Like many other words that evoke stigma and discrimination (such as 'addict' or 'substance abuse') the TCHCP works hard to eliminate these stereotypes in vocabulary.

'Lived experience' is an increasingly common qualification for job postings with agencies and organizations. Lived experience is a form of knowledge and should be valued for its unique and important contribution. People hired or included based on their lived experience deserve equitable pay, support, and access to the same rights as other employees in the workplace.



Jennifer S' STORY

I finished treatment and cleared the Hepatitis C virus. But it wasn't always like that ...

Before coming to the TCHCP, I really didn't have the education or knowledge to know that treatment was even possible or could be covered by the government, if I qualified. I had Hepatitis C for many years and my doctors didn't really tell me anything about it. The doctor I had before I became homeless would do liver tests, but not for Hepatitis C. He never spoke about it with me so I figured I didn't have it anymore. When he retired, my next doctor tested me again and said I still had it and set me up to go to a hospital for more tests. The specialist said I could come back in 6 months to a year and could maybe do treatment then, only if I remained sober during that time. My doctor and the specialist were always really abrupt and said they wouldn't give me any information about treatment until I was 'ready' for it. They talked down to me.

Around this time, I became homeless. Through a worker with the HOPE Program of Ontario Works, I was introduced to the Toronto Community Hepatitis C Program and thank god! I was feeling hopeless with the stress of no treatment, no housing, no support and felt mentally unbalanced. Through the program, I was able to obtain mental health care, a liver specialist, a psychiatrist, a family physician, and a Hep C nurse. I was never stigmatized or talked down to. I practiced harm reduction and was completely honest for the first time in my life with the health care team. I was able to find housing and start treatment. I received support from the whole team, especially from the group facilitator and mental health counsellor. I gained knowledge about the virus and about the side effects, and learned that everyone's experience of Hep C and treatment is different. Most of all I had major support from the other people in the group. The men in the group were very helpful as I was the first woman to receive treatment in the program!

Treatment was very brutal for the six months I was on it, so it was a blessing that I had so much support to get through it. I had many side effects from feeling extremely tired, to brain fog, shortness of breath, vomiting, diarrhea, itchy skin, a metal taste in my mouth, a change in my taste for certain foods. These were just the worst ones – there were too many more to mention. I am so happy I cleared the virus. A few months after treatment stopped, I started feeling much better.

While in treatment I also attended the Community Support Worker training, and today I have two part-time jobs as a support worker with Hepatitis C programs. I now have direction in life, jobs I love and can give back to the community due to this whole experience.

HEALTHCARE SERVICES

“You get the feeling that they [the health care team] actually care, you know? They’re very thorough, they cover everything. And even things that aren’t part of ‘treatment’, they’ll help you with it.” – TCHCP client

The TCHCP aims to be holistic and client-centred. Program clients may receive both HCV-specific and more general primary health care services. Preparing for treatment often requires having to first address other serious health issues, as well as multiple social determinants of health including: helping people to find or maintain stable housing, improving income supports (helping people get disability benefits), and stabilizing drug or alcohol use. Many clients have not had comprehensive primary health care in many years, or at all, and often have other acute and chronic physical and mental health issues that need to be addressed before their Hepatitis C can be treated. As much as possible, clients prioritize their own health issues and needs and are supported to achieve the health and well-being goals that they have identified for themselves.

When someone is receiving treatment for HCV, they will see a clinician each week during group to receive their injection, pick up their medication for the following week, and have their health status monitored. Blood work is also collected at this time, on site. Clients can also access a range of other social and health services and programs available at each of the health centres.

Treatment preparedness is the main goal of the TCHCP and is worked towards in both the group setting and on an individual level. The program also allows for a flexible pre-treatment process; some clients need time to develop trust and to commit to treatment, while others are able to start treatment almost right away. However, it may not be possible for, or the choice of, every person in the program to initiate treatment. The main reasons people are not able to start treatment in the TCHCP are because they are denied government funding for treatment medication³ or because they have other health conditions that need to be prioritized. The average time from intake into the program to when members start treatment is about 11 months (with a range of 4 months to just over 2 years). Although treatment preparation may seem to take a long time, it builds a vital foundation for successful treatment. No one who has started HCV treatment through the program has stopped unless they were not responding (as is the case for 20–50% of people who initiate HCV treatment).

For the TCHCP, ‘treatment’ is not just about initiating anti-viral medications for HCV. Some clients may decide that they do not wish to pursue treatment and are still able to achieve other positive and important health outcomes through the program. Treatment might mean taking care of other health issues or it may mean finding and maintaining housing after years on the street. Investing

³ For people without private health insurance, funding for Hepatitis C treatment medications is covered through the Ministry of Health and Long Term Care’s Exceptional Access Program (EAP). Applicants must meet certain clinical thresholds of illness in order to receive approval. Participants who are ready and prepared to do treatment are often denied funding because they are not yet sick enough.

time in these other components is often a necessary first step and is key for overall improved health, long-term.

The principles of harm reduction are integral to the philosophy of care throughout the health centres where the TCHCP is based. For health care providers this means taking a holistic approach and addressing substance use as only one part of a larger conversation regarding client health, which also includes other social determinants like housing and income. The TCHCP does not have an addictions specialist as part of its clinical care team. The program does not require or promote abstinence and

encourages clients to talk openly and without fear of punishment about their substance use. Honest conversations about substance use allow staff to provide better care overall since they actually know what is really going on in people's lives. Staff and clients have noted that the focus on health and well-being and not substance use per se has helped some clients to stop, reduce or become more stable in their drug or alcohol use. Although some might assume that current drug users are not likely to be stable enough for HCV treatment, many clients will be able to continue to use drugs throughout treatment without incident. Alcohol use is often a bigger barrier to treatment than other substances.

Craig's STORY

I've been living with Hepatitis C for over 20 years. I found out after donating blood, when I was sent a letter telling me that I had an infectious disease. My family doctor admitted that he knew very little about Hepatitis C and told me that there was no treatment available at the time.

