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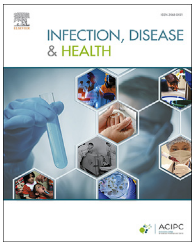

Research paper

"I'm obviously not dying so it's not something I need to sort out today": Considering hepatitis C treatment in the era of direct acting antivirals

C. Wright [a], S. Cogger [a], K. Hsieh [a], S. Goutzamanis [b], M. Hellard [a],
P. Higgs [c,*]

[a] Burnet Institute, Melbourne, Vic 3004, Australia
[b] Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, Vic 3004, Australia
[c] La Trobe University, Department of Public Health, Bundoora, Vic 3083, Australia

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Abstract *Background:* People who inject drugs are the group at greatest risk of hepatitis C virus (HCV) infection. The advent of new direct-acting antiviral (DAA) treatment provides opportunities for increased uptake of therapy.

Methods: We conducted in-depth interviews with thirty HCV positive participants from the SuperMIX cohort study. Interviews were transcribed, coded, and analysed for emerging themes and similarities between participants. General descriptions and critical interpretation of themes were generated and selective quotes extracted verbatim to best illustrate the critical themes.

Results: Participants described their experiences of living with HCV, their knowledge of HCV treatment accessibility, and information on the types of support ain themes: Understanding the need for treatment; Knowledge and framing of treatment access; and Support during treatment.

Conclusion: The new, highly effective DAAs for the treatment of HCV are heralded as the potential beginning of HCV elimination, especially in settings where scale up is high. Our data from active PWID show that the availability of DAA medications in and of themselves is likely not to be enough to ensure that PWID will come forward for HCV treatment in sufficient numbers to drive elimination.

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* Corresponding author.
E-mail addresses: cassandra.wright@burnet.edu.au (C. Wright), shelleycogger@gmail.com (S. Cogger), kevinhsieh18@gmail.com (K. Hsieh), sgou16@student.monash.edu (S. Goutzamanis), hellard@burnet.edu.au (M. Hellard), p.higgs@latrobe.edu.au (P. Higgs).

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Highlights

- Availability of DAA medications in and of themselves is not enough to ensure people will come forward for HCV treatment.
- Understanding the preferred models of HCV care for people who inject drugs can ensure adequate scale up of treatment.
- Understanding the needs of those who have yet to engage in HCV care will be crucial in continuing the treatment momentum.

Introduction

The hepatitis C virus (HCV) affects an estimated 71 million people worldwide [1,2]. In Australia, approximately 170,000 people are currently estimated to be living with chronic HCV, despite the availability of new, highly effective hepatitis C treatment [3,4]. HCV is the major cause of liver-related diseases including cirrhosis, liver failure and hepatocellular carcinoma [5]. People who inject drugs (PWID) are the key risk group for HCV infection, however it is unknown how many are currently in treatment, being managed or have health care workers providing support [6]. This is a common phenomenon across other World Bank classified high-income countries [7].

Historically, few Australian PWID have undergone HCV treatment in any one year [8—10]. Low treatment uptake has been attributed to individual, clinician and systemic barriers including stigma and the criminalization of illicit drug injecting [11—16]. In March 2016, the Australian Government listed new generation direct-acting antiviral (DAA) medications on their list of subsidised medications available through the Pharmaceutical Benefits Scheme. These medicines are highly effective, have few side-effects and require a shorter treatment regimen. This led to a rapid increase in the numbers of people being treated, with estimates indicating over 58,000 people have started treatment since the medication was made available [4]. Surveillance data suggest that the proportion of PWID engaging in treatment has increased substantially since the introduction of DAAs, although there is limited data available on people who are current injectors [17—19].

