



Taming systems to create enabling environments for HCV treatment: Negotiating trust in the drug and alcohol setting

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ABSTRACT

HCV (hepatitis C) treatment uptake among the population most affected – people who inject drugs – is suboptimal. Hospital based treatment provision is one evidenced barrier to HCV treatment uptake. In response, HCV treatment is increasingly located in treatment settings seen as more amenable to people who inject drugs, such as drug and alcohol services. We explored the accessibility of HCV treatment provision at two such partnerships. Data collection comprised qualitative interviews collected in 2011 and 2012 with 35 service users and 14 service providers of HCV treatment in London, United Kingdom. We draw here primarily on thematic analyses of service provider accounts, yet narratives relating to trust and environment emerged unsolicited in both user and provider accounts of negotiated HCV treatment access. A key theme in service provider accounts were strategies they deployed to ‘tame’ the treatment system so as to create an ‘enabling environment’ of care, in which trust was a critical feature. This ‘taming’ of the system was enacted through practices of ‘negotiated flexibility’, including in relation to appointments, eligibility, and phlebotomy. Service user accounts accentuated familiar environments and known health providers as those most trusted, and the potentially stigmatising effects of negotiating treatment in unfamiliar territory, especially hospital settings. Whilst noting the effects of provider strategies to negotiate flexibility on behalf of would-be patients seeking treatment, we conclude by noting the limits of trust relations in settings of constrained choice.

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Introduction

Worldwide an estimated 180 million people live with chronic hepatitis C (HCV) (World Health Organisation, 2011), with attributable deaths now surpassing HIV related mortality in developed countries such as the USA (Ly et al., 2012). Unlike HIV, HCV can be eradicated with biomedical treatments; successful in 50–85% of cases (Ghany, Strader, Thomas, & Seeff, 2009). HCV is concentrated in populations of people who inject drugs (PWID), with over 90% of new infections in developed countries attributable to drug injecting practices (Palmateer et al., 2010). Widespread HCV treatment provision for current injectors can act as an effective preventative measure, reducing the pool of communicable disease in the population (Martin et al., 2011). PWID have demonstrated interest in HCV treatment uptake (Canfield, Smyth, & Batki, 2010; Treloar & Holt, 2008), and in many countries current injecting is no longer a contraindication to treatment access. Yet, in the UK and internationally, HCV treatment uptake among PWID is low (Lazarus, Shete, Eramova, Merkinaite, & Matic, 2007; Martin et al., 2011).

A recent review of the literature has identified a number of social structural barriers to HCV treatment access and uptake for PWID, akin to those experienced by PWID in regard to HIV treatment access (Harris & Rhodes, submitted for publication). These include constraints posed by homelessness, stigma, criminalisation, transport access and affordability, drug and income procurement priorities and mistrust in hospital-based care (Lally, Montstream-Quas, Tanaka, Tedeschi, & Morrow, 2008; Neale, 2008; Swan et al., 2010; Treloar, Newland, Rance, & Hopwood, 2010). Trust in health care providers is evidenced as a key facilitator to health care engagement (Thom & Campbell, 1997), particularly among marginalised populations such as PWID (Ostertag, Wright, Broadhead, & Altice, 2006; Swan et al., 2010) and people living with HIV (Carr, 2001; Osilla et al., 2009). This trust can be constrained among PWID by experiences of stigmatisation and related collective narratives of mistrust in expert systems (Ostertag et al., 2006).

The health care ‘system’ is not necessarily a stable structural barrier in and of itself, but can be more productively viewed as an assemblage of interactions, in which drugs, procedures, medical instruments, architecture, protocols and staff come together to produce certain effects – some stigmatising (Latour, 2005). Labyrinthine corridors, confusing signage, lengthy waiting times,

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complex referral routes, rigid eligibility criteria and inflexible appointment structures can interact to produce distrust, despite positive individual staff practices (Paterson, Backmund, Hirsch, & Yim, 2007). Many of these constraining assemblages are associated with the hospital setting, and in order to facilitate HCV treatment access and uptake among PWID, moves have been made to situate HCV treatment provision in locations felt to be more amenable to PWID, especially drug and alcohol (D&A) services (Treloar & Holt, 2008). D&A services are not, however, immune to mistrust among PWID, with many characterised as employing highly surveillant and disciplining practices especially regarding opiate substitution therapy (OST) provision (Rance, Newland, Hopwood, & Treloar, 2012).

