Tensions in relation: how peer support is experienced and received in a hepatitis C treatment intervention

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Abstract

Background:

Peer support and involvement is recognised as a vital component of hepatitis C (HCV) treatment provision for marginalised populations, such as people who inject drugs (PWID). Developments in HCV treatments enable increased provision in community settings – expanding the possibilities for meaningful peer involvement in HCV treatment plans. To date, HCV peer support has generally been viewed as a positive intervention, with little critical reflection on the ways social structures, policies, health and drug services and social identity impact on how peer support is experienced and received.

Methods:

We report on the qualitative component of a UK-based intervention designed to increase HCV diagnosis and treatment in primary care and drug treatment settings. Data were collected between 2014 and 2016. Pre-Intervention, a total of 35 PWID clients took part in nine in-depth interviews and four focus groups. In addition, 22 drug services and intervention providers took part in two focus groups and nine interviews. Post-intervention, one focus group and eight interviews were conducted with 13 PWID clients, and four focus groups and ten interviews were conducted with 26 drug services and intervention providers. Our data generation and thematic analysis focused on the peer education and buddy support component of the intervention.

Results:

Participants had common expectations of the peer role (to ‘just be there’) and its occupants’ attributes (empathy, trustworthy, etc.). However, in practice, peers faced constraints on realising these expectations. A ‘recovery’ dominated drug treatment ethos in the UK appeared to influence the selection of ‘recovery champions’ as peers for the intervention. This created tensions in relations with clients, particularly when risk-adverse discourses were internalised by the peers. Peers were poorly integrated and supported within the service, affecting opportunities to relate and build trust with clients. Thus, the scope for peer support to impact on the nature and extent of clients’ testing and treatment for HCV was limited.

Conclusion:

The efficacy of peer involvement can be constrained by organisational structures and boundaries – especially regarding who is deemed to be ‘a peer’. Peer programmes take time and care to implement and weave into wider recovery and harm reduction frameworks.

Keywords:

Peer support; Hepatitis C virus; PWID; Qualitative Methods; injection drug use; treatment

Background

Peer support and involvement is recognised as a vital component of hepatitis C (HCV) treatment provision for marginalised populations, such as people who inject drugs (PWID). In recent times, the possibilities for meaningful peer involvement in HCV treatment plans have increased with the development of Interferon-free direct-acting antiviral therapies (DAAs). These relatively simple, tolerable and highly effective treatments enhance the opportunities for provision in community settings, such as drug treatment centres (Alavi et al., 2013; Harris, Arnsten & Litwin, 2010). In the context of simplified drug regimens, barriers to testing and treatment uptake are still likely, particularly if hospital appointments for initial assessments are involved. A wealth of qualitative research illustrates barriers to tertiary care services for PWID due to accessibility issues, historical discrimination and/or anticipated stigma (Harris et al., 2013, Swan et al., 2010). Here peer accompaniment has the potential to make an important difference. Indeed, peers could be vitally important throughout the cascade of care, especially regarding case-finding and challenging the ubiquity of messages held by PWID regarding the difficulty of traditional HCV treatment (Whiteley et al., 2016). Peer support may also be important to facilitate treatment adherence and post-treatment prevention support to avoid reinfection. If peers are to be involved in such support provision, it is important that their views and experiences are taken into consideration in the development, oversight and implementation of new initiatives.

To date, HCV peer support has generally been viewed as a positive intervention. The involvement of peers in HCV testing and treatment provision can: help reduce PWID fears of testing and treatment; improve PWID HCV knowledge and engagement through the care cascade; improve healthcare provider appreciation of PWID needs; and challenge structural barriers (Crawford & Bath, 2013; Norman et al., 2008; Roose et al., 2014; Harris et al., 2014). At the same time as providing a generally positive valuation, researchers often reify and package peer support such that its implementation can seem somewhat fixed and straightforward, irrespective of social and service contexts or the concerns of PWID and those who take on peer roles. In this respect, HCV peer functions tend to reduce to a toolkit comprising the co-facilitation of treatment, chaperoning patients to hospital appointments and engaging in educative activities within and outside of drug service settings (Norman et al., 2008; Crawford & Bath, 2013; Roose et al., 2014; Treloar et al., 2015).

Much of this previous research has been done with little critical reflection on how social structures, policies, health and drug services and social identity impact on the ways in which peer support is experienced and received (Treloar et al., 2011). A recent systematic review (MacLellan et al., 2015) of peer support workers' experiences across all health contexts found only one study reporting on the perspectives of HCV peer workers (Norman et al., 2008) and it appears only one study has been published since (Treloar et al., 2015); both originate from Australia. HCV peers' experiences of their roles, especially in the UK context, remain relatively unexplored. Moreover, little is known about drug treatment clients' and providers' perspectives on and experiences of HCV peer support. The aim of this study, therefore, was to conduct a critical qualitative exploration of HCV peer support implementation in drug treatment settings from multiple perspectives in order to inform the successful scale-up of HCV treatment provision for marginalised populations in the DAA era.

Methods

Setting & Rationale

This paper reports findings from the qualitative component of a complex intervention study aiming to increase HCV diagnosis and treatment in primary care and drug treatment settings (HepCATT: Hepatitis C Awareness Through to Treatment). Two interventions were developed, implemented and evaluated – one for primary care services, the other for drug treatment services. We report on the intervention implemented in three UK drug treatment centres. These centres serve people with drug and alcohol addictions and are funded by a range of sources. Briefly, the year-long intervention comprised: a HCV nurse facilitator on-site for two days a week; on-site HCV testing (ad hoc and planned sessions); streamlined treatment pathways; a peer education and buddy system; and drug service provider education. The intervention coincided with the introduction of DAA treatments in the UK. In this study, clients were variously prescribed Pegylated Interferon and Ribavirin, a combination of Pegylated Interferon and Ribavirin with DAAs, or purely DAA treatment, depending upon their genotype and the policies of the local healthcare authorities, which were in development during the intervention.

