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Full title: Understanding hepatitis C intervention success: Qualitative findings from the HepCATT study

Running title: Understanding HCV intervention success

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Abstract

Background

The United Kingdom has committed to eliminating viral hepatitis as a public health threat. Innovative interventions for marginalised populations are required to realise this goal. In 2016, the HepCATT study team implemented a complex hepatitis C (HCV) intervention in three English drug treatment services, with five controls. We report qualitative study findings from two intervention sites to explore intervention success and transferability potential.

Methods

The intervention comprised multiple components, including a nurse facilitator, peer support and education initiatives. Qualitative data were generated at baseline (2014) and post-intervention (2016) at two sites through in-depth interviews, focus groups and observations. The 96 participants comprised drug service and intervention providers and clients with an injecting history. Data were triangulated and thematically analysed.

Findings

Client engagement with a HCV treatment service rose from 16 at baseline to 147 in 2016. There was no comparable increase at the five control sites. Baseline testing and treatment barriers included: limited HCV knowledge; fear of diagnosis and treatment; precarious living circumstances and service-specific obstacles. Treatment engagement was aided by: intervention timeliness; improved communication structures; personalised care; streamlined testing and treatment pathways; peer support.

Conclusion

Multiple interrelated components influenced the increased levels of treatment engagement documented in HepCATT. The nurse facilitator, involved in implementation and innovation, was key to intervention success. Baseline barriers correspond with international literature – indicating transferability potential. Control data indicate that biomedical innovation alone is not sufficient to increase engagement amongst the most marginalised. Sustainable resourcing of community services is crucial to effect change.

Keywords: hepatitis C; intervention; treatment; people who inject drugs; qualitative

Introduction

In 2016 the United Kingdom (UK), with 193 other countries, committed to eliminating viral hepatitis as a public health threat by 2030 [1]. This ambitious goal requires the development of innovative interventions targeted at marginalised populations. In the UK, as in other high income countries, over 90% of incident hepatitis C virus (HCV) cases are among people who inject drugs (PWID) [2].

Modelling studies indicate that HCV treatment scale up among PWID reduces transmission opportunity, thus enabling elimination [3, 4]. HCV case finding in drug treatment services (DTS) is projected to be cost-effective, particularly when associated with increased treatment uptake [5]. New, highly tolerable and effective, direct-acting antiviral (DAA) treatments can capacitate community provision and treatment scale up – but not without attention to the manifold barriers faced by PWID in accessing care.

HCV testing and treatment barriers for PWID have been extensively reported [6-10]. Some, such as interferon side-effect concerns, are likely to be ameliorated by increased access to and awareness of interferon-free DAA therapies. Other barriers are more intransigent. These include: injecting and HCV-related stigma; mistrust between PWID and health care providers; material deprivation and competing priorities; rigid tertiary care requirements and difficulties accessing and navigating care provided in hospital settings [6, 10]. HCV testing and treatment interventions in DTS are, however, not necessarily straightforward, particularly when associated with rigid and/or punitive opioid substitution therapy (OST) provision [11]. Meaningful peer involvement can facilitate engagement [12-14], as can: HCV training for drug service providers; community nurse placements; contingency management; and dried blood spot (DBS) testing [12, 13, 15-17]. Qualitative studies [14, 18] suggest that cultural and management changes in DTS are also needed to support HCV case finding. These include: changing performance targets; reorientating workloads and prioritisation; reconfiguring client assessment forms and databases; enhancing community partnerships and involvement.

Together the evidence indicates that increasing HCV testing and treatment uptake among PWID requires a range of interventions. In the UK context, effective collaboration between the affected community and their organisations, local DTS, commissioners (responsible for planning and commissioning healthcare services in each locality), drug strategy teams and specialist hepatitis services is vital for intervention success. The HepCATT (Evaluation of interventions designed to increase diagnosis and treatment of patients with HCV infection in drug treatment settings) study team worked with these stakeholders to implement and evaluate a complex intervention, with the aim of informing best practice for HCV treatment engagement among PWID [19]. This paper reports findings from the qualitative study arm, which aimed to inform and assess the intervention.

Methods

The intervention

The intervention was implemented in three DTS in different English cities. Sites were required to: represent rural and urban settings; have a client base of >200 PWID; be reasonably intervention 'naïve'; and able to facilitate local HCV provider and commissioner support. Intervention components comprised: the appointment of a HCV nurse facilitator; a peer education and buddy system; HCV information resources and education initiatives; DBS testing; streamlining and integration of HCV and OST service provision; and liaison with stakeholders to agree HCV case finding and treatment targets. Five control sites were selected, according to the same size specification.