Trust in the context of HCV treatment

Trust as a sociological concept has been multiply defined. Common to many definitions are conceptual linkages between trust, vulnerability, familiarity, risk and agency. A need for trust is heightened in situations of vulnerability. For Davies (1999), trust is: “an embodiment of expectations that vulnerabilities will be protected rather than exploited”. Based both on prior experiences and on perceptions of future risks, trust helps to simplify and rationalise difficult decision-making processes (Luhmann, 1979). Familiarity influences decisions to (mis)trust, with prior experiences and knowledge of an individual, situation and/or system informing calculations of risk (Luhmann, 1979; Meyer & Ward, 2009). This risk calculus perspective tends to conceptualise trust as an active stance, a decision taken by a rational agent in a context of viable choice (Meyer & Ward, 2009). No less a decision, trust may stem from a ‘leap of faith’, particularly in regard to systems-based or ‘faceless’ trust (Giddens, 1990). Trust has been differentiated from dependency, the latter formulated as ‘involuntary trust’; where decisions take place in contexts of limited or highly constrained choice (Gilson, 2003; Meyer & Ward, 2009). What it is to ‘choose’ however, can be seen to contain its own constraints, with notions of viable choice legitimated only within certain parameters (Barbour, 2011). This is especially the case for marginalised individuals for whom economies of status and value may differ from those held by the ‘mainstream’.

Decisions regarding HCV treatment commencement for PWID are complex, both for service users and providers. Prior to treatment commencement individuals face uncertainty in regard to treatment success, as well as in relation to the duration, type and intensity of potential treatment side effects. The standard combination treatment for HCV, comprising pegylated interferon and ribavirin, has duration of six to 12 months, with a 50–85% cure rate depending on genotype (Ghany et al., 2009). Drug toxicity is a primary barrier to treatment uptake and completion, with common side-effects including anaemia, depression, anxiety, fatigue, flu-like symptoms, nausea, alopecia and insomnia. Cases of psychosis, mania and suicide have also been reported (Ghany et al., 2009). In addition, PWID often have multiple and conflicting health, social and emotional needs (Lally et al., 2008; Neale, 2008) and may be reticent to place their trust in biomedical treatment regimes. HCV treatment risk and benefit calculations are necessary by providers as well as service users especially in regard to the possible exacerbation of pre-existing physical or psychological co-morbidities.

The extant literature drawing on trust in relation to PWID and HCV primarily concentrates on uncertainty management around transmission risk practices, such as needle and syringe sharing. Trust has been found to play a vital role in risk calculus decisions, especially in situations of uncertainty where trust can act as the equivalence of, or substitute for, knowledge (Rhodes et al., 2008). While trusting relationships have been found to enable enhanced social support and protective health behaviours, for example the adoption of safe

injecting advice from a friend or provider (Jauffret-Roustide et al., 2012; Kirst, 2009), they can also act symbolically to bracket risk and influence less protective behaviours such as syringe sharing in contexts of trust and intimacy (Kirst, 2009; Rhodes et al., 2008). Research addressing health care among PWID and/or those who live with HIV suggests a positive relationship between health care uptake and trust in providers, the latter influenced by good communication, mutual respect and continuity of care (Carr, 2001; Jauffret-Roustide et al., 2012; Swan et al., 2010). The majority of this research to date focuses on ‘patient perspectives’ and the factors affecting patient–provider relations, with a dearth of literature focussing on the role of treatment setting or environment in the production of trust relations, and a lack of emphasis on health care providers’ accounts.

We explore how providers of HCV treatment conceptualise and employ ‘trust’ in their efforts to engage PWID in HCV treatment and care. Drawing upon qualitative research nested inside two London-based HCV treatment partnerships with drug and alcohol services, we explore how certain assemblages within the environments of hospital-based and D&A service-based treatment settings interact to foster stigmatisation and mistrust. Specifically, we describe the capacity and efforts of providers to modify or ‘tame’ their treatment environments, and the procedures enacted within them, in order to win the trust of their would-be patients, PWID. We explore how PWID account for their experiences of negotiating access to HCV treatment more fully elsewhere, especially in relation to the ‘patient citizenship’ negotiated between service users and providers (Rhodes, Harris, & Martin, 2013). Using this case study, we conclude by asking under what conditions can trust in HCV treatment systems become possible?

Method

Aim

The study aimed to assess the accessibility and quality of HCV treatment provision for PWID located at D&A services in London, United Kingdom.

Sites

We focused on two partnerships providing HCV treatment at D&A services in different areas of London. Site A is an established partnership between a hospital hepatology service, a specialist D&A service, and a regional blood borne virus (BBV) service. Operating since 2005, this partnership provides a low threshold community-based HCV treatment outreach programme to individuals with complex addiction problems and multiple co-morbidities. A BBV nurse practitioner provides daily HCV testing and care at the D&A service as part of a broad package of interventions, with a consultant hepatologist available in a monthly clinic.

