



This is a repository copy of *Reasons for missed appointments with a hepatitis C outreach clinic: A qualitative study*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/109820/>

Version: Accepted Version

Article:

Poll, R., Allmark, P. and Tod, A.M. orcid.org/0000-0001-6336-3747 (2016) Reasons for missed appointments with a hepatitis C outreach clinic: A qualitative study. *International Journal of Drug Policy*, 39. pp. 130-137. ISSN 0955-3959

<https://doi.org/10.1016/j.drugpo.2015.12.027>

Article available under the terms of the CC-BY-NC-ND licence
(<https://creativecommons.org/licenses/by-nc-nd/4.0/>)

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can't change the article in any way or use it commercially. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Accepted Manuscript

Title: Reasons for missed appointments with a hepatitis C outreach clinic: a qualitative study

Author: Ray Poll Peter Allmark Angela Mary Tod

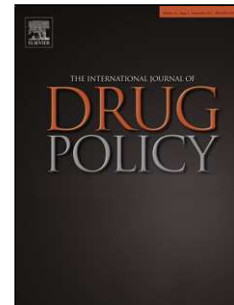
PII: S0955-3959(16)30017-2
DOI: <http://dx.doi.org/doi:10.1016/j.drugpo.2015.12.027>
Reference: DRUPOL 1728

To appear in: *International Journal of Drug Policy*

Received date: 16-4-2015
Revised date: 7-11-2015
Accepted date: 10-12-2015

Please cite this article as: Poll, R., Allmark, P., and Tod, A. M., Reasons for missed appointments with a hepatitis C outreach clinic: a qualitative study, *International Journal of Drug Policy* (2016), <http://dx.doi.org/10.1016/j.drugpo.2015.12.027>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.



Reasons for missed appointments with a hepatitis C outreach clinic: a qualitative study.

Dr Ray Poll^a (corresponding author)

^aDepartment of Infection and Tropical Medicine, The Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF, England, United Kingdom

ray.poll@sth.nhs.uk

Dr Peter Allmark

^bCentre for Health and Social Care Research, Montgomery House, 32 Collegiate Crescent, Collegiate Campus, Sheffield S10 2BP, England, United Kingdom

p.allmark@shu.ac.uk

Professor Angela Mary Tod

^cFaculty of Human and Medical Sciences, Room 5.319, Jean McFarlane Building, Oxford Road, Manchester M13 9PL, England, United Kingdom

angela.tod@manchester.ac.uk

^aSheffield Teaching Hospitals NHS Foundation Trust

^bSheffield Hallam University

^cUniversity of Manchester

Reasons for missed appointments with a hepatitis C outreach clinic: a qualitative study

Abstract

Background

Non-attendance in drug service hepatitis C outreach clinics means clients miss the opportunity of being given lifestyle advice and referral to hospital for assessment and treatment. A similar problem is experienced in other services throughout the UK. A qualitative study was undertaken to investigate the problem.

Methods

Clients with a history of not attending the outreach clinic were invited to participate during a routine drug clinic appointment. A contact details sheet with a preferred telephone number was completed by those agreeing to take part. Verbal consent was taken and a telephone interview took place. The participants were remunerated for taking part with a five pounds high street voucher. The 'framework method' was used to analyse the data with key themes identified.

Results

Twenty-eight telephone interviews were undertaken from April to June 2012. All the clients gave 'prima-facie' reasons for non-attendance including '*not a priority*' and '*forgot*'.

However, the study indicates these are insufficient to explain the various experiences and influences. Underlying reasons that impacted upon attendance were identified. These reasons relate to (i) client characteristics e.g. '*priority*' to score drugs and the '*cost of travel*' (ii) clinic service e.g. '*difficult journey*' to the clinic and timing of the '*appointment*'. The reasons operated within a complex context where other factors had an impact including addiction, welfare policy, stigma and the nature of hepatitis C itself.

Conclusion

The study revealed that beneath apparently simple explanations for non-attendance, such as clients' chaotic lifestyle resulting in them forgetting or not being bothered to attend, there were far more complex and varied underlying reasons. This has important implications for drug policy including the need to better incorporate clients' perspectives. Policy that is based only on the simple, surface reasons is unlikely to be effective.

Keywords

Hepatitis C, missed appointments, reasons, outreach, drug use, telephone interviews

Background

Hepatitis C is a blood-borne virus which primarily affects the liver. In the UK people who inject drugs (PWID) are at greatest risk of infection. Approximately half of all PWID have been infected with hepatitis C through the sharing of blood contaminated equipment (e.g. syringes, needles, spoons, filters and water) (Public Health England [PHE], 2014). Individuals are also at risk of infection if they have received medical or dental treatment abroad in countries where hepatitis C is common and infection control inadequate. For example, there is a higher prevalence of hepatitis C infection among people of Asian or British Asian (2.3%) and Eastern European (5.1%) origin living in England (PHE, 2014). Other less common routes of transmission in the UK include: from an infected mother to her baby, unprotected sex with a hepatitis C-positive partner (although this increases if the infected person is also HIV positive), tattooing, skin piercing or acupuncture using unsterile equipment, and sharing razors or toothbrushes contaminated with infected blood. However, the key population affected by hepatitis C in the UK are PWID.

Without treatment, chronic hepatitis C can cause advanced liver disease (cirrhosis), liver cancer (hepatocellular carcinoma [HCC]) and thus sometimes death (World Health Organisation [WHO], 2014). As such, people with hepatitis C need to engage with health services for specialist medical assessment, advice about lifestyle changes to reduce further harm to the liver and to avoid infecting others, and to receive curative antiviral therapy (Department of Health [DoH], 2002).