A qualitative assessment was conducted pre- and post-intervention, which included interviews and focus groups at two of the three services sites. The principle aim of this was to inform and assess the intervention, with a focus on the peer education and buddy support component. In each site, the peer support system was set up by the Hepatitis C Trust, a UK charity, which gave initial training and on-going support to newly recruited peers and buddies, as well as drug service staff. The set-up of this system therefore escaped Crawford and Bath's (2013) previous categorisation of 'community controlled' (implemented by peer based drug user organisations in partnership with local service providers) and 'service generated' (initiated and managed by health/drug services) models. Though it shared elements of both categories, the HepCATT model occupied a nebulous middle ground between the two.

Sample

A purposive sample of PWID clients of the two drug treatment service sites was recruited via on-site drug treatment staff both pre- and post-intervention. The pre-intervention client sample was split into those who had previously tested positive for HCV but not entered treatment and those who had never had a test for HCV. Drug service staff (key workers, nurses, team leaders) who came into contact with PWID clients and intervention providers (nurse facilitators, buddies and peers) were also recruited. Post-intervention, the client sample was divided into those who had 'engaged' with the intervention (defined as attending an appointment at the hospital to discuss results and treatment options and deciding whether to go through with treatment or not) and those who had 'not engaged' (i.e. not been tested or not transitioned to discussing test results at the hospital during the intervention). Recruitment problems meant significantly fewer clients participated post-intervention, and there were not enough participants to form more than one focus group. The drug services found it incredibly difficult to recruit 'non-engagers' at both sites. At the outset of the study, the idea was to recruit some people post-intervention who had also been interviewed pre-intervention. This was only possible in three cases due to clients disengaging from the drug service during the intervention, and the unavailability of clients to take part in the study post-intervention.

Likewise, drug service staff who had experience of the intervention in some way (e.g. referring clients, receiving education, overseeing the peer system) and intervention providers (nurse facilitators, buddies and peers) were also recruited. Data collection took place between 2014 and 2016. All participants read an Information Sheet about the study and had opportunities to ask questions before giving their informed consent to participate. Ethical approval was obtained from the LSHTM Research Ethics Committee [8935] and the NHS Health Research Authority's National Research Ethics Service [IS/EM/0062].

Interviews, Focus Groups & Observations

Participants were invited to take part in a one-to-one interview or focus group and they made the decision as to which one they preferred. Pre-Intervention, a total of 35 PWID clients took part in nine in-depth interviews and four focus groups. In addition, 22 drug services and intervention providers took part in two focus groups and nine interviews. Post-intervention, one focus group and eight interviews were conducted with 13 PWID clients, and four focus groups and ten interviews were conducted with 26 drug services and intervention providers. In total there were 96 participants, 10 of whom from all sub-samples took part both pre- and post-intervention (see Table 1) Data collection stopped when thematic saturation had been reached. Interviews lasted between 30-75 minutes and focus groups lasted between 1-2.5 hours. These took place in private rooms at the drug treatment services. All interviews were conducted one-to-one. They were especially useful for clients who did not want to discuss their experiences, views and practices of drug use and HCV testing in front of their peers, and they allowed a more complete exploration of an individual's HCV narrative. The option of an interview also allowed providers, peers and buddies greater freedom to discuss HCV in confidence, without the fear that others might negatively appraise their knowledge and experience. Provider, peer and buddy interviews proved useful for a more thorough questioning of individuals' knowledge of the HepCATT intervention and HCV which was more complicated in the focus groups. Focus groups, in contrast, were employed to see 1) how different sample groups discussed HCV together, and 2) how they debated both ideas for (pre-intervention) and their experiences of (post-intervention) the intervention. In both interviews and focus groups the same topic guides were used. With clients, topic guides explored: experience and knowledge of HCV; barriers to testing and treatment; ideas for a HCV intervention including peer support (pre-intervention); experience of the intervention as a whole and peer support in particular (post-intervention). With drug service staff, topic guides explored: current provision for HCV within the centre; current uptake of HCV services; ideas for a HCV intervention with emphasis on a peer support element (pre-intervention); experiences of the intervention and reflections on the peer support element (post-intervention).With intervention providers, topic guides covered: their role in the intervention; expectations for the intervention; perceived challenges; support needs and motivations for involvement (all pre-intervention); experiences of the intervention; impressions of what worked and what did not; challenges they faced; whether their support needs had been met and improvements that could be made (post-intervention). Topic guides were developed by both authors. OB conducted the interviews and focus groups. Interviews and focus groups were audio recorded using an encrypted digital audio recorder. Clients, peers and buddies received £15 in cash or vouchers for their time and expertise, all other participants were unpaid.

Table 1: A cross-section of the study sample by data collection method

		#Focus Groups	#Interviews	#Participants
Pre-Intervention	PWID Clients	4	9	35
	Drug services and Intervention Providers	2	9	22
Post-Intervention	PWID Clients	1	8	13
	Drug services and Intervention Providers	4	10	26
TOTAL		11	36	96*

*With 10 participants taking part both pre-and post-intervention.

In addition to the interviews and focus groups, observations were made of the spatial layout of the drug treatment centres, and how HepCATT was advertised and given a physical presence within the sites. OB sat in on HepCATT buddy drop-in sessions with clients, and observed client, client-buddy, buddy-peer educator, and client-service provider interactions in canteen and waiting areas at the two sites. These observations enabled a fuller understanding of the socio-spatial functioning of

HepCATT and the drug service. Observations were recorded in field notes immediately after the events and interactions. These, along with field notes from interviews and focus groups, were uploaded to NVIVO 11 to supplement the analysis.