Site B is a pilot partnership between a hospital viral hepatitis service and a community D&A service. Operational since mid-2011, one full-time Physical Health Harm Reduction Nurse (PHHRN) was employed to coordinate HCV treatment for the initial one year duration of the pilot. The PHHRN and a BBV service nurse work with the D&A team to identify and refer service users, provide HCV testing and harm reduction, as well as support them in their HCV treatment. The treatment element of the service comprises a weekly half-day HCV outreach clinic located at the D&A service and staffed by a hospital-based viral hepatitis nurse, and a monthly outreach clinic staffed by a consultant hepatologist.

Ethics

Approvals were obtained from the London School of Hygiene and Tropical Medicine Ethics Committee (ref: 5630) and the North

London Regional Ethics Committee (ref: 11/H0724/5). Interviews commenced after informed consent was obtained and all participants have been provided with pseudonyms.

Data collection

Data collection took place from June 2011 to January 2012. Participants were referred from the collaborating D&A and HCV treatment services. The primary mode of data collection was the qualitative in-depth interview, facilitated by a topic guide. Interviews typically lasted between 60 and 90 min, were conducted in a private room at the recruiting service and audio-recorded with participants' consent. Topics informing the interviews ranged from – for service users – experiences of HCV testing, diagnosis, referral and treatment to service evaluation and improvement. Health care providers were asked to provide an overview of their role and the history of the service, protocols relating to HCV testing, referral and treatment and service evaluation and improvements.

Analysis

Audio recordings were transcribed verbatim and coded in two linked phases. The first level coding drew upon a combination of a priori themes reflected in the study topic guide and in vivo codes. These themes were re-analysed to develop concept driven categories. Analyses were assisted by NVivo8 software. Trust did not feature as a topic in the interview questions, but arose as a predominant theme in participant narratives. Setting, in relation to the demarcation between the environment of the hospital and the D&A service, also arose as a primary unit of analysis.

Participants

Participants comprised 35 HCV positive PWID and 14 service providers, both recruited from the two HCV treatment partnerships. HCV positive participants were purposively sampled to include those with recent, established and no experience of HCV treatment; 17 of whom were recruited from site A and 18 from site B. Participants were predominately male (29; 83%) and averaged 45 years old (range 26–60 years). Twenty one (60%) identified as White British and 33 (91%) were in receipt of welfare benefits, with only three in full-time employment. The majority (32; 92%) received OST with eight (23%) currently injecting illicit drugs, primarily heroin and crack-cocaine. Twelve service users had completed HCV treatment (nine successfully), six were in the midst of treatment, 13 were waiting for or contemplating treatment and treatment had been interrupted for four.

Seven service providers were recruited from site A and seven from site B. These comprised two consultant hepatologists (one from each site), four BBV nurses (3 from site A, 1 from site B), two hospital-based hepatitis nurses (both from site B), one D&A nurse tasked with setting up the HCV outreach clinic and facilitating referrals (at site B), one consultant psychiatrist (from site A), two D&A team managers (one from each site), one administrative worker (from site A), and one former representative of the pharmaceutical company funding the HCV outreach service (at site B).

Findings

The hospital environment featured in participants' narratives as a barrier to HCV treatment access. Providers positioned the D&A environment as more accessible for PWID due to its familiarity as well as more amenable to structural modifications than the hospital system. Such patient-friendly modifications or structural 'taming' sought to open up the system to easier navigation on the

part of patients, and were found to occur through practices of 'negotiated flexibility'. We describe here three key domains of negotiated flexibility: appointments; eligibility; and phlebotomy. We also go on to note some of the limits such taming strategy, and in doing so, draw upon a further example: the delivery of OST.

The unfamiliar hospital environment: estrangement

The hospital setting is not necessarily a stable structural barrier in and of itself, but assembled through a variety of interactions which come together to produce structural effects. Dillon (site B) relates how the production of stigma through one of these interactions created a barrier to accessing hospital-based HCV treatment:

I was really badly treated and I know loads of people that have been treated abysmally down there, really blatant discrimination ... Just looking with disgust, clear disgust in the nurses' faces, 'You're drug addicts, oh, so you got it through injecting, well you should know better'.

This experience led Dillon to avow that he would never undertake hospital-based HCV treatment. While Dillon's assertion is framed in terms of direct experience, narratives of mistrust circulating among peers also act to dissuade access:

People are saying, 'they [hospital staff] are bastards' to me and they've probably never been to [hospital], it's just that went around so it's fact, you know, if it's not fact, it becomes fact after a while. (Dillon, Site B)

Expectations of stigma, based on cultural narratives and the experiences of peers, can in this way reproduce, foreground and make 'fact' experiences of mistrust. Mistrust can be a protective strategy for marginalised individuals, particularly in regard to an unknown or suspicious 'Other' such as the hospital, replete with its associations of authority and potential stigma.

