Home | Mailing list Hot topics Contact



This entry is our analysis of a study considered particularly relevant to improving outcomes from drug or alcohol interventions in the UK. The original study was not published by Findings; click Title to order a copy. Free reprints may be available from the authors – click prepared e-mail. The summary conveys the findings and views expressed in the study. Below is a commentary from Drug and Alcohol Findings.

Links to other documents. Hover over for notes. Click to highlight passage referred to. Unfold extra text Tweet Copy title and link | Comment/query |

Send email for updates your.email@address SEND

▶ Improving access to care for people who inject drugs: qualitative evaluation of Project ITTREAT – an integrated community hepatitis C service.

Phillips C., Schulkind J., O'Sullivan M. et al.

Journal of Viral Hepatitis: 2020, 27, p. 176-187.

Unable to obtain a copy by clicking title? Try asking the author for a reprint by adapting this prepared e-mail or by writing to Dr at c.j.jones@surrey.ac.uk.

A UK-based project placed a dedicated full-time hepatitis C nurse into a drug and alcohol treatment service. The experiences of people who inject drugs and attended the service reveal the degree to which this strategy can remove barriers to the infection treatment so crucial to containing the virus.

SUMMARY Injecting drug use remains the greatest risk factor for hepatitis C. Globally, 67% of people who inject drugs have been infected with the hepatitis C virus at some point. However, there are numerous barriers to this population accessing treatment for hepatitis C:

- At the **patient level** barriers include: poor engagement with secondary care; asymptomatic nature of the disease; the effect of stigma and prior negative experiences with health services; and myths associated with antiviral treatment and liver biopsy.
- At the provider level barriers include: failure to understand the complex needs of people who inject drugs; lack of awareness and lack of a priority among healthcare professionals; bureaucratic and inflexible hospital environment; prejudice and reluctance to treat those with ongoing alcohol and drug use; misconceptions regarding treatment efficacy and reinfection in people who inject drugs; and lack of a multidisciplinary approach, with less than ideal interactions between addiction specialists and medical specialists dealing with the consequences of chronic hepatitis.
- At the national level barriers include: restricted access to antiviral drugs; and lack of accurate data on the frequency, pattern, causes and risk factors of hepatitis C.

In the UK hospital outreach into local drug and alcohol treatment services - typically nurses supporting care outside of the hospital setting - is safe, cost-effective, with good uptake and treatment outcomes similar to (and in some cases better than) hepatitis C treatment in a hospital or other treatment

setting (1 2 3 4). The featured study explored the experiences and perceptions of clients and staff within an integrated hepatitis C and drug and alcohol treatment service to understand the extent to which this could remove barriers to hepatitis C diagnosis and treatment.

Project Integrated Test-Stage and Treat (ITTREAT) commenced in December 2013 as a two-year project, but was subsequently extended for six years until December 2021. ITTREAT was located at one of the largest city-based drug and alcohol treatment services in South East England. A full-time hepatitis nurse offered blood-borne virus testing – using finger prick 'dry blood spot testing' (less invasive than drawing blood from a vein) – and hepatitis B vaccinations to people attending the drug and alcohol treatment service. If tests confirmed that the virus was active and needed treatment, patients were contacted via phone or in person and offered further tests and treatment, under the supervision of a liver specialist.

Clinics were run on a flexible, 'drop in' basis, and all clients were provided with a contact phone number for the nurse. The hepatitis C nurse worked closely with other healthcare professionals both within the community (eg, GPs and care coordinators) and the hospital (eg, vascular access team). Drug and alcohol treatment staff were also trained by the nurse to perform screening for blood-borne viruses.

Interviews with clients. Clients of the drug and alcohol treatment service who had been offered and/or were engaged in the hepatitis C service were eligible to participate in the study.

Key points From summary and commentary

Project Integrated Test-Stage and Treat (ITTREAT) was established to mitigate barriers to hepatitis ${\sf C}$ care by providing an integrated service within a local drug and alcohol treatment centre. The featured study aimed to explore the experiences of clients and staff involved in ITTREAT between 2014 and 2016.

The presence of a dedicated healthcare worker, positive narratives of hepatitis C treatment from peers, and stability within drug and alcohol recovery were all important facilitators and motivators that enabled clients to address their hepatitis C diagnosis and access treatment.

These findings highlight the positive impact of a personalised, community-based (as opposed to hospital-based) service.

HEPATITIS C

A positive test for hepatitis C antibodies indicates exposure to the hepatitis C virus at some point, but cannot confirm current infection.