The availability of DAA treatment regimens provides the opportunity to reduce HCV prevalence and transmission by treating active PWID simultaneously with their injecting networks [20]. Mathematical modelling has demonstrated that using this approach, it is feasible to reduce prevalence of HCV among PWID from 50% to 40% in only a 10 year period [21]. Expert physicians have even suggested that elimination of HCV within a 20 year timeframe is now possible [22,23]. However, to achieve HCV elimination, a key issue will be to engage with active PWID and increase their participation in HCV treatment, care and support. While the new DAA treatment regimens offer improved efficacy, there is still evidence that barriers to HCV treatment remain unaddressed [24,25], with PWID not receiving the full benefits these medications offer [26]. For example, there is evidence that suggests that some PWID are being 'warehoused' for treatment by physicians [18], which presents a significant barrier to elimination goals [24—26].

Despite the study being conducted prior to the wide availability of DAAs in Australia, the findings of the study still provide some important lessons to improving HCV treatment uptake today. In this paper we explore the experiences of a group of current injectors living with chronic HCV drawn from a cohort of PWID in Melbourne, Australia. We describe their understandings and perceptions related to their lived experience of HCV and, from these, outline possible improved models of HCV care, treatment and support.

Methods

We conducted a phenomenological qualitative study using in-depth interviews with 30 PWID of diverse gender, age and ethnicity. Purposive sampling was used to recruit a sub-sample of participants from within the SuperMIX Study, Australia's largest prospective cohort of PWID. SuperMIX is a combination of two cohorts; the Networks II Study, established in 2005 [27] and the Melbourne Injecting Drug User Cohort Study, established in 2009 [28]. Consenting participants are currently interviewed annually with a structured questionnaire by field-based researchers who also collect a venous blood sample for blood borne virus (BBV) testing. At baseline, 43% of the SuperMIX cohort had serological evidence of current HCV infection.

Using assertive outreach across four sites in Melbourne, fieldwork researchers approached participants in-person and invited them to participate in this qualitative study. Participants were told that the researchers aimed to understand their understanding of HCV treatments and any treatment experiences. If they agreed, their phone number was provided to the interviewers who contacted them and arranged an interview. Recruitment ceased when the researchers felt that a level of data saturation had been reached with regards to the main aims of the study, and with consideration of including diverse perspectives. Only three participants declined to participate in the research, citing reasons of being too busy and not wanting to talk about their life at this point in time.

Inclusion criteria were (1) self-reported and (2) serological evidence of chronic HCV infection. We obtained informed verbal consent from interested participants who met the inclusion criteria.

The in-depth interviews were completed between April 2014 and January 2015 in a private room onsite or a purpose-built study van and lasted between 30 and 75 min.

The first 6 interviews were conducted by the two researchers together (KH, PH) and a de-briefing was undertaken at the end of each interview. PH (male) had a PhD and more than 20 years of experience in qualitative research; KH (male) had an undergraduate degree in science and took part in intensive training in qualitative research prior to conducting interviews. The following 22 interviews were conducted by KH with de-briefing held fortnightly between the research team to reflect on field notes taken. PH conducted the last 2 interviews on his own. He was known to about half the participants due to his prior work conducting interviews on the SuperMIX study; KH had no prior relationship with any participant.

Upon completion of the interview, participants were reimbursed $50 AUD as compensation for their time and travel expenses incurred. An interview guide was developed prior to the study and included questions framed to elicit participant understandings and experiences of HCV testing, diagnosis and previous treatment (see supplementary data). The suitability of models of HCV care and treatment outside of the tertiary hospital setting were also explored.

Interviews were digitally recorded, uploaded to a secure network drive and transcribed verbatim. We assigned pseudonyms to participants to protect their identity. Transcripts were reviewed and checked for accuracy against the audio-recordings.

We used an iterative process of thematic coding to analyse the data. Two researchers (CW, KH) read a preliminary sample of transcripts and agreed on a suitable coding framework that was checked and revised with the senior author (PH); the framework was also revised as needed throughout the analysis process. The construction of coding frames involved discussion of codes and negotiating differences until consensus was achieved. An additional coding frame was subsequently constructed to organise the data under more concept-driven categories that had been identified in the interviews and which reflected the emerging themes. The data were then analysed with specific consideration given to the understanding the need for HCV treatment, knowledge of HCV treatment access and the potential models of care with the new DAAs. Coding was completed using QSR NVivo software version 10.