According to interviewed providers, referred PWID infrequently attended hospital-based HCV treatment appointments. Reasons posited for appointment non-attendance included: hospitals rigid eligibility criteria, multiple pre-treatment appointments, and lack of suitably tailored services for PWID. Such accounts also emphasised hospitals as unfamiliar territory, as 'foreign' land:

Well partly the transport [is a barrier] but I think it's a psychological thing for a lot of our patients, they're very entrenched in their own environment. You talk to a lot of patients here who've lived all their lives in the East End and they don't know the West End ... that's a foreign land to them it really is. You tell them that you've got an appointment at [X] Hospital, well you might as well say it's in Timbuktu because they have no idea where that is. (BBV nurse 1, site A)

Zones of trust, mis(trust) and neutrality are mapped; informed by layers of personal and peer experience. Outside an individuals' familiar and knowable environment lies an unfamiliar grey area where not enough experiences have been laid for zones of (mis) trust to be adequately mapped. If it is in this grey area that the treatment hospital is situated, participants are less likely to access it. As Eric (Site B) says:

You have to go round in circles ... you need a map to find it [hospital] and then when you do you've got to ask somebody which way is it. It's not easy.

Non-attendance at appointments may, therefore, not just be an issue of access to funds for transport or of prior negative experiences in hospital settings, but involve a reticence to move outside of

a familiar environment mapped into negotiable trust zones. Negotiating such boundary crossings not only entertains risk (unknowns), it requires considerable work to successfully navigate, especially when entering from a position of difference or marginalisation (Rhodes et al., 2013). The capacity to quickly assess and negotiate a known environment is of particular importance to individuals whose daily activities, such as the transaction and carrying of drugs, are criminalised. This is at once a symbolic and physical concern. For many PWID, for example, it is vital to remain proximate to certain mapped locations, such as the methadone dispensing pharmacy and needle exchange, which may only be accessible at certain times of day.

Not only is the hospital environment constructed as the unknown and mistrusted Other, but the unknowability or 'difference' of PWID within this setting can also reproduce stigmatising and alienating practices. Davey (Site B) speaks of one such encounter:

As soon as I told the consultant what drugs, what medication I was on he was like, 'Ooh'. He sort of like recoiled ... There's a personal judgment on you.

Anxiety about being judged 'out of place' can result in participants missing appointments or acting 'inappropriately', thus reproducing a shared sense of felt difference as well as perpetuating stereotypes of PWID as problematic and unreliable. Kaveh, an Italian immigrant, (Site A) explains:

I don't think it's a language barrier. I think it's more a question of what I am perceived to be. ... Sometimes it's very difficult to go through, this immediate preconception, 'You come from there. You come from the *drug* clinic.' ... It makes me so nervous that when I'm here [the hospital] I do really stupid things.

A fear of judgement, coupled with the unfamiliar language and environment of the hospital, can thus coalesce to produce and reproduce, rather than bridge, *difference*. Service providers can seek to tame such difference by allowing it to unfold within certain parameters of managed 'acceptability'. As noted here, however, this approach is limited by what constitutes 'acceptable' behaviour in the hospital environment:

They [PWID] can be mistrustful of healthcare and a lot have had bad experiences ... They may use different language and they may swear a lot because that's the language they use. They go into hospital and have the frustrations that hospital has ... So when they do get frustrated and start shouting, they're then labelled as a troublemaker and the whole thing escalates and they're kicked out of hospital.

The familiar drug and alcohol setting: engagement

HCV treatment provision at D&A services seeks to overcome some of the barriers posed by the estrangement between PWID and the hospital setting. The D&A service may not necessarily be a trusted location, but calculations regarding HCV treatment uptake are potentially simplified due to its familiarity. As Davey (Site B) says: "it [D&A service] was a familiar place to us and that's what made us think, I'll come back and I'll try it [HCV treatment]". Jed also draws on notions of familiarity when outlining the benefits of site B:

Because you're more familiar with the place and you know bits about it ... plus there's other people coming and using the same service as well. So you get to meet other people. Which you probably wouldn't do at the hospital because ... in the waiting room everybody's got different problems. And you don't want to talk about things. But here, you know roughly what the

problem's going to be with another person. So you're more likely to talk about it.

