Access to hepatitis C treatment for people who inject drugs: A case study of challenges and successes in drug and alcohol settings

Magdalena Harris, Tim Rhodes, Anthea Martin
London School of Hygiene and Tropical Medicine
magdalena.harris@lshtm.ac.uk

World Health Organization
REGIONAL OFFICE FOR Europe

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

Overview

- Why HCV treatment in D&A?
- The study / sites & participants
- Challenges
- Successes
- Discussion / recommendations

Why HCV treatment in D&A settings?

- PWID interested in HCV treatment - uptake low
- Multiple barriers to access, uptake & completion
  - Social structural barriers (homelessness, poverty, geographical isolation, criminalisation, OST access, lack of social supports, caring demands)
  - Hospital–based treatment barriers (Inconvenience, waiting times, rigid criteria, stigma and discrimination)

"I wouldn't have gone to hospital [for HCV treatment]... I was really, really badly treated and I know loads of people that have been treated abysmally down there, really blatant discrimination." (Len, SU, Site B).

- D&A: convenience & familiarity (non-judgemental??)

The study

- What are the facilitators and barriers to HCV treatment access, uptake and completion for PWID in D&A settings?

- Sites: 2 partnerships between London D&A and hepatology services: Site A (established) & B (pilot)

- Interviews:

  34 service users: 29 male, 5 female
  : Aged 31 – 60, average 44 yrs
  : 33 on opiate substitution therapy (OST)
  : Tx status: Not started: 14 ; Interrupted: 5
  Completed: 13 (SVR: 9 =yes, 3 = no), Ongoing: 3.

  13 service providers: Hepatologists, BBV nurse specialists, psychiatrists, D&A managers & BBV nurses.

Partnership challenges

- Negotiating organisational cultures / mistrust
- Workloads, training requirements
- Eligibility criteria
- Infrastructure issues
- Boundaries/aftercare
- Co-morbidities / psychiatric support

Organisational cultures/mistrust

"The two services are very different ... We look as though we are very regimented ... [liaison] was good at saying to us 'they don't understand where you are coming from, they think you're being very formal' and then saying to them 'well they have to do it, those are the governance structures at [hospital].'"

(Senior Viral Hepatitis nurse, Hospital Site B)

"[Hospital] is an elitist organisation that sees themselves as the pioneers and at the forefront of everything"

(BBV nurse, D&A Site B)

Workloads/ training

"The commissioner's slant is that we need to support the key workers in improving their skills to take blood and do the screening themselves. It's the same old problem, their caseloads are getting bigger, as individuals they're being asked to do more, whether or not they achieve that. I mean the expertise won't be there, the knowledge won't be there." (BBV nurse, D&A Site B)

Eligibility criteria?

"We'd never done an outreach service and we'd never treated drug users so we tried to come up with a sensible criteria of no more than 40 units of alcohol a week, stable injecting drug use, a couple of times a week ... stable home life, they needed a fridge ... one of the consultants said I don't want any injecting of crack, they felt that it made patients more vulnerable. So that's how the referral criteria came about".

(Senior Viral Hepatitis Nurse, Hospital Site B)

"The problem with all those [criteria]:'mustn't be doing this, mustn't be doing that,' is that you can get into terrible, pointless and fruitless discussions with the patients and withholding treatment when actually, it is worth a go ... [We] don't care if they are injecting or not injecting. Don't care about any of that as long as they are stable" (Psychiatrist, D&A Site A)

Innovative practice / What works?

- Flexible appointment policies
- Holistic care
- Service user involvement
- Tailored phlebotomy services
- Practical supports
- Continuity of care

Flexible appointment policies

"We're quite flexible about seeing patients, we don't necessarily have an appointment system ... Usually, I will see patients as and when they come in, I'll pick them out of the waiting area or they'll ask to see me."

(BBV nurse, D&A Site A)

[Flexible appointments are important] "because sometimes you don't know how you are going to be feeling. Sometimes you can wake up and when you going through depression and that, you get your ups and your downs, Its a tackle each day really. You've got bad drug habits, drink habits, depression." (James, SU, Site A)

Holistic care

"That is why it worked well, because [the service] wasn't dedicated to just doing hep C treatment, it was a health service for drug and alcohol users. So it started off for hep B vaccination ... then it was wound care, they had a midwife that was doing smears ... everything was evolving, based on the needs of the client group ... and the hep C treatment evolved out of that." (BBV nurse, D&A service Site B)

Service user involvement

"When we started treatment, [the hepatologist] went and he saw 3 or 4 patients. He [asked] 'what do you think of the service, what could we do better' and they really appreciated that, because it's valuing their opinion and their input because they're the ones who are using the service."

(Senior Viral Hepatitis Nurse, Hospital Site B)

Tailored phlebotomy

I kept on saying to [hospital phlebotomist], 'Look, you know, my veins are a nightmare, you know, let me do it'. [She said] 'Oh you people, you think you know about your veins and all that, when you know nothing'. (Dillon, SU, Site B)

"I've had clients come that immediately say "you're not testing me because nobody can get blood off me, I'm not having you poke around and stab me". Then I'll just have to get through that barrier and ... listen to them because very often, they do know where the vein is because they use their veins to inject so they know which veins."

(BBV nurse, D&A Site B)

Benefits ....

"For once I'm actually sticking to something and doing something. Because usually I fuck things up, so I feel really proud of myself for sticking through it, but I don't want to talk to soon because I ain't finished yet, but to get this far that's even an achievement for me." (Alec, SU, Site A)

"I don't think I'll be going back to injecting drugs...The treatment's really handy in the sense that I'm going to jeopardise so much if I use. ...It's much easier to just abstain from [injecting]. But I don't think I would have been able to do this treatment not being on the methadone." (Sam, SU, Site B)

Cautions ….

"They're writing you your prescription, if your key worker tells you to do this [go for an appointment] you do it." (Len, SU, Site B)

"One of my nurses, she had a patient on treatment who never used to turn up for his appointments. She knew where he would be, in which doorway on the High Road. So if he didn't come, she'd go and get him. So you just get to know your patients, get to know where they are."(Manager BBV team, Site A)

Conclusions

- Multiple barriers to HCV treatment for PWID in hospital settings
- Research shown that PWID interested in, and can successfully complete HCV Tx
- Need for tailored client-centred treatment
- Challenges for institutional partnerships
- However – possible, feasible & successful

Recommendations

- Taking treatment to service users
- Peer support / involvement
- Flexible appointment policies
- Holistic care
- Tailored phlebotomy services
- Flexible OST provision
- Flexible adjunct prescribing protocols
- Enhanced information provision
- Continuity of care
- Benefit & accommodation support provision

Acknowledgements

- The 34 service user participants
- The 13 service providers
- Lorraine Hewitt House & Kings College Hospital
- Specialist Addiction Unit & Royal London Hospital
- The European Commission
- The World Health Organisation Regional Office for Europe
- Centre for Research on Drugs and Health Behaviour, LSHTM