A National HCV charity facilitated the peer and buddy system, demarcating distinct roles for each. Peers, required to have experience of living with HCV, were primarily responsible for providing education and training. Buddies, not required to have lived experience of HCV, took a supportive role - accompanying clients to hospital appointments, for example (for more detail see [21]).

The primary intervention outcome was 'engagement with a HCV treatment service'. Engagement comprised: testing (HCV RNA, genotype, viral load); liver disease assessment and attendance at a consultation appointment. The outcome of engagement, rather than treatment uptake, reflects the uncertain UK treatment landscape at the time of the study, where DAA treatments were not available to all, with eligibility dependent on disease severity (people with cirrhosis given priority) and genotype. Quantitative baseline data for 2014 were collected retrospectively from the intervention and control sites.

Intervention outcomes

Across the three sites at baseline (2014) only 16 clients were engaged with a HCV treatment service. This increased to 147 in the intervention year (Table 1). Equivalent data for the five control sites showed no evidence of any increase from baseline in rates of referral, attendance, engagement, or treatment. See [19] for details.

Table 1. The HCV cascade of care at the 3 intervention sites (see end of manuscript)

The qualitative study

The qualitative study was conducted pre- and post-intervention at two of the three intervention sites. Two sites (one rural, one urban) were chosen to aid project manageability with no qualitative data collected at the third site, where a change of drug service management necessitated a later intervention start date.

Sample and data generation

Data were generated between 2014 and 2016. Forty-eight PWID and 48 drug service and intervention providers (n=96) participated in 36 in-depth interviews and 11 focus groups pre and post-intervention (Table 2). DTS clients who currently or previously injected illicit drugs ('PWID') were

recruited through DTS staff and purposively sampled for variation in HCV testing and treatment history. The 48 PWID participants comprised 10 women and 38 men, with an age range of 19 – 69 years old. Providers, comprising DTS staff (key workers, nurses, team leaders) and intervention implementers (NFs, peers and buddies), were recruited directly by the research team. Interviews lasted between 30-75 minutes, focus groups between 1-2.5 hours. All were conducted by OB in private rooms at the DTS.

Table 2: Sample by data generation method (see end of manuscript)

The pre-intervention client sample was divided into those who had previously tested positive for HCV but not entered treatment and those who had never had a test for HCV. Post-intervention, the client sample was divided into those who had ‘engaged’ with the intervention and those who had ‘not engaged’ (i.e. not been tested or attended a consultation at the treatment service). Fewer clients participated post-intervention, with ‘non-engagers’ difficult to recruit at both sites.

The same topic guides were developed (by OB and MH) for both focus groups and interviews. At baseline, we aimed to: contextualise the pre-intervention setting; explore patient and provider intervention perceptions and needs; and unpack existing barriers and facilitators to HCV testing and treatment engagement. Baseline data analysis informed intervention design and implementation; also providing a comparator to assess intervention impact. Intervention topic guides, employed 6-8 months after baseline, explored the perceived impact and efficacy of intervention components, with a focus on peer support acceptability and fit. Observations were made of the spatial layout of the DTS, and how HepCATT was advertised and given a physical presence within the sites. OB sat in on peer support drop-in sessions with clients, and observed interactions in canteen and waiting areas. Observations were recorded in field notes; uploaded to NVIVO 11 to supplement analysis.

Analysis

We conducted a thematic analysis [20], with a coding framework incorporating both deductive (a priori) and inductive (data driven) codes. Data were analysed by the first two authors through triangulation using: (a) multiple methods (interviews, focus groups, observations); (b) multiple participant perspectives (service providers, clients); (c) multiple intervention sites; and (d) time points (pre/post intervention). The primary focus of triangulation was to identify congruence and divergence, including deviant cases for follow-up, and to maximise the confidence with which judgements were made. As part of this process, we presented findings to the wider HepCATT study team, including members of the Hepatitis C Trust and DTS staff.

Ethics

Ethical approval was obtained from the LSHTM Research Ethics Committee [8935] and the National Research Ethics Service [I5/EM/0062]. All participants read an Information Sheet and had opportunities to ask questions before providing written consent. Clients, peers and buddies received £15 in cash or vouchers for their time and expertise.

Findings

To contextualise and unpack the factors relating to intervention outcomes we first provide a summary of pre-intervention testing and treatment barriers, before addressing the post-intervention findings.