Analysis

A thematic analysis (Braun & Clarke, 2006) was conducted on anonymised transcripts and field notes, with the assistance of NVIVO 11. A coding framework, devised by both authors, drew upon a combination of deductive themes reflected in the topic guides and inductive coding. Data were analysed by both authors through triangulation using: (a) multiple forms of qualitative data (interviews, focus groups, observations); (b) multiple forms of participant perspective (service providers, clients); (c) multiple intervention sites; and (d) multiple time points (pre/post intervention). The primary focus of triangulation was to identify congruence and divergence, including deviant cases for further follow-up or investigation, as well as to maximise the confidence with which judgements were made regarding potential relative intervention effects. As part of the process of refining the conclusions, the authors presented findings to the wider HepCATT study team, which included members of the Hepatitis C Trust and drug treatment centre staff.

Defining Peers and Buddies

Pre-intervention, a role distinction was established within the peer support service by the Hepatitis C Trust between ‘peer educators’ and ‘buddies’. Peer educators were defined as people who had experienced HCV. They were tasked with delivering training to stakeholders (e.g. homeless shelter staff) and clients by talking about their experiences of drug use, HCV testing and HCV treatment, and by imparting five key HCV messages in line with their Hepatitis C Trust training. These messages were:

1. If you are HCV negative you can stay HCV negative by using drugs safely and not sharing injecting equipment including spoons, water and filters
2. HCV is a blood-borne virus and not transmitted by other bodily fluids
3. The only way to tell if you are HCV positive is to get a test – don't just assume you've got HCV
4. If you've got HCV you can take control and do something about it
5. If you are HCV positive, treatment is available for drug users

The life story/key messages format was designed by the Hepatitis C Trust. Whilst this had not been determined by the peers, they reported no objection to it. Indeed, it was one they appeared to agree with and endorse. They described gaining confidence from and enjoying the opportunity to talk freely to clients and service professionals about their experiences. The key messages met with no disagreement – with all peers happy to impart these to clients.

Buddies were defined as people who could sympathise with a client's situation and share experiences, but not necessarily have experienced HCV. Their role was to meet clients informally for a coffee and a chat at the drug centre or elsewhere, and accompany clients to testing and treatment if desired. Again, buddies reported satisfaction with their planned role pre-intervention, though they had little input into its design.

The parameters of the peer and buddy roles were explored with participants during data collection.

Results

Commonalities in Anticipation

Participants (clients, prospective peers and buddies, drug workers) had some common expectations when anticipating peer and buddy roles. Peers and buddies were expected to: be in a position to share their experiences (drug use, HCV treatment); understand the situations of PWID clients and other clients; have good knowledge of HCV; to 'just be there'; and assist with key practical tasks.

"I would have loved a buddy when I was going through treatment, I would have loved someone to have been there, someone I could offload to… I would have loved to have said 'oh, I'm feeling really bad today'." (Client, Site A)

"I'd like them to have been on drugs their selves so they experienced it and they're not talking out of a textbook." (Client, Site B)

This chimed with the reasons peers/buddies gave for wanting to do their roles. For some, the experience of not having anyone to turn to and not having had access to reliable information when they were diagnosed was a reason to become a peer, so others would not have to experience similar situations. In general, peers' and buddies' accounts emphasised their desire to improve understanding of HCV among PWID and help them feel more comfortable with the idea of treatment:

"I think it helps other people, because I've been through that myself. And if it helps one person to get to the hospital… I always used to be terrified. I went on my own, which was daunting, to say the least, and I didn't know anything. I just knew nothing. Everything just went straight over my head. And if I'd have had a buddy then, I'd have learnt a bit more. It was only as I stopped the treatment, well, not literally stopped the treatment, but, just before, I found out the ins and outs of hepatitis, so yeah." (Prospective Peer, Site A)

Personal experiences of being marginalised by friends and family, consequent on diagnosis disclosure, were drawn on by peers as another reason to volunteer. By doing so, they hoped to lessen the isolation of others.

There was a general consensus among the different participant groups in the study about key practical tasks that it would be beneficial for peers and buddies to assist clients with. These included: reminding clients about clinical appointments by text message or phone call; attending these appointments with clients; and taking notes, if consent was obtained. Clients drew on past experiences of hospital appointments to make recommendations:

"Although the doctor goes through things, at the time your head's not straight because you're still taking drugs or whatever… there was loads of stuff he said to me, absolutely loads. It just flew past my head." (Client, Site B)

Similiarly, peers and buddies could recognise the importance of these domains from their own experience:

"I missed 99% of everything that was said to me [during my consultations at the hospital] ... I was still stuck in my chaos. I didn't understand anything that was being said." (Prospective Buddy, Site A)

A further way in which peers and buddies were perceived to offer practical assistance was in liaising with clients' families, if clients agreed. There was an appreciation that an engaged family could know the client more intimately and potentially be able to provide a level of support that peers and buddies could not.

In a similar way to Norman et al.'s (2008) interview strategy, participants were asked what the key attributes of a peer and buddy would be. Participant groups were fairly unified in stating that people taking on the role should be: honest, trustworthy, reliable, passionate, motivated, self-confident, accepting, empathic, reassuring, non-hierarchical, communicative, proactive and informative:

"I tell my own story, my life story ... My role is to inform people about the fact that this disease is out there and that it can kill. I've got five points to get across. And then to get people to feel a little bit more reassured that there is light at the end of the tunnel if they go for treatment." (Prospective Peer, Site B)

Tensions in Relation

A key question emerged through discussion with peers, clients and service providers: Who gets to be a peer/buddy? Whilst the unity in terms of psychological attributes was relatively clear across the sample, when situated within the organisational structures of the drug service, the types of people who could take on the roles were differentiated.