Results

Two-thirds (n = 20) of participants were male and the median age was 36.5 years. Participants reported living with HCV for a median of 12 years (range 1—20 years). At the time of the interview, most (n = 22) were currently being prescribed pharmacotherapy (methadone or buprenorphine-naloxone) for their opiate/opioid dependency. While 11 participants reported being previously offered HCV treatment, only two reported any personal experience of undertaking HCV treatment. None had experience of interferon-free treatment regimens (Table 1).

Participants described their experiences of living with HCV, their knowledge of HCV treatment accessibility, and information on the types of support they perceived were required during HCV treatment. Our main aim was to learn from previous HCV treatment models to better inform the implementation and roll out of new models of care using DAAs for PWID. We synthesised our findings into three main themes, which are outlined in the paper: *Understanding the need for treatment*; *Knowledge and framing of treatment access*; and *Support during treatment*.

Table 1 Outlines participant characteristics.

Demographic characteristics	N
Gender	
Male	14
Female	9
Age	
Mean	35
English spoken at Home	
Yes	21
No	2
Highest Level of education	
<Year 10	11
Yr 10—11	4
Yr 12/higher/trade	8
In paid employment	
Yes	8
No	15
Stable Accommodation	
Yes	19
No	4
Prison history	
Yes	16
No	7
Currently on OST	
Yes	16
No	7
Ever offered HCV treatment	
Yes	8
No	15
Ever had HCV treatment	
Yes	2
No	21

Understanding the need for treatment

> *I've been hep* [C] *positive for so many years but I don't feel that I can attribute anything that's happened to me directly to hep. So I don't actually feel at this point that hepatitis has affected me, I know it has internally at some point but I don't really feel it.* (David)

The extent to which participants were able to recognise HCV symptoms or understand their poor health as resulting from their HCV infection was a key influence on their treatment-seeking behaviour. Several participants considered their HCV to be relatively mild and believed that treatment was not required until they were demonstrably unwell. This was evident even in the context of HCV-related clinical consultations with a physician. For instance, as illustrated below, when Max was previously offered HCV treatment by doctors, he reported that he hadn't '*really take[n] them seriously*':

> *When my skin starts turning yellow and my eyeballs are bright yellow then I'll go and get some treatment for it. I've always been quite a lethargic person … And I have been lethargic lately as well but I remember before I even started using I was quite lethargic so I don't know if I attribute that to hep C or not.* (Max)

Narratives about the ambiguous nature of HCV symptoms were common, particularly those highlighting the similarity of physical symptoms like lethargy to those of other illnesses like depression. Participants showed varied understandings of HCV symptomatology; while Max was uncertain about the cause of his lethargy, a number of other participants directly attributed their poor health to HCV. Overall, however, most participants expressed uncertainty about the cause of their symptoms and were unable to identify which of their health issues might be related to HCV and which were due to other conditions.

> *Sometimes I do* [feel unwell] *but then I don't know whether it's the hep C, you know what I mean? I don't know the side effects of it or like any problems that other people have with it.* (James)

Like James, Sophie also reported a lack of knowledge regarding the symptoms of chronic HCV infection, but claimed that she was also experiencing fatigue more often than previously. While she described this tiredness as possibly linked to her HCV infection, for her there was no clear relationship between her general health status and chronic HCV:

> *I don't really know to be honest the bad things about it, the side effects. I wouldn't have a clue … like last year I don't know if it's the kid but I get really fatigued a lot. I don't know if it's stress and that but I shake a lot now. I never used to be this tired. Some days where if I slept a bit in the day I couldn't sleep at night where I can do both now and that's not like me …* (Sophie)

Conversely, other participants who reported fatigue described being aware of the negative effect of HCV on their daily lives. Stewart reported experiencing common HCV related symptoms like fatigue, as well as mood swings and poor appetite. He spoke of the '*physical and mental*' strain that living with the disease was having on his life.