After my doctor died, I tried to find another doctor in Toronto but got turned away or pushed out everywhere I went. No one would take my physical pain or depression seriously. Several health care providers told me I was just a drug addict and that I'd be fine. At the time, getting help felt near impossible.

Then, a few years ago, I ran into an old friend who told me about the Toronto Community Hepatitis C Program. By the end of my first group, I was already doing assessments and had a new family doctor. The group gave me a positive focus each week and helped me get through some rough spots in my life. I'm now a member of the Patient Advisory Board and have been able to get back to using my creative talents in several arts-based programs and a cooking group.

It has been a long road to HCV treatment. Before I could begin treatment, other physical health issues had to be dealt with such as kidney stones, gall bladder surgery and anemia. My treatment was further delayed when I was denied provincial funding because my Hepatitis C wasn't making me sick enough. Thankfully, I remembered that I still had access to private insurance and could access treatment this way. I also decided to wait until the new 'triple' therapy was available. For people with my genotype (1) who haven't tried treatment before, this new treatment would increase my likelihood of success. Given everything that I've already survived in my life, I'm confident that I will get past Hepatitis C too.

The Group Therapy Model

Group therapy is an increasingly common tool in comprehensive medical care and can range from education to more focused psychological interventions. Different types of group support models have been employed to help people cope with the stress of a variety of medical illnesses including: breast cancer, cardiac disease, diabetes, brain injury and HIV/AIDS. Group facilitators may have a range of professional backgrounds or may not have any formal credentials. Research has demonstrated that group therapy can be as beneficial to clients as individual psychotherapy. Groups help clients through a complex interplay of a number of factors. Eleven elements of the group model experience have been identified as important to the positive therapeutic change process*, they are:

1. Instillation of hope (belief or confidence in the treatment, general positive expectations)
2. Universality (validation in shared experience)
3. Imparting information (didactic information, advice, direct guidance)
4. Altruism (benefit from the opportunity to help other peers)
5. Development of socialization techniques (social skills including conflict resolution, empathy, responsiveness)
6. Existential factors (awareness and acceptance of the limits of life)
7. Corrective recapitulation of primary family group (group serves as model where old familial conflicts are relived correctively)
8. Imitative behavior (modeling of other members, facilitators)
9. Group cohesiveness (members' sense of group solidarity, belonging and mutual support)
10. Interpersonal learning (improved communication, self-awareness, relationships)
11. Catharsis (expression/disclosure of emotion, working with these feelings)

Despite evidence of the positive outcomes of the group model, the myth pervades that marginalized individuals will not be able to engage and benefit from group therapy. In fact, group therapies are particularly useful for individuals who live with stigma, social isolation or who require new coping skills.

The TCHCP has recently completed an evaluation of the group component of the program. Early findings suggest that group cohesiveness, a vital condition for positive health outcomes, is very strong and contradicts the above-mentioned previous misconceptions.

* From: *The Theory and Practice of Group Psychotherapy* by D. Yalom and M. Leszcz.

THE GROUP

"If you had cancer or some other disease, it's not good to be on your own. This is one of those things ... and it's good that the group is here, because without it, I don't think that a lot of these people would be getting treatment" – TCHCP client

At the heart of the Toronto Community Hepatitis C Program is a weekly psycho-educational group. Each site runs one group per week for up to 20 people. Each group lasts 2 hours and runs on a 16–18 week cycle. Groups are 'closed' after the 4th week, when no new members are admitted. Members are welcome to attend multiple group cycles if they are currently on treatment, have recently finished treatment, or are actively preparing for treatment.

Group members are given a \$10 honorarium and transportation tokens each week to help remove some of the financial barriers to participation. Public transit is quite expensive in Toronto and can be a significant barrier for many people in terms of their ability to attend appointments and participate fully in the community. The honorarium helps offset any income that might have been lost as a result of attending the group and also helps to underscore the important role and expectation that group members will share their knowledge and become HCV educators within their social networks and the broader community. A healthy meal is also provided and members are encouraged to take home leftovers. Providing food helps to reduce food insecurity and also helps to create an inviting and social atmosphere.

The group is facilitated by two staff (the HCV Program Coordinator and Case Manager or Outreach Worker) who have extensive

harm reduction and HCV knowledge, as well as years of experience working directly with people who have experienced poverty, homelessness, mental health issues, incarceration, and marginalization due to substance use. The group facilitators work from a perspective of deeply felt anti-oppression and egalitarian principles. Group members are treated as equals and are respected for the experience and knowledge they too bring to the group.

The group is established as a welcoming space where a sense of community and mutual support are nurtured and where illicit substance use and other stigmatized behaviors or life circumstances can be discussed openly and without fear of judgment or punishment. Groups begin with a check-in where members can let one another know how they are doing, what issues or challenges they may be struggling with, discuss how treatment or treatment preparation is going, and are then able to receive support or advice from others in the group. This important process can sometimes take up to an hour. After check-in is complete, a short presentation or topic of discussion is introduced. Each week is focused on a different educational topic. These topics include: Hepatitis C 101, Hepatitis C treatment, safer substance use/harm reduction strategies, liver health, nutrition, mental health and well-being.

Topics have evolved over time in response to member needs and remain flexible so that timely issues can be addressed each cycle. For example, 'dealing with bed bugs' is an occasional focus of groups where and when this is a pressing concern. Group discussions are often led by guest speakers from other community agencies, the TCHCP specialists, as well as by past group members. Each group cycle also incorporates a therapeutic art project. Past art projects have included working with clay/pottery, photo-voice, collage, and body mapping. For a complete list of current topics used in the groups, please see Appendix A. For more information about the art projects, please see page 28.

The group is a bridge to clinical care. For members with more chaotic lives, the group brings an element of consistency and stability, which helps people to prepare for treatment. Regular attendance at the group is likewise a good indicator for the clinical team that someone is stable enough for treatment. The group also helps to build trust with the health care provider team. Many program clients have had negative experiences with health care providers in the past. Hearing the first-hand, affirmative experiences of other group members and being able to first establish positive relationships with the group facilitators helps to ease some of these concerns.