Within drug treatment settings a hierarchy of unpaid positions existed, only some of which were deemed suitable by providers for fulfilling HCV peer/buddy roles:

"We've got three different levels, at least. 'Peer Mentors' wouldn't do this type of work; they can work on the café, and still be using [drugs] occasionally, but they can't be using on the day they're working in the café. The next level up is the 'Recovery Champion', where they have to be off all medication and, well, they can still be in service, but off medication. The next level is 'Volunteer', at least six months out of treatment, or not ever been in treatment, and clean and done volunteer training." (Provider, Site B)

Drug service managers considered people who had 'recovered' from drug dependency – 'Recovery Champions' – to be ideal peers/buddies. This was because they had already been checked through the UK Disclosure and Barring Service, and they were experienced unpaid helpers who presented reduced risk in terms of their potential to over-step boundaries in relation to other clients.

From a service manager’s perspective, the person performing the peer and buddy roles was:

“Ideally a person who’s been through, or is going through, or has experience of it [HCV] and who is willing to support another person. We have a Volunteer and a Recovery Champion training package, we’re just going to utilise them [in the intervention]. We know which Recovery Champions have been affected personally, or their significant other has, because we ask that, and we can record that information. I still have two; they’re now Volunteers, but they were my original BBV peers so they’ve both been through treatment themselves successfully.” (Provider, Site A)

The constitution of a Recovery Champion appeared to be a confluence of subjective biographical moment and internalization of drug service governmental strategy. From the management’s perspective, the candidate’s ‘recovered’ status and degree of adherence to the organisational ethos were prioritised over experience of HCV because they could be relied upon to dovetail with managerial priorities: *“I started off as a recovery champion ... [x] approached me about HepCATT ... I didn’t know anything about hep C, I don’t know anyone that’s had it” (Buddy, Site A)*. Indeed, a candidate’s resonance with the drug service ethos could be prioritised over experience of drug use too: *“A peer doesn’t have to be someone who has been drug using it could be anyone” (Provider, Site B).*

At the outset of the intervention, providers emphasized the importance of ‘recovery’ per se – whether from drug addiction or HCV infection. This contrasted with clients’ emphasis on the benefits of being paired with a peer or buddy who was still going through HCV treatment:

"It doesn't even have to be someone who's been through the treatment, it could be someone who's actually getting treatment, but they're like maybe six or seven months into the treatment, and they think, oh I know how bad it was, because I know, I'd, if I'd been a few months into it and I was feeling a lot better, I know for a fact you picked up the phone and said, oh someone in [location] is going for Interferon, you wouldn't mind taking them, I wouldn't have no problem going with them and sitting with them for the hour or whatever, and having a chat with them." (Client, Site B)

Whilst these issues show how organisational policies shape who can occupy the roles, and how providers and clients can be in conflict about this, there were also tensions in client-peer/buddy relations. For instance, clients defined 'empathy' as a key attribute for peers and buddies prior to the intervention, yet in practice this appeared to be compromised by the selection of peers and buddies based on their recovery status. For example, peers and buddies at one site spoke of clients in disparaging terms as: *"living in a world of chaos"; "dirty"; "unhygienic",* with one stating: *"I haven't buddied anyone so far, I have one ready to go, she's very obstructive towards anyone, she's a pain".* These references can be seen to align with discourses common to recovery settings where distancing mechanisms (clean vs. dirty, for example) operate to demarcate groups.

'Governing the peer's heart'

Clients stated that they wanted peers and buddies who were *'doing it from the heart'* so they could relate to them on a personal level: *"I just think it's come deep from the heart with someone that's been on heroin" (Client, Site B).*

However, peers and buddies were instead constituted and governed through organisational practices, which meant they could not freely engage with clients. Effectively, peers' and buddies' *hearts* were partially bound by systemic and hierarchical governance.

A peer coordinator role was instituted at both sites to both oversee the buddies/peers and be a link to senior management. For managers, this coordinator role was ideally filled by a key worker whose workload could be reduced; who had a certain interest and experience in working with people who have BBVs; who recognised the importance of support group work; who had knowledge of likely congruence between peers/buddies and clients; and who could ensure an open communication channel between the peers, themselves and their managers.

From an organisational perspective, the coordinator role was crucial as it helped ensure service consistency and sustained peers' and buddies' enthusiasm. The coordinator delivered peer training, maintained a peer database, was a point of contact for peers/buddies to discuss on-going issues, arranged for expense payments to be made, matched buddies to clients consequent upon nurses' referrals, convened wider forums which included clinical staff and drug key workers, and gave support and supervision:

It is sometimes about making the peer feel safe as well and that they have got someone to speak to at any point if they have got questions, need any support." (Provider, Site A)

The matching of buddies to clients by coordinators therefore took the establishment of congruence away from buddies' control: *"I'm hoping I get a girl, hoping. But if I get a man, I get a man. I'll deal with him: 'in your place'! I'd be fine" (Prospective Buddy, Site A).*

Bi-monthly training and awareness days were carried out to maintain peers'/buddies' motivation and engagement, and reinforce messages around confidentiality and role boundaries such that peers became aligned with the organisational ethos: *"[Training includes] safeguarding, confidentiality, customer service, general health and safety stuff. They're given a general overview of what you should be like in a professional environment, even down to the things you should wear" (Provider, Site A).*

In a competitive service provision environment this appeared crucial, as any role boundary transgression by peers/buddies could be perceived as damaging to the organisation's prospects of securing future tenders, hence they were closely monitored. Drug centre management anxieties about accountability and competitive reputation thus produced and sustained certain types of peers and buddies that were best suited to fulfill organisational policies: *"[they have to] give something back, but with[in] boundaries" (Provider, Site B).*

Moreover, peers and buddies were conceived as people who the organisation, through this coordinator, needed to keep motivated via incentives such as encouraging their participation in organisation-run sports tournaments, conferences and free training sessions on a range of activities. This was done to stave off boredom if the peer/buddy had not been matched to a client, as idleness was perceived as both a threat to dropout and an opportunity for engagement.