Non-attendance for initial outpatient appointments at hepatitis C clinics is 'high', median per 'comprehensive service provider' (CSP) being 10-24% (Parkes et al, 2006). Furthermore, attendance declines from diagnosis to treatment. The CSPs are units across the UK mainly led by Hepatologists and Infectious Disease physicians who devote some of their clinical time (with support from nurses) providing assessment, care and treatment for infected

people. Fifty percent of CSPs see more than 40 new patients a year. One quarter of CSPs have outreach services, largely located in prisons or drug and alcohol services (Parkes et al, 2006). However, there are no data on non-attendance in the latter.

In the North of England, two hospital facilitated hepatitis C outreach clinics located within drug treatment services were established to increase diagnosis rates and subsequent attendance at the hospital clinic. The outreach clinics were run by the nurse consultant from the hospital team and clients arranged an appointment via the drug clinic. Occasionally clients would be seen without an appointment or drop-in if there was a vacant appointment slot. The two outreach clinics were run fortnightly on different days and times i.e. morning or afternoon respectively. Over time, diagnosis rates had improved (with more testing being done by the drug service staff). However, non-attendance (up to 60%) in the outreach clinics meant clients missed the opportunity of referral by this route to the hospital for care and treatment. As such, the non-attendance that helped stimulate the formation of outreach clinics remained a problem for those clinics themselves.

To explain non-attendance by PWID with hepatitis C, the phrases 'chaotic lifestyle' and 'hard-to-reach' have been used (Moriarty et al, 2001; Irving et al, 2006; Parkes et al, 2006; Bruggmann, 2012; Hepatitis C Trust, 2013; Mravčik et al, 2013; Scottish Intercollegiate Guidelines Network [SIGN], 2013). These phrases can imply blame of patients for missed appointments; the former particularly suggests there is little that can be done to improve attendance.

Despite this blame hypothesis, non-attendance in non-outreach settings has been investigated. A hospital clinic in the North of England found no differences between PWID with hepatitis C that did or did not attend (Cousins et al, 2011). In Scotland, the mean travel time of 20 minutes to a specialist centre was not found to be a factor for non-attendance but

other factors were identified: living in more deprived areas; younger age; male gender; current or past injecting drug use; excess alcohol consumption (more than 21 units per week); and higher body mass index (Astell-Burt et al, 2012). A qualitative study in Canada (Butt et al, 2013) identified six themes to explain non-attendance (including patients who delayed or deferred care) throughout the disease course i.e. from primary to specialist care (see Box 1). The study appeared to include a range of hepatitis C treatment services including community and walk-in clinics that would be considered 'outreach settings'. Thus, a further reflection of the findings from the Butt et al (2013) study is provided at the beginning of the discussion.

[Insert Box 1 here]

Hence missed appointments are clearly a problem in hepatitis C settings and put those infected at high risk of significant morbidity and mortality (as well as them running the risk of infecting others). However, there is a lack of evidence from the UK about the reasons for missed appointments, particularly in the outreach setting. Although the issue has been investigated qualitatively in Canada the findings may not be generalisable to the UK due to different health care systems and cultures; if the reasons for missed appointments were known then solutions might be put in place. The study reported here aimed to investigate the non-attendance problem in outreach clinics using qualitative methods in a UK population and was undertaken as part of a doctorate.

Methods

Ethics approval was granted by the South Yorkshire NHS Research Ethics Committee study number 12/YH/0078. The methods and techniques of the study including interview questions were developed with two ex-service users, known as Ambassadors, from the local Drug and Alcohol Action Team (DAAT). They were invited to comment on the study forms,

including the participant information leaflet and interview guide, and the best way of getting participants to speak about non-attendance, including negative things about the service.

Setting

The interview participants were recruited from two drug treatment clinics in a city in the North of England. 'Service 1' was a GP led treatment clinic for clients with non-complex opiate addiction and was located outside the city centre. 'Service 2' was run by consultant psychiatrists, treated clients with complex needs including underlying mental health problems and was situated closer to the city centre. Both were co-located with the drug service. These two treatment services were able to provide a range of participants in terms of age, demographics, drug history, co-morbidity and distance to travel.

Sample

Purposive sampling meant an adequate range of relevant characteristics were included. These were: age; length of drug use; hepatitis C diagnosis; home; and family and employment circumstance. Client exclusion criteria included:

- Clients who had not missed at least one appointment with the hepatitis C outreach clinic before April 2011;
- Clients who cancelled an appointment, re-booked and attended;
- Clients who were not able to or did not want to give informed consent to participate;
- and
- Clients unable to speak English.

On the basis of guidance on qualitative sampling, it was anticipated that a total sample of approximately 30 would be sufficient (Baker et al, 2012). This would allow within and cross-case-orientated analysis reflecting variations within the sample (Sandelowski, 1995). The final interview sample totalled 28 participants. At this point no new themes, topics or

concerns were emerging from the data. Saturation was deemed to have been reached and data collection was stopped (Wallace, 2005)

Identification and recruitment of participants

The interview participants were identified from electronic data kept by the drug service staff and previous outreach clinic lists. As part of the researcher's professional role he was able to view this data as a member of the clients' care team (and he ran the outreach clinic). At a routine appointment, at the end of their consultation, the staff of the drug treatment service offered clients with a history of not attending the outreach clinic an information leaflet. They invited the client to participate in, and gave a brief explanation of the study. This enabled any clients with a low level of literacy to talk with a member of staff about the research. Those interested in participating and who agreed to speak with the researcher were asked to complete and sign a contact sheet giving their telephone number. These completed sheets were securely sealed in an envelope and placed in the researcher's pigeon-hole to collect. If a client did not have a phone number then a face-to-face interview at the drug service was offered; in the event, this was arranged on one occasion and the client did not attend. Details of those declining were recorded to avoid any future requests. The participants were remunerated for taking part with a £5 high street voucher. The researcher was well-placed to access this so-called 'hard-to-reach' population from a research perspective because of his close working relationship with the drug service.