Pre-intervention: testing and treatment barriers

Pre-intervention, clients displayed variable HCV testing and treatment knowledge. Very few at either site were aware of what HCV testing entailed and the difference between detecting antibodies only and chronic infection through polymerase chain reaction (PCR) tests. Participants who had not been tested for HCV described: service obstacles, including perceived lack of testing availability;

perceptions of minimal HCV risk due to relatively safe injecting practices and/or lack of symptoms; confusion about the testing and treatment process; fear of a positive diagnosis and HCV stigma; concerns about interferon treatment; aversion to having a venous sample taken; and a desire to move away from a drug user identity: “It can make a person frustrated or angry if someone keeps asking them about hepatitis and you have left it [injecting drugs] behind ... it doesn’t apply to me.” (Client, Untested, Site B)

Untested clients, in particular, spoke of limited psycho-social ‘stability’. This was informed by multiple pressures, such as: substance dependence; temporary and inadequate housing; limited work options; comorbidities; difficult familial relationships; poverty; and engagement in illicit economies. While these pressures were differently configured and experienced, they often led to a deprioritisation of HCV: “I’ve got mental health issues as well. I was homeless and that is one of the reasons why I didn’t get tested before I went into prison, because of the situation that I was in” (Client, Untested, Site A). Many clients experiencing precarity felt that testing could be additionally destabilising if it revealed them to be HCV positive: “What if it drives you back to the drugs?” (Client, Untested, Site A)

Clients who had tested positive, but not received treatment, recounted perceptions of GPs’ lack of interest in them and HCV more generally. Additional treatment barriers comprised: competing priorities of substance dependence, comorbidities and housing instability; reluctance to commence interferon treatment and perceived unavailability of DAA treatments; perceptions of low treatment worth; abstinence requirements; lack of urgency related to felt wellness; lack of social support, physical immobility and problems accessing transport – often due to poverty:

It’s [hospital] a long walk up the hill, maybe two miles to the top ... A lot of our clients don’t have cars or transport or things like that, and they’re in ill health quite a lot of the time. (Keyworker Site A)

In addition, systemic problems of limited healthcare funding for HCV, few HCV specialist staff in treating hospitals, disjointed care provision between services, and perceptions of disciplinarian tactics used by hospitals, placed additional barriers on treatment uptake: “One strike and you’re out. It seems to be getting tighter and tighter” (Keyworker, Site A).

Post-intervention: testing and treatment facilitators

Multiple interrelated factors influenced the increased levels of treatment engagement documented in HepCATT. These included: intervention timeliness; personalised and flexible care; improved HCV communication structures; better HCV testing and treatment pathways, and the provision of a peer education and buddy support system. The latter has been addressed [21]; here, we report on the former four domains.

Timeliness: capitalising on stability and new treatments

For many clients, moments of psycho-social stability in their lives allowed them to entertain the prospect of getting HCV testing and/or treatment. For some, the intervention coincided with these moments, enabling engagement. Realising clients’ stability could be short-lived, nurse facilitators’ aimed for quick treatment assessment referrals – ideally within two-three weeks. In practice, referrals took longer – generally due to hospital-related factors such as lack of clinic capacity. In such situations, swift and clear communication to clients (and their key workers) reassured that the appointment was forthcoming. All clients during the intervention reported receiving letters when referred to the Site A HCV clinic: an improvement on the uneven communication reported pre-intervention.

The intervention co-occurred with the growth in availability and use of DAAs in the UK; knowledge of new treatments was seen to influence clients’ engagement. Providers noted that positive feedback from clients who had undergone DAA treatment created a “ripple effect” among clients and staff.

DAA prioritisation restrictions could, however, cause tensions and falsely raise expectations. For this reason, some staff chose not to publicise new treatments:

I'm not telling anyone at the moment [about DAAs] ... otherwise they get their hopes up ... if you're a [genotype] three you're having interferon so it's a 50/50 chance so I'm better not saying anything to anybody. (Nurse Facilitator, Site B)

One Site B client was heartened by his perception that the nurse facilitator had “fought” to get him access to DAA treatment. He felt it was the right time to commence as he had ceased injecting and was reassured that DAA tolerability would allow him to continue working.