This also led to a perception among drug services staff that peers and buddies could not work without close supervision because the role might entail a considerable emotional burden for people vulnerable to relapse. As such, they framed the dilemma as being resolvable through governmental means:

"People would need supervision, wouldn't they? They would be taking rather a lot of emotion, possibly, from the client and, possibly still, the nature of peers per se is they're not quite in the workplace themselves normally, so might have a few 'not quite healed' things going on themselves" (Provider, Site B).

"People who have been in recovery who are peer mentors, we have had two people die, and it's a very risky period of overdose, isn't it?" (Provider, Site B).

Interestingly, clients and some providers shared a view that a peer or buddy would be, principally, *"somebody I could rant to, someone that will listen"*. The peer/buddy, for the clients and providers here, was not conceived as being a problem-solver or advisor, more someone who could absorb the unrestrained outpourings of a person grappling with the realities of their illness. Such a view would seemingly place the peer/buddy in an irreconcilable bind given the simultaneous governmental rationalisation of their role: if that 'rant' contained information sensitive to the security and reputation of the organisation, how might the peer square their competing loyalties? In relation to this, one provider brought up the issue of accountability: *"Will they be accountable, or won't they? Is that going to put more pressure on them? You may as well have a professional if you're going to make them do feedbacks, reporting, anything like that" (Provider, Site B).* In saying this, some providers appeared to understand the dilemma facing peers/buddies, recognising that organisational practices could be particularly problematic to the delivery of their roles.

Bonding vs. Boundaries

In contrast to providers, clients wanted peers/buddies to escape an organisational role, and be people who they could relate to on a personal level, unencumbered by drug service accountabilities apart from confidentiality. However, there was some reluctance from peers and buddies to build personal relationships consequent upon their internalisation of risk discourses: *"It's about boundaries, safeguarding ...A lot of service users could misinterpret your support. They've never had a friendship ...So you've got to be careful." (Peer, Site A)*

Indeed, there were signs that peers/buddies internalised the drug service's risk-averse discourse exacerbating the distancing mechanisms fostered within recovery settings. For example, both providers and peers/buddies conceived one-to-one appointments and the car as sites of risk and potential boundary transgression:

"At the moment we're not supposed to let Recovery Champions do one-to-ones with people, but here we're talking about 'letting them loose' on appointments with clients." (Provider, Site A)

"Boundaries can become blurred. Physically taking someone in your car to appointments, there's a risk." (Buddy, Site B)

That said, peers and buddies felt that trust was important in their client relationships: *"[clients] have got to be able to trust the fact that you are a genuine safe person to travel with. They've got to feel that they can talk to you" (Peer, Site B).* Yet, this conflicted with boundary concerns in relation to sensitive disclosures (e.g. about drug taking). In this respect, 'trust' was not complete, and circumscribed by organisational rather than personal limits: *"If I feel it's a danger or safeguarding issue, or anything like that, I will speak to someone about it, make no bones. So if you've got anything like that you don't want me to hear then don't tell me" (Peer, Site B).* Indeed, some clients anticipated negative outcomes with respect to trust because of the close elision of a peer with the drug service:

"They'd judge you but they'd act like they're your friend, and that'd fuck with our heads, because we think they're our friends and then they're turning round." (Client, Site B)

"He'd talk to you like you're a normal person. He'd keep all the information to himself, but they've got a job to do, so they'd judge you." (Client, Site B)

Furthermore, some clients felt *"let down"* by buddies who had failed to keep appointments with them during the intervention. This had the effect of undermining trust and any further opportunities for bonding: *"They offered me this buddy system that would take me to appointments and that. He took me once and then every other time 'oh, I can't make it'. And it's like, hang on a minute, I'm the one with the fucking disease here, you're supposed to be helping me" (Client, Site B).*

Peers mainly delivered their life stories to groups within highly structured situations, where personal bonds had limited capacity to blossom. Further, whilst 'education' was something that clients felt they required, the nature of this education appeared to be at odds with some of the key messages delivered by the peers, via the Hepatitis C Trust. For instance, most clients were aware that HCV could be contracted through injecting paraphernalia, yet this was still a key message and one that peers felt clients lacked awareness of.

One peer felt that clients did not need to know much about him: *"I'm there to buddy them to get to treatment, and that's it. I don't want, I'm not going to be their friend, I'm not going to tell them my secrets or anything like that" (Peer, Site B).* Buddies were slightly more open to forming personal relations with clients, appreciating that there was a need for a bond to form, but certain topics were still deemed off-limits: *"To get to know each other you've got to do that coffee, breakfast together and talk. You've got to get to know your service user, and they've got to get to know you. You can talk about your likes in music, TV programmes, just never discuss family. I wouldn't discuss my family. You've got to protect your own little bubble" (Buddy, Site*

A). Nevertheless, peers and buddies were often inhibited somewhat, suggesting that trusting bonds might not easily come to fruition. Clients, on the other hand, were generally keener to state the importance of an open two-way relationship: *"I give you that help and you show me some back. And then we're on an even keel and then nobody can ever say any bullshit about you. You know what I'm saying?" (Client, Site B).*

Moreover, the peer's use of the verb 'to buddy' suggested that the role was functional and instrumental; it was not the kind of relationship where, as one client had hoped, they might "*have a laugh" (Client, Site B)* together. Boundaries between clients and peers/buddies were not flexible and emergent during their relationships, but fixed *a priori* ones, that had limited respect for sensitivity of personal circumstance, and which, for this client cohort, could potentially upset fragile states of stability.

A Search for Legitimacy

Peers and buddies had not been fully integrated into the HCV treatment provision within HepCATT, or indeed the drug center services as a whole. Compounding this, some HCV positive clients and drug services staff at both sites were unaware of the peer service: *"I wasn't aware of that service, no" (Provider, Site A).* Furthermore, some clients, especially those undertaking courses of DAAs, did not feel a need for a buddy, or preferred to go to hospital with a family member: *"I don't know if it was mentioned for that particular thing [HCV], but I know there is a buddy system in place… I am quite happy to go to the hospital on my own" (Client, Site A).* All of this fuelled a feeling amongst peers and especially buddies that they had been underutilised.