> *It just makes you lazy, like you haven't got the energy to do anything … it's weird to explain, like it* [HCV] *just puts you back when you're doing nothing.* (Stewart)

Others highlighted the impact of tiredness over time on their general daily activities, limiting their workforce participation and social engagement:

> *Well I probably haven't looked as far into it as what I probably should 'cause I think at the start I never really felt too much different than what I'd ever felt from it. Over the years it probably has made a decent difference … even like trying to work a whole week was really … It was more than just not being fit; it was being tired when I shouldn't be.* (Troy)

Interview data showed a clear need to better inform PWID to understand the long-term severe health consequences of HCV before they can contemplate the need for interventions to prevent future liver complications. For some participants, it was not until observing liver cirrhosis, cancer or death among their peers that they even considered learning more about HCV treatment and management options. As David's narrative highlights, understanding the consequences of an untreated chronic infection makes the option of earlier HCV treatment more attractive.

> *Before it does actually start affecting me, if this option* [HCV treatment] *is feasible, I'd take it instead of having to address it in 10 years' time when I've got liver failure or whatever else it's gonna be.* (David)

While most participants understood the consequences of living with HCV over time, interviews revealed that few considered HCV treatment to be necessary at this particular point in their lives:

> *I'm obviously not dying so it's* [HCV treatment is] *not something I need to sort out today.* (James)

On the whole, data from the group of people living with HCV in our study showed limited understandings of HCV symptoms. Participants with the capacity to express their understandings of HCV symptomology, appeared to be in a better position to assess and prioritise their need for HCV treatment and management (particularly the need for ongoing liver function monitoring). In our study, the PWID we interviewed without a strong awareness of the health consequences of prolonged HCV infection were less likely than those with better knowledge to report a need for treatment.

Knowledge and framing of treatment access

Knowledge of interferon-based treatments for HCV varied. Generally, those participants who reported prior and current involvement in peer education, a prison history, and/or a close association with a needle and syringe program (NSP) were better informed than participants without these characteristics. Most understood that treatment for HCV was available, but could not elaborate on the specifics of what treatment entailed.

Several narratives showed how widespread reports of the negative side effects of interferon-based treatments had deterred people from seeking HCV treatment altogether.

> *I think the anecdotal evidence that was getting out there, how it was affecting people, was probably putting off a lot of other people. I know it did me, just from hearing how awful the side effects were. I had sworn off never doing that treatment.* (Candice)

Lengthy treatment times were also reported as a major barrier to seeking treatment, as Chelsea noted:

> [I heard] *it was hard to function for that six months or whatever months they were doing it. And this is people who aren't using and who are quite healthy … it's not something that I feel like I can take the time out to do — to be ill for six months and hopefully be better at the end … If I was symptomatic, it'd be a different story.* (Chelsea)

Participants reported receiving what they perceived to be honest and forthright information from health professionals. Narratives suggested that in discussions about HCV most health practitioners gave due consideration to participants' unique circumstances and the potential individual impact of treatment side effects. This patient-centred approach is essential for engaging active PWID in appropriate and timely health interventions to prevent HCV morbidity and mortality. Our data showed that one of the most powerful influences on participants' decisions about accessing treatment was the way in which health practitioners framed the side effects of HCV treatment in patient discussions. Understanding the implications of such framing on treatment access is essential if we are to increase HCV treatment uptake among PWID. As an example, Eve explains how she interpreted and acted on her doctor's advice regarding treatment:

> *Well if I'm not sick then I'm fine, but that's why the doctor advised me not to do it now so, he said, 'you're going to be throwing up, you're going to have sweats'. I'm not going to put my kids through that so I'd rather wait until they get a bit older and they don't have to see that.* (Eve)

Other participants spoke of poor knowledge of HCV treatment among their health practitioners, or of perceiving an apparent reluctance to disclose essential information on side effects. When we asked Georgia whether her doctor had explained to her the possible treatment side effects, she replied '*no, not really*'. In the absence of evidence from a respected health professional, she instead reported relying extensively on her own observations and stories from her network of peers:

> *I heard about* [HCV treatment] *and saw people be extremely ill for that period. You know, and being a university student and a single mother, I just didn't know at what point, I could be in a position and be that sick. Yeah, look, it's hard to sort of articulate. I didn't know how sick I was going to be and how it would affect my life.* (Georgia)

Treatment access

Other participants in our study reported that the information provided to them by health professionals had actually prevented them from accessing treatment. Their experiences showed that HCV treatment is still difficult to access for PWID even when they actively seek it. Despite her willingness to begin HCV treatment 10 years ago, Megan recalled being informed by a general practitioner that abstinence was required before treatment could commence and that she needed to be '*clean for two years*'. In the Victorian context, PWID have been eligible for HCV treatment regardless of current drug use status since at least 2005.

> *I didn't think I'd be able to go and get it done* [HCV treatment] *because I got told about the two-year thing. I was just thinking I wanted to get it but I couldn't because I'm using.* (Megan)

Megan reported not seeking HCV treatment ever since — an example of a clinician/provider barrier to access. Narratives like hers exemplify the doubt many active PWID have about their eligibility for HCV treatment. Sophie best epitomised this uncertainty. In her interview she hesitated before disclosing her drug use because she was unsure of the potential implications of her status on her eligibility for treatment, even in the context of research participation.

> *If you do the program* [HCV treatment] *and you still use after, is that okay? You know what I mean? Like I'm being honest, as long as I take the right precautions not to get it* [HCV] *again?* (Sophie)

When probed about the reasons for her uncertainty, Sophie mentioned the stories she had heard of other injectors being denied HCV treatment because of honestly reporting their drug injecting practices. Misinformation like this circulating between PWID in our study was evidently a crucial barrier to seeking further information from health practitioners about accessing HCV treatment.

Given our data were mostly collected in 2014, prior to the widespread use of DAAs, it was not surprising that few participants were aware of them. Availability being previously limited to specialised tertiary settings such as clinical trials and compassionate access schemes promoted by hospitals. A large proportion of participants reported having heard that '*something was out there*', but expressed uncertainty relating to what these new medications involved and what they meant for curing HCV. The eight participants who reported good knowledge of the new DAA treatment regimens had either previously sought HCV treatment information or been heavily involved in formal peer education activities with the local drug user organisation. However, even these participants had limited and sometimes inaccurate knowledge.

Several participants reported waiting for new HCV treatment options for extensive periods of time. This 'warehousing' of people for treatment, in which physicians have explicitly recommended that people wait years for the new treatments, is a well-recognised phenomena [18,29]. Many of our participants reported that they had been recommended to wait for treatment for years prior, which fuelled a strong sense of scepticism and mistrust in some participants.

> *I don't believe* [it] *almost until I see it … This release date, we've been hearing about it and it's been contradicted … for over 10 years.* (Percy)

Provision of misleading information about treatments to participants in our study instilled in them an apparent mistrust of the health care system. As a consequence, many expressed doubt regarding the likely efficacy and limited side effects of the new HCV treatment regimens. The reduced side-effect profile of the new DAA medications is expected to be a strong 'selling point' that will attract PWID to HCV treatment compared with previous interferon-based treatment regimens. If this appeal is to be harnessed, it is essential that simple, balanced and accurate information regarding DAAs be disseminated to PWID through both formal and informal sources and networks.

Models of treatment, care and support

Existing models of HCV care are typically centred in tertiary hospitals. However, there is support for hepatitis nurses to conduct outreach clinics at community-based primary health services and in prison settings. As only two of 30 participants reported previous HCV treatment experience, almost all relied on their prior experiences of accessing other services for information about the steps required to access treatment. Several participants proposed that they would prefer to receive treatment at places where they had previously received information and education about HCV care and management.