Familiarity with individual service providers aids engagement, as Eric (Site B) states: "I wouldn't have gone to that [service] if it hadn't been for her [BBV nurse]". Bibi (Site A) says of her consultant:

He really shows that he cares, he remembers what we spoke about the last time, even three or six months after, he remembers. He knows my weakness, my fear of things and he helps me.

In Giddens' (1990) terms, individual health care workers can be seen to act as 'access points' for, or representatives of, the health care system. Trust in an individual provider has the potential to modify – if not facilitate – the need for systems-based trust. Individual trust relationships between users and providers seek to humanise medical interactions as well as reduce the distance of individual-system differences and their extent of unknowns, whether that 'system' be the health care system in general or HCV treatment regimes in particular. Yet, unlike the hospital setting, in the D&A services clients may develop long-standing relationships with particular 'keyworkers', on whom they come to rely for directional guidance as well as social support in their treatment journeys. For Mick (Site A) his keyworker "was like a big brother ... we were close".

Taming the system: negotiated flexibility

Familiarity plays a role in moderating the mistrust many PWID have towards expert systems. While D&A services are not necessarily trusted more by PWID than hospitals, various elements of the hospital environment can coalesce to produce and exacerbate experiences of estrangement. These elements, due perhaps to their entrenchment and multiplicity, appeared to be less amenable to 'taming' in the hospital setting than in D&A services:

Hospitals, it's not that they won't do it, they can't do it. They can't tailor the system to fit the client, they can't have open access outpatients' appointments where you just turn up when you want to, they can't do that. You can't run a hospital like that unfortunately. So that's why our client group don't fit that. (BBV nurse, Site B)

In order to tailor or 'tame' the system the providers in both partnerships instigated modifications to traditional treatment regimes. We place many of these modifications under the rubric of 'negotiated flexibility', whereby various levels of flexibility were enacted to 'tame' elements of the treatment assemblage. We describe below three such examples: eligibility criteria; managing appointments; and providing phlebotomy services.

Example 1: eligibility criteria

Although clinical guidelines in the UK do not preclude people who are currently injecting from treatment access, this is still used as exclusion criteria by many hospitals. Participants frequently spoke of being refused hospital-based HCV treatment due to their drug use (see Rhodes et al., 2013). As Jed (Site B) said: "The words were 'we don't want you injecting drugs. It's as simple as that'". The determining of eligibility criteria was a fundamental modification enacted at both services, and for both was a practice in negotiation:

We'd never done an outreach service and we'd never treated drug users so we tried to come up with a sensible criteria of no more than 40 units of alcohol a week, stable injecting drug use ... stable home life, they needed a fridge ... one of the consultants said I don't want any injecting of crack, they felt that it

made patients more vulnerable. So that's how the referral criteria came about. (HCV nurse 1, Site B)

An initial lack of familiarity with HCV treatment provision for PWID meant that providers from site B were yet to map the bounds within which they could deliver the treatment. This was also evident in the early days of the established service:

We tried, initially, to start with patients who had good looking blood counts and relatively low drug use, mainly to get the nursing staff familiar with treating people ... we started with what we saw as lower hanging fruit and very quickly moved on to all and sundry. (Hepatologist, Site A)

From this point the bounds around acceptable eligibility criteria were in a state of constant re-negotiation and flux, expanding outward as service users with more complex needs completed treatment:

I want to roll the barrier down ... We want to be getting to the stage where quite a large proportion of people are dropping out of treatment and then we know that we've hit the bottom, we've treated to the level that is reasonable. (Hepatologist, Site A)

Cases cited by this service of marginalised individuals in their care included a homeless man, with no benefits, who successfully completed HCV treatment while living in a storage container. The treatment nurse provided him with a sleeping bag and reports that he is now in receipt of government benefits.

This 'rolling down' of the eligibility barrier, could however result in tensions. Conscious of the challenges engaging in treatment while homeless, participants such as Kaveh (Site A) spoke of being unwilling to attempt treatment while unstably housed:

I don't know what to do. I want to take care of my health and at the same time if I take care of my health I haven't got a place to stay ... I don't see myself on the street with the heavy treatment, being debilitated all the time. Where to go? I travel from bench to bench.

While Kaveh was adamant that he did not want to commence HCV treatment while homeless, some providers spoke of the need encourage treatment uptake while accommodating these difficulties:

Well they're always their priorities but a lot of our patients, their life will always be some major thing going on like that. So that will not change for them, they'll always be homeless or in a hostel or whatever. You can't wait until they're more stable, this may never happen, we've got to work with that (BBV nurse 1, Site A)

Example 2: appointment schedules

Negotiated flexibility was evident also in regard to the (de) structuring of appointment schedules and the tailoring of timed appointments according to the service users' needs:

[It is] not doing silly things like booking an alcohol dependent patient in for an afternoon appointment and then wondering why they get there pissed at 4 o'clock ... if someone's injecting heroin three or four times a day, they've got to score in the morning, why give them a 9 o'clock appointment when you know they're not going to make it. (BBV nurse 2, Site A)

This approach presupposes familiarity with the daily routines of people with drug and alcohol dependences, but also an acceptance of on-going and fluctuating substance use during the course of treatment.