Buddies and peers were rarely present at the drug services apart from when they had appointments: *"Because I'm a volunteer, I'm either at home, or working, or at [another organisation], or here. I'm just all over the shop" (Buddy, Site B).* They felt they had not been given dedicated space through which they could become more visible to clients and were therefore searching for legitimacy in order to give their role purpose and to be more active. Ideally, they wanted a physical presence in the sites' cafés or waiting areas, where they could be seen by clients and given more possibilities for contact time, yet this had been slow to be realised. Indeed, buddies had few opportunities to meet clients (e.g. within client-key worker meetings) and bond with them prior to hospital appointments. Another issue that prevented contact consisted in peers and buddies not being able to use their own personal phones to speak to clients, but not being given work phones either: *"If you read [the drug treatment service's] policies on telephones, staff have work phones, but volunteers don't have work phones so there's a potential problem there" (Peer, Site B).*

This search for legitimacy also included a desire to be given clinical responsibilities. Some buddies, peers and clients thought they should be trained in HCV testing. Providers and clinical staff were less keen on this, however, as they believed it would blur the boundaries between a peer and a key worker or nurse, which they wanted to maintain: *"Personally, I think it takes away from the clinical element, from the workers' responsibility slightly" (Provider, Site A); "There wouldn't be much point in the nurse then [if peers could do HCV testing]" (Provider, Site B).* As such, providers and nurse facilitators conceived peers and buddies as supplementary functional resources for the intervention. For them, peers and buddies could help support their work by, for example, speaking to clients who repeatedly did not attend clinical appointments to see if this changed their behaviour, but they were otherwise cleaved from clinical responsibilities. Indeed, they felt the peers' and buddies' roles should be concerned simply with support and shared experience. Yet, clients had hoped peers would ideally have good knowledge of local testing and treatment services and be able to signpost them to related services and key individuals, such as nurses. Furthermore, hinting at the practical blurring of peer and clinical functions, peers anticipated clients would require most support if they were taking Interferon, but suggested that they would not require it if they were to take DAAs.

A further aspect of their marginalisation concerned the extent to which peers and buddies were regarded as *workers.* Peers and buddies saw their roles as *"a proper job"* although they wanted options for being paid and obtaining professional accreditation. Ideally, peers and buddies wanted to be able to choose from a list of accreditation options and specialise in project work or social support, something broader and more transferrable than a health certificate. Key workers reiterated this need for meaningful training: *"You feel as though you're actually doing something; it's something that's recognised" (Provider, Site A).*

Most peers/buddies aspired to be key workers: "*I would be lying if I didn't say that I would want maybe to get employment in this area or keep working in this area after the project" (Peer, Site B); "I suppose what I'd like in the end is to go to college and get connected to one of the clinics and be there to support people" (Buddy, Site A).*

Indeed this meant some peers and buddies acted in a more boundaried way with clients as they felt a pathway to a professional role was at stake during the intervention.

Peers, buddies and some key workers felt that funding peers would increase applications, improve retention and enhance future job prospects. However, clients seemed most concerned that the role was voluntary and therefore more authentic and trustworthy: *"If I walked in here and somebody was working here voluntarily, willing to take every day out of their own time to talk to people about hep C, about taking drugs and things like that, I'd respect them a lot more than anybody sat behind that desk" (Client, Site B).*

The assumption that volunteers needed to be 'passionate', but that this was not essential for workers, seemed an awkward tension. Indeed, reflecting this, most providers felt that if peers and buddies were paid then their role would be less 'genuine': *"I think once you start paying people to be a peer, you kind of lose the momentum of being a peer and the genuineness that comes with volunteering" (Provider, Site A)*. Additionally, some providers felt that maintaining the distinction between workers and peers helped lower organisational costs: *"If it's a peer, it's voluntary, it's very cost-effective, isn't it?" (Provider, Site A).*

Discussion

Critical reflection on how social structures, policies, health and drug services and social identity impact on the experience and reception of a peer support service for HCV in two UK drug treatment centres reveals a number of congruities and tensions.

Decontextualised Peers & Buddies

First, there was much agreement between clients, drug service and intervention providers on what peers and buddies should be as decontextualised entities. In a similar way to Norman et al.'s (2008) findings, participants broadly expected peers and buddies to offer generalised support ('just being there') and be empathic and trustworthy. Likewise, echoing the study by Norman and colleagues, experience of HCV, injecting drug use and/or personal skills were held to be important elements for the roles, though no element was unanimously prioritised.

Tensions in Relation & The Recovery Ethos

When peers and buddies were placed in practice and in relation to other social roles and organisational policies there were, however, tensions. Drug service organisational frameworks limited who could become a peer or buddy. Relatedly, peers' and buddies' adherence to organisational structures could create tensions with clients as boundaries were often enacted rigidly rather than flexibly. In part, this was due to a search for (and lack of attaining) legitimacy, with peer work often viewed as a step towards paid employment in the service.

