

THE FUTURE OF HEP C CARE FOR PEOPLE WHO USE DRUGS: LESSONS FROM A COMMUNITY- BASED, HARM REDUCTION, CLIENT-DRIVEN PROGRAM IN TORONTO, CANADA

ZOË DODD

10TH AUSTRALASIAN VIRAL HEPATITIS CONFERENCE



TORONTO COMMUNITY
HEP C PROGRAM

OVERVIEW

- History of the program
- Program model
- Program outcomes
- Challenges and strategies related to this work



DEDICATION & ACKNOWLEDGMENT



TORONTO COMMUNITY
HEP C PROGRAM

HEPATITIS C: CANADIAN CONTEXT

- 250,000 Canadians infected with HCV (1% prevalence) with 5,000 to 8,000 new cases each year [Remis, 2004]
- Majority of new infections (70%) occur among people who inject drugs [Patrick, 2000]
- Tainted blood supply
- Only 1-6% of illicit substance users with HCV have received treatment [Grebel et al, 2009]
- HCV also disproportionately affects people who are low income, people in prison, people with mental health issues, aboriginal people and street involved youth
- Large country with huge rural areas, history of colonization
- No pre/post test guidelines for Hep C, no national strategy, restrictions on access to hep c treatment

A BIT ABOUT ME ...



TORONTO COMMUNITY
HEP C PROGRAM

PROGRAM HISTORY

- Created to address misinformation about Hep C, coupled with lack of interest/discrimination by health care providers to support people who use drugs
- Started as a small support group in the basement of a NGO
- Principles of mutual aid, peer-to-peer support, harm reduction, community development
- Psycho-education support, accompaniment to appointments, monthly Hep C testing clinic, Hep C workshops/events for frontline workers
- Goals: enable people to advocate for themselves within health care system and to create peer hep c ambassadors
- No access to treatment ... HIV treatment model as inspiration



TORONTO COMMUNITY HEP C PROGRAM

- Multi-disciplinary health and social service team
- Located at 3 community health centres
- HCV Treatment/Health Care anchored to Treatment Group
- Psycho-social/educational group support
 - Hep C 101 group (3 weeks)
 - Treatment support (weekly, ongoing)
 - Continuing Care Group (drop-in)
- On-site ID specialist support (monthly) and consultation (as needed)
- Case management re: SDOH
- Mental health counselling
- Arts programming
- People with lived experience of HCV in advisory and staff roles



TORONTO COMMUNITY
HEP C PROGRAM

INVOLVEMENT OF PWLE IN PROGRAM

- Peer-to-peer support encouraged in groups
- Patient Advisory Board
- Peer Training
- Community Support Worker positions





PROGRAM DEMOGRAPHICS

Age	54 years
Male	75%
Disability benefits, primary income (>1,000 CAD/month)	69%
IDU – lifetime history	88%
IDU past 30 days	10%
Opiate substitution therapy	22%
Drug use (non IDU, not incl. marijuana) past 30 days	31%
Genotype 1	76%
F 3/4	58%
History of mental health hospitalization	25%
History of incarceration	85%

PROGRAM ACCESS & OUTCOMES

- 34% of clients hear about us from word of mouth (often from knowing a past client)
- 1 in 5 (19% RS / 22% RS) of our clients initiate treatment.
 - This is comparable to rates in other models with patients who don't use drugs. Less than 2% of ppl living with HCV in Canada have been treated.
- Housing stability was the only factor associated with treatment initiation (drug use was not a factor RS)
- Housing stability and proportion receiving ODSP improve significantly for program clients (PS)
- SVR rates are comparable to clinical trials (old meds)
- 40% of clients have a serious mental health issue (RS), with program outcomes that are comparable to clients without SMI
- Our group dropout rate (19% GS) is low compared to other group models (30-40%)
- Group cohesion and therapeutic alliance (key indicators of positive therapeutic outcomes) are consistently very strong and comparable to other groups (GS)

