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## 'Fighting a losing battle': prisoners' perspectives of treatment as prevention for hepatitis C with inadequate primary prevention measures

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### ABSTRACT

Hepatitis C virus (HCV) is a global public health concern. Prisoners are particularly affected, with high prevalence and ongoing HCV transmission. The Surveillance and Treatment of Prisoners with hepatitis C (SToP-C) study is implementing the first trial of HCV treatment as prevention (TasP) in the prison setting, i.e., scaling up treatment at sufficient scale to achieve a preventive effect. This qualitative sub-study sought to explore prisoners' perceptions of feasibility of TasP. Participants were recruited from four correctional centres in New South Wales, Australia, including one women's prison. Thirty-two prisoners with a history of injecting drug use participated in interviews prior to prison-wide HCV treatment scale-up. All participants had been screened for HCV within the previous 6 months; half ( $n=16$ ) had chronic HCV;  $n=2$  were awaiting test results. Concerns regarding prisoner movements (e.g. transferred to another prison, or incarceration-release-incarceration) and perceived subsequent risks for HCV reinfection were consistently raised as a major challenge for TasP elimination efforts. Suggestions for harm reduction measures to assist TasP effectiveness (and reduce risk of re-infection) included education and prison needle syringe programmes. Prisoners remain concerned about long-term effectiveness of TasP efforts without access to effective prevention measures and subsequent risk of (re-)infection.

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### Introduction

Hepatitis C virus (HCV) is a global public health concern, particularly within the prison setting. There is an estimated 15% prevalence of chronic HCV among the world's prison population (Dolan et al., 2016). In Australia, chronic prevalence is similar to the global estimate (Hajarizadeh et al., 2017), with evidence of ongoing high-level HCV transmission (Cunningham et al., 2017).

The high rates of HCV among the prisoner population has been attributed to the mass incarceration of drug users (Dolan et al., 2016; WHO, 2014), as well as acquisitive crimes to support drug use (such as theft) (AIHW, 2015). Prison is routinely considered a 'high risk' setting for HCV (UNODC, 2014; WHO, 2014), due to greater prevalence and increased risk of exposure because of a gap in health care that includes harm reduction measures unavailable to incarcerated injecting drug users (Cunningham et al., 2017; Harkness, Levy, Evans, & Wenke, 2017; Larney et al., 2013; Treloar, McCredie, & Lloyd, 2016). While the number of injecting episodes decreases in the prison setting, the frequency of needle and equipment sharing increases (in the absence of available harm reduction measures), thus making per event probability of transmission much higher among people who inject drugs in prison

(Cunningham et al., 2017). In Scotland, rates of HCV transmission are lower in prison compared with incidence in the community. However, modelling has shown that reducing incidence within the prisoner population will reduce rates of transmission within the community (as the time immediately following release is when HCV transmission is most likely to occur) (Jack et al., 2017).

New treatments, known as direct-acting antivirals (DAAs), are rapidly changing the HCV treatment landscape around the globe (Lam, Jeffers, Younoszai, Fazel, & Younoszi, 2015). DAA regimens are daily oral tablets with minimal side effects and efficacy of greater than 95% (Pawlotsky, 2014). On 1 March 2016, DAAs became widely available under universal health care in Australia (Minister for Health, 2015), for adults with chronic HCV, including those incarcerated, irrespective of liver disease stage, injecting status, or reinfection.

Treatment as prevention (TasP) is an elimination theory which proposes that treatment scale-up at significant levels will provide a preventive effect against new transmissions by reducing the overall pool of infectiousness (Grebely, Matthews, Lloyd, & Dore, 2013). Mathematical modelling has shown that TasP is likely to be an effective elimination strategy in the community (Hickman, De Angelis, Vickerman, Hutchinson, & Martin, 2015),

