

HEPATITIS C TREATMENT: PEER INSIGHTS TO UNDERSTANDING ENABLERS AND IMPEDIMENTS TO DAA UPTAKE AMONG PEOPLE WHO INJECT DRUGS

Susan Chong^{1,2} & Graham Brown¹

¹ Australian Research Centre in Sex, Health and Society, La Trobe University

² Department of Public Health, La Trobe University

Background

The listing of direct-acting antiviral (DAA) medicines for people with hepatitis C on the Australian Pharmaceutical Benefit Scheme has set the trajectory to eliminate hepatitis C. A key component is treatment for people who inject drugs living with hepatitis C. Initial uptake of treatment among people who inject was promising but uptake is now slowing. This study investigated the evolving barriers and motivators for people who inject to access DAA medicines and the implications for scaling-up testing and treatment. Different strategies may be required to engage people who inject drugs who are reluctant or sceptical about the new DAA treatment or may have barriers to accessing treatment.

An 18-month project was developed in collaboration with three peer-led organisations – ‘Harm Reduction Victoria’, ‘New South Wales Users and AIDS Association’ and ‘Peer Based Harm Reduction Western Australia’. These organisations have on-the-ground insights from their networks of people who inject regarding their current attitudes, beliefs and experiences related to the access and scale-up of DAA treatment among people who inject drugs. Three ‘broadsheets’ were produced presenting findings and recommendations for rapid dissemination to stakeholders working in the hepatitis C and blood borne viruses sectors.

Method

Peer workers from the injecting community have unique insight into the experiences of people who inject, including those who may not participate in research/consultations. This study drew on the perspectives of peer workers and volunteers and their networks to investigate experiences of people who inject regarding DAA treatment scale-up.

Nine focus groups and five semi-structured interviews (N = 75 participants) were conducted across Australia in three phases with:

- i. Peer workers and volunteers from three collaborating peer-organisations to obtain insights on people who injects uptake of DAA treatment.
- ii. individual persons who inject on their engagement with DAA treatment.

Thematic analysis was conducted on the data collected.

Findings

Stumbling blocks to hepatitis C testing and accessing DAA treatment

- I.
 - A) Inconsistencies in hepatitis C knowledge
 - B) Uncertainties about direct-acting antivirals medicines, e.g. side-effects, eligibility for and access to treatment
 - C) Current health status, e.g. poor vein health
 - D) Hepatitis C stigma
 - E) Implications of hepatitis C diagnosis

“A whole Pandora’s Box of conversations you don’t want to have”

“when people find out [the person who injects has hepatitis C] ... they’ve got the problem, you are actually a junkie ... that’s all the stigma”

“Some people are scared that [hepatitis C] will impact on future prospects ... child protection, employment ... once it’s recorded it’s recorded.”

- II. Deep-rooted obstacles within themselves that are akin to a ‘cloud’ of doubts, - “Lots of people [who inject drugs] say that they are not deserving of [treatment]”

“It doesn’t take much to just derail you ... we’ve all got a lot of this ... negative self-talk going on and internal conflict”

“when you miss an appointment then you feel like crap because someone’s gone and done all this stuff for you, trying to get you in and you miss it and then you feel bad because someone’s done work for you and you haven’t turned up and it’s like I can’t put them through that again ... guilt”

Health service providers and DAA treatment

Being stigmatised and discriminated against while seeking medical assistance adversely influences the health seeking behaviour of people who inject, and deters contact with health services unless unavoidable.

“One bad experience can scare people ... like the fear of experiencing stigma can stop people from doing something [hepatitis C test and/or treatment]”

Positive experiences with non-judgemental and considerate health workers are likely to encourage repeat visits by people who currently inject. ‘Untroublesome’ and empathetic service providers are promoted among the network of injectors.

“if you have got a good doctor, you will travel”

Value of a peer workforce

Non-peer needle syringe programs (NSP) are perceived as more ‘user-friendly’ if an identified peer worker(s) is integral in their workforce. Meaningful participation of peers signals a service is informed by, and values, the expertise of people who inject.

“[Peer worker] has been in the same environment [drug use] so they can relate. I can be honest within myself to talk to you and I know that you’re not going to piss in my pocket and hate me and look at me and throw daggers at me while I’m asking you a simple question about an issue of drugs. That’s the difference.”

Recommendations

We found generalised hepatitis C treatment awareness campaigns were having reduced impact, and conflicting advice and messaging detracted from testing and DAA treatment efforts. In addition, stigmatising experiences encountered by people who inject were undermining scale-up programs. We propose the following:

- Different and targeted approaches and communication emphasising the benefits and relevance of DAA treatment are needed, to enhance confidence and re-invigorate interest in DAA treatment
- Consistency and alignment across all sectors in DAA treatment information, e.g. eligibility, cost, side-effects, ‘cure’ definition, particularly in regional and country areas are crucial
- Good practice by health providers works and should be shared within injecting networks - non-judgemental, prompt, and user-friendly assistance and support at health services and treatment sites are vital
- Inter-sectoral collaboration to address complex social and systemic barriers to treatment, e.g. homelessness and food insecurity is critical – ‘life matters’
- Regional and country areas require strategic investment to strengthen health services and peer-led initiatives to scale-up DAA treatment
- Embedding a peer workforce at a needle syringe program site would demonstrate commitment to engaging with the injecting community. Organisational leadership, structure and resourcing are essential to support integration of peer approaches.

Conclusion

Peer workers and volunteers “feel the pulse” of the injecting community and their insights are vital to the development of approaches to increase access to DAA treatment. Harm reduction and hepatitis C agencies have integrated findings from this research to strengthen policy advocacy strategies and health promotion interventions to tailor to communities of people who inject.