When hepatitis C is first contracted most people either do not experience any noticeable symptoms, or experience symptoms that are similar to many other short-term infections. This means they are unlikely to seek medical attention, and if they do, doctors would not necessarily suspect or test for hepatitis C.

A small proportion of those infected with hepatitis C will naturally clear the virus from their body in the first six months. However, estimates from Public Health England suggest that 3 in 4 people will develop a chronic infection, a primary cause of cirrhosis and liver cancer.

This included 15 people who had historically declined, were waiting to start, were currently receiving, or who had completed hepatitis C treatment. The interviews lasted between 30 and 60 minutes, and topics included: history of injecting drug use; experience of initial hepatitis C diagnosis; barriers and motivators to engaging in hepatitis C

1 of 4 16/10/2020, 08:56 testing and treatment; experiences of other healthcare services, including in the community; and areas for future service improvement.

All interview participants were self-described as being of white ethnicity and 80% were male. Most were aged 35–44 years (40%) or 45–54 (40%). Nearly half (47%) were unemployed, and all were people who currently or formerly injected illicit drugs. Two had successfully completed their 'rehabilitation', and the rest considered their recovery to be ongoing. Of the 15 interviews, 11 took place in 2014 and 2015 during the transition from interferon-based medication to direct-acting antiviral medication; the remainder were completed in 2016. Most interviewed clients had received or were receiving interferon-based hepatitis C treatment. [Compared with interferon-based treatments, direct-acting antiviral medications can be taken orally (as opposed to injected), are taken over a shorter period of time, are associated with fewer side effects, and have a higher rate of effectiveness.]

Focus groups with staff. All staff based at the drug and alcohol treatment service (excluding the hepatitis C nurse) were invited to participate in one of two focus groups. Each focus group lasted an hour and included: the challenges in hepatitis C testing and treatment uptake; experiences of hospital and community-based services; and areas for future service improvement.

The 15 participating members of staff were roughly equally split between men and women, most (75%) were aged 45–54 years, and almost all (93%) described themselves as being of white ethnicity. Duration of employment at the drug and alcohol treatment ranged from 1 to 20 years.

Main findings

Facilitators to accessing hepatitis C care

1. Trusting client-provider relationships

The close relationship between clients and their key worker/care coordinator at the drug and alcohol treatment service was clear. This relationship acted as an entry point into hepatitis C care. Staff described initiating discussions around hepatitis C care and then referring clients to the onsite hepatitis nurse once they were ready to engage. Interestingly, the way staff perceived it was that their role was to 'sell' hepatitis C care.

The relationship between clients and the hepatitis C nurse was also central to their engagement with Project ITTREAT. Participants valued her non-judgemental, personal and friendly approach. The interviews highlighted the importance of a holistic and personalised approach when the nurse engaged with clients – supporting their housing applications and mental health needs, for example, as well as their hepatitis C treatment.

2. Hepatitis C care as part of the recovery pathway

Successful recovery from drug and alcohol dependence empowered clients to seek hepatitis C treatment. Both clients and staff also saw hepatitis C treatment as the natural, next step in the recovery pathway. Infection was inextricably linked to drug use; once stable in recovery, participants wanted to disassociate themselves from the stigma attached to hepatitis C infection.

"I suppose some of it ties into the stigma again, you know I wanted to be clear and, you know, as free from anything drug-related ... as quickly as possible." (Participant number 1, four years since diagnosis)

Following recovery, participants expressed both a greater awareness of the health impacts of untreated hepatitis C and a heightened sense of their own mortality. With the picture no longer clouded by withdrawal symptoms, clients were more likely to attribute their physical symptoms to hepatitis C, which acted as a motivator to seeking treatment.

3. Mitigation of previous negative experiences of secondary care

Clients expressed reluctance to engage in hospital-based health services for either their general health needs or for hepatitis C treatment. Mistrust, fear and bad experiences of hospitals were widely reported. Project ITTREAT removed many of these experiences by sidestepping hospitals. Being able to access hepatitis C care without having to attend the hospital-based services was positively welcomed.

"And you do hear people talking about their bad experiences: feeling judged up at A&E. I think self-worth and self-esteem has got a lot to do with going up to the hospital: "I'm not worthy of their time", "[my problems are] self-inflicted", "why should they care about me?"" (Staff member, focus group number 1)

Hospital-based bureaucracy emerged as a system-level barrier, especially the inconvenience of travelling to hospital, the inflexibility of appointment times, and lengthy appointment waits. These were overcome by the flexible approach adopted by ITTREAT.