Personalised and Flexible Care

Nurse facilitators and key workers endeavoured to ensure a person-centered approach to client care. Co-located at the DTS and hospital, nurse facilitatorss provided a “familiar face” for clients at both sites. Clients, key workers and buddies remarked on the nurse facilitator’ss communication skills and the sense of care they brought to their interactions with clients. In Site B, the nurse facilitator sent clients text messages the day before their hospital appointments and actively tried to secure them access to DAA treatments. In Site A, the nurse facilitator made sure hospital appointment times corresponded with clients’ needs: “One gentleman had social anxiety, couldn’t manage to sit in a packed waiting room, so I gave him an appointment at ten to nine when it’s clear, he came in and the buddy sat outside” (Nurse Facilitator, Site A).

Both nurses instigated a rapid, person-centred approach to test result delivery, proactively hunting out clients: “If it’s positive, I’ll make a plan to meet them ... I’ll go out my way to find them” (Nurse Facilitator, Site B). From the clients’ perspective, this personalised approach was highly valued:

She’s even phoned me up to say, listen, don’t forget, if you don’t want to go, let me know. She’s good enough, she could have just sent me a letter out and just said, well, I sent him a letter, he never turned up. (Client, Engaged, Site B)

For clients testing positive who no longer came to the service, the Site B nurse facilitator contacted their GP to deliver the result. If the result was negative, she would update the client's profile on the computer system and add a note to their key worker to inform the client. HCV treatment information was provided with testing results, with no pressure to commence. Both sites placed emphasis on on-going engagement, with treatment as an open option. This was seen as vital for clients who traditionally might not be deemed eligible:

Certainly we've had patients come to clinic who, on paper, you wouldn't go there. You wouldn't go there with interferon based treatments but for quite a few of them if there is the right support there and you build up that relationship ... It is possible and I'm a strong advocate of that because I think at the moment people with mental health problems are likely widely excluded from treatment. (Nurse Facilitator, Site B)

Pre-intervention, the detrimental impact of immediate hospital discharge for those who could not attend appointments was noted. The Site A nurse facilitator personalised this interaction, with the aim of minimising client perceptions of judgement or exclusion:

If we find out that they've not attended a clinic appointment and there's a reason, like one girl broke a leg, then I'll send a letter out and say 'sorry, I heard about your broken leg, I have discharged you from the service. However, I've included a self-referral form. If you want to come back within the next six months fill it in and give it to your key worker' so we're not closing the door. (Nurse Facilitator, Site A)

Key workers also endeavoured to personalise clients' care throughout their HCV treatment journey; discussing testing and treatment options with them and sending text message reminders about hospital appointments with the option of peer support.

HCV visibility and communication structures

Embedding HCV as a priority within the sites was an intervention imperative. To facilitate this, nurse facilitators fostered regular communication channels with key workers. At Site A, the nurse facilitator attended weekly team meetings to give feedback on client referrals and progress. She asked staff whether they had spoken to clients on a targeted list about their referral intentions and whether these prompts had helped. The Site B nurse facilitator provided key workers with HCV information and intervention updates, particularly regarding the progress of specific clients. Both sites arranged visits and talks from representatives of the Hepatitis C Trust, also a HCV consultant (Site A), to improve staff knowledge and aid HCV prioritisation.

Key workers commented that one of the most beneficial aspects of HepCATT was being copied into correspondence between the hospital teams and clients. This allowed them to prepare their clients for appointments and make necessary arrangements to ensure attendance. Moreover, it gave them faith that the HCV referral process was working, which enhanced their willingness to support and promote HepCATT: “It [email communication from hospital] made you confident that it’s, the system’s going to work for a start, that we’re all communicating with each other” (Keyworker, Site A). At the same time, this process allowed the client to feel “valued” and know that they had a committed professional support network around them.

At both sites, it was clearly communicated to clients who the nurse facilitator was, particularly at Site B, where she was more visible owing to her hands-on testing role and nurse uniform. The medical role and uniform was seen to have positive effect on client engagement by aiding legitimacy and credibility:

I’ve had two clients who are now engaging in the actual treatment process, which, in all truth, if this project hadn’t have been, they wouldn’t have took time out to engage in treatment and that. [As a key worker] you can talk till you’re blue in the face, but the fact

that a nurse is sat in front of them, in the nurse's uniform, and giving them the advice and letting them know, that speaks volumes. (Keyworker, Site B)

This excerpt also illustrates the value of an 'outsider' coming in to champion HCV; one who can circumvent entrenched, potentially detrimental, key worker-client dynamics.