Data collection

Twenty-eight telephone interviews were undertaken from April to June 2012. The interviews were undertaken by telephone rather than face-to-face (see rationale – Box 2). The telephone interviews were conducted by the researcher at a time convenient to the participant. The participants had received an information sheet before the telephone call; at the time of the call before the interview started this information was restated and verbal consent obtained and recorded. This process had been agreed with the NHS Research

Ethics Committee owing to the difficulty of obtaining written consent from this client group. The interviews were taped and downloaded onto a password protected computer. Basic demographic details were collected. An interview schedule was devised from the related literature, expert opinion of clinicians and clinical expertise of the researcher, and insights from the Ambassadors. The schedule comprised four key questions: a) Can you tell me what made it difficult for you to keep an appointment with the hepatitis C outreach clinic; b) Is there anything about the clinic environment or the way that people are treated that may influence if they turn up; c) What do you think are the reasons for other people not attending the hepatitis C outreach clinic; and d) telephone or text reminders have been tried to improve attendance at clinics. How do they work? Who would they work for? Why would they work? In the interviews, the participants were invited to give their own reasons for non-attendance and also to suggest reasons for non-attendance of others. This was an interview strategy designed to facilitate response where, for example, a participant was reluctant to own up to particular reasons. As such, the analysis did not focus on any difference between the two types of question. As it was, there seemed little difference between answers to the two types anyway.

[Insert Box 2 here]

Data analysis

The interviews were transcribed verbatim by a medical secretary covered by a confidentiality agreement. The researcher subsequently read each transcript alongside the relevant tape for accuracy. The 'framework method' was used to analyse the client interviews (Ritchie et al, 2003). This is a well-established process of thematic review that involves coding, developing and applying an analytical framework, charting and sorting the material into key issues and themes. The background literature was used to devise the initial analytical framework. This comprised of the themes: drug use/addiction; poverty; services; psychosocial; hepatitis C – beliefs and expectations; diagnosis and testing; others; and

solutions. As well as being a practical means of reducing the data, summarising the data during 'charting' allowed the supervisors of the study to engage with the data and offer their viewpoints without needing to read all the transcripts (Gale et al, 2013). Charting also ensured that close attention was paid to describing the data using the participants' words and accounts in the first instance, before moving onto interpretation. The interpretation of the data (last stage of the framework) lends itself to explanation of phenomena (such as missed appointments) particularly if the data are rich enough (Gale et al, 2013).

Results

Demographic information is summarised in Table 1.

[Insert Table 1 here]

All the clients gave surface or 'prima-facie' reasons for non-attendance: 'not a priority'; 'forgot'; 'not bothered' and 'others' e.g. felt ill. However, the study revealed the reasons for forgetting or not being bothered which varied greatly between clients. These reasons themselves operated within a complex context of factors including welfare policy, addiction, stigma, and importantly idiosyncratic features of hepatitis C itself (see Figure 1: Thematic framework). The participants typically gave multiple factors for not keeping appointments.

[Insert Figure 1 here]

Reasons for non-attendance

The reasons for non-attendance are categorised under the themes: (i) 'client characteristics' and (ii) 'clinic service'. For the full thematic schema and all the reasons for non-attendance, see Table 2.

[Insert Table 2 here]

(i) Client characteristics

Substance misusing lifestyle

The participants reported using drugs (sometimes alcohol) as a 'priority' over attending appointments to avoid suffering the effects of withdrawal; (this was also the main factor influencing the prima-facie reason 'not a priority'). The participants described not being able to go for an appointment until they felt well. For example:

"... I need time to get a drink to sort myself out because I'm ill if I don't have that". (P14, 33 yrs)

Further, prior to scoring drugs, the participants may have had every intention to attend the appointment afterward but, scoring had taken longer than they planned.

"... I used to miss appointments because I were dependent on drugs ... I might planned it to obtain drugs before my appointment time with drug dealers and it never goes to plan so that's why I used to be late ...". (P8, 26 yrs)

Other factors (see Table 2) linked to a 'substance misusing lifestyle' included: 'multiple appointments' with other agencies or services and prioritising which to attend and being 'high' which were both influential in forgetting the clinic appointment. The effect of drug use and being 'high' was also a factor in helping people to deny having hepatitis C. The participants talked about trying to pretend or forget about having the infection. They did not want to be reminded of it because: they were scared of other people knowing they were infected due to the stigma it carried; believed the treatment was not curative and were scared of the side-effects; and wanted to avoid suffering from low mood and being suicidal again.

“... I think that’s sort of one of the reasons that people probably just being off their heads, not really accepting what’s going off or just forgetting about it because they’re still using stuff ”.

(P6, 22 yrs)

Further, the asymptomatic nature of hepatitis C impacted on denial of being infected and made it easy to put to the back of one’s mind. For other participants the absence of symptoms made them “think twice” about going for a test, and taking time off work to keep an appointment. One participant said it was okay to delay attending for treatment until they became “sick”.