Through the group, members are also able to access individual case management. The case manager is one of the group facilitators and provides one-on-one assistance with housing issues, income supports, referrals to other services, informal counselling, and accompaniment to appointments outside the centre.

A closed group allows members to better establish trust and rapport with one another and with program staff. The length of the group cycle was set because it provides both enough time to cover all of the educational aspects of HCV treatment and related issues, and because it also gives the group enough time to become a cohesive and supportive entity. Allowing members to attend multiple group cycles helps to ensure that any information missed due to absence or while someone was visiting with the health care team will be caught in another cycle. Information about HCV can be complex and many participants have almost no knowledge about their HCV when the group begins. Attending multiple group cycles also helps for members who may have cognitive or literacy issues and who need to hear information several times before it can be absorbed and well understood.

One of the goals of the group is to help build the capacity of each member so that they become "expert patients" in the area of Hepatitis C – able to manage their disease, advocate for themselves and make informed choices about their care and treatment. Many people say they knew almost nothing or had misconceptions about Hepatitis C when they first joined the program. For example, many people believe they have HCV but have never received the second stage confirmatory test. It is quite common for people to come to the group and then find out that they cleared HCV on their own. Many more come who do not even know their genotype or anything about their treatment options. Through the group and in conversations with the health care provider team, participants receive extensive information about their HCV and about



their health in general. Members are also encouraged to become “HCV ambassadors”, to talk to their friends and in their networks about HCV transmission and treatment.

In addition to the high quality and relevant information about HCV that the group provides, it is also an important place of connection for mutual support and peer knowledge. Peer-to-peer support is encouraged within and beyond the group. Friendships between members often form and continue outside of group time. People who are further along in their treatment process act as resources and mentors for newer members. Those who have recently finished treatment are able to offer encouragement and reassurance to individuals who are currently struggling with the difficult side effects of treatment.

“The thing about these classes is that you can talk to the other people that are already on treatment, you can kind of relate and figure out what it’s going to be like for you. It’s different for everybody, but at least you can see improvement as it’s happening with other people.” – TCHCP client

The group is also a place for individual empowerment and community development. Group members are supported to self-reflect and to critically analyze the social forces and systemic structures that impact their lives and shape their behaviors, perpetuate HCV transmission, create barriers to treatment, impact substance use and other related issues. Group members are encouraged to address these issues collectively and are supported to attend relevant network meetings and community events.

Women & Transwomen’s Group

The TCHCP recently started two drop-in groups, one for women and transwomen only and one for people who have completed treatment or are unable to do treatment.

The women and transwomen-only group was created to address the lower number of women participating in the regular psycho-educational group. Overall, only about 30% of group members are women or transwomen. This group is held once a week at one centre and is a more informal drop-in for women who are Hepatitis C positive or at risk of acquiring HCV. The Hepatitis C treatment nurse is available to speak with participants during the drop-in time. Women/transwomen are also able to access treatment and receive supports through this group. Food is provided at the drop-in and each week there is an educational or personal development discussion on HCV and/or topics specific to women and transwomen. Activities also include art projects, guest speakers and films. This format was decided on after discussions with staff, the Patient Advisory Board and a focus group with HCV positive women in the community. Because women often prioritize the needs of others over their own health and are more likely to report feeling stigmatized, a casual but safe space was created where women could come whenever they are able to discuss their unique health issues.



Post-Treatment Group

"When we were on the streets we were known as 'heavy' people, right? And look at us now. You would never know before we came to these groups that we were able to sit down and talk to people like we do now. We wouldn't think that!" – TCHCP client

Post-treatment can be a very difficult time for people who have come to rely on the community and stability of the weekly group and the support of the team, for not only their Hepatitis C but other health and personal issues as well. Finishing treatment or leaving the group for other reasons can feel isolating and depressing. For some clients, this is the first positive health care experience they have ever had and the first time they have been able to address some of their health and social issues in a positive way. Having to suddenly let go of the regular support of a team of health care workers and peers can be very difficult, especially for people who have been in the group for several years. The post-treatment

group provides a place to transition and to continue the positive relationships and self-care that have been established. The need for support post-treatment or for members who are not able to initiate treatment due to funding denial or because they had other health issues that made them too sick for treatment, is something that both clients and staff identified as a vital program need. In response, the program created a weekly drop-in group for clients interested in this type of ongoing support. The group takes place over dinner time at one of the centres and has a rotating focus of movies, art making, cooking and discussions. Meals are planned and prepared by the group. Discussions and activities take place as the group cooks and eats together. Two Community Support Workers facilitate the group. Even clients who have cleared the virus still appreciate having a connection to the program and people who they have formed a community with over the course of their treatment.





Jennifer B's STORY

I went to my first group in January 2010. I self-referred to the TCHCP after learning about it through the street grapevine. Initially, the idea of being a part of a group was anxiety-provoking. I considered myself someone who doesn't like people and I certainly avoided situations where I was one of many. I was not a people person, much less a group person. Despite my initial trepidation, I still attended the group weekly but I remained quiet, reserved and watchful.

My reasons for attending, at least in the beginning, had less to do with Hepatitis C and more to do with obtaining assistance getting onto ODSP and with housing. I had heard that you could get help with things like this if you went to the group. I continued to attend the group once these issues were resolved because on some level I was able to recognize that I was doing something positive for myself ... I was slowly becoming engaged.

Being Hepatitis C positive, along with the stigmatization, marginalization and dehumanization I experienced was, I found, not just unique to me. It was also something that my fellow group members experienced. These common bonds provided the foundation on which my sense of belonging and community/family was born. With time, I learned to trust both in myself and in the group.

The group provides a space in which I am accepted and have a very meaningful say in my care. In group there is no hierarchy – we are all equal - we decide the path our health care is going to take. It's collaborative but each one of us is the driver of our own bus. It really is "nothing for us, without us".