4. Positive narratives of hepatitis C care

Clients and staff members discussed the influence of 'word of mouth' stories of hepatitis C treatment from peers in recovery. Negative stories have dissuaded clients from seeking treatment, but positive narratives encourage participants to engage in care, especially, clients' experiences with direct-acting antiviral medication.

"I found out about the new treatment that's available, and thought I'd wait. And then I forgot about it; conveniently shoved it in that place that you don't think about it, and [Hepatitis C nurse] called me and said, "do you wanna go up for a trial on this?" So were just waiting to hear ... I think it's here, well it's through [Hepatitis C nurse] – she'd be able to tell you and it's the shorter treatment and it doesn't have the depression side effects. And to be honest I'd wait years for that treatment, rather than take the risk of having the negative side effects." (Participant number 3, 20 months since diagnosis)

Barriers to accessing hepatitis C care

1. Lack of stability

2 of 4 16/10/2020, 08:56

Instability emerged as a central factor preventing participants from accessing hepatitis C treatment. Meeting health needs was seen as competing with the exigencies of social circumstances, including homelessness or lack of permanent accommodation, unemployment, and imprisonment.

"But because erm, my life was just chaos at the time ... I was homeless, I was trying to hold down a job and ... yeah it was just sort of really impossible for me to kind of have enough consistency to start doing the treatment." (Participant number 2, one year since diagnosis)

Furthermore, emotional instability due to complex mental health problems, lack of strong social networks and, in particular, ongoing drug and alcohol use, were seen as key factors in determining clients' stability and ability to engage in treatment.

2. Stigma

Stigma relating to hepatitis C led to an initial reluctance amongst participants to accept the diagnosis, and an unwillingness to disclose their diagnosis to friends, family members and partners. This led to a delay in accessing information and treatment. Before engaging with the community service, participants reported very little knowledge of the health consequences of hepatitis C.

One considerable barrier to engagement with Project ITTREAT that emerged was the stigma associated with the physical premises of the drug and alcohol treatment programme. This was particularly evident among participants who were stable in recovery, no longer perceiving themselves as an 'addict'. This caused some participants to express their preference for a separate hepatitis C service in the community.

"Yeah, I used to have that a lot, kind of walking up the steps at the traffic lights and there are kind of loads of cars, kind of gridlock, and you know you're almost advertising yourself as like an addict walking up the steps." (Participant number 13, two years since diagnosis)

3. Negative discourse around testing and treatment

Participants described negative anecdotes from their peers about hepatitis testing and treatment, revolving around the risk of substance use relapse [and potentially contracting the virus again], treatment-related side effects, the length of the course of treatment, and the need for painful liver biopsies.

"Yeah, and its side effects, cos back then as well it was all interferon and people were telling me it's like chemotherapy: you're gonna lose your hair and all sorts. And I was thinking, I don't feel ill ... I'm not putting myself through all that." (Participant number 14, six years since diagnosis)

The authors' conclusions

The featured study found that a community hepatitis clinic could successfully facilitate access hepatitis C treatment among people who use drugs. The presence of a dedicated healthcare worker, positive narratives of hepatitis C treatment from peers, and stability within drug and alcohol recovery were all important facilitators and motivators that enabled clients to address their hepatitis C diagnosis and access treatment.

Most facilitators were related to Project ITTREAT itself (trusting client–provider relationship, hepatitis C care as part of recovery process, mitigation of previous negative experiences of secondary care), while others such as the theme 'positive narratives of hepatitis C care' were reflective of both Project ITTREAT and newer treatments for hepatitis C.

Negative discourses around hepatitis C treatment were largely related to the older treatments and procedures for liver biopsies, while stigma attached to the clinic site was specific to the ITTREAT project. Stigma around hepatitis C and a lack of stability were general barriers reported in this cohort.

An unanticipated barrier for those who had graduated from drug use and opioid substitution therapy treatment was the stigma generated by locating the community hepatitis clinic within the drug and alcohol treatment service.

A limitation of the study is that the clients' perspective reflected only attendees of Project ITTREAT, and therefore excluded the experiences of people accessing drug and alcohol treatment who were not engaged in hepatitis C treatment through the project.

FINDINGS COMMENTARY In order to reduce hepatitis C to the low levels advocated by the World Health Organization, harm reduction interventions and hepatitis C treatment will be needed. While opioid substitution therapy and needle exchange programmes can reduce the rate of new chronic infections ('incidence'), the World Health Organization cautions that the number of people infected ('prevalence') and mortality could remain high for a generation without treating those already infected.