Numerous pre-treatment appointments in the hospital setting were reported as a barrier to treatment uptake, with treatment

delays and multiple appointments associated by some service users with surveillance and discipline, particularly in regard to the fulfilment of more traditional abstinence based eligibility criteria:

I was injecting heroin and they're 'oh let's give six months to see if you stop to use', then I stopped [injecting] but I was smoking but they knew I was lying anyway, then 'I'll give you another three months, let's give another six months'. I didn't bother with it [HCV treatment]. (Kyle, Site B)

Significant in this excerpt is the phrase 'they knew I was lying anyway', speaking to an environment of mutual distrust permeating the medical encounter, exacerbated by the common practice of urine testing to verify abstinence. Service providers also spoke of the multiple appointment system as a barrier; indeed, as a purposeful hurdle instigated in order to assess treatment 'commitment' and 'deservedness':

What historically seems to have happened with patients at some other kind of specialist services, it's almost like they're given a set of appointments to jump through, to make sure that if they keep turning up and turning up, that eventually that means they're committed and then you can start treatment. I don't think that works for this group of patients, they perceive that as nothing happening and it's a pointless exercise. What you need to do, as soon as a patient says that they're interested in treatment, is you need to start them then. (BBV nurse 2, Site A)

This provider adds that once PWID have started treatment, additional work can be undertaken to maintain their commitment. Given the nature of the treatment regime (multiple side effects, some which may exacerbate existing co-morbidities), there is a potential tension here between eliminating possible barriers to treatment, such as numerous appointments, and adequately insuring that an individual is indeed 'ready' for treatment commencement.

Example 3: phlebotomy services

Necessary for the commencement and maintenance of HCV treatment are regular blood tests. PWID often have difficult venous access, and the experience of having blood taken by mainstream services can be stressful and stigmatising:

I kept on saying to [hospital phlebotomist], 'Look, you know, my veins are a nightmare, you know, let me do it'. [She said] 'Oh you people, you think you know about your veins and all that, when you know nothing'. (Dillon, Site B)

Such stressful experiences can be exacerbated by rigid hospital phlebotomy protocols, as the BBV nurse (Site A) explains:

The [hospital] phlebotomist is only trained to – 'allowed' to take blood from the arm, nowhere else, that's the first place that in PWID that the veins are shot. So they'll stick them six or seven times in a hopeless attempt to get blood out of them and then they won't turn up again. It is traumatic ... I think they need to trust you somewhat before they allow you to stick pins in them.

The partnerships, in contrast, provided on-site phlebotomy services with relaxed protocols, in which blood was able to be taken from sites such as the groin and neck, and in some cases by the service users themselves. Key to developing trusting relationships was the ability of the phlebotomist to listen to and work with the service user:

I listen to them because very often, they do know where the vein is because they use their veins to inject so they know which veins. (BBV nurse, site B)

In addition, flexibility was negotiated not only around the sites of venous access, but the amount of blood to be taken: “You’re only doing what is absolutely crucial. I’ve researched the minimum volumes for each test so we have that information.” (HCV nurse 1, Site B)

Limits to practices of negotiated flexibility

Trust has been conceptualised in terms of active decision making, agency and choice, as opposed to dependency where decisions take place in situations of constrained choice (Gilson, 2003; Meyer & Ward, 2009). This raises the question of how effectively trust relations can be capacitated for PWID, many of whom operate within various structural constraints. Crucially, however, provider narratives undo this trust/dependency distinction: positioning trust not in opposition to constraint, but vital in the face of it:

My patients have a set of problems that prevents them addressing their healthcare problems and there has to be a high degree of being proactive with them, to make them address it, otherwise you’re going to be sat here empowering them until they’re on the hospital bed dying ... I think we’re quite matriarchal about it, rightly or wrongly with some patients, it’s ‘I am the nurse and I do know, I’m telling you, you need to do this now, you do need to do it’. (BBV nurse 2, Site A)

‘Empowerment’ in this context relates to ‘the power to choose’, with the provider’s concern being that the ‘right’ choice might be deferred until it is too late. Which choice is ‘right’ is not, however, always obvious and can be a source of tension and dilemma for both parties. Kaveh, as we saw, was reticent to undergo treatment while homeless, yet – due to the state of his liver disease – was strongly encouraged by providers to do so.