Improved testing and treatment pathways

Nurse facilitators were proactive in improving testing and treatment pathways, with different strategies aligned to site context. The Site B nurse facilitator had a clear directive to test and was strategic in targeting clients who came in to pick up their OST prescriptions. At Site A, key workers had been trained in DBS testing prior to the intervention; there was little need for the nurse facilitator to take this role. To counter this reduced opportunity to engage clients in treatment conversations she designed a self-referral procedure. Forms were placed on the reception counter next to a small post box, or available from key-workers. By self-referring, clients were able to discretely signal their ownership over the HCV treatment decision. This enabled GPs to be bypassed, giving clients a direct link to the treating hospital. It also served as a proxy to help to establish a relationship between the nurse, the key workers and the clients. For example, posters in consultation rooms advertising self-referral could prompt discussion between clients and key workers:

Self-referral forms are meant for clients, but when they're having their one-to-ones what could be easier as part of a motivational interview when somebody says 'yeah, I'm going to look at my Hep C' – there you go, fill it in. (Nurse Facilitator, Site A)

The self-referral form played a role in reorienting decision-making with regard to determining a client's readiness to test and treat, affecting pathways to engagement:

"Key workers have come to me and said, 'my client's filled this [self-referral form] in and they're not ready' and [I would say], 'yes, they clearly are ready.' And I think it's been accepted after that." (Nurse Facilitator, Site A).

A similar negotiation took place at Site B, which the nurse facilitator sought to bypass by engaging clients directly:

That's why I go and get people myself because I make my own decision whether they're suitable or not. Not that I'm going against the key worker but they might not know or they may say, oh he doesn't use needles. Well yeah, might not use needles now but did he use needles 30 years ago? Has he ever been tested before? So I just prefer to go and ask them myself. (Nurse Facilitator, Site B)

As a result of these initiatives, staff perceptions of client "readiness" to engage with HCV changed during the intervention, with more key workers willing to recommend that "chaotic" clients discuss their options with the nurse facilitator.

Discussion

Qualitative research is uniquely placed to explore community intervention needs and to unpack the local social and contextual factors shaping intervention delivery and impact. This is crucial to inform recommendations for implementation, scale up and transferability. Intervention results were impressive, showing a clear improvement in client engagement with treatment services. At baseline (2014), 16 clients were engaged with a treatment service across the three sites. This rose to 143 clients in the intervention year (2016). At the two qualitative study sites engagement increased from 13 at baseline to 123 in 2016. Without control data, much of this increase could be attributed to changes in the HCV treatment landscape, such as increased availability and awareness of DAA treatments. Remarkably, given this "therapeutic revolution" [22], there was no increase in client engagement reported at the control sites from 2014 – 2016 [19]. The intervention figures delineate efficacy, but also illustrate that biomedical innovation alone is not sufficient to increase engagement amongst the most marginalised. Social-structural supports, resourced personnel and changes to care pathways are crucial to effect change.

Participant reported testing and treatment barriers pre-intervention reflect those detailed in the qualitative literature. These include: limited HCV knowledge and testing confusion; perceptions of limited HCV risk or relevance; fear of HCV diagnosis and treatment; phlebotomy concerns; low treatment worth or 'deservedness'; stigma and service access issues, often specific to tertiary care [7, 14, 23-28]. Participants detailed multiple social and structural pressures which led to a de-prioritisation of HCV, with concomitant fears that HCV diagnosis and/or treatment could precipitate additional social and psychological instability [14, 26, 28-30]. Structural and service specific barriers included an apparent lack of GP interest and accessibility, rigid hospital eligibility and appointment structures, and difficult access [27, 30, 31]. As previously argued [32, 33] the rationale for situating HCV interventions in community settings such as DTS is strong. The resonance of participant-identified barriers at baseline with those documented in the international literature indicates potential for HepCATT intervention transferability and reach.

This was a complex intervention with multiple components, including: educational support for clients and staff; strengthening of pathways between community and tertiary care; DBS testing; peer support; and integration of a nurse facilitator at each site. The nurse facilitator was an integral part of the intervention, and responsible for many of the intervention innovations. It is therefore difficult, and perhaps spurious, to try to tease out the differential impact of each component in isolation from the nurse facilitator. This dedicated placement worked in several ways to convey legitimacy and weight to HCV as a priority at the sites. Firstly, the part time placement illustrated a monetary investment in the DTS – practically and symbolically important in a period of increased disinvestment in and cutbacks to drug services in the UK. Secondly, the placement was associated with a Department of Health funded intervention and several notable University Institutions; the presence of research team members on site also requires note as a potential intervention impact [34]. Thirdly, the placement was an external and medical appointee. Although not specified in the job description, all three facilitator appointments were nurses. The nurse role was seen to provide legitimacy and

gravitas to HCV information provision, testing and referral, with an external placement obviating any counterproductive and entrenched client-staff dynamics.