> *Well I figured there's St Vinnies* [local hospital] *like I got told that they're doing it there.* (Megan)

> *I'd probably talk to* [employees at a local NSP] *and then go to the GP and stuff like that.* (Joel)

Due to the all-oral DAA medications being a daily dosed treatment, a number of participants believed that integrating HCV treatment within Opioid Substitution Treatment (OST) programs would be an optimal point of access. In Victoria OST is almost exclusively delivered through community-based pharmacies. Some participants on OST reasoned that the integration of these two programs would enable their access to HCV treatment within a location that was (for the most part) already frequented daily. This group highlighted the perceived benefits of concurrently receiving their HCV treatment and OST medications — helping to create a '*routine*'. Community OST pharmacies are currently being explored as a viable option for promoting greater access to HCV treatment [30].

> *No I'd prefer to just take it with my methadone you know. If I had takeaways*[1] *I'd put it next to my takeaways and I'd take them, you know what I mean?* (Jessie)

This view was shared by the majority of participants in our study who were participating in OST at the time of interview. When asked about his first preference for accessing HCV treatment, Geoffrey quickly and definitively suggested that the local '*pharmacy would be the best*.' He emphasised that for him this model of care would facilitate treatment compliance, enabling him to '*remember to take it every day*'. Sophie also believed that applying some structure to medication-dosing would be advantageous:

> *I don't know if you can pick it up through the chemist, like that would be good because they're strict with your dose — you have to sign and give them a script and that. Or through either a worker or a hospital but yeah I mean, if you're able to go to the chemist, it would probably be the best.* (Sophie)

By contrast, other participants expressed wariness about this model of care being the only alternative, particularly for PWID who were not in OST. In her interview, Chelsea carefully noted that HCV treatment provision from within community-based pharmacies may only be appropriate for groups of '*people who are on* [OST] *programs*' and strongly reinforced the need for patient-centred HCV treatment models of care. Individualised, innovative HCV treatment models of care are especially pertinent for PWID in rural and regional Australia who are already underserved by the OST system.

> *There's so many different variables I guess, 'cause if you're living in the country, picking up your methadone once a week. And you're getting six takeaways, then you'd have to cater for that, the hep C treatment as well.* (Chelsea)

Like Chelsea, Georgia also highlighted the importance of a patient-centred approach in her interview, particularly with regards to issues already experienced by PWID with OST takeaway doses and buprenorphine-naloxone '*double dosing*'.[2] She believed that medication dispensing through community-based pharmacies was potentially problematic if this was the only available treatment model for PWID.

> *If it was a person on methadone, and they had to get the methadone every day, I don't think they would struggle to keep up with treatment. But someone like me, on Suboxone, and I do know other people on Suboxone that get double dosed and just get takeaways for the rest of the week. Now, that could stuff up.* (Georgia)

Other participants expressed concern about the suggestion of daily supervision of their HCV DAA treatment regimen and strongly believed that they should remain in control of their own medications, as per other chronic disease management strategies. Anthony suggested receiving the '*three months' worth*' of medication in '*one go*' so he could manage his own treatment regimen, as he describes below:

> *They're done and that way I don't have to worry about back and forth and getting them, if I can do that. Because the doctors already write three months of scripts for other drugs so I'm sure we can work that out ... So all I gotta do now is when I wake up and have my coffee in the morning I know to have one of them with it, you know what I mean? So when I get my meds out at night so I don't forget I'll get one of them and I'll sit it on my dresser because I've got a little coaster for my cup in the morning, I'll just sit that on the coaster. You see I've already come up with what I'll do.* (Anthony)

Some participants referred to the inherent restrictions the Victorian OST system already imposed on their day-to-day lives, with narratives suggesting that this model of care might pose barriers for some to HCV treatment. In her interview, Paris emphasised that the journey each day to the pharmacy was too much of a hindrance to her daily routine. When asked if a requirement for daily dosing would

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[1] Takeaways are doses of OST that the person is provided with by the pharmacist to be taken at home.