Other reasons linked to a ‘substance misusing lifestyle’ were spent ‘*money*’ on drugs and did not have the bus fare to attend; and ‘*crime*’ such as keeping a low profile to avoid detection by the police, having to appear in court and being in prison. Thus, due to a number of factors it would appear that the clinic was ‘hard-to-reach’.

Co-morbidity

Participants with ‘physical co-morbidity’ reported having ‘*bad or sore legs*’ and they had difficulty with walking. For some, this was a drug use consequence, and caused poor circulation, pain, abscesses and swelling probably due to previous deep vein thrombi.

“... sometimes I haven’t got the bus fare to get there and back and I don’t feel like walking there and back because I’ve got bad legs as it is to be honest”. (P16, 39 yrs)

A further physical consequence of drug use reported by the participants, and a reason for not attending, was a blood test was needed to confirm hepatitis C and they had ‘*poor veins*’. The participants described several attempts by staff to get blood, often unsuccessfully, because staff did not listen to clients about where best to locate a vein and may have used needles that were too big.

“... we hate it, absolutely hate it. It takes ages to get any kind of blood out even a dribble and when you tell somebody where to go they’ll be going oh no, no, no like they know best but you end up coming out looking like that thing off ... with cotton wool balls all over us where we’ve been speared a million times”. (P3, 42yrs)

Additional factors related to testing for hepatitis C and not turning up were being scared of a positive diagnosis because they believed the infection was not curable, that it resulted in premature death and they would feel ashamed if they were infected because of perceived stigma.

Other factors (see Table 2) for ‘physical co-morbidity’ and missed appointments included: a ‘*short illness*’ which led to forgetting the appointment or to notify the clinic of their absence; and a period of ‘*long illness*’ which meant being unable to travel to the clinic or needing to resolve this before hepatitis C.

Participants with ‘psychological co-morbidity’ indicated that suffering from ‘*agoraphobia*’ was a non-attendance reason. They described fears of leaving the house and meeting people (including workers they did not know), having panic attacks and staying in their own area to avoid the city and “crowds”.

“I don’t go out a lot. I mean I go out every day but it’s only in my area. I don’t go to town. I am not right good with crowds ... I am not right good you know I get I feel closed in ... I don’t like being in big areas you know like when I go to town I don’t like it, I feel everybody’s rushing at me I start to panic. I don’t like being in that kind of place for too long so I tend to you know stay local you know where I know my area”. (P21, 41 yrs)

Other factors (see Table 2) relating to ‘psychological co-morbidity’ included: suffering from ‘*depression*’ and lacking the motivation to do things or face people; suffering from a ‘*mental*

illness' and taking medication which caused excessive tiredness and not being awake until the afternoon; and having a '*bad day*'.

In summary, it would appear that due to physical and psychological factors, and the stigma of hepatitis C, that the journey to the clinic was difficult and it was hard-to-reach.

Income

Most of the participants received state benefits (see Table 1) with some having their payments reduced because of recent welfare reforms. In addition, a small number were having money deducted to pay off arrears. The participants said the high '*cost of travel*' contributed to non-attendance.

"Not having enough money to get to catch the bus there. If they haven't got enough money then maybe they might not be able to come from where they live. If they come from [part of the city] and you have to come all the way down to the [name of the hospital] it's a long way without having any money in your pocket isn't it?" (P7, 39 yrs)

Other factors (see Table 2) for missed appointments linked to '*income*' included '*phone*' which was sold to get money for drugs due to the cravings of addiction or not having enough money to put credit on it which meant being unable to ring the clinic and made it hard-to-reach or to receive appointment reminders. Also, '*work*' and being unable to take time off because: embarrassed telling their employer about having hepatitis C due to its stigmatising nature and not feeling unwell due to the asymptomatic nature of the infection; would lose pay; busy and forgot the appointment, and working far away. For one participant who did not always get his bus fare reimbursed by the clinic he had '*other priorities*' to spend his money on.

Social networks

Having '*children*' was a reason for non-attendance due to competing demands. The participants explained that: there might not be anyone else to look after them; they needed collecting from school or contact with their child arranged through social services was on weekdays and not at the weekend.

Other reasons (see Table 2) for '*social networks*' and non-attendance included: being '*busy*' due to social events or other activities; and '*non-disclosure*' and avoiding talking about hepatitis C with other people because of perceived stigma and they felt "dirty".

(ii) Clinic service

The second theme comprised of factors about where and how the clinic operated.

Location

As previously highlighted participants suggested that it was a 'difficult journey' to the outreach clinic. The long '*distance*' involved getting two buses which can be troublesome.

"Yes, but living out here you have to change buses and all that carry on". (P1, 63 yrs)

The participants gave other factors (see Table 2) which meant it was a 'difficult journey'. The factors that create a difficult journey are not straightforward or the same as those for staff. For example, having to rely on a lift due to difficulty walking, making sure they did not go into town to score drugs with past drug using acquaintances, having poor veins and potential difficulties with a blood test, and being scared of testing positive for hepatitis C because of stigma.

Other factors for missed appointments linked to 'location' were: '*relationship with clients*' whereby people wanted to avoid meeting other clients in the clinic because of problems

between them including being tempted to score drugs; '*not hospital*' where some people may prefer to go about their hepatitis C because it was where they managed to get a blood sample, it was simpler to explain to other people where they were going and the appointment may be taken more seriously. One participant was concerned about '*confidentiality*', seeing the nurse from the hospital team and being seen by other clients. Thus, even within a drug treatment clinic it would appear that people perceive stigma within their own community.