Dynamics circumvented by the external placement include those pertaining to HCV treatment worth and 'readiness'. Client perceptions of low treatment 'worth' can unintentionally be reinforced by staff beliefs and messages regarding treatment 'readiness' [25]. Other innovations also ameliorated these dynamics. The self-referral system, for example, enabled client ownership of the referral process – signalling 'readiness' in those potentially deemed otherwise. This, in turn, helped shift key workers' perceptions of their clients and the HCV treatment system. The self-referral system capitalised on the transience of client presence at the treatment centre and their self-identified windows of 'stability' and HCV interest. It circumvented the need for initial, possibly difficult, conversations about risk practices with providers. This intervention is highly transferrable across settings, but in order to be effective and ethical, it requires a strong and responsive pathway in place between self referral, testing, diagnosis, treatment referral and assessment opportunity.

The HepCATT intervention did not incorporate HCV treatment provision at the DTS, as recommended to ameliorate barriers associated with tertiary care [16, 33, 35, 36]. In this respect the increase in treatment engagement is all the more remarkable – given that clients were required to attend at least one hospital appointment to fulfil engagement criteria. In order to aid hospital attendance the intervention implemented: peer 'buddy' support; correspondence with and appointment reminders through key workers; and visibility of the nurse facilitator at both the drug service and hospital sites, providing continuity of care and a 'familiar face' in what may have been otherwise perceived as a hostile environment. Client engagement is contextually dependent – variables such as hospital distance; availability of financial and practical support to attend appointments and hospital appointment waiting time will impact attendance [10]. Swift and supported testing pathways and referrals in DTS can aid engagement, alongside peer and travel supports. Institutional barriers, such

as immediate hospital discharge for non-attendance, may not always be amenable to intervention [31]. Notable, however, was the way in which swift and thoughtful communication from nurse facilitators to clients and key workers acted to tame and mitigate the damage associated with these barriers for clients.

At both sites, the option for treatment was provided as an open door – something clients could come back to when it suited them and be personally assisted to obtain. It is important to acknowledge that the decision to undertake treatment will be informed by many factors, only some of which may be amenable to intervention. These include: patient priorities; co-morbidities; viral genotype; degree of underlying liver damage; potential duration of treatment; and how easy and acceptable HCV treatment is to access by people who are unstably housed or incarcerated. Attuned to the complexities of clients' lives, the nurse facilitators created a space for engagement when clients were ready – importantly not withholding testing or HCV discussion due to perceived instability. Meaningful involvement of those 'on the ground' is crucial for intervention implementation and success. Elsewhere we detail the peer and buddy intervention components, along with the limitations of the intervention in fully supporting and integrating these at the sites [21]. Key worker involvement appeared better supported, with nurse facilitators proactively developing regular communication channels with key workers about the intervention and their clients' progress. Opening up communication channels to include key workers is vital, with the HepCATT study illustrating the multiple benefits of including key workers in hospital-client correspondence.

Uneven availability of DAA treatments, particularly to PWID, during the time of the intervention influenced the primary outcome measure of 'engagement with a treatment service' rather than 'treatment commencement'. This uncertainty was reflected in the reticence of nurse facilitators to publicise this treatment advance – with the ethical implications of inadvertently promoting curative but potentially unavailable treatments, a topic of debate among the qualitative team during the

intervention fieldwork. The ethics of an intervention of this kind, in a context of limited treatment access, is fundamental to consider. Also crucial is consideration of the ethics of interventions that enable needed resource in services – but only for the time period of the study. In order to gain and maintain community and provider trust it is necessary that interventions, such as HepCATT, can be sustainable. In a context of frequent retendering and budget restrictions in UK drug treatment services, dedicated resources may be required to enable PWID to fully benefit from the DAA treatment ‘revolution’.

Conclusion

In conclusion, multiple interrelated components influenced the increased levels of treatment engagement documented in HepCATT. Many were implemented and innovated by the nurse facilitator – this appointment was key to intervention success. Meaningful involvement of key workers in the testing and treatment pathways helped embed HCV as a priority at the DTS. Improved communication structures, along with a treatment self-referral system, operated to reconfigure staff perceptions of client ‘readiness’ for treatment – particularly those deemed ‘chaotic’. The uneven availability of DAA treatments at the time of the intervention informed the outcome measure of ‘engagement’ and highlighted the importance of reflecting on the ethical implications of intervention promise and sustainability.