I started treatment in the spring of 2011 but, unfortunately, was only a partial-responder. I'm hoping to try the new triple therapy as soon as telaprevir becomes available. I intend to stay involved in the program regardless of what happens. The meaningful involvement of people with lived experience of HCV is a guiding principle upon which the TCHCP operates and is the single most important reason for my staying engaged and becoming further engaged beyond the group.

In September 2010, I become a founding member of the TCHCP Patient Advisory Board. I also completed the Community Support Worker training and was subsequently hired to be an HCV Community Support Worker for the program.



ART PROJECTS

Art has been an integral component of recent TCHCP groups. For the past three years, every group cycle has included an art project which takes place over 3–4 group sessions. A collective exhibit of the art made at all three centres is held after the completion of each group cycle or in conjunction with a relevant event such as World Hepatitis Day. Art projects to date have included: photovoice, clay mask-making, collage and body-mapping.

Photovoice project – Photovoice is a method often used in community development as a tool for expressing community issues and in advocating for social change. The objective of this project was to document and reflect on the strengths and concerns of people living with Hepatitis C. Group members were given disposable cameras, taught how to take photographs and how to communicate using photographic images and as well looked at examples of other community-based photovoice projects. Participants then took the cameras with them and were asked to take pictures that represented their experiences of living with Hepatitis C. After the photos were

developed, group members presented them to one another and were asked to select their favourite. One picture was enlarged and framed for each participant. These images, along with a reflective story about each photograph, can be found on the project's blog: <http://livingwithhcv.blogspot.com>.

Mask project – For the mask project, a professional potter came to the group and taught participants how to work with clay. Participants were asked to create a 'mask' which represented how they related to the stigma of having Hepatitis C and to consider the various masks or personas that each of us wear, that we project and that are projected onto us by others.

Plate Collage project – For the collage project, participants were given stacks of magazines and clear plates. Images from the magazines were selected to represent the positive aspects of people's lives or what 'nourishes' their happiness. These were then glued face up on the bottom of the plates. The focus of this particular art project was to help members examine and reflect on the strengths in their lives.



Body Mapping project – Body Mapping is an activity where participants tell a visual story about their health, relationships and life histories, depicted on a traced outline of each person's body. Body maps use symbols, words, colours, and timelines. They can be used as a therapeutic technique, research method, and dialogue or information tool. TCHCP clients were encouraged to use their body maps to depict and explore their unique Hepatitis C journey.

Quilt project – With a grant from Ontario Arts Council, the program was recently able to undertake a second clay-based art project. Group members decided on the project focus and this time chose to create a hanging 'quilt'. Each group member created his/her own piece of the 'quilt' which then fits together with the other group members' pieces, like a puzzle. The groups created a single artist statement for the project which is: *Separate we are many, together we are one. Each of us is unique and individual but together we make one community – one family.*

The art projects contribute to improved social connectedness, self-examination, self-expression, healing, and have been valuable

tools for advocacy for addressing issues of stigma and discrimination, inequality, poverty and social exclusion. Participants have reported that the art projects are fun and have helped them to both connect and open up to one another in unexpected and positive ways. The creations and images are engaging and powerful educational tools and have been displayed at conferences, meetings, and trainings. The process itself is equally or even more important than the final product as a therapeutic technique that facilitates relaxation, groundedness, and healing.

Not every group member is initially excited about the idea of making art. Some may not have had the chance to make art or to connect with art in the past. Everyone is strongly encouraged to at least try the art project or to come and just observe the process for other group members. In each group, the vast majority of members participate in some way – if they do not end up creating their own art work, they will often assist someone else or will complete at least some aspect of the art making process.



COMMUNITY DEVELOPMENT & ADVOCACY

"You get so used to being downtrodden, that you think that it's your lot in life, and you don't deserve any better. You come here, you listen to people tell you that "no, you don't have to put up with a lot of that stuff, and you do have rights" and yah, it does make you more able to advocate for yourself ... because you can say, no, hey, wait a second, that's wrong ..."
– TCHCP client

Strengthening the capacity of and encouraging clients to advocate for their individual and collective rights and choices is an important program principle and group orientation. Through the group, participants learn about and get connected to other community resources. The group also provides a place for isolated individuals to form a community and social network. Clients are a diverse group but share common needs, problems and strengths. The program encourages collective action and organization and aims to equip participants with the necessary skills for community leadership, as well as critical awareness at a personal, program and community level.

Since finishing treatment or stabilizing their health through the TCHCP, many people have gone back to school, worked as

advisors or consultants for other community-based programs and agencies, become public speakers for other agencies on issues of HCV and/or HIV, and/or have obtained harm reduction or HCV education jobs at other agencies.

The TCHCP actively supports and participates in a number of coalitions and events to address the social determinants of Hepatitis C. This includes: Pride, Prisoners Justice Day, Overdose Awareness Week, International Drug Users Day, Toronto Stop the Cut's Network, Raise the Rates Campaign, World Hepatitis Day, the Canadian Coalition of Organizations responding to Hepatitis B and C, Toronto Harm Reduction Alliance, Toronto Drug Users Union, and the Toronto Hepatitis C Alliance. Program clients and staff of the TCHCP also participate in advisory, training and professional development activities including workshops at Toronto Public Health and other agencies, participation in the Toronto Drug Strategy Secretariat, presenting at research conferences, and training for other multi-disciplinary Hepatitis C teams.

PATIENT ADVISORY BOARD

The TCHCP Patient Advisory Board (PAB) was established in the fall of 2010 to help ensure the meaningful participation of people living with HCV in the development, implementation, and evaluation of the program. PAB members participate in partnership meetings, presentations, workshops, training, and strategic planning for the TCHCP.

The PAB is made up of 2 group members from each group who are elected by other group members. Members serve a two-year term. As much as possible, the Patient Advisory Board also attempts to be representative of the diversity of the overall group make-up, including different stages of treatment and treatment outcomes.