Delivery

Some participants reported that not getting '*reimbursement*' of travel costs was a factor for non-attendance. They did not have the correct and in-date letter from the benefit office and that obtaining it could involve waiting in a long queue.

"... when I get there I ask for bus fare back and they can't give it to me because I haven't got a letter from the social. ... they've already seen a letter from the social and nothing has changed since then. ... It is a bit of a pain because I have to go to the social, wait in a queue sometimes it's right long, massive, wait for a letter and then go to [name of drug clinic]. It's a bit of a headache to be honest". (P16, 39 yrs)

The participants also gave issues (see Table 2) related to the 'appointment'. One of these was being expected to attend the outreach clinic on a '*different appointment*' to the one for their substitution treatment script. This finding seems unsurprising when participants reported already having '*multiple appointments*' and having to decide which to prioritise and attend. There were a variety of other factors which were not straightforward or simply due to the time of day or not having it written down.

Discussion

Despite a different health system and culture the findings from the research into non-attendance in hepatitis C in Canada (Butt et al, 2013) appear to largely concur with those in this study. However, there appear to be a small number of factors which were not identified in the latter. These factors were:

- Within the 'self-protection' theme the requirement of frequent in-person visits to the clinic when ill due to treatment side-effects;
- Under 'knowledge gaps' reported by patients, being able to differentiate symptoms related to hepatitis C from other conditions, how often a person needed to be monitored by a health professional and how to self-manage the disease; and
- Within 'access to services' the long wait to see a hepatitis C specialist or a worker from a support service such as social work, mental health or addiction services.

Current explanations for missed appointments in the setting of hepatitis C in the literature (including those of a prima-facie nature) insufficiently describe why people miss appointments. This study provides in depth evidence to explain the complexity of why people do not attend appointments including the underlying reasons for some of these inadequate explanations.

The notions that individuals lead 'chaotic lifestyles' and that hepatitis C is 'not a priority' for PWID are frequently used by staff and commentators to explain poor uptake of screening and lack of engagement with health services and treatment amongst PWID with hepatitis C (Irving et al, 2006; Parkes et al, 2006; Mravčik et al, 2013; SIGN, 2013). This study gives some insight and in part challenges this. For example, the clients' first priority was often to score drugs. It was necessary largely to avoid suffering from withdrawal and it may have taken longer than planned to obtain drugs. In such cases, the participants arguably had well-ordered lives but the organisational focus was on getting drugs above all else. Thus,

what to outsiders looks like a chaotic lifestyle is to those within it well organised around an overwhelming drug-addiction-driven priority. Further, this study revealed numerous different explanations for prima-facie reasons including forgetting. The underlying explanations for forgot included: having appointments with other agencies e.g. housing, probation and the job centre to remember and attend; using drugs; being busy at work and looking after children. This has important implications for policy because when the reasons for missed appointments are not known sufficiently then the solutions to improve attendance and the redesign of services may be inadequate. For example, the use of text or telephone reminders adopted by many services is likely to have limited effectiveness in this setting.

This study also revealed the wide range and variability of peoples' experience of missed appointments. Typically, each participant gave many reasons for not keeping an appointment across and within the two key themes identified. In addition, the factors or sub-themes were experienced differently by the participants; for example the explanation around 'crime' comprised a number of experiences such as having to keep a low profile from the police, appearing in court or being in prison. Thus, numerous factors for not turning up to appointments were played out in different ways in different combinations by different people. The reasons always played out in a complex context of factors including addiction, welfare policy, stigma and social inequalities (Paterson et al, 2007; Mouton, 2011; Stewart et al, 2012; Harris et al, 2013; Treloar et al, 2013). There is evidence of several structural factors within hospital settings that promote stigmatisation of drug users with hepatitis C (Paterson et al, 2013) that were highlighted in this study including being seen by others in the waiting room with the nurse from the hospital hepatitis C clinic. It may also be the case that a factor like 'delivery' and '*reimbursement*' could be seen as an individual (lack of income) or a wider contextual (poverty) theme. Policy-makers need to take into account the wide variability of factors and the wider determinants of health that contribute to missed appointments in this setting. Solutions do not adequately address the complexity of the problem where they focus solely or primarily on individual lifestyles and behaviour.

The findings of the study reveal the importance of where and how services are delivered. However, in contrast to other literature for hepatitis C and related groups where the distance and location are cited as contributing to missed appointments (Hayter, 2005; Morrison et al, 2011; Butt et al, 2013) this research based on the perspectives of clients revealed the complexity of what is meant by a term such as a 'difficult journey'. The factors that made for a difficult journey include: having to get two buses; the timing of the appointment, such as whether it was morning or afternoon; whether the appointment was on a different day to the clients' substitution treatment script; the cost of travel and difficulties with reimbursement; and physical and psychological co-morbidity such as problems with walking and suffering from agoraphobia which for some meant relying on a lift. In a sense all missed appointments are the product of a difficult journey – this study and others shows how much this so. Again as a prima-facie reason for non-attendance or other non-compliance it is often reported that PWID with hepatitis C are 'hard-to-reach' (Moriarty et al, 2001; Parkes et al, 2006; Bruggmann, 2012; Hepatitis C Trust, 2013). But this study indicates it is arguably services rather than clients that are hard-to-reach. Currently many services are co-located within drug services on the assumption that this makes them more accessible to clients but this research identified numerous factors which challenge this such as avoidance of other PWID and of the drug using lifestyle.