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References

1. World Health Organisation, *Global Health Sector Strategy on Viral Hepatitis 2016-2021*. 2016, World Health Organisation: Geneva.
2. Public Health England, *Hepatitis C in the UK: 2015 Report*. 2015, Public Health England: London.
3. Martin, N.K., et al., *Prioritization of HCV treatment in the direct-acting antiviral era: An economic evaluation*. *Journal of Hepatology*, 2016.
4. Martin, N., et al., *Hepatitis C virus treatment for prevention among people who inject drugs: Modeling treatment scale-up in the age of direct-acting antivirals*. *Hepatology*, 2013. **58**(5): p. 1598-1609.
5. Martin, N.K., et al., *The cost-effectiveness of HCV antiviral treatment for injecting drug user populations*. *Hepatology*, 2012. **55**(1): p. 49-57.
6. Treloar, C., J. Rance, and M. Backmund, *Understanding Barriers to Hepatitis C Virus Care and Stigmatization From a Social Perspective*. *Clinical Infectious Diseases*, 2013. **57**(suppl 2): p. S51-S55.
7. Swan, D., et al., *Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: a qualitative exploration*. *AIDS Patient Care & Stds*, 2010. **24**(12): p. 753-62.
8. Strauss, S.M., et al., *Barriers and facilitators to undergoing hepatitis C virus (HCV) testing through drug treatment programs*. *Journal of Drug Issues*, 2008. **38**(4): p. 1161-1185.
9. Wolfe, D., et al., *Human rights and access to hepatitis C treatment for people who inject drugs*. *International Journal of Drug Policy*, 2015. **26**(11): p. 1072-1080.
10. Harris, M. and T. Rhodes, *Hepatitis C treatment access and uptake for people who inject drugs: A review mapping the role of social factors*. *Harm Reduction Journal*, 2013. **10**(7).
11. Rance, J., et al., *The politics of place(ment): Problematising the provision of hepatitis C treatment within opiate substitution clinics*. *Social Science & Medicine*, 2012. **74**(2): p. 245-253.

12. Crawford, S. and N. Bath, *Peer Support Models for People With a History of Injecting Drug Use Undertaking Assessment and Treatment for Hepatitis C Virus Infection*. *Clinical Infectious Diseases*, 2013. **57**(suppl 2): p. S75-S79.
13. Aitken, C.K., M. Kerger, and N. Crofts, *Peer-delivered hepatitis c testing and counselling: A means of improving the health of injecting drug users*. *Drug and Alcohol Review*, 2002. **21**(1): p. 33-37.
14. Harris, M., B. McDonald, and T. Rhodes, *Hepatitis C testing for people who inject drugs in the United Kingdom: Why is uptake so low? Drugs: education, prevention, and policy*, 2014. **21**(4): p. 333-342.
15. Hickman, M., et al., *Increasing the uptake of hepatitis C virus testing among injecting drug users in specialist drug treatment and prison settings by using dried blood spots for diagnostic testing: A cluster randomized controlled trial*. *Journal of Viral Hepatitis*, 2008. **15**(4): p. 250-254.
16. Treloar, C. and J. Rance, *How to build trustworthy hepatitis C services in an opioid treatment clinic? A qualitative study of clients and health workers in a co-located setting*. *International Journal of Drug Policy*, 2014. **25**(5): p. 865-870.
17. Coats, J.T. and J.F. Dillon, *The effect of introducing point-of-care or dried blood spot analysis on the uptake of hepatitis C virus testing in high-risk populations: A systematic review of the literature*. *Int J Drug Policy*, 2015. **26**(11): p. 1050-5.
18. Treloar, C., et al., *"Fitness for duty": Social, organisational and structural influences on the design and conduct of candidate hepatitis C vaccine trials involving people who inject drugs*. *Vaccine*, 2010. **28**(32): p. 5228-5236.
19. Harrison, G., et al., *Evaluation of an intervention designed to increase treatment engagement of HCV-infected individuals attending drug treatment services in England*. *Gut*, under review.
20. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. *Qualitative Research in Psychology*, 2006. **3**(2): p. 77-101.
21. Bonnington, O. and M. Harris, *Tensions in relation: how peer support is experienced and received in a hepatitis C treatment intervention*. *International Journal of Drug Policy*, 2017. **in press**.
22. Zoulim, F., et al., *Hepatitis C virus treatment in the real world: optimising treatment and access to therapies*. *Gut*, 2015. **64**(11): p. 1824-1833.
23. Khaw, F.M., L. Stobbart, and M.J. Murtagh, *'I just keep thinking I haven't got it because I'm not yellow': A qualitative study of the factors that influence the uptake of Hepatitis C testing by prisoners*. *BMC Public Health*, 2007. **7**.
24. Harris, M., E. Ward, and C. Gore, *Finding the undiagnosed: A qualitative exploration of hepatitis C diagnosis delay in the United Kingdom*. *Journal of Viral Hepatitis*, 2016. **23**(6): p. 479-486.
25. Rhodes, T., M. Harris, and A. Martin, *Negotiating access to medical treatment and the making of patient citizenship: the case of hepatitis C treatment*. *Sociology of Health & Illness*, 2013. **35**(7): p. 1023-1044.
26. Craine, N., et al., *Hepatitis C testing and injecting risk behaviour: The results of a UK based pilot study*. *International Journal of Drug Policy*, 2004. **15**(2): p. 115-122.
27. Jordan, A.E., et al., *Perceptions of drug users regarding hepatitis C screening and care: a qualitative study*. *Harm Reduct J*, 2013. **10**.
28. Treloar, C. and T. Rhodes, *The lived experience of hepatitis C and its treatment among injecting drug users: qualitative synthesis*. *Qualitative Health Research*, 2009. **19**(9): p. 1321-34.
29. Jones, L., et al., *Views and experiences of hepatitis C testing and diagnosis among people who inject drugs: Systematic review of qualitative research*. *International Journal of Drug Policy*, 2014. **25**(2): p. 204-211.

