

The needs of PWID in the future of HCV care: Implications for treatment as prevention

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Sources

Review of international literature: TasP for HCV & HIV; PWID human rights & harm reduction; qualitative HCV treatment studies

Staying Safe: (London 2010 – 2012)

- Exploration of social practices of long-term HCV avoidance
- 2-3 life history interviews with 37 PWID (22 HCV -, 15 HCV +)

HCV Treatment for PWID: Barriers & Facilitators (London 2011)

- Assessment of HCV treatment provision in D&A settings
- Interviews: 34 HCV + PWID, 13 service providers
- Literature review (Harris & Rhodes, 2013)

HCV treatment journey (London 2012 – 2016)

- Patient, provider & system perspectives: HCV treatment journey & supports
- Longitudinal interviews: 27 HCV+ participants, 18 providers/stakeholders
- Ethnographic HCV clinic observations: 100+ hours



Treatment as prevention for HCV: The promise

- **Eradication**

Modelling projections: Prioritisation & scale up of HCV treatment for PWID → prevent transmission → reduce popn prevalence → HCV elimination/eradication

Availability of DAAs “sparks an ethical call for HCV eradication and provides essential tools to spearhead the effort” [1]

- **Access**

Current context: HCV treatment routinely denied to PWID (>1% global access)

Stability assumptions and requirements further restrict access

The criteria for treatment at [X Hospital] is no drug use. Within outreach it was stable drug use – 2 to 3 times a week. (Clinical Nurse Specialist)

I know our local service won't treat them, so what's the point [of referral]? (GP)

→ **TasP a potentially powerful treatment access advocacy tool**



Treatment as prevention for HCV: Concerns

- Population needs = individual needs?

“Treatment prevents future incident HCV cases by reducing the number of transmitters, eventually stifling the epidemic.” [2]

“I am not a transmitter. That’s electricity” [3]

Alienating language → Coercive/mandatory testing & treatment? (prison, drug services)

- Implications for prevention as prevention?

“In the absence of herd immunity universal eradication of HCV is the only way to prevent reinfection” [4].

Implications for social/structural interventions?

“Treatment is not a substitute to the removal of the vulnerabilities that place people at risk of infection in the first place”. [5]

2. Hagan et al., (2013). *Treat Trends in Microbiology*, 21(12), 625-633
3. Jude Byrne in Swan T. (2014). HIV i-base/Treatment Action Group Pipeline Report.
4. Sussman et al. (2014). *Clinical Gastroenterology and Hepatology*, 12(4), 533-536.
5. Nguyen et al. (2011) *AIDS*, 25(3), 291-293



HCV treatment barriers for PWID

- **Individual**

Concerns about treatment side-effects, efficacy & duration; stigma/confidentiality; venous access; limited knowledge; mistrust

- **Clinical**

Concerns about co-morbidities, adherence, substance use, re-infection & side effect management; perceptions of treatment 'readiness', 'worthiness' & eligibility.

- **Social/structural**

Homelessness; poverty; geographical isolation; stigma; criminalisation; marginalisation; inadequate OST access; limited social supports; caring demands; eligibility barriers; treatment funding & allocation policies; lack of insurance; alienating, confusing & stigmatising health care systems.



Addressing the needs of PWID

- **Enabling treatment environments**
 - Community-based care
 - Meaningful peer involvement
 - Responsive service provision
- **Enabling living/social environments**
 - Accommodation
 - Social supports
 - Community empowerment & engagement
- **Enabling policy environments**
 - Scale up of prevention as prevention
 - Universal HCV treatment access
 - Law reform/human rights commitment



Enabling treatment:

Community based care

- Multiple barriers to hospital-based care:
 - Complex referral & appointment systems; waiting times; rigid attendance & eligibility policies; distance/unfamiliarity; stigma & discrimination

I wouldn't have gone to hospital [for HCV treatment] ... I was really badly treated ... really blatant discrimination. (Dillon)

- Movement of HCV treatment into community settings
 - One-stop shop: familiar, accessible, convenient.