Finally, advances in technology and treatment in hepatitis C continually evolve. It is important to remember that clients' information and education needs to reflect these developments. For example, the arrival of new drugs which not only offers improved rates of cure for most patients but also means shorter duration of treatment and greater tolerability in the absence of interferon related side-effects for some patients (National Institute for Health and Care Excellence [NICE], 2015). In addition, the availability of a Fibroscan® test, a non-invasive scan using sound waves to measure liver stiffness – a surrogate marker for scarring (fibrosis) of the liver has been used by some services for a few years. Thus, the beliefs and barriers around treatment expressed in this study need to be addressed by new information

and service delivery strategies. The role for peers and peer mentors is something that has been identified in the literature (Australian Injecting and Illicit Drug Users League [AIVL], 2010). It is suggested that well-resourced and properly supported peer support models will reduce a number of barriers to care and treatment including: reducing the intimidating nature of the hospital setting; and supporting people through the treatment contemplation phase and lowering treatment anxiety.

As has been illustrated a strength of this qualitative study is the depth of insight it offers into clients' experiences and reasons for missed appointments. Insofar as this is a qualitative study, the findings are not straightforwardly generalisable to other services. Nonetheless, the findings form the basis for a discussion about ways to change service delivery to improve attendance which can then be evaluated with further studies. Again, there will be no one solution to help improve attendance but a number of solutions will be required, therefore any intervention will need to take into account the complexity of non-attendance. Thus, this study provides valuable insight into the reasons for missed appointments that can feed into the 'development' stage of the Medical Research Council [MRC] framework for complex interventions (MRC, 2000; MRC, 2006).

Conclusions

The apparently simple phenomenon of non-attendance at hepatitis C outreach clinics is often given simple catch-all explanations relating to the chaotic drug-using lifestyle of clients. And the clients themselves give simple prima-facie reasons that accord with these explanations. Such simplicity is deceptive and can be hazardous for policy-makers. Investment in a reminder system to tackle people forgetting to attend may be wasted where such 'forgetting' is a manifestation of many other factors, such as prioritisation of obtaining drugs. This study provides detail on the complex factors that underlie the surface reasons for non-attendance. Some of these do not sit neatly together. For example, while some

clients disliked multiple appointments and valued getting a script at the same time as their outreach appointment, others found the placing alongside of drug and hepatitis clinics a problem if they were trying to avoid getting caught up again in a drug using lifestyle. As such, the policy implications of this study are not straightforward. Thus, whilst the recent advances in treatment have been well received by clinical services the capability for them to deliver the new drugs remains a problem. The findings of this study provide a basis for the development of policies grounded in a more complex picture than that usually provided.

Accepted Manuscript

References

Astell-Burt, T., Flowerdrew, R., Boyle, P., and Dillon, J. (2012). Is travel-time to a specialist centre a risk factor for non-referral, non-attendance and loss to follow-up among patients with hepatitis C (HCV) infection? *Social Science and Medicine*, **75**:240-247.

Australian Injecting and Illicit Drug Users League. (2010). Hepatitis C Models of Access and Service Delivery for People With a History of Injecting Drug Use. Retrieved 29 September 2015 from <http://www.aivl.org.au/wp-content/uploads/Hep-C-Models-of-Access-Service-Delivery-Paper.pdf>

Baker, S., and Edwards, R. (2012). How many qualitative interviews is enough? Retrieved 16 April 2015 from http://eprints.ncrm.ac.uk/2273/4/how_many_interviews.pdf

Bruggmann, P. (2012). Accessing Hepatitis C patients who are difficult to reach: it is time to overcome barriers. *Journal of Viral Hepatitis*, **19**:829-835.

Butt, G., McGuinness, L., Buller-Taylor, T., and Mitchell, S. (2013). Reasons for Nonattendance across the Hepatitis C Disease Course. *International Scholarly Research Notices Nursing*. Retrieved 22nd March 2015 from <http://dx.doi.org/10.1155/2013/579529>

Carr, E., and Worth, A. (2001). The use of telephone interview for research. *Nursing Times Research*, **6**(1):511-524.

Cousins, C., Baxter, J., Russell, S., and Vilar F. (2011). Non-Attendance at Hospital Clinics for Hepatitis C Among Intravenous Drug Users: Barriers and Potential Solutions: Category: Clinical Lesson. *Journal of Infection*, **63**(6):e65-e66.

Denscombe, M. (2003). *The Good Research Guide: for small-scale social research projects*. (2nd ed.) Berkshire: Open University Press, (Chapter 1).

Department of Health. (2002). *Hepatitis C Strategy for England*. Retrieved 22nd March 2015 from
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4059510.pdf

Gale, N., Heath, G., Cameron, E., Rashid, S., and Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multidisciplinary research. *BMC Medical Research Methodology*. Retrieved 22nd March 2015 from
<http://www.biomedcentral.com/content/pdf/1471-2288-13-117.pdf>

Harris, M., and Rhodes, T. (2013). Hepatitis C treatment access and uptake for people who inject drugs: a review mapping the role of social factors. *Harm Reduction Journal*. Retrieved 27 March 2015 from
<http://www.harmreductionjournal.com/content/10/1/7>

Hayter, M. (2005). Reaching Marginalized Young People Through Sexual Health Nursing Outreach Clinics: Evaluating Service Use and the Views of Service Users. *Public Health Nursing*, **22**(4):339-346.

Hepatitis C Trust. (2013). *The Uncomfortable Truth – Hepatitis C in England: The State of the Nation*. Retrieved 22 March 2015 from
<http://www.hcvaction.org.uk/resource/uncomfortable-truth-hepatitis-c-england-state-nation>

Irving, W., Smith, S., Cater, R., Pugh, S., Neal, K., Coupland, C., Ryder, S., Thomson, B., Pringle, M., Bicknell, M., and Hippisley-Cox, J. (2006). Clinical pathways for patients with

newly diagnosed hepatitis C – What actually happens. *Journal of Viral Hepatitis*, **13**(4):264-271.