While providers sought to foster service user treatment engagement through making their treatment systems more open and flexible, their capacity to create trust among potential patients was limited by a variety of symbolic and systemic constraints. For many PWID, for example, methadone prescription and provision assemblages are imbued with power relations that limit and constrain trust and agency. Dillon’s (Site B) comment is illustrative:

It’s just sit there and keep your head down and shut up because they’re writing your scripts. It’s always been like that, it always will: the person who writes the script, they hold the power; you’re not going to do anything to piss them off.

While Dillon refers to the constraint felt in appointments with his methadone prescribing GP, this sense of constraint is liable to permeate other encounters and settings associated with methadone provision. While at both services HCV treatment was provided on an outreach basis by nurses, their co-location with OST prescribers could pose a symbolic barrier to trust for service users, also constraining their perceived ability to: a) feel able to turn down HCV treatment, and b) disclose continued drug use with HCV treatment nurses. While it was evident that the nurses were open to hearing about drug use fluctuations, and that this in no way precluded treatment access, what was less clear was the confidentiality of such disclosures or their impact on access to OST ‘takeaways’ – a case example in regard to the limits of negotiated flexibility.

Example 4: opioid substitution treatment

Methadone provision did not appear to be an area where ‘negotiated flexibility’ had been instigated by either service. In regard to the creation of trust and service user engagement this was a notable omission, with service users overwhelmingly framing takeaway provision in terms of trust generation. As Jeff (Site A) said: “I get it [methadone] weekly, I’ve been trusted for a long time.” The

provision of methadone takeaways appeared for service users as a tangible instantiation of trust, perhaps more so than the other areas of negotiated flexibility instituted by the two partnerships. These modifications were framed by providers largely in regard to gaining the trust of PWID, and less in regard to demonstrating the providers trust in them. Trust however, operates most effectively when it is mutually reinforcing (Carr, 2001), and indeed, trust messages sent by methadone provision were drawn on by service users to inform personal notions of agency, responsibility and self-worth:

I had a stage when I was supervised and after I was unsupervised. And now I’m still unsupervised. So take [methadone] home, and in that way, I can deal with my bits what I need to do daily ... You’re not a kid no more. If you don’t care about yourself, then that’s when you’ll stop doing what you’re supposed to do. (Mick, Site A)

In contrast, Hakki spoke of his anger about being on daily supervised consumption:

I’ve been on the [methadone] script for about 8 months now and they still supervise. I don’t know what they think I’m going to do ... I’m too angry with the system at the moment. I don’t really engage ... why don’t they trust me? (Hakki, Site A)

Hakki’s anger is likely to perpetuate his limbo on supervised consumption until he is assessed as ‘engaging’ sufficiently and also may impact on his ability or inclination to seek support for his continuing HCV treatment. While the services are notable in their instigation of flexible modifications, Hakki’s situation brings to mind the requirements for successful ‘engagement’ in the hospital system, where the receipt of services depends on the ability to modulate frustrations in an acceptable manner.

Discussion

In this article we highlight the role of trust generation in the creation of enabling HCV treatment environments, as well as the limits of particular treatment assemblages to modification. The generalizability of our findings are limited inevitably to the samples and settings selected, with the methods employed precluding a grounded analysis in which issues related to trust could be further explored with participants. Our analysis however, generates questions apposite for future research, specifically in regard to the role of constraint and agency in trust generation, and whether distinctions between trust and dependency have been previously overstated. Whilst trust decisions may be cast as active and deliberative on the basis of risk calculus, in practice they are often socially habituated differently in different social contexts, and necessitate an acceptance of, and way of dealing with, the unknown, especially in relation to the trust placed in large expert systems detached from everyday and familiar social relations. Thus, the notion of being ‘free to choose’ in relation to trust (Gilson, 2003; Meyer & Ward, 2009) is questionable, as such choices are inevitably subject to constraint. Crucially, being context-dependent the parameters of choice-making vary in relation to economies of power, status and value. For those relatively less powerful, such as the socially marginalized, trust decisions unavoidably involve greater choice constraint and thus also, heighten risks. This introduces two important related questions: To what extent can unfamiliar expert systems be actively trusted, and to what extent can they be modified to genuinely empower active trust decisions on the part of their users?