[2] Double dosing is when a person is prescribed two times the daily dose to be taken at once to allow less frequent attendance at the pharmacy.

prevent her from accessing HCV treatment, she responded with a confident '*yes*'. In the quote below, Paris articulated the restrictions that maintaining a daily methadone program already had on her regular movements:

> *It's a pain in the arse but it's not that far from my house so it's alright, it's just when I need to go you know out of town down to Geelong to see my family — you can't just take off, you know?* (Paris)

Adherence and treatment compliance

Despite these concerns, the majority of participants on OST in our study seemed adamant that providing HCV treatment through a community-based pharmacy would ensure their adherence to daily dosing. Although participants were advised that DAAs were unlikely to provide them with immediate HCV related symptomatic relief, they appeared certain that adherence to the all-oral treatment regimen would be unproblematic. When asked to describe their previous experiences of adherence to prescribed medications, participants disclosed sometimes missing a dose of certain daily regimens, such as antibiotics or the oral contraceptive pill. However, participants deemed that a course of HCV DAA treatment was '*important medication*' and were confident their compliance would be optimal. As Percy noted:

> *Yeah it's gotta be your own personal motivation, you've gotta remember to take the tablets every day. Obviously there's a lot of people out there that that would be beyond them from what I observe. But me — I'm motivated to do it — I'd go and pick it up like methadone at the chemist if I had to.* (Percy)

Participants cited engagement in a regular routine as crucial to ensuring their adherence to the all-oral HCV DAA treatment. For example, some described implementing recall techniques that included taking their medications at the same time every day, and receiving reminders from a friend or family member. Max even suggested the possibility for daily institutional reminders, such as '*sending a text*' to remind people to take the medication, which is a method well developed and used in the field of sexual health [31].

Support during treatment

Participants expressed significant concern about the level of personal support required for their journey through HCV treatment. Minh's individual experience, however, suggested that having a support network while undergoing HCV treatment was not always completely necessary. He was one of two participants in our study with experience of interferon-based HCV treatment. Minh emphasised that he '*never*' spoke to other people living with HCV, let alone other PWID who had undertaken treatment. This emphasis may reflect his previous experiences of stigma and discrimination as an ethnic Vietnamese injector as much as it was an avoidance of individual support. His narrative exemplified a sense of stoicism despite describing his previous treatment experience as difficult:

> *It's hard to tell you 'cause I'm going cold turkey with the heroin too, so it's the same effect from the medication I don't really know much. But before I heard the doctor say it's* [the side effects are] *similar to heroin withdrawal.* (Minh)

In contrast, Percy showed far less assurance in his interview when considering the absence of support during HCV treatment.

> *For me personally, I'd need to be handled a bit with kid gloves I think because of my mental state. Yeah so I don't know if I'm the right even person to answer that question because I don't know how I'm gonna react.* (Percy)

Stewart's views aligned with Percy, stating his belief that there was a definite need for support during treatment for HCV. He reported already regularly communicating with health practitioners at a local primary health care centre for PWID and assumed that workers at this kind of service would be available to support him through his HCV treatment experience.

> *Oh probably at least ring me on a daily basis or something. Especially if they* [health care workers] *know the treatment's intense. So you definitely need support out especially if you don't have family to come check up on you at any time. So I'm looking at all those odds and ends.* (Stewart)

To provide this support, some participants suggested a need for health practitioners to regularly and proactively evaluate their ongoing capacity to adhere to treatment. David emphasised the need for frequent contact — described as a '*facial interaction*' in which a '*conversation*' with the '*pharmacist*' allowed health professionals to be '*more aware of where you are mentally*':

> *From my perspective I need that person to see me consistently whether it's just once every five, 'cause usually from their perspective they're able to take an outside view of actually how you're presenting and how you're travelling … you're actually seeing your provider everyday … you're having a facial interaction, you're actually having a conversation and they're more aware of where you are mentally.* (David)

