Hepatitis C testing & treatment for PWID:

Barriers and facilitators

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THE CENTRE
FOR RESEARCH ON DRUGS
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Overview

- LSHTM Research
- Max: a case study
- HCV testing : barriers & facilitators
- HCV treatment : barriers & facilitators
- Working in partnership: successes & challenges
- Recommendations

The research

- *Staying Safe (2009 – 2012)*

Q: What helps long term injectors stay hep C free?

Sites: Brixton and Islington, London

Interviews: 38 PWID (2 interviews & life timeline)

- *Hepatitis C treatment study (2011 – 2012)*

Q: How well is hep C treatment provided in D&A settings?

Sites: 2 partnerships between D&A and hospital services

Interviews: 36 service users & 13 service providers

Case study: Max (38 yrs old, 20 yrs injecting)

"I've never had a test. I don't want a test … I don't feel I'd be strong enough in my mind if I did have it to handle it and it could make me spiral worse out of control. That would be my reason. "

"I had one doctor who tried to, you know, "Oh you need to go and get tested," and like he'd frighten me then and I'd go and see another doctor next time."

"They said to go up to the hospital [for a hep C test]. And it's like, I couldn't be bothered to go up the hospital."

What is it about getting tested, why does it scare you so much?

"Just the fright of it, if I did have it probably, I don't know, the fright of it." (Max, SU, SS)

Max cont.

"So if I did have it, if I did, what would happen? What would happen then when you've got it. Where do you go from there?"

"As long as I know it's curable then I can face it."

"She can't get blood out of me. She can't get blood out of me."

"When I got it done I was really grateful and happy and I thought well I'm glad I got that done. But it's madness not having it done before isn't it, really."

"I'm glad because you lot basically made me get tested 'cause I wouldn't have got tested, I would have just left it, I would have."

Testing: barriers (lessons from Max)

- Fear / HCV literacy
- The D&A encounter : mechanisms of 'offering'
- Hospital & GP settings / stigma
- Phlebotomy
- Also: RNA testing & results delivery

Fear / the D&A encounter

1. Fear: HCV literacy

2. D&A services – just ticking the box?
   - Forms
   - Knowledge deficits
   - Training needs

"The NTA guidelines are about offering [testing]. They're not about delivering. And those two words are extremely different" (Hepatologist, London)

Hospital & GP settings

If they said, go to the hospital – fuck that. I don't like hospitals. (Ros, SS)

I am registered with a GP I think. But she's such a cow and she just treats me like shit because I'm a drug user, and I don't go. (Jeff, SS)

If a doctor wanted to examine us and I'd roll my sleeves up and I've got track marks, it was embarrassing man, it was horrible. (Colin, SS)

Phlebotomy

I kept on saying to [nurse], ‘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, HCVtx)

“They’re telling me to go and have blood tests, I can’t go and have blood tests because they can’t get any blood and they can’t get a vein … I just don’t go.” (Malcolm, SS)

Results / PCR

"Even when I was in hospital and they said they're taking blood off you, they don't tell you the results then, they don't tell you nothing." (Malcolm, SS)

"While I was in gaol … they just never come back with any results. So I presumed that everything was perfectly alright … and obviously I wasn't clear." (Jack, HCVtx)

"They didn't tell us it was just the antibodies, they just said, "you've got Hep C", so I just left it at that and thought, "right, just leave it, I've got Hep C and what?" (Abby, SS)

"I had Hep C. In my head with Hep C I was dying … in my head everything was lost. If I was HIV I just, I didn't care. I was Hepatitis C positive and for me it was enough to give up life" (Marco, SS)

Testing: facilitators

- Knowledge: HCV & treatment literacy (support & access)

"As soon as I found out I wanted to know how to get this out of the way. What treatment could I do to get rid of it? … So I knew. Not knowing where you stand is worse than knowing, I think."
(Jeff, HCVtx)

- On-site skilled, non-judgemental and flexible phlebotomist (also DBS testing)

"I've had clients that say "you're not testing me because nobody can get blood off me" … [I] 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, London D&A)

Treatment: barriers

- Hospital setting

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

- Eligibility criteria

"I didn't realise that you could be on treatment if you're using occasionally. When I heard that, I told them, 'Well in that case, I want to start the treatment straightaway'." (Ben, HCVtx)

- Also – stigma, side effects, lack of supports, unstable housing, gender, other priorities etc….

Gender

[Service user rep] said that a lot of women users don't want to come to services like this.

"Because they're intimidated by the men … they suffer in silence. They suffer in silence, they just buy it on the street, buy their Valium, buy the Methadone here and there, do what they can to survive. And then there's the fear if they've got kids." (Abby, SS)

"The ones you see at [service] are mostly sex workers and they obviously don't want to be feeling unwell when they've got to work. We've had a few women, young women, who wanted the treatment because they wanted to get it cleared before they had children. But we've got a few older women who really, really need to get treatment and they're not doing it."

(BBV head, London D&A)

Treatment in D&A settings

"We're going to a place that's convenient for patients, it's a place they know, it's a place they feel comfortable, it's a place where their key worker can come to the consultation too, if they want. They can coincide it with any appointments they've got there. It's good for us for learning, for seeing what the drug and alcohol setting is like, what issues they face." (Viral Hepatitis Nurse, London Hospital)

What works

- Flexibility (appointments, eligibility, substance use, OST provision)

  "We're quite flexible about seeing patients, we don't necessarily have an appointment system ." (BBV nurse, London D&A)

- Holistic care

  "That is why it worked well, [the service] wasn't dedicated to just doing hep C treatment, it was a health service for drug and alcohol users. 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, London D&A)

- Service user involvement

  "I said to [hospital] it's a good time for peer supporters to be involved [in hep C treatment], but we want something in return. So they've offered us any training that we want, anything to do with blood, which is cool" (Len, SS)

Working in partnership: Challenges

- Organisational 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, London Hospital)

- Work loads / priorities

"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, London D&A)

Treatment: 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 [treatment] … to get this far that's even an achievement for me." (Alec, HCVtx)

"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."

(Sam, HCVtx)

Conclusions

- Multiple barriers to HCV testing and treatment for PWID (mainstream services, phlebotomy, fear, stigma etc)
- Low HCV literacy among service users and providers
- RNA tests – mandatory? Reporting back on ALL results.
- Research shown that PWID interested in, and can successfully complete HCV Tx
- Treatment & testing in D&A services – increased flexibility
- Challenges for institutional partnerships
- However – possible, feasible & successful

Recommendations

- Taking testing and treatment to service users (outreach, D&A services)
- Enhanced HCV information provision (fear tactics don't work)
- Training : Service users and service providers
- Service user involvement
- Female friendly services
- Tailored onsite phlebotomy services
- Flexibility: eligibility criteria, substance use, appointment policies, OST access

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