



Hepatitis C Treatment Access In Context

A role for qualitative research

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Outline

- **How to think about treatment access**
 - Treatment engagement as a product of social condition
- **Preliminary findings from a qualitative case study**
 - Narratives of treatment contemplation and expectation (“set”)
 - Systemic factors shaping the accessibility of treatment (“setting”)
- **Implications**
 - Practices to modify systems to facilitate treatment accessibility
 - Narratives of treatment expectation are shaped by system effects
 - Qualitative research has a role in future intervention pilot studies

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Unpacking treatment access

- **Individual-level effects**
 - Toxicity, side-effects
 - Treatment literacy, knowledge, expectation, intention, decision
- **Meso-system effects**
 - Care setting (familiarity, adaptability, organisational culture, expertise)
 - Administration processes (appointments, waiting, eligibility)
 - Communication processes (user-provider therapeutic and social relations)
 - Intervention processes (integrated, tailored and social intervention)
- **Macro-system effects**
 - Social stigma, constructions of ‘deservedness’ and ‘patienthood’
 - Cultural scripts regarding treatment expectation and effect
 - Structural conditions (housing, income, geography, criminalisation, policy)

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London case study

- **2 sites**
 - Partnerships between drug/alcohol and hepatology services
- **Interviews with service users (n=35)**
 - 29 male, 6 female
 - 32 receiving opioid substitution therapy
 - Treatment: 13 not started; 6 ongoing; 4 interrupted; 12 completed (9 SVR)
- **Interviews with service providers (n=14)**
 - Hepatologists, blood-borne virus nurse specialists, psychiatrists, drug/alcohol service managers

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A: “Set” – how participants’ narratives of hepatitis C and treatment expectation shape their help-seeking...

three themes:

- liminality of hepatitis C
- rationed treatment expectation
- treatment as ‘recovery’

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The liminality of hepatitis C

Felt wellness – help-seeking postponed

I wasn’t feeling pain or anything. I would have been happy going through life not having the treatment. [Stevie]

Felt sickness – treat when it hurts

It is only now that I’m starting to feel a bit ill that I want to do something about it... I don’t know what the symptoms for hep C are, but I know I don’t feel as well as I used to... I just haven’t got the ‘get up and go’. I haven’t got the strength I used to have, and I get tired easily... I shouldn’t be as debilitated as I am by my age, so it must be the hep C, that’s what I’m starting to realise. Maybe if I could get the hep C treatment, then maybe I’d start feeling better? [Johnny]

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The liminality of treatment

Illness liminality compounded by treatment uncertainty

From what I know, the cure is worse... The medicine is worse than how ill you are... There is no point putting yourself through a year’s worth of trouble for nothing... I’m not critically ill, so I mean I could carry on without treatment and not be too bad... Maybe I’m better off just as I am. [Johnny]

What’s the point in going and having treatment where I’m going to have bad side-effects? [Stevie]

He said more like a 35% chance [to clear the virus] to be realistic about it. I was thinking what’s the point of even starting it then, if it’s got such a bad chance? [Mark]

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Rationed treatment expectation

Treatment is not an automatic entitlement

I’d build up, from chatting to other people and stuff, that treatment for hepatitis was rationed, they didn’t treat IV users. I got feedback ‘You don’t want to bother because they’re not going to treat you’, and my experience was the same as well, I hadn’t been treated... It was terrible, it was really awful. No one would treat me. [Peter]

Ah, a drug addict, she’s inferior and somehow deserves it. I can help you, but now you have to be grateful! [Bibi]

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Rationed treatment expectation

Treatment entitlement requires performing stability

I said to them basically that I still kept on slipping up, that I was injecting drugs, every whatever it was... It was every like now and then, but I was still injecting. And he [clinic nurse] said to me 'Look, the only way we're going to accept you in for treatment is if you stop injecting, right, and don't take drugs'. So, I thought, 'Oh, bloody hell, that's going to be really difficult'...

The words were 'We don't want you injecting drugs. It's as simple as that'. It affects your treatment. You can re-infect yourself, so what's the point?'... [Jed]

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Rationed treatment expectation

Treatment entitlement is a negotiation

I'd given up injecting, and I was just relapsing a little bit with smoking every now and then, so I felt that I could be given the treatment... Because I was smoking it, 'You've got to stop doing that, and you have to come back in three months, and if you've abstained then we'll look at your next steps'...

They didn't really want to treat me... It eventually got to the stage that I actually hadn't injected for about eight months...