Marcus, A., and Crane, L. (1986). Telephone surveys in Public Health Research. *Medical Care*, **24**(2):97-112.

Medical Research Council. (2000). A framework for development and evaluation of RCTs for complex interventions to improve health. Retrieved 27 March 2015 from <http://www.mrc.ac.uk/documents/pdf/rcts-for-complex-interventions-to-improve-health/>

Medical Research Council. (2006). Developing and evaluating complex interventions: new guidance. Retrieved 27 March 2015 from <http://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/>

Moriarty, H., Kemp, R., and Robinson, G. (2001). Hepatitis services at an injecting drug user outreach clinic. *New Zealand Medical Journal*, **114**:105-106.

Morrison, C., Betney, K., and McCulloch, C (The TASC Agency). (2011). A report on a study exploring non-attendance at specialist clinical HIV services in Scotland. Retrieved 27 March 2015 from <http://www.hivscotland.com/our-policy-work/policy-document-library/view-document/a-report-on-a-study-exploring-non-attendance-at-specialist-clinical-hiv-services-in-scotland/>

Mouton, M. (2011). “More Than a Liver”: Social Work’s Contribution to the Well-Being of People Undergoing Treatment for Hepatitis C. *Journal of Social Work Practice in the Addictions*, **11**:40-59.

Mravčik, V., Strada, L., Štolfa, J., Bencko, V., Groshkova, T., Reimer, J., and Schulte, B. (2013). Factors associated with uptake, adherence and efficiency of hepatitis C treatment in people who inject drugs: a literature review. *Patient Preference and Adherence*. Retrieved 22nd March 2015 from <http://dx.doi.org/10.2147/PPA.S49113>

National Institute for Health and Care Excellence. (2015). Sofosbuvir for treating chronic hepatitis C. Retrieved 27 March 2015 from <http://www.nice.org.uk/guidance/ta330/resources/guidance-sofosbuvir-for-treating-chronic-hepatitisc-pdf>

Parkes, J., Roderick, P., Bennett-Lloyd, B., and Rosenberg, W. (2006). Variation in Hepatitis C services may lead to inequity of health-care provision: a survey of the organisation and delivery of services in the United Kingdom. *BMC Public Health*. Retrieved 22nd March 2015 from <http://discovery.ucl.ac.uk/1340653/1/1471-2458-6-3.pdf>

Paterson, B., Backmund, M., Hirsch, G., and Yim, C. (2007). The depiction of stigmatization in research about hepatitis C. *International Journal of Drug Policy*, **18**(5):364-373.

Paterson, B., Hirsch, G., and Andres, K. (2013). Structural factors that promote stigmatization of drug users with hepatitis C in hospital emergency departments. *International Journal of Drug Policy*, **24**(5):471-478.

Public Health England. (2014). Hepatitis C in the UK: 2014 report. Retrieved 22nd March 2015 from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/337115/HCV_in_the_UK_2014_24_July.pdf

Ritchie, J., Spencer, L., and O'Connor, W. (2003). Carrying out qualitative analysis. In J. Ritchie, and J. Lewis (Eds), *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (pp. 219-262). London: Sage Publications Ltd.

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing and Health*, **18**(2):179-183.

Scottish Intercollegiate Guidelines Network. (2013). Management of hepatitis C: A national clinical guideline. Retrieved 22 March 2015 from <http://www.sign.ac.uk/pdf/sign133.pdf>

Treloar, C., and Rhodes, T. (2009). The Lived Experience of Hepatitis C and its Treatment Among Injecting Drug Users: Qualitative Synthesis. *Qualitative Health Research*, **19**(9):1321-1334.

Treloar, C., Rance, J., and Backmund, M. (2013). Understanding Barriers to Hepatitis C Virus Care and Stigmatization From a Social Perspective. *Clinical Infectious Diseases*, **57**(S2): S51-55.

Stewart, B., Mikocka-Walus, A., Harley, H., and Andrews, J. (2012). Help-seeking and coping with the psychosocial burden of chronic hepatitis C: A qualitative study of patient, Hepatologist, and counsellor perspectives. *International Journal of Nursing Studies*, **49**:560-569.

Wallace, S. (2005). Observing method: recognizing the significance of belief, discipline, position and documentation in observational studies. In I. Holloway (Ed), *Qualitative Research in Health Care* (pp. 71-85). Berkshire, Open University Press.

World Health Organisation. (2014). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Retrieved 22nd March 2015 from http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1