The PAB meets monthly (or more often, when needed). Meetings are chaired by one of the two patient co-chairs, with administrative support from the HCV Program Coordinator. The co-chairs also attend the bi-monthly partnership meeting where staff from all sites gather to discuss program and research issues. PAB members are paid an honorarium for their time at meetings and other events that they attend on behalf of the program.

The PAB has three main roles: (1) to provide feedback on existing program components, practices, and issues (2) to provide guidance and input into program development, research, evaluation, and training (3) to conduct public education and awareness regarding HCV through presentations and other public speaking engagements.

The PAB is an important source of immediate and honest client feedback, providing a mediated and safe way for current group members to voice concerns. The PAB has been an important source of innovative ideas for research and program development and has identified and advised on emerging priorities for the program such as the development of our post-treatment group and women/transwomen group. Other accomplishments include helping to deliver training to new multi-disciplinary HCV teams, participating in the Toronto Hep C Alliance and Toronto Harm Reduction Alliance, planning and participating in World Hepatitis Day events, assisting with staff hiring, advising on the development of an HCV specific stigma survey, reviewing research manuscripts and other program documents (like this one!).

In a focus group that was held with members of the Patient Advisory Board members in February 2012, members felt that their participation in the PAB had positive program and personal impacts. On a program level, members said that they feel that the PAB helps to keep the program sites connected to one another and to the community. They felt that their role as community educators among people living with HCV (or at risk) is better received and more effective than if the same information were delivered by health care professionals. Members also felt that the PAB keeps the program client-centred and responsive to the real needs of clients. On a personal level, members said that their participation in the PAB has improved their communication skills, especially around group participation and public speaking. Members also expressed that being part of the PAB was empowering and reported improved self-esteem, as well as a welcome sense of purpose and accomplishment.

COMMUNITY SUPPORT WORKER TRAINING

Hepatitis C Program initiated its first Community Support Worker training program. The purpose of this program was to increase the capacity of program clients to act as support workers for their peers within the TCHCP or at other agencies elsewhere in the community. The creation and implementation of this training program is a continuation of the TCHCP's fundamental belief that involving people with lived experience of Hepatitis C in its ongoing program development is essential to improved program delivery and health outcomes.

Training was offered to 12 current or former TCHCP clients at any stage of pre/post HCV treatment, with equal representation from all three of the program sites. The training program consisted of 15 weekly, 2-hour sessions held at one of the Health Centres. An honorarium of \$10 and transit tokens were provided each week, as well as coffee/tea and a light snack. The HCV Case Manager provided overall development and coordination for the program, as well as providing support for program participants and led several of the training sessions.

Training sessions focused on skills building and covered topics such as: communication, self-care, boundaries, and advocacy. *Please see Appendix B for a complete list of session topics.* Each session took a participatory learning approach with an emphasis on

scenarios and problem-solving. Discussions were often participant driven and/or led by staff or peer workers from other programs or community agencies. The purpose for having a variety of presenters/session facilitators was twofold; to expose participants to a variety of presentation and learning styles, and to introduce them to other community agencies/workers and vice versa.

A graduation party and ceremony was held one week after the last training session. Each graduate received a certificate and a short speech was made that highlighted each person's growth and contributions within the training program.

The results of the first evaluation of the TCHCP Community Support Worker Training program indicated that HCV knowledge and confidence increased after the training, as did indicators of self-esteem, empowerment, social support and quality of life. Participants have reported that the training taught them how to positively re-frame stigmatized life experiences and created a positive space where participants were able to learn from, and how to support, their peers.

*"I realized that my experience is relevant and that I could use it to help someone out. [The training] taught me how to deal with situations in a more positive manner. Finally my downfall can be used to my advantage. And finally – I'm an expert – about freakin' time."
– TCHCP client*



Robert's STORY

When I found the TCHCP I was very sick. As a member of the LGBTQ community, I never felt comfortable with my care in the medical system. I managed a lot of how I was feeling without good information and on my own. The TCHCP changed my life. The care and support I received through the program was a big part of my success at clearing the virus. I was the first one to clear the virus in my group! Despite being

thrilled to have cleared the virus, the post-treatment phase of my care was a difficult time for me for many reasons.

Leaving the group and ending treatment meant I was back in my 'pre-treatment' world and all that came with it. I had a lot of side effects from the medication while on treatment and was coming off these effects as I tried to detox my body from all of the medications. I had also learned a lot about self-care, nutrition and harm reduction for alcohol and drug use through the group and was trying to incorporate that into my life now that I had a second chance at healthier living. I wanted to celebrate my success at clearing the virus and get re-connected to the LGBTQ community but this was difficult for me as I had been sick a long time and had stopped working and socializing. There was a sense of loss and mourning for my old ways. I isolated myself as I transitioned into being without the virus. I was worried about re-infection.

At times it became overwhelming and falling back into familiar habits to cope was easy to do. I began seeing the program's mental health counsellor. A year of weekly one-on-one counselling sessions helped me to make the connections post-treatment that I needed to become fully integrated and happy and to stay healthy in mind, body, and spirit.

I also began to volunteer in Hepatitis C and Harm Reduction related programs and community agencies. I had a strong desire to give back and do meaningful work and pass on my knowledge and experience to other people who had Hepatitis C and who were not accessing care, support or treatment.

The post-treatment phase is so crucial for people transitioning from treatment of the Hepatitis C virus back into their own life. I continue to benefit from the TCHCP post-treatment, attending a weekly group where we cook and discuss issues, and I am now employed as a Hepatitis C worker and community support advocate and activist.

PROGRAM OUTCOMES

Since 2007, the TCHCP has provided Hepatitis C treatment, support and education to individuals who would otherwise never have received this care. Our treatment success rates are as good or better than clinical trials in mainstream health care settings. The program also has other important positive impacts for clients, including increased knowledge about HCV and the ability to self-advocate, improved sense of community-belonging and overall well-being.