Trust is both a condition and an outcome of the process of negotiation (Carr, 2001); necessary to initially engage people with

the idea of HCV treatment and sustained and built over time through the instantiation of practices of negotiated flexibility. This can be a fragile and continually negotiated process which may wax and wane at different points of time. Participants highlighted the role of personal relationships in trust creation, pointing to the role of intimacy in taming unfamiliarity and generating trust (Giddens, 1990). Such relationships can modify, but also be undermined by, elements of the treatment 'system' assemblage. Certain environments were spoken of as more amenable to 'taming' than others. While elements of the hospital assemblage were experienced as beyond reach or influence, providers were able to instigate modifications to traditional treatment regimes within the D&A setting. Some elements however, such as OST provision, can be constrained by systemic regulations. Therefore both providers and patients can find themselves locked into power relations which are slow to change.

The giving of trust often carries more risk for people with minimal resources, especially those who are marginalised by mainstream cultures (Bourgois & Schonberg, 2009; Gilson, 2003). To trust in a biomedical regime with uncertain efficacy and variable side effects, in order to rid oneself of an illness that may not be a pressing priority, can be a hard call. While the partnerships involved in this study worked to facilitate enabling treatment environments through the taming and easing of restrictions, there is a potential tension between encouraging treatment and commencing individuals on an arduous regime for which they may not be adequately prepared. Power relations between PWID and OST prescribers mean that in not all instances is the D&A setting a benign environment enabling un-encumbered choice. Service users can feel constrained in their ability to disclose current drug use to HCV treatment providers, particularly if they are receiving unsupervised OST on the proviso of abstinence from illicit drug consumption. While the two services provided an environment tolerant to ongoing drug use during HCV treatment, it is unclear how this affected OST prescribing and access protocols.

While a majority of the literature reports favourably on HCV treatment provision in D&A settings, recommended services generally offer a comprehensive program of multidisciplinary care and support, with provision for service user input and/or peer support. A growing body of Australian-based research identifies the dangers inherent in just 'adding on' HCV treatment to D&A services that are ill equipped to offer flexible and multi-disciplinary care. This literature is notable for its critique of the stigmatising and constraining capacity of OST settings, and the potentially detrimental impact of HCV provision in highly regulated and surveillant OST clinics (Fraser & valentine, 2008; Rance et al., 2012; Treloar & Fraser, 2009). The Australian OST context, is however, distinct from that in the UK – in which regional Drug Action Teams are mandated to ensure that the views and experiences of service users are incorporated into the development, delivery and commissioning of services. The pilot project in particular displayed a commitment to service user input with a service user representative sitting on the interview panel for the BBV nurse appointment and feeding into all stages of the pilot scheme development. Crucially, this involvement provides not only a voice for the priorities and needs of PWID but sends vital messages regarding trust.

Communities of PWID, like other marginalised groups, often develop alternative economies of status and value from those recognised by the 'mainstream' (Bourgois & Schonberg, 2009; Harris & Rhodes, 2012b). These alternate economies influence attitudes towards and (mis)trust placed in specific 'access points' and claims making by health care and other service providers. Trust creation is vital in the establishment of enabling treatment environments; however the development of this trust needs to be mutually constitutive – with attention given to the pragmatic needs and

priorities of service users, such as holistic care and the provision of OST takeaways (Harris & Rhodes, 2012b; Harris & Rhodes, 2012a). Gilson (2003) draws on the distinction between affirmative and transformative remedies for injustice in relation to health care access for marginalised populations. HCV treatment access for PWID can be seen as an affirmative remedy for injustice – it aims to "correct the inequitable outcomes of existing social arrangements without disturbing the unequal structures of power and resources that generate them" (2003: 1463). However, the creation of enabling HCV treatment environments can move beyond this to have a transformative aspect, by "challenging existing group identities and differences in order to raise the self-esteem of currently devalued groups" (Gilson, 2003, p. 1466). In order for this process to be transformative, mechanisms of dialogue, consultation and participation involving the partnership organisations, policy representatives, and most crucially, PWID, need to take place – remedies that, as Gilson says, must be built in recognition of wider societal inequalities.

Conclusion

For marginalised populations, such as PWID, experiences of stigmatisation and circulating narratives of mistrust in expert systems can dissuade health care engagement. Introducing HCV treatment into D&A settings is one way to ameliorate some of the barriers associated with hospital based care, including that of unfamiliarity. D&A services are not necessarily trusted settings by all who utilise them, but their familiarity can aid ease of negotiation – with the idiosyncrasies of certain service providers known and calculated for in interaction. For providers also, familiarity aids negotiation, manifest in their tailored 'taming' of protocols in line with service users' needs. While this 'taming' facilitated an enabling treatment environment, it is important to be reflexive about the constraining power relationships inherent in D&A service provision and how these may be further modified to enable PWID 'choice'.

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