Accepted Manuscript

Table 1: Participant characteristics

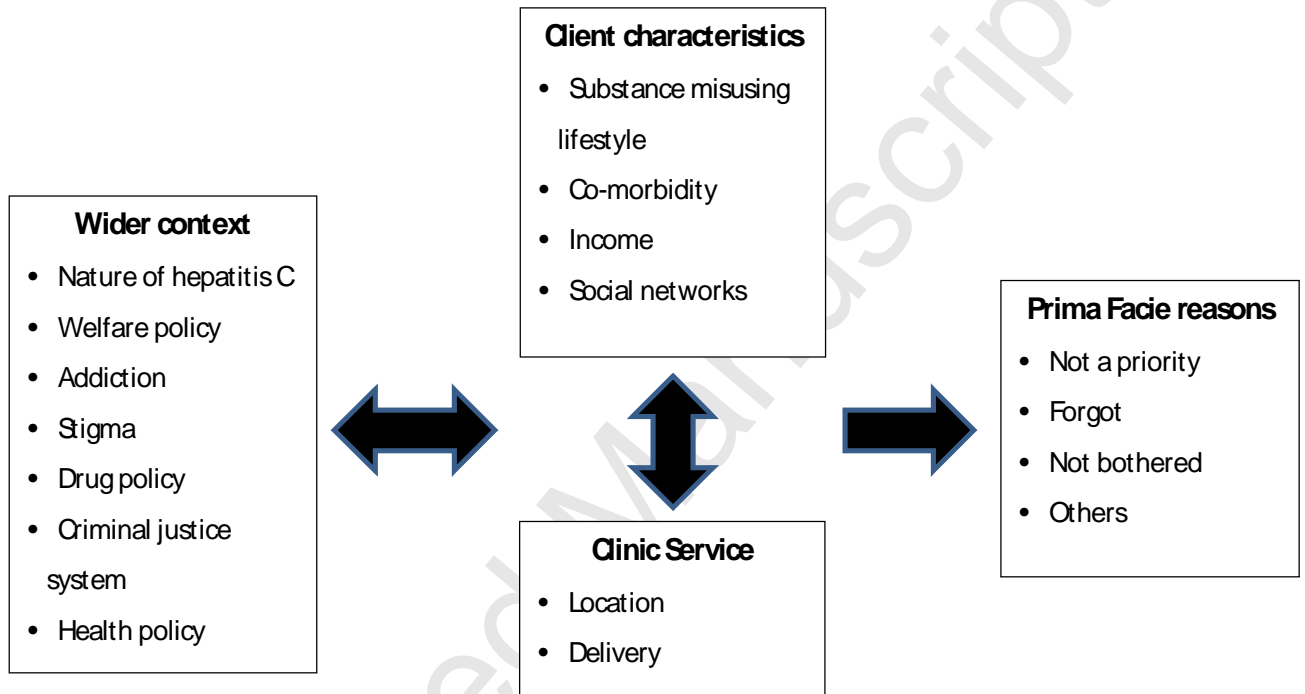
Characteristics	No. of Participants
<u>Demographic</u>	
Male	23/28 (82%)
Female	5/28 (18%)
Age range	22 – 63 years (median 39 years)
Had partner	7/9 (78%)
No partner	2/9 (22%)
Had children	12
Lived with others	10/14 (72%)
Lived in hostel	2/14 (14%)
Lived alone	2/14 (14%)
Working	4/17 (24%)
On benefits	13/17 (76%)
<u>Drug use</u>	
Within last few months	2/14 (14%)
Not recent	12/14 (86%)
<u>Hepatitis C status</u>	
Chronic infection	21/26 (81%)
Past infection	3/26 (12%)
Not sure	2/26 (7%)

The denominator varies because not all information was available from all clients.

Table 2: Full thematic schema – Non-attendance at drug service hepatitis C outreach clinics

'Prima-facie' reasons	Client Characteristics	Clinic Service
<ul style="list-style-type: none"> • Not a priority • Forgot • Not Bothered • Others <ul style="list-style-type: none"> > Poor motivation > Felt ill > Weather > No reason 	<ul style="list-style-type: none"> • Substance misusing lifestyle <ul style="list-style-type: none"> > Priority - Withdrawal > Busy > Multiple appointments > Money > High > Psychosocial > Homeless > Crime > Avoid town > Start life • Co-morbidity <ul style="list-style-type: none"> > Physical <ul style="list-style-type: none"> - Bad/sore legs - Poor veins - Short illness - Long illness > Psychological <ul style="list-style-type: none"> - Agoraphobia - Depression - Mental illness - Bad day • Social networks <ul style="list-style-type: none"> > Children > Busy > Non-disclosure • Income <ul style="list-style-type: none"> > Cost of travel > Phone > Work > Other priorities 	<ul style="list-style-type: none"> • Location <ul style="list-style-type: none"> > Difficult journey - Distance - Rely on lift - No transport - No bus stop - Bus > Relationship with clients > Not hospital > Confidentiality • Delivery <ul style="list-style-type: none"> > Re-imburement > Appointment - Not morning - Waiting - Different appointment - No card/letter - Lost paper - Wrong date - "Counselling" - Drug clinic nurse > Relationship with staff > Entrance

Figure 1: Thematic Framework – Reasons for non-attendance at drug service hepatitis C outreach clinics



Conflict of Interest Statement

The authors declare they have no conflict of interests.

Accepted Manuscript

Box 1: Themes for non-attendance (Butt et al, 2013)

- perceived to be treated differently by others following disclosure of hepatitis C;
- patients weighed up the benefits of attending;
- patients had multiple and sometimes conflicting priorities in their lives;
- deficits in knowledge about hepatitis C;
- 'system' factors meaning the service was difficult to access;
- 'system' factors impacting on patients' ability to engage with care.

Box 2: Rationale for telephone interviews

- the nature of the research topic meant participants may not turn up for an interview;
- PWID may live in parts of the city which might be considered unsafe to visit for face-to-face interviews (Marcus et al, 1986);
- the cost of undertaking telephone interviews, in terms of time, effort and money, is lower than face-to-face interviews (Denscombe, 2003);
- the relative anonymity of telephone interviews, lack of face-to-face contact and the establishment of confidentiality may enable participants to talk honestly and openly about their experiences (Carr et al, 2001); and
- most of the clients, like most of the general population, were regular users of mobile and land-line phones and so familiar and comfortable with them.