Clinical Outcomes

In 2010 we reviewed client medical charts from the beginning of our program (March 14, 2007) to July 31, 2010 and collected data for anyone who had attended at least 1 group meeting. We collected information on socio-demographics, group attendance, health care use and HCV treatment. Out of 129 charts, 114 people had a viral load test completed and 110 had a detectable amount of the HCV virus.

Our findings are summarized here and on page 14. They have also been published in the *Journal of Viral Hepatology* – see references.

Our review of patient charts revealed that 22% of eligible TCHCP clients started HCV treatment. This proportion is high when we consider the barriers facing our clients and that, in general, only about 1% of people with HCV who use illicit substances initiate treatment (Grebley, 2009). Prior to joining the TCHCP only 4 people had started treatment elsewhere and only one had completed it.

Of those clients who initiated treatment, only three missed any of the weekly injections and no one stopped doing treatment, unless they were a non-responder. Among those with genotype 1 (72), 54% achieved a sustained virologic response (SVR). For people with genotype 2 or 3 (38), this rate was 91%. An SVR means that the Hepatitis C virus is no longer detectable in your blood and is measured six months after treatment is completed. These SVR rates are the same as for more general populations and mainstream treatment models.

Participating in the TCHCP also improved overall access to health care. Only 19% of clients in the study had seen an HCV specialist prior to joining the program, but 59% accessed the TCHCP HCV specialist. Similarly, 53% were seen by the psychiatrist who, it should be noted, only joined the program about half way through the chart review period. The majority of program participants also received preventative primary health care including vaccinations for Hepatitis A (80% of those who were non-immune) and Hepatitis B (74%).

Further analysis of this data revealed that there was no significant association between drug use and treatment initiation. Whether or not someone was a current illicit drug user at intake had no relationship to whether or not they started treatment. The only factor that was

significantly associated with starting treatment was housing status. People with stable housing at intake were more likely to start treatment.

The TCHCP works hard to help people find housing or improve their housing situations, if necessary, before treatment begins. However, we have still successfully treated people who lived at homeless shelters while on treatment and have continued to treat people who become homeless as we worked with them to secure new housing. The program has also successfully transferred treatment to prison for clients who were incarcerated during the course of treatment.

Psycho-Social/Educational Outcomes

“It makes you more aware. It gives you an element of control over your life that you may not have realized that you had before. It gives you some kind of hope” – TCHCP client

In addition to initiating HCV assessment or treatment, the Toronto Community Hepatitis C Program has other important impacts for clients who attend the majority of one or more group cycles.

Throughout 2011/2012, we conducted three focus groups with clients (N=14) and interviews with staff (N=12), representative of all sites. Clients had attended at least 75% of one group since July 2010. Staff were representative of the multidisciplinary nature of the program team.

Psycho-social program outcomes identified include:

- Increased knowledge of Hepatitis C and capacity to share this knowledge with others
- Increased capacity to self-advocate
- Improved sense of community belonging, resilience and hope
- Development of interpersonal life skills
- Reduced or stable substance use
- Improved mental health and well-being

“My grandkids wouldn’t even kiss me on the cheek before, and now they kiss me on the cheek again. You go through a lot until you find out. And if it wasn’t for this program, I wouldn’t have found this stuff out. I took home the material I’ve gotten from the class and stuff. People come over and see it ... and I’ll show them the facts.” – TCHCP client

A retrospective chart review of clients who participated in the program up to August 2010, confirmed that clients (N=9) with serious mental health issues (defined as having one of a diagnosis of bipolar disorder or psychosis, past suicide attempt, or history of hospitalization for mental health reason) did equally well on HCV treatment, as compared with clients (N= 15) without serious mental health issues. SVR rates were comparable between the two groups, as were rates of depression while on treatment.

A qualitative study which interviewed 20 program clients also found that the program supported positive change for participants on a number of levels. A key finding was the critical relationship of the program structure to the group experience. Having a weekly, closed group with concurrent clinical services provided a vital space where participants were able to form meaningful and supportive relationships. The strength of these relationships, along with the structure provided by the group, supported participants' behavioural change. For some participants, these changes were quite monumental in scope and included returning to school or finding employment. For others, the positive change that occurred as a result of the group might simply be starting to eat two meals a day or abstaining from alcohol one day per week.

Several more research studies which will document some of the program's psycho-social outcomes are currently underway. Please contact us for more information.

Staff Impact

The program has also had a positive impact for staff on their own practices including improved: awareness regarding harm reduction concepts and strategies, ability to provide health care within a harm reduction framework, knowledge of how to work with people's readiness for change and how to develop care plans that address the social determinants of health. Staff has found the program to be personally rewarding work and many feel it has given them a renewed sense of hope to see how people with histories of extreme marginalization can do well in the right setting provided that resources are available.



PROGRAM CHALLENGES

Working with clients to overcome their extreme marginalization, poverty, past traumas and negative experiences with health care is challenging. It can require an intense amount of resources and time in order to address all of the historic damage and systemic barriers, but these issues cannot be separated from HCV treatment. Adding to this challenge is the lack of community and hospital-based mental health supports to address trauma and other issues, such as individual counselling. Mental health crisis supports are also limited. Models of mental health support that incorporate harm reduction principles are likewise rare. Alcohol use is a bigger barrier to treatment for many of our clients than other substances. The lack of integration between mental health and substance use services makes it very difficult for people dealing with both issues to access care for either. Clients are often ready to move forward with their lives and to address some of their past issues and challenges but are held back by the lack of community resources.

The community that the TCHCP serves experiences a disproportionately high mortality rate. It is not uncommon for group members to die – either from complications of their HCV, other health issues or from overdose. The death of a group member can be particularly difficult for other participants where strong cohesion and a sense of community have been established in the group. The loss of clients is difficult for both clients and staff.

Addressing the social determinants of health that lie beyond individual provider control, such as the lack of affordable housing and low social assistance rates, coupled with cuts to supplementary income supports like the special diet and start-up funds, is a major

challenge when trying to optimize the social determinants of health with clients. Systemic health care issues are another challenge. Access to tests and to new treatment medications is not always timely and the wait can be very frustrating for participants. Provincial funding denials are another barrier to treatment for some clients. After months of pre-treatment assessment work and self-care, being denied funding for medications is very discouraging and can create setbacks.