Whilst clients anticipated having strong relationships with peers pre-intervention, the realities of the intervention saw the development of relationships that were sub-optimal, with some clients feeling ‘let down’ by ‘unreliable’ buddies. These relationships were structured by, for example, the lack of opportunities given to clients and buddies to meet and bond prior to hospital appointments. This contrasts with previous research (Crawford & Bath, 2013; Treloar et al., 2015). Indeed, there is a wealth of literature reporting the positive influence of peers on continued engagement in HCV treatment amongst PWID (Galindo et al., 2007; Norman et al., 2008; Rance and Treloar, 2012; Alavi et al., 2013; Ti et al., 2013; Rance and Treloar, 2014; Batchelder et al., 2015; Charlebois et al., 2012; Grebely et al., 2010; Harris et al., 2014). Two functions of peers are cited as important in this regard; first, their role in promoting patient empowerment and second their role in sharing their experiences of HCV testing and treatment (Norman et al., 2008; Treloar et al., 2013). Within the present study, however, the relative invisibility of peers and buddies to clients undermined or restricted positive effects on empowerment. Relatedly, there were too few opportunities to share experiences either at formal presentation sessions or informal discussions in on-site cafés and waiting areas. Moreover, many buddies had not experienced HCV testing and treatment, and some did not identify as PWID (current or past), which restricted the capacity for congruence between them and clients. In the future, peer and buddy programs should carefully consider the importance of congruence between clients and peer/buddies when recruiting people to these roles. This will help ensure the effectiveness of these services.

In practice, peers and buddies faced constraints on realising clients’ and providers’ expectations. A ‘recovery’ dominated drug treatment ethos in the UK appeared to influence the selection of ‘recovery champions’ as peers for the intervention. Peers’ tensions in their relations with clients were localised within a constellation of the prestige given to Recovery Champions, internalised risk discourses and a search for legitimacy – especially the aspiration to become a key worker. Peers were poorly integrated and supported within the service, affecting opportunities to relate and build trust with clients. Thus, the scope for peer support to impact the nature and extent of clients’ testing and treatment for HCV was limited.

Search for Legitimacy

Peers and buddies felt both frustrated and peripheral during the intervention. The experience of being marginalised within the service reflects experiences of peers in previous interventions (Musgrove, 2011; Crawford & Bath, 2013). Unlike Norman et al.’s (2008) peer, HepCATT peers and buddies were unpaid roles in the intervention, which restricted their status as ‘workers’. Compounding this, functions of peers that have been highlighted in previous research were sometimes taken on by nurses and drug services staff. The role was often reduced to limited educational exchange (of the individualistic kind – see Treloar et al., 2011) and chaperoning clients to treatment, rather than helping them prepare for and assisting during it or “facilitating referrals” (Treloar et al., 2015: 996).

Peers were not involved in the set-up of HCV treatment delivery to the same extent as the peer educator in the study by Norman and colleagues (2008). There, the peer educator played a “fundamental role” in the support of clients pre-, during, and post-treatment, seeing most clients face-to-face about once every week. At the time of the

HepCATT evaluation, there had only been minimal support pre- and during, and virtually no support post-treatment in either site. Recent research in Australia (Keats et al., 2015) suggests clients tend to have much longer meetings with peers compared to nurses (>60mins compared to 15), discussing general HCV issues, education, support and treatment options. The curtailing of the role and contact time between clients and peers in HepCATT therefore suggests a missed opportunity.

Buddies felt underutilised. In part this was because of the lack of integration within HepCATT and the lack of advertising of the buddy service. However, some clients simply did not feel a need for the service, preferring instead to go to appointments with friends, family or alone. This in part reflects recent speculation by Treloar et al., (2015) that interferon-free treatment means there is less of a need for peer workers as the treatment is easier to tolerate. That said, there is evidence to suggest that PWID value peer support highly in the DAA era, and there is also a need to counter negative client expectations of DAA regimens that are intertwined with interferon-based treatment (Whiteley et al., 2016).

Not all clients were aware that a HCV peer support service was in place at the drug treatment service, chiming with findings elsewhere (Treloar et al., 2015). Moreover, not all staff were aware of it either, which meant they did not alert their clients to it. However, staff who were aware of the peer support service could see the benefits that it was beginning to bring to the HCV treatment provision within the drug clinic, suggesting a nascent ‘transformative effect’ (Crawford & Bath, 2013).

Space & Marginalisation

Treloar et al. (2011) have previously highlighted restrictions on the availability of social space *beyond* drug clinics for peer education and support. Our study finds restrictions on space *within* drug clinics too. One previous study (Treloar et al., 2015) has reported on HCV peers' spatial restrictions within drug treatment settings, describing how certain 'staff areas' are deemed off-limits, principally to prevent access to medications or protect peers from allegations regarding missing medications. In the present study, the spatial restrictions and lack of a coherent and visible presence within the drug centre undermined peers' and buddies' search for legitimacy. Moreover, the study by Norman et al. (2008) demonstrated the importance of client-peer communication by phone, yet this was restricted in the present intervention due to organisational policy. In order to increase visibility and trust, there is a need for peers to work in on-site cafés or other client-facing roles where they can build rapport, but still be seen to be distinct enough from other drug treatment staff roles.

Limitations

Unlike some other studies of peer support models and interventions which have assessed them after a period of years (e.g. Grebely et al., 2010; Treloar et al., 2015) our study reported on only the very early stages of the set up a peer support system and it is conceivable that given more time some of the issues raised in this paper may have been overcome and better relationships between clients, peers and drug service staff established. That said, our study presents insight into what the early teething problems of such systems can be and can provide pointers with respect to better practice. The difficulties of recruiting ‘non-engager’ clients in this study limits the generalisability of the findings.

Conclusion

Peer programs take considerable effort to carefully implement in drug treatment settings and weave into wider recovery and harm reduction frameworks. Whilst there can be significant agreement on what the role of peers and buddies should be in principle, there are significant institutional and practical obstacles to overcome before peers and buddies become integrated and positive benefits are seen. The efficacy of peer involvement can be constrained by organisational structures - especially regarding who is deemed to be ‘a peer’ - and organisational policies on boundaries. We concur with Crawford and Bath (2013) that organisational barriers in highly regulated drug services environments need to be lessened to facilitate acceptance of peers and facilitate their interactions with clients. Moreover, peers need to be welcomed as part of the clinical team for HCV, rather than be kept as a separate service. Yet, questions remain as to the extent a HCV peer service can be visible enough within generic drug treatment settings. Acknowledging (and working with) different stakeholder perspectives on what a peer and peer service are will be key for successful interventions.