The featured study found that a hepatitis C clinic sited in a drug and alcohol treatment service could overcome many of the barriers to treatment that could or would have deterred people who use drugs from using a similar service located in the more typical hospital setting, including through:

- √ capitalising on the close relationship between clients and their key workers/care coordinators;
- ✓ hepatitis C nurses adopting a non-judgemental, personal and friendly approach, and supporting the wider needs of patients including their housing and mental health needs;
- ✓ cultivating positive experiences, conveyed by 'word of mouth' from peers.

However, as the authors acknowledged, these findings reflect what happened with people who engaged with the service, not the people who did not.

An unanticipated barrier of running a hepatitis C service from a drug and alcohol treatment service

3 of 4 16/10/2020, 08:56

was stigma associated with attending the drug and alcohol treatment service itself, especially for people who considered themselves 'in recovery' or 'recovered' and wanted to distance themselves from the identity position of 'addict'.

At the time of publication, the Project ITTREAT trial had not yet concluded. In 2018, interim clinical data was published, indicating high service uptake and hepatitis C treatment outcomes comparable to secondary care. Up to this point:

- 485 people had been recruited;
- almost all (97%) received dry blood spot testing;
 prevalence of hepatitis C antibodies was high (56%) and current hepatitis C infection even higher (81%);
- of those with a current infection, 80% received a non-invasive procedure to determine liver damage; 45% had significant fibrosis (scarring of the liver), and 25% had cirrhosis (more severe and long-term scarring of the liver preventing the liver from working properly);
- 60% commenced hepatitis C treatment and all but 2% complied with treatment; the remaining 30% of people with a current infection were not considered 'good candidates' for treatment (eg, because they had complex needs and circumstances).

When hepatitis C is first contracted most people either do not experience any noticeable symptoms, or experience symptoms that are similar to many other short-term infections. This means they are unlikely to seek medical attention, and if they do, doctors would not necessarily suspect or test for hepatitis C. Giving insight into this, especially from the stigmatised and marginalised perspectives of people who inject drugs, the featured study found that participants expressed a greater awareness of the health impacts of untreated hepatitis C and a heightened sense of their own mortality when they were on the journey to recovery. Without withdrawal symptoms, clients were more likely to attribute their physical symptoms to hepatitis C, which acted as a motivator to seeking treatment.

Treatment for hepatitis C continues to evolve, though it cannot be assumed that people eligible for treatment would know this and may have reservations based on their knowledge or perceptions of older types of treatment. Since the World Health Organization issued its first guidelines for the screening, care and treatment of people with hepatitis C infection in 2014, several new medicines have been approved. Compared with interferonbased treatments, direct-acting antiviral medications can be taken orally (as opposed to injected), are taken over a shorter period of time, are associated with fewer side effects, and have a higher rate of effectiveness.

An Effectiveness Bank hot topic goes more in-depth into the scale and urgency of the task of eliminating hepatitis C, which in 1993 was described as the invisible "sleeping giant".

Last revised 16 October 2020. First uploaded 08 September 2020

- ► Comment/query
- ► Give us your feedback on the site (two-minute survey)
- Open Effectiveness Bank home page
 Add your name to the mailing list to be alerted to new studies and other site updates

Top 10 most closely related documents on this site. For more try a subject or free text search

DOCUMENT 2017 Drug misuse and dependence: UK guidelines on clinical management

DOCUMENT 2011 Prevention and control of infectious diseases among people who inject drugs

STUDY 2009 Relating counselor attributes to client engagement in England

STUDY 2018 Impact of current and scaled-up levels of hepatitis C prevention and treatment interventions for people who inject drugs in three UK settings – what is required to achieve the WHO's HCV elimination targets?

STUDY 2010 Effect of motivational interviewing on reduction of alcohol use

STUDY 2015 Navigating the alcohol treatment pathway: A qualitative study from the service users' perspective

STUDY 2008 Does following research-derived practice guidelines improve opiate-dependent patients' outcomes under everyday practice conditions? Results of the Multisite Opiate Substitution Treatment study

REVIEW 2010 Optimal provision of needle and syringe programmes for injecting drug users: a systematic review

MATRIX CELL 2017 Drug Treatment Matrix cell B1: Practitioners; Reducing harm

STUDY 2002 The grand design: lessons from DATOS

4 of 4 16/10/2020, 08:56