Hepatitis C is a health issue that carries extreme stigma and has sensitive political implications. The people most affected by HCV are not politically popular or well positioned to be able to advocate for themselves. Political ideology often trumps evidence and this may mean that program funding or funding for complimentary programs that would benefit clients is limited and/or unstable. Austerity measures and other policies that target marginalized individuals, such as the harsh criminalization of drug use and stricter sentencing, will continue to fuel the HCV epidemic and will create additional treatment barriers and delays.

Acknowledging our own assumptions and values as service providers is an ongoing challenge. For example, 'stable' housing may not mean the same thing for every client. A rooming house where someone has lived for years and where they have friends and other supports in place may be a suitable place from which to do treatment. Re-locating someone to an isolated bachelor apartment could be very de-stabilizing and might delay treatment unnecessarily. Being truly open-minded and aware of our own biases requires constant attention and reflexivity.



KEY PROGRAM COMPONENTS

“I don’t think there is a number one thing. It’s everything together that makes it work”
– TCHCP client

In interviews and focus groups last winter, staff and clients were asked to identify what key elements and practices of the Toronto Community Hepatitis C Program they felt were critical to its success. Below are some of the key components that were felt to be transferable:

Community-Based

Locate your program in a place where people have already had or are likely to have a positive service experience. These are generally community-based agencies that are well connected to their communities, have a reputation for providing a safe and compassionate space for marginalized individuals, and that can offer clients integrated supports. Bring specialists to the community. Primary care providers are an under-utilized resource in the management of many diseases. A mentorship model where specialists train and support primary care providers to provide care in a community setting is more efficient than the referral system. Offer as many services as possible under one roof.

Group Model

Anchoring the provision of health care services around an educational support group is an effective way to establish connection with, and provide health care services for,

marginalized clients. The group should be established as a consistent, safe, and accepting space. Group facilitators should present educational information in a way that encourages discussion and peer-to-peer knowledge exchange and support. Hire group facilitators who have a strong connection and commitment to the community and who have some personal experience with the issues your clients are facing.

Interprofessional, Collaborative Care

Put in place an integrated and inter-professional program team, which includes both regulated and unregulated health care professionals and peer workers. No single team member has to be the expert or know everything. A team where different people know different parts and know when and who to ask when questions arise will serve your clients best. Offer clients a range of mental health supports, (group, psychiatrist, counsellor, case management) to help ensure clients get the type of support they need. Have staff available that can support clients and address the social determinants of health outside of the group time.

Strive to create a program culture that values each person’s role and contribution on the team. Expect role flexibility. Every team member will need to go beyond his/her traditional job description or scope of practice at some point and roles may sometimes overlap. Commit to team

building through monthly educational team meetings and planning retreats. Be willing to “learn from, with and about other team members” (CAIPE, 2002). This is known as Interprofessional Education and is a process and commitment to learning that helps to support collaborative practice.

Partnerships

Sharing experience and resources, and learning together will make the work seem less daunting, and will be a support for your staff and program. Get to know the other health and social service providers who work with your clients (specifically and in general). Make connections with mainstream HCV treatment centres. They may be able to support your more medically complex clients and you can support their clients with psycho-social needs. Link with other programs in your agency and integrate your program so that your clients can be supported in areas that may be beyond your immediate capacity or scope. Support from management is key and supportive leadership at this level is essential for both program start-up and sustainability.

Client-Centred

Don’t make assumptions about your clients. Give people choices and set achievable goals so that everyone in the program can achieve some success towards improving their health. Hepatitis C treatment is the point of connection with clients, but it might not always be their first or only goal. Anti-viral treatment may not be the best choice or an option for everyone and treatment could mean different things to different people. Help manage treatment and program expectations by being clear about all of the various treatment outcomes. Allow for a flexible pre-treatment process and give

clients time to develop trust and to commit to treatment. This will also allow health care providers to get to know clients well and to figure out what some of the treatment concerns and risks might be. Don’t give up on people. Give them space to come back if life gets in the way.

Harm Reduction

Harm reduction is a set of strategies focused on reducing the health, social and economic harms related to substance use. Harm reduction programs are often focused on reducing the specific harms associated with substance use, such as HIV or Hepatitis C. More broadly, harm reduction is a pragmatic, non-judgmental approach to service provision that recognizes the human rights of all individuals; regardless of what substances they use, and does not require abstinence as a condition of service. Clients have voiced appreciation for this approach; for giving them the space to think about how and why they use substances while they receive support for whatever issues they choose to prioritize. Many clients will be able to continue to use substances throughout treatment without incident.

Client Involvement

The meaningful involvement of your target client group in the planning and ongoing development of your program will strengthen its accountability, innovation, relevancy, and quality of care. It will help to anticipate program needs and challenges and will improve program engagement and service uptake. Employ people with lived experience in your program delivery. Peers are often more successful than professionals in passing on information and sharing knowledge. Research has also documented

that client engagement in care and service is especially important for improving the health of marginalized populations. Allow time and allocate funding for client involvement. It may take some time to build trust with clients who have been extremely marginalized and to develop the skills and confidence to contribute. Offer varying levels of and opportunities for engagement so that clients can contribute regardless of where they are in their lives.

Advocacy

It is important to be aware of the larger, systemic issues that impact your clients, to advocate for your clients at a systemic level and to encourage them to do the same. Be part of networks, alliances and political activities that work to address the social determinants of disease. Health care workers, social service providers and researchers should also work to change harmful policies and practices within their own communities of practice. Staff should be willing to support clients by advocating for them on an individual level with other health care providers, around disability benefits, and with landlords, for example.