CHALLENGES

- History of Hep C funding has been stop/start
- Conservative federal government for 10 years, until recently
- Working with a government who only pretends to be your friend
- Still no political motivation
- Current Hep C workforce is under resourced and overworked
- Criteria for treatment – restrictive
- Time from approval of meds to availability to the general public
- Palliative care, liver cancer and transplants
- People we are working with impacted by **poverty**, lack of housing, low social assistance rates, unemployment, trauma, incarceration



STRATEGIES/REFLECTIONS

- Didn't wait for research. Take risks, be creative.
- Brought the response in to the community
- Put people with lived experience in everything we did
- Find your allies – progressive people, harm reduction networks
- Groups – creating and supporting community – my own community and service users
- People who use drugs are not a homogenous group. People who use drugs are people.

FINAL THOUGHTS

- Hep C response has always been about exclusion – drug pricing and stigma
- Hep C treatment needs to be delivered in the community
- Not treating people who use drugs is discrimination
- Discrimination is killing people
- Keep going. Hope is our only option.
- It's not just about Hep C ... broader forces at play, it's about community.



Optimism is an absolute necessity. Even if it's only optimism of the will ... and pessimism of the intellect ... we have to encourage that sense of community, particularly at a time when neoliberalism attempts to force people to think of themselves only in individual terms and not in collective terms. It is in collectivities that we find reservoirs of hope and optimism.

~ Angela Davis

Hope is not like a lottery ticket you can sit on the sofa and clutch, feeling lucky.... hope is an ax you break down doors with in an emergency.

~Rebecca Solnit, Hope in the Dark

A victory doesn't mean that everything is now going to be nice forever and we can therefore all go lounge around until the end of time. Some activists are afraid that if we acknowledge victory, people will give up the struggle. I've long been more afraid that people will give up and go home or never get started in the first place if they think no victory is possible or fail to recognize the victories already achieved. Marriage equality is not the end of homophobia, but it's something to celebrate. A victory is a milestone on the road, evidence that sometimes we win, and encouragement to keep going, not to stop.

Rebecca Solnit, Hope in the Dark

TCHCP PUBLICATIONS

Charlebois A, Lee L, Cooper E, Mason K, Powis J. **Factors Associated with HCV antiviral treatment uptake among participants of a community-based HCV programme for marginalized patients.** *J Viral Hepat.* 2012;19(12): 836-42. [RS]

Sockalingam, S., Blank, D., Banga CA., Mason, K., Dodd, Z., Powis, J. **A novel program for treating patients with trimorbidity: hepatitis C, serious mental illness and active substance use.** *Eur. Journal of Gastroenterology & Hepatology.* 2013 Dec; 25(12):1377-84. [RS]

Woolhouse, S., Cooper, E., Pickard, A. **“It gives me a sense of belonging”: providing integrated health care and treatment to people with HCV engaged in a psycho-educational support group.** *International Journal of Drug Policy.* 2013. 24(6): 550-557. [QS]

Dodd, Z., Banga, CA., Mason, K., Meaney, C., Leszcz, L., Sockalingam, S. **Engagement in Group Psychotherapy Among Marginalized Individuals with Hepatitis C.** *Int’l J of Group Psychotherapy.* 1–23, 2016

Mason, K., Dodd, Z., Sockalingam, S., Altenberg, J., Meaney, C., Millson, P., Powis, J. **Beyond Viral Response: a prospective evaluation of a community-based, multi-disciplinary, peer-driven model of HCV treatment and support.** [Int J Drug Policy.](#) 2015; 26(10):1007-13. [PS]

Toronto Community Hep C Program Guide Book. Available in English or French from CATIE:
<http://www.catie.ca/en/resources/toronto-community-hep-c-program-guide-book>

ACKNOWLEDGEMENTS

- Program sites: South Riverdale Community Health Centre, Regent Park Community Health Centre and Sherbourne Health Centre
- TCHCP Patient Advisory Board
- Funder: Hepatitis C Secretariat, AIDS and Hepatitis C Programs, Ontario Ministry of Health and Long-Term Care.
- Hundreds of clients who have accessed us over the years

Email – **zdodd@srchc.com**