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References

Alavi, M., Grebely, J., Micallef, M., Dunlop, A. J., Balcomb, A. C., Day, C. A., Treloar, C., Bath, N., Haber, P.S., Dore, G.J. & Enhancing Treatment for Hepatitis C in Opioid Substitution Settings (ETHOS) Study Group. (2013). Assessment and treatment of hepatitis C virus infection among people who inject drugs in the opioid substitution setting: ETHOS study. *Clinical Infectious Diseases*, *57*(suppl 2), S62-S69.

Batchelder, A. W., Peyser, D., Nahvi, S., Arnsten, J. H., & Litwin, A. H. (2015). “Hepatitis C treatment turned me around:” Psychological and behavioral transformation related to hepatitis C treatment. *Drug and Alcohol Dependence*, *153*, 66-71.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Charlebois, A., Lee, L., Cooper, E., Mason, K., & Powis, J. (2012). Factors associated with HCV antiviral treatment uptake among participants of a community-based HCV programme for marginalized patients. *Journal of Viral Hepatitis*, *19*(12), 836-842.

Crawford, S., & Bath, N. (2013). Peer support models for people with a history of injecting drug use undertaking assessment and treatment for hepatitis C virus infection. *Clinical Infectious Diseases*, *57*(suppl 2), S75-S79.

Galindo, L., Maginnis, T., Wallace, G., Hansen, A., & Sylvestre, D. (2007). Education by peers is the key to success. *International Journal of Drug Policy*, *18*(5), 411-416.

Grebely, J., Knight, E., Genoway, K. A., Viljoen, M., Khara, M., Elliott, D., Gallagher, L., Storms, M., Raffa, J.D., DeVlaming, S. & Duncan, F. (2010). Optimizing assessment and treatment for hepatitis C virus infection in illicit drug users: a novel model incorporating multidisciplinary care and peer support. *European Journal of Gastroenterology & Hepatology*, *22*(3), 270-277.

Harris Jr, K. A., Arnsten, J. H., & Litwin, A. H. (2010). Successful integration of hepatitis C evaluation and treatment services with methadone maintenance. *Journal of addiction medicine*, *4*(1), 20.

Harris, M., Rhodes, T., & Martin, A. (2013). Taming systems to create enabling environments for HCV treatment: negotiating trust in the drug and alcohol setting. *Social Science & Medicine*, *83*, 19-26.

Harris, M., McDonald, B., & Rhodes, T. (2014). Hepatitis C testing for people who inject drugs in the United Kingdom: Why is uptake so low?. *Drugs: Education, Prevention and Policy*, *21*(4), 333-342.

Keats, J., Micallef, M., Grebely, J., Hazelwood, S., Everingham, H., Shrestha, N., Jones, T., Bath, N., Treloar, C., Dore, G.J. & Dunlop, A. (2015). Assessment and delivery of treatment for hepatitis C virus infection in an opioid substitution treatment clinic with integrated peer-based support in Newcastle, Australia. *International Journal of Drug Policy*, *26*(10), 999-1006.

MacLellan, J., Surey, J., Abubakar, I., & Stagg, H. R. (2015). Peer Support Workers in Health: A Qualitative Metasynthesis of Their Experiences. *PloS one*, *10*(10), e0141122.

Musgrove, S. M. (2011). NUAA's ETHOS Projects: The story of a Hep C peer support worker & his clinic. In *2nd international symposium on hepatitis in substance users*.

Norman, J., Walsh, N. M., Mugavin, J., Stoové, M. A., Kelsall, J., Austin, K., & Lintzeris, N. (2008). The acceptability and feasibility of peer worker support role in community based HCV treatment for injecting drug users. *Harm Reduction Journal*, *5*(1), 1.

Rance, J., & Treloar, C. (2012). *Integrating treatment: Key findings from a qualitative evaluation of the Enhancing Treatment of Hepatitis C in Opiate Substitution Settings (ETHOS) study*. National Centre in HIV Social Research.

Rance, J., & Treloar, C. (2014). ‘Not just Methadone Tracy’: transformations in service- user identity following the introduction of hepatitis C treatment into Australian opiate substitution settings. *Addiction*, *109*(3), 452-459.

Roose, R. J., Cockerham-Colas, L., Soloway, I., Batchelder, A., & Litwin, A. H. (2014). Reducing barriers to hepatitis C treatment among drug users: An integrated hepatitis C peer education and support program. *Journal of Health Care for the Poor and Underserved*, *25*(2), 652-662.

Swan, D., Long, J., Carr, O., Flanagan, J., Irish, H., Keating, S., ... & Moloney, J. (2010). Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: a qualitative exploration. *AIDS patient care and STDs*, *24*(12), 753-762.

Ti, L., Kaplan, K., Hayashi, K., Suwannawong, P., Wood, E., & Kerr, T. (2013). Low rates of hepatitis C testing among people who inject drugs in Thailand: implications for peer-based interventions. *Journal of Public Health*, fds105.

Treloar, C., Rance, J., Laybutt, B., & Crawford, S. (2011). Structural constraints on the training of peer educators in hepatitis C prevention. *Health Education Research*, *27*(2), 248-257.

Treloar, C., Rance, J., Bath, N., Everingham, H., Micallef, M., Day, C., Hazelwood, S., Grebely, J. & Dore, G. J. (2015). Evaluation of two community-controlled peer support services for assessment and treatment of hepatitis C virus infection in opioid substitution treatment clinics: The ETHOS study, Australia. *International Journal of Drug Policy*, 26(10), 992-998.

Whiteley, D., Whittaker, A., Elliott, L., & Cunningham-Burley, S. (2016). The lived experience of interferon-free treatments for hepatitis C: A thematic analysis. *International Journal of Drug Policy*, *38*, 21-28.