Working in partnership: Challenges and innovations in HCV treatment for people who inject drugs

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Overview

- Why D&A?
- The study / sites & participants
- Challenges
  - Organisational
  - For service users
- Innovations / what works
- Discussion / conclusion

Why HCV treatment in D&A settings?

- PWID interested in HCV treatment - uptake low
- Multiple barriers to access, uptake & completion
  - Policy / funding / structural barriers (housing, transport, criminalisation, OST access, financial & 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, South London).

- 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: East London & South London
- 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.

Site specifics

- East London: Specialist D&A + Hepatology (2005 -)
  - SU with multiple co-morbidities
  - "we will treat anything that walks"
  - Medically orientated – Provision of acute healthcare
  - All key workers are nurses, BBV team
- South London: Community D&A + Hepatology (2011 –)
  - D&A nurse facilitating treatment
  - Hospital-based nurse provides weekly HCV Tx outreach
  - Mental health/social care orientated
  - Strong history of service user involvement

Partnership challenges & decisions

- Organisational cultures / mistrust
- Workloads, training requirements
- Infrastructure: Information sharing / testing
- Eligibility criteria
- Adjunct prescribing
- 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].'" (Mary, Senior Viral Hepatitis nurse, South London Hospital)

"[Hospital] is an elitist organisation that sees themselves as the pioneers and at the forefront of everything. Well actually, they're not at the forefront of outreach services because it's been done very successfully in different areas ... [the hepatologist] is not confident or trusting in respect of nurses leading on it [HCV Tx]." (Sarah, BBV nurse, South London D&A)

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." (Sarah, BBV nurse, South London D&A)

Infrastructure / confidentiality

"We've had difficulty with the two IT departments interacting and understanding what we need because those systems still aren't set up properly. So we've had to find ways around, we've had to send information via NHS net, we've had to make notes with just initials on so that confidential information isn't identifiable"
(Mary, Senior Viral Hepatitis Nurse, South London Hospital)

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".
(Mary, Senior Viral Hepatitis Nurse, South London Hospital)

"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" (Brett, Psychiatrist, East London D&A)

Adjunct prescribing?

"You can give medications to try and support people through [HCV treatment] and that's one thing about this outreach treatment that I think is missing, they haven't taken that into account ... getting [service users] through the week if they're feeling dreadful and nauseous, if you're saying you have to go to your GP to go and get an antiemetic, is that person going to walk out the door and think 'do you know what, sod it, I'm not doing it'. But if you give them the packet of tablets in their hands, are they going to say 'alright, well let's give this another week and see how we get on' and it might be that week that it actually gets a bit better." (Sarah, BBV nurse, South London D&A)

Boundaries /(aftercare?)

"Some of our patients don't have many friends and quite a lot of them are estranged from their family ... you have to be careful, you have to make sure that the patient understands that you are ultimately doing your job and you're not their friend ... some patients who are having trouble at the end of treatment, disengaging a bit, we actually carry on seeing them for a few weeks, every couple of weeks ... because it's funny how they can start acting out a bit towards the end and getting a real pain ... I think it's panic, sometimes, that treatment is finishing, they've got quite reliant on you."
(Mary, Manager BBV team, East London D&A)

Service user concerns /challenges

- HCV treatment side effects (adjunct prescribing?)
- Service provision: information / mistrust
  : OST (supervised?)
  : provider attitudes
  : phlebotomy
  : confidentiality
- Support needs: caring responsibilities/home help
  : aftercare
- Structural issues: housing/transport/benefits

(mis)information / mistrust

"They never said nothing like "yes it [HCV] could clear and then be alright for a little while then come back". I didn't know that." (Sam, SU, South London)

"I was relapsing, I think they [urine] tested me as well for that ... To see whether or not you're lying to them ... they don't want you to mess up the treatment, if you take certain drugs on top of the [HCV] treatment the contraindications of those drugs could really give you quite a bad time." (Sam, SU, South London)

OST / supervision

"Knowing that I've got it there, to wake up in the morning. I haven't got to rush out to get it at the chemist before I've even had a wash or anything ... I get it weekly, I've been trusted for a long time"
(Matt, SU, East London, weekly pick-ups)

"I've been on the script for about 7, 8 months now and they still supervise. I don't know what they think I'm going to do. It's just silly really. It pisses me off... I'm too angry with the system at the moment. I don't really engage." (Alec, SU, East London)

Provider attitudes

"The main thing is to be treated with respect, that is, just the same as everybody else. Service users just want to be treated properly, not as a problem" (Len, SU rep, South London)

"There is a lot of evidence that having someone on reception who takes an interest, who's quite welcoming [makes a difference] ... In the general hospital you get our patients who might not have had a bath for six months and they walk in late and the receptionist maybe doesn't understand about people with drug problems so bites their head off and they say "well, fuck off then", and you never see them again. The first experience of a clinic is so important."
(Brett, Psychiatrist, East London D&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."
(Kate, BBV nurse, East London D&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, East London)

Holistic care

"Its been quite an organic growth, we've picked up things like tissue viability skills, skills around leg ulcer dressings and things like that because we were trying to meet the needs of our patients" (Kate, BBV nurse, East London D&A)

"That is why it worked well, because [the East London] 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." (Sarah, BBV nurse, South London D&A service)

Service user involvement

"I said to [hospital] it's a good time for peer supporters to be involved, 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, SU rep, South London D&A)

"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."
(Mary, Senior Viral Hepatitis Nurse, South London Hospital)

Tailored phlebotomy

"You do have to have good phlebotomy skills, otherwise you're going to make your life and their life a misery ... you've got to be able to go just anywhere. So I think that can be a barrier, from what I've seen of some other services."
(Ellen, Manager BBV team, East London D&A)

"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."(Sarah, BBV nurse, South London D&A)

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, East London)

"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. And plus it's going to make me feel shit on top of all this medication. 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 ... it must help alleviate some of the symptoms."
(Sam, SU, South London)

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, South London)

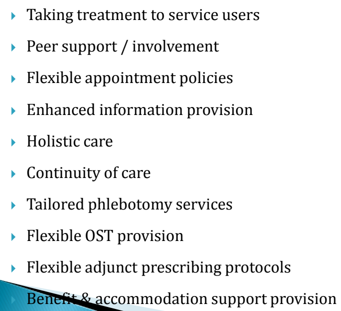
"One of my nurses, she had a patient on treatment who never used to turn up for his appointments. She knew where he would be, in which doorway on the High Road. So if he didn't come, she'd go and get him. So you just get to know your patients, get to know where they are."
(Ellen, Manager BBV team, East London D&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
- Enhanced information provision
- Holistic care
- Continuity of care
- Tailored phlebotomy services
- Flexible OST provision
- Flexible adjunct prescribing protocols
- 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
- World Health Organisation