I went down to the doctor and said 'Look, I've had enough of this, I've been doing my best, I've done my best to give up injecting, which I've done... I'm not stupid. Don't treat me like an idiot'... [Jed]

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Rationed treatment expectation

Treatment as recovery habituates help-seeking delay

She [specialist] said I'd have to stop doing everything, you know, because I was still using occasionally... For at least a year, six months to a year, for my body to be clear before they could start treatment... So I went away thinking, 'Well, I don't know how I'm going to, you know, it's going to be harder than I thought'... I wasn't injecting, but I was just occasionally, like twice a week, I'd have a little smoke. But she said I'd have to cut all that out. It got into my head that I had to be totally clean before I could start treatment... I just thought well, this treatment is just something I'm just going to have to wait for. [Ben]

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Rationed treatment expectation

Treatment as recovery governs access deservedness

I had to keep my mouth shut, and you know, I wasn't a productive member of society, that's what I felt. I wasn't someone who was going to make a difference to society, you know. He had more important patients than me, that's what I felt, you know...

He was like a 'cure them' doctor. He wanted to cure me... Why should I give it to a junkie when I can be treating a more productive member of society? [Peter]

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B: “Setting” – how treatment setting shapes the treatment experience and narratives of treatment engagement...

four themes:

- administrative processes
- eligibility criteria
- integrating holistic care
- tailoring intervention

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Treatment setting

The inaccessibility of the hospital system

I wouldn't have gone to hospital [for treatment]... I was really, really badly treated, and I know loads of people that have been treated abysmally down there, really blatant discrimination... People are saying ‘They are bastards to me, and they’ve probably never been to [hospital]’, half of them. It’s just that went around so it’s fact, you know, if not a fact it becomes a fact after a while. [Dillon]

They don’t fit the box so you’ve got to make the box fit them, and I think that’s where it all falls down with secondary care and hospital. Hospitals, it’s not that they won’t do it, they can’t do it. They can’t tailor the system to fit the client. [Nurse]

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Treatment setting

The familiarity of drug/alcohol services

I went to go and see them in [Hospital] and they seemed weird. Different, just different... It wasn’t as personal... Having a friendly face there is definitely under estimated... As soon as I told the consultant what drugs, what medication I was on, he was like ‘Oooh’, he sort of like recoiled a bit. [Kyle]

A lot of it is personal interaction... And they’re in an environment where there are people they can trust. So you’re not coming to see some strange consultant in a strange environment. You’re on home turf with nursing staff who’ve looked after you for years, who you’ve got some degree of trust with. [Hepatologist]

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Administrative processes

Appointments as a hurdle to access

I wanted to do something about it, and it was though they [hospital] were like stopping me or just, you know, putting walls in my way to get treatment. And it’s like, you know, ‘I don’t want treatment then’, you know, ‘Have your treatment. Fuck you’, sort of thing. [Dillon]

There is quite a complicated bedding into the system... I think putting those hurdles in place, they don’t come, they give in. So, if you say you’ve got to have four clinic appointments before you can start treatment, they drift away by the end of the second one... Why the hell should you bother keep coming back if you’re not getting anywhere? [Hepatologist]

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Administrative processes

Flexible appointments as a facilitator to access

It's almost like they're given a set of appointments to jump through, to make sure, in some way, that if they keep turning up and turning up, that eventually that means they're committed and then you start treatment. I don't actually think that works... What you need to do, as soon as a patient says that they're interested in treatment, is to start them then... It's worked with us... [D&A Nurse]

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. [D&A Nurse]

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Eligibility criteria

We'd never done an outreach services, 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... stable home life, they needed a fridge... One of the consultants said I don't want any injecting of crack, they felt it made patients more vulnerable. So that's how the referral criteria came about. [D&A Nurse]

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... as long as they are stable. [D&A Psychiatrist]

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Integrating holistic care

It's 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. [D&A Nurse]

That is why it worked well, because 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. [D&A Nurse]

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Tailored intervention

The example of phlebotomy

In hospital based services... they're only allowed to take blood out of their arms, and maybe their hands, which are the first veins to go. So that is a huge barrier. [D&A Nurse]

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]

I've had clients come that immediately say... 'I'm not having you poke around and stab me'... Listen to them because very often, they do know where the vein is, because they use their veins to inject. [D&A Nurse]

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Summary

- **Set**
 - A narrative of ambiguity concerning illness identity and treatment effect
 - A narrative of rationed treatment expectation and entitlement
 - A narrative of treatment as part of a trajectory towards recovery
 - **Habituated treatment delay until felt sickness or self recovery**
- **Setting**
 - Mistrust in the health care system, especially hospital settings, act as a barrier to treatment uptake
 - Providers facilitated user engagement by 'taming' systems through 'negotiated flexibility' regarding appointments, eligibility, and tailored intervention
 - **Drug and alcohol settings more amenable to adaptation**

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Case study references



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Acknowledgements

- ▶ Service users
- ▶ Service providers
- ▶ The services involved
- ▶ The European Commission
- ▶ The World Health Organisation Regional Office for Europe
- ▶ National Institutes of Health Research
- ▶ Helene Wells and Emma Jolley at LSHTM

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