It's got everything in the one place ... you're in the building with like minded people and it's easier. (Dillon)

- Cautions
 - Drug treatment & prison settings can connote surveillance & enhance mistrust
 - Adherence requirements can alienate (DOT, bottle return policies)
 - Treatment but no prevention in prison: an ethical challenge [6]



Enabling treatment:

Meaningful peer involvement

- Transformative capacity – for peers, clients & services

*“The peer support model was recognized to have **transformed the services and subsequently the experiences of service users.**” [4]*

- Required from service inception

*When we started treatment, [consultant asked] ... ‘what do you think of the service, what could we do better’ ... **it’s valuing their opinion and their input** because they’re the ones who are using the service. (BBV Nurse)*

- Cautions

- Can be tokenistic involvement / limited collaborative input
- Need for adequate support, training, professional recognition & payment
- Pilot interventions: sustainability impacts on community trust & engagement
- Definitions of ‘peer’ often unclear, can still exclude & marginalise



Enabling living:

'A flat of my own'

Accommodation → life transformation → treatment contemplation:

I've never had that feeling of security before ... It changes everything absolutely, it gives you a base you can build on ... it gives me the ability to think long term as well which is things like sorting out me Methadone treatment and sorting out my hepatitis C treatment [having a flat] made me feel a lot better about everything (Rufus)

I was made street homeless in July ... I had to go to hospital. I had twenty admissions for being drunk and I got really ill... I had to drink just to cope with my situation, it was really bad. (Alec)



Enabling living:

Community empowerment initiatives

From marginalisation / isolation

They [women] suffer in silence, they just buy it [methadone] on the street ... do what they can to survive. And then there's the fear if they've got kids. That's one of the big issues, it's their kids. (Abby)

... to solidarity / empowerment

Grief and Loss Education and Action Project engages women who are past or current drug users and who have had children apprehended by [social services] in the sharing of lived experiences, coping strategies, art-making, and action planning to work toward creating a transformed child welfare system ... group members have participated in several public speaking engagements.

<http://www.srchc.ca/program/common-ground-program>

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Enabling policy:

Commitment to human rights / equity of access

- Criminalisation impacts treatment access, engagement & adherence (ART)
- Fear of identification & incarceration impacts treatment & testing uptake:
Sometimes I'm afraid I might be sick with AIDS but I'd rather be sick and free than go to get tested, get arrested and be sick in detox or re-education through labour. [8]
- Treatment access is a human rights issue
Access geographically uneven; eligibility restrictions contravene international guidelines & impact on perceptions of treatment worth - thwarting activism

8 . Jürgens et al., *The Lancet*, 376(9739), 475-485.



Enabling policy:

Commitment to accessible & flexible harm reduction

- Effective & ethical TasP = Scaled up NSP + OST + HCV Treatment [9]
- Global NSP coverage is 2 needles & syringes per PWID per month [10]

OST flexibility aids trust & treatment engagement

I've been on [OST] script for 8 months now and they still supervise ... I'm too angry with the system at the moment. I don't really engage. (Hakki)

NSP locations & associations determine access

I'm telling [key worker] that I'm cutting down the gear and she wants to know why I'm coming round every week and getting fifty works' when I'm giving up the gear. (Colin)

9. Martin et al. (2013) *Clinical Infectious Diseases*, 57(suppl 2), S39-S45.

10. Cook et al. (2014). Harm Reduction International.



In conclusion

Meeting PWID needs → optimises TasP

- Commitment to enabling environment interventions
 - DAAs: alleviation of many individual/clinical level barriers
 - Structural / policy barriers to engagement remain
 - TasP will fail without increased commitment to prevention as prevention
 - Meaningful community involvement is crucial
- Community empowerment → increased engagement & ownership

They [PWID] have such low self esteem, they won't make a fuss, they really don't jump up and down. The idea that tranches of people with haemophilia could not be offered hepatitis C treatment because it was inconvenient or something, it's just an extraordinary concept and they would make a huge fuss, but the drug users just accept that they're not worth it and they won't go there. [Hepatologist]



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