30. Lally, M.A., et al., *A qualitative study among injection drug using women in Rhode Island: attitudes toward testing, treatment, and vaccination for hepatitis and HIV*. *AIDS Patient Care & Stds*, 2008. **22**(1): p. 53-64.
31. Harris, M., T. Rhodes, and A. Martin, *Taming systems to create enabling environments for HCV treatment: negotiating trust in the drug and alcohol setting*. *Soc Sci Med*, 2013. **83**: p. 19-26.
32. Alavi, M., et al., *Assessment and treatment of hepatitis C virus infection among people who inject drugs in the opioid substitution setting: ETHOS study*. *Clin Infect Dis*, 2013. **57**.
33. Bruggmann, P. and A.H. Litwin, *Models of Care for the Management of Hepatitis C Virus Among People Who Inject Drugs: One Size Does Not Fit All*. *Clinical Infectious Diseases*, 2013. **57**(suppl 2): p. S56-S61.
34. Landsberger, H.A., *Hawthorne Revisited*. 1958, New York: Ithaca.
35. Rance, J., C. Treloar, and Ethos Study Group, *'Not just methadone Tracy': transformations in service-user identity following the introduction of hepatitis C treatment into Australian opiate substitution settings*. *Addiction*, 2014. **109**(3): p. 452-9.
36. Alavi, M., et al., *Assessment and Treatment of Hepatitis C Virus Infection Among People Who Inject Drugs in the Opioid Substitution Setting: ETHOS Study*. *Clinical Infectious Diseases*, 2013. **57**(suppl 2): p. S62-S69.

TABLES

Table 1. The HCV cascade of care at the 3 intervention sites [19]

	Site A		Site B		Site C	
	Baseline n (%)	Intervention n (%)	Baseline n (%)	Intervention n (%)	Baseline n (%)	Intervention n (%)
Hep C +ve PWID	87	100	173	236	30	62
Referred	29 (33)	97 (97)	11 (6)	112 (47)	17 (57)	37 (60)
Attended	15 (17)	67 (67)	3 (1)	68 (21)	5 (17)	24 (53)
Engaged	10 (11)	55* (55)	3 (1)	68* (21)	3 (10)	20* (39)
Treated	2 (2)	15 (15)	1 (0.6)	31 (13)	0 (0)	8 (13)

* Includes 3 (Site A), 2 (Site B) and 1 (Site C) clients discovered to be PCR negative

Table 2: Sample by data generation method

		Focus Groups (n)	Interviews (n)	Participants (n)
Pre- Intervention	PWID	<u>4 groups (n=26)</u>	9	35
	Providers	<u>2 groups (n=13)</u>	9	22
Post- Intervention	PWID	<u>1 group (n=5)</u>	8	13
	Providers	<u>4 groups (n=16)</u>	10	26
TOTAL		<u>11 groups (n=50)</u>	36	96 *

*includes 10 who took part in both pre- and post- intervention components