David continued by suggesting a perceived need for a '*network between myself, my doctor and whoever is giving me the tablets*'. His idea of a '*whole treatment plan*' highlighted good communication between all players involved in the provision of HCV treatment. David articulated the type of information and support he would like:

> *But then you're feeling a bit better so we'll start back on it, so I'm telling you now there's going to be inconsistencies with taking it so you need to do the best way to regulate that and support the person too …* (David)

Some women in our study offered a gendered perspective regarding perceived potential struggles through the system providing new DAA treatment regimens. Maryanne emphasised there were '*more barriers to women*' accessing HCV treatment, especially for mothers with children. She expressed concern about the impacts of any potential side effects on parenting and spoke of how '*treatment can make you feel*' while balancing '*commitments and responsibilities with kids*'. Maryanne also believed that access to formal and informal peer networks was an important source of experiential support throughout treatment, particularly with regards to information provision and sharing.

> *Yeah … peers, people in the know, 'cause nearly everybody I know who uses also has hep C and it's* [HCV treatment] *not really something that people talk about a lot. There's a real lack of awareness I think, but with peers it's more normalised and they really understand about drug use.* (Maryanne)

Strengths and limitations

These data were collected from a cohort of PWID that have developed strong relationships with the research team that have been working with them since 2008.

Following the completion of the study, highly-effective DAAs were made available much sooner than was expected in Australia. As such, our findings reflect a different context to the current situation in Australia. This said, our findings remain relevant to the many contexts where DAAs are not widely accessible to PWID.

Discussion

Highly effective DAAs for the treatment of HCV are being heralded as the potential beginning of HCV elimination, especially in settings in which a range of treatment models are being considered [22]. However, as our data from active PWID show, the availability of DAA medications in and of themselves is not enough to ensure that PWID will come forward for HCV treatment in sufficient numbers to drive elimination.

As we have shown, a system of providing HCV treatment is required that allows clinicians — together with PWID — to develop models of care for the management and treatment of HCV that are innovative, flexible and responsive. There is a need to correct and counter misinformation about the new treatment regimens, and for expanding the models of care on offer beyond tertiary hospital settings. Already this is starting to take shape with outreach clinics operating in primary care settings as well as other welfare and housing services [32]. Our data show some support among PWID for the provision of DAAs through high threshold (daily dosing) and low threshold (monthly dosing) programs in community-based pharmacies. Further, our study revealed a need to implement and deliver various peer driven and other social supports for PWID throughout their HCV treatment journey. Experientially-based peer support can be both formal (such as through programs implemented in HCV treatment settings) and informal (such as through networks of peers and other workers at low threshold services like NSPs) [33].

Further research and programmatic work is required to ensure that services offering the HCV treatment system are available, accessible and patient-centred. If elimination of HCV is a serious ambition of policymakers, service providers and clinicians then attention should be focused on those at highest risk of infection and transmission — active PWID. The development of new HCV treatment programs that enable PWID to access DAAs in settings outside the tertiary hospital are essential. Any hurdles to DAA treatment access will severely undermine the potential to reduce infection incidence and prevalence, and thus the elimination goals established by the World Health Organization [34].

Individual/patient, clinician/provider and systemic barriers to HCV treatment are already well-documented and understood especially in clinical drug treatment settings [35,36]. Our task is to use this knowledge to develop and deliver a range of models of care that work to support and encourage PWID to come forward for HCV treatment now that the new DAA medications are becoming more widely available.

Ethics

The study was approved by the Curtin University human research ethics committee (#HR207/2013).

Authorship statement

The design for the study was developed by MH and PH and further refined with input from CW, KH and SC. Data collection was conducted by KH and PH. The initial manuscript draft by PH, SC and CW was developed from the Honours thesis of KH. Manuscript refinement was made by SG and MH. All authors agreed on the final submitted manuscript.

Conflicts of interest

PH and MH declare investigator-initiated research funding from Gilead Sciences and Abbvie Pharmaceuticals for research not directly connected to this manuscript.

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Provenance and peer review

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.idh.2018.10.006.

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