“People gotta care. Like, you can’t just do this job to clock hours. You gotta care about people to do this” – TCHCP client

People

The people who occupy the positions are as important as the positions themselves. Be sure to hire staff with a strong understanding and respect for your clients’ challenges and strengths. Find committed individuals with shared core values of social justice, compassion, acceptance, anti-oppression and harm reduction. Hire some

staff with lived experience of some of the issues facing your clients. Hire people who are personally dedicated and passionate about challenging the stigmas facing marginalized populations. Hire people who genuinely care about your clients and who feel that it is our collective responsibility to improve the overall well-being of vulnerable community members. Hire managers who care as much as frontline staff.

Holistic

Marginalized individuals with complex health issues will likely be facing other health and social issues. Hepatitis C is often the access point or the bridge for connecting people to supports that they have not been able to access in the past. Clients will have multiple health and social issues that need to be addressed with a bio-psycho-social-spiritual approach. The ability to offer a range of holistic, integrated supports and services that address all of these issues, including the social determinants of health, is critical to program success and to your clients’ long term overall good health.

CONCLUSION

The TCHCP has successfully provided HCV treatment and support to many people who would otherwise never have received this care. Unfortunately, our work is just a drop in the bucket – there are many, many more people who need access to adequate HCV testing, education, supports and treatment.

More interprofessional, community-based Hepatitis C teams are needed. In addition, hospital-based programs need to provide better education and supports for individuals who seek treatment in this setting. Wherever treatment is delivered, it must be client-centred and non-judgmental. Improved access to publicly funded HCV medications and timely access to new treatment options is also required. There is also a need to establish better guidelines for health care providers and to ensure that everyone who is at risk for HCV receives adequate screening, second stage confirmatory testing and counselling about their condition and treatment options. If the burden of Hepatitis C is ever to be adequately addressed, public education around HCV prevention and the greater availability and implementation of harm reduction strategies and approaches is essential. Laws and policies that continue to contribute to the epidemic must also be changed.

We hope that this program guide will inspire others to adopt similar models of care for clients who face multiple barriers and have complex health issues.

Please get in touch with us to learn more.



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RESOURCES

Below is a selection of other manuals, papers, documents and places to go for further reading about Hepatitis C, harm reduction, peer or group support models of health care:

CATIE - www.catie.ca. Check out their website for all kinds of accessible Canadian-based information and resources on Hepatitis C and HIV, including their Hepatitis C Peer Support Group Manual

The Hepatitis C Support Project (HCSP) is a non-profit organization run by and for people living with HCV. Check out their website, the HCV Advocate, for information and resources. The website can be found at: www.hcvadvocate.org.

The Crack Users Project: A Manual. Street Health. 2007. Available at: www.streethealth.ca.

Below the Radar: Exploring Substance Use in Rural Ontario. Kathy Hardill. 2011. Available at: www.substanceusestrategynetwork.org/resources.html

Shifting Roles: Peer Harm Reduction Work at a Multicultural Community Health Centre. Rebecca Penn, et al. 2011. Centre for Addiction and Mental Health & Regent Park Community Health Centre.

Peer Manual – A guide for peer workers and agencies. Toronto Harm Reduction Task Force. 2003. Available at: www.canadianharmreduction.com.

Harm Reduction at Work: A guide for organizations employing people who use drugs. Raffi Balian and Cheryl White. 2010. Open Society Foundations. Available at: www.soros.org/harm-reduction.

Super Hos – Women in the Know: A project and resource guide by sex workers. 2010. Street Health and Regent Park Community Health Centre. Available at: www.streethealth.ca.

PROS & CONS: A Guide to Creating Successful Community-based HIV and HCV Programs for Prisoners. 2011. Prisoners with HIV/AIDS Support Action Network (PASAN). Available at www.pasan.org.

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Dedication

We would like to dedicate this guide to all of the people who courageously decided to seek Hepatitis C treatment and support through the TCHCP and elsewhere; and to the many people we have lost.

We would like to make a special dedication to Stephen Henry who cleared the Hep C virus in the fall of 2011. He was a cherished friend, advocate and an original member of the Patient Advisory Board. He had contributed so much to the program. Stephen was killed in December 2011, his memory lives on.

Thanks and dedication also to Michael Carden (1969 to 2012) whose research and dedication to providing Hepatitis C treatment to people who use drugs influenced many of our decisions to move forward with the development of this program.



Toronto Community Hep C Program Guide Book. South Riverdale Community Health Centre. Toronto: 2012.

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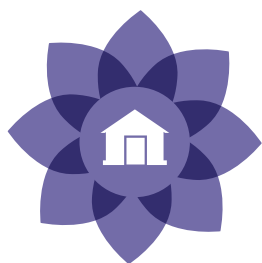
APPENDIX A: GROUP SESSION TOPICS

1. *Intro to the Group – ground rules, expectations, overview*
2. *Intro to Hepatitis A,B, C*
3. *Hepatitis C 101*
4. *HIV, Hepatitis C and HIV co-infection*
5. *Tests and Vaccinations*
6. *Mental Health*
7. *HCV Treatment*
8. *Preparing for HCV Treatment*
9. *Managing treatment side effects and the post treatment experience*
10. *Harm Reduction*
11. *Nutrition*
12. *Self-Care*
13. *Steps to Wellness*
14. *ART project – 3 sessions and display/party*
15. *Hep C Overview/Review*
16. *Last Session – group party*

Other topics that are covered from time to time, as needed, include: bed bugs, housing, diabetes, acu-detox, smoking cessation, goal setting/action planning.

APPENDIX B: COMMUNITY SUPPORT WORKER TRAINING SESSION TOPICS

1. *Introduction to Peer Work*
2. *Hepatitis C: Basics*
3. *Hepatitis C: Advanced*
4. *Hepatitis C: Healthy Living*
5. *Effective Communication/Listening Skills*
6. *Mental Health issues/illness*
7. *Harm Reduction Strategies*
8. *Conflict Resolution/Crisis Management*
9. *Ethical issues/Boundaries/Confidentiality*
10. *Housing & Income Issues*
11. *Safety for Peer Workers/De-briefing/Self-care*
12. *Community Resources*
13. *Advocacy*
14. *Graduation Ceremony*



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