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Toronto Community Hepatitis C Program Meets People Where They're At to Improve Access to Information and Treatment

Background

The Toronto Community Hepatitis C Program (TCHCP) is a health care program based on harm reduction principles. It brings together professionals from various disciplines to provide hep C (hep C) support and treatment to people living with chronic hepatitis C in Toronto.

The TCHCP is anchored by a series of hep C education and support groups that have built a community of peers with similar experiences and easy access to hep C treatment and general medical care.

The TCHCP is a partnership between the South Riverdale Community Health Centre, the Regent Park Community Health Centre, and the Sherbourne Health Centre, with integrated and on-site specialist support from Michael Garron Hospital.

Hep C is a curable virus that attacks the liver. It is spread only by blood-to-blood contact, and is most commonly transmitted in North America by sharing needles. It affects about 240,000 to 300,000 Canadians, in large part those who use illicit drugs, Aboriginal people, people in prison, people who are homeless or have low income, and street-involved youth.

Zoë Dodd, Hepatitis C Program Coordinator (second from left), sits with staff and volunteers marking World Hepatitis Day.

Despite the availability of effective treatments, many people with hep C who actively use or have used illicit substances have difficulty getting even basic information about their illness. This is due to a variety of factors:

- Misperceptions and stigma among health care professionals can contribute to beliefs that

people with hep C are not worth educating or treating because they won't follow their treatment properly or are more likely to get re-infected.

- Most specialists are either not able or not willing to provide treatment in a way that addresses the many complex social issues facing those who are most at risk of hep C.

This lack of access to treatment and information means that many people living with hep C are misinformed about the impacts of the virus and how it can be treated.

TCHCP Coordinator, Zoe Dodd, stresses the importance of support groups in filling this void: "Groups are places to heal, feel accepted, and feel less isolated. Being part of the group might even help people to build different relationships that can help them live healthier, more satisfying lives."

Approach

The TCHCP began in 2007 to create a much-needed opportunity for people living with hep C to learn about their virus. Initially, the groups were only able to offer support and information.

"After the groups had been running for a while, people started asking for better access to hep C treatment and access to medical care in general. We knew that we were in a good position to help because we already had people coming to the groups, we just needed health care providers to come too," Dodd explains.

Community-based health care centres were places where people living with Hep C already felt comfortable accessing health care. After identifying a specialist who was willing to mentor primary health care providers and meet people living with Hep C in the community, the program evolved to its current form.

Today, the TCHCP consists of a group of physicians, nurse specialists, and nurse practitioners who are available to offer clinical care while clients attend the psycho-educational support group. Members leave the group for appointments or check-ups and then return when they're finished. Program staff also provide case management and one-on-one support.

New participants are invited to attend a three-week introductory group to learn about hep C basics and if they are eligible for drug and treatment coverage (without private insurance, the province of Ontario requires a certain degree of liver damage before coverage is approved). At the conclusion of the introductory group, participants can attend a weekly ongoing treatment group at any of the three partner sites.

Group topics include basic information about the effects of hep C, the sources and impacts of social stigma, effects on mental health, and liver health.

Each group session lasts two hours - the first hour of the group is reserved for checking in with group members and discussing important things that are happening in their lives. The second hour is spent covering educational topics related to hep C, with occasional presentations or workshops from

external facilitators.

Promotion of the program relies primarily on word-of-mouth from past or current participants and most members join through self-referral.

Unlike many other group programs, TCHCP doesn't exclude so-called 'challenging' people, such as those who actively use substances or who have anger management issues. The TCHCP groups require prospective members to be pursuing hep C treatment and/or have an interest in learning more about the hepatitis C virus.

Members are given $10 plus transportation tokens to address potential financial barriers to participation and to reinforce the expectation that members will develop into community hep C educators themselves. Meals are also provided at each session.

What works and why

TCHCP structure

Dodd believes that the TCHCP (and the groups at its core) have been successful because they prioritized building trust, providing opportunities for personal empowerment, building community connections, and normalizing the experiences of people living with hep C. Providing necessary health care services onsite during group sessions also shows commitment to meeting people where they are at in a very tangible way.

Program values

The harm reduction focus of the TCHCP and its staff means that substance use is not treated as a problem to be solved or prioritized above all else. Dodd says this is important because "it gives people the space to concentrate on improving their own health goals instead of feeling coerced by professionals to focus on and limit their substance use."

Social and political awareness

The TCHCP group facilitators play a critical role in ensuring the program's success and values. The groups provide a space for individual self-reflection and critical analysis about the social and political forces that impact the lives of people living with hep C, perpetuate the conditions that promote hep C transmission, and create barriers to treatment.

Members are encouraged to address these issues by drawing on the strength of their community and joining with other relevant networks.

The program's group facilitators must have a strong understanding of how social, political, and economic conditions impact the lives of people living with hep C and must be able to have conversations that make these concepts relatable and useful.

As Dodd says, "group facilitators have to be on a similar level to the group members. They need to be willing to engage with the same degree of honesty that they expect from group members, and they have to be able to listen to what gets shared without judgment."

Community

Facilitators must also be committed to community building, aware of what's happening in the neighbourhoods where group members live, and supportive of the issues that impact their lives. This helps reinforce the importance of political and social awareness to reduce stigma and normalize people's experiences. It also actively demonstrates solidarity with members.

Lessons learned

TCHCP staff value the importance of demonstrating the impact of their approach through evaluation and research of the therapeutic and clinical value of integrating education and community development principles with psycho-educational groups.

"What we want to do is establish this kind of work as a viable approach to health care for marginalized groups and individuals, and to expand the availability of access to hep C treatment to those who need it," says Dodd.

Research published recently by the TCHCP demonstrated treatment outcomes comparable to clinical trials in mainstream healthcare settings and comparable outcomes for people living with serious mental health issues. The findings also indicate high levels of group cohesion and therapeutic alliance, as well as improvements in the overall well-being and quality of life for TCHCP clients.

For more information contact:

Zoë Dodd
Hepatitis C Program Coordinator
Urban Health Team
Toronto Community Hep C Program
South Riverdale Community Health Centre
416-461-1925 Ext. 247

Related resources:

Toronto Community Hepatitis C Program Guide

Engagement in Group Psychotherapy Among Marginalized Individuals With Hepatitis C
(Dodd Z, et al.)

Beyond viral response: A prospective evaluation of a community-based, multi-disciplinary, peer-driven model of HCV treatment and support
(Mason K, et al.)

"It gives me a sense of belonging": Providing integrated health care and treatment to people with HCV engaged in a psycho-educational support group (Woolhouse S, et al.)

Author:
Matt Hollingshead

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