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in combination with primary prevention programmes including opioid substitution therapy (OST) and access to sterile equipment, such as through needle syringe programmes (NSPs) (Martin, Vickerman, Dore, & Hickman, 2015; Martin et al., 2011). In Australia, all states and territories offer OST in prison, but access is usually strictly limited with eligibility varying across jurisdictions (e.g. OST is only available to female prisoners in Queensland) (AIHW, 2015). Current preventive strategies for the transmission of blood-borne viruses among the prisoner population include bleach, or Fincol (a quaternary amine disinfectant (JASOL, North Ryde, NSW, Australia)). However, there is no evidence indicating Fincol is an effective strategy for decontaminating injecting equipment in real world circumstances for HCV (Doerrbecker et al., 2011). Although bleach is recommended as a *secondary strategy* to NSPs for reducing transmission (Jürgens, Ball, & Verster, 2009; WHO, 2007), there are issues of access within prisons, whereby Fincol or other bleach alternatives may be not readily accessible or feasible in all prisons within Australia (AIHW, 2015) or internationally (Michel et al., 2015; Zurhold & Stöver, 2016). No studies have yet shown the real-world implications of TasP efforts, although some studies are currently underway (Hajarizadeh et al., 2016). The Surveillance and Treatment of Prisoners with hepatitis C (SToP-C) is a trial of HCV TasP in the prison setting, incorporating a surveillance phase to monitor HCV incidence followed by a DAA-based HCV treatment scale-up phase and ongoing surveillance.

Prison needle syringe programmes (PNSPs) are frequently recommended as an optimal harm reduction strategy to reduce transmission of blood-borne viruses in the prison setting among those who inject drugs whilst incarcerated (Harkness et al., 2017; Lines et al., 2006; Stoové, Treloar, Maher, Tyrrell, & Wallace, 2015; Stöver & Hariga, 2016; Zurhold & Stöver, 2016). Only eight countries currently implement PNSPs (all of which are in Europe and Asia) (UNODC, 2014). Canada is in the process of piloting a PNSP with plans for full national roll-out of PNSPs to all their correctional facilities (Correctional Service Canada, 2018). This policy change has been attributed to ongoing litigation from a person who contracted HCV through injecting drug use whilst incarcerated.

Marginalised individuals are often the most affected by policies, yet often have the least opportunity to advocate for their needs or contribute to the development of those policies which most affect them (Gaventa & Cornwall, 2015; Lancaster, Ritter, & Stafford, 2013; Lancaster, Santana, Madden, & Ritter, 2015). People who inject drugs are highly marginalised (AIVL, 2010; Cama, Brener, Wilson, & von Hippel, 2016), with those incarcerated commonly experiencing further stigma and discrimination (Cope, 2000), as well as routine exclusion from any participation in relevant policy discussion. This paper reports on perceptions of prisoners living with or at risk of HCV regarding feasibility of TasP efforts within current harm reduction and prevention strategies in the prison setting.

## Methods

The SToP-C trial is being implemented in four prisons across New South Wales, including one women's facility, and across

all security classifications (minimum, medium, and maximum). This qualitative component recruited eight participants from each of the four participating prisons, with a total of 32 prisoners participating in semi-structured in-depth interviews. Potential participants, i.e., those enrolled in the study and reporting a lifetime history of injecting drug use, were recruited via dedicated study nurses located at each of the facilities, with preliminary verbal consent provided. Participants were then called up to the interview area where the consent form was reviewed before written consent was obtained. The nurses did not retain records of participants who declined to participate in the qualitative component of the study. Interviews were conducted after study enrolment (during the surveillance phase) and before treatment scale-up.

All participants had a history of injecting drug use (i.e. risk of HCV) and had been tested for HCV within the previous 6 months. Participants were asked about current and suggested strategies for HCV prevention, barriers and facilitators to HCV treatment, risks of re-infection, and injecting cultures and networks within the prison setting, as well as demographic questions including age of initiation to injecting drug use and history of HCV. These interviews were completed prior to the HCV treatment scale-up phase of SToP-C to ascertain participants' perceptions and acceptability of TasP within the prison setting.

Interviews were transcribed verbatim and de-identified. Transcripts were coded using NVivo 11 qualitative software. Inductive coding was undertaken to identify emerging themes (Saldaña, 2013). The second round of coding was completed using latent thematic analysis (Braun & Clarke, 2006) to identify the ways in which the data were ascribed to each of the broader themes identified in the first round of coding. When quoted, participants' gender, security classification, and recent HCV test result are noted.

Three research ethics committees provided approval for this sub-study: Justice Health & Forensic Mental Health Network Human Research Ethics Committee (G621/13); Corrective Services Ethics Committee (5 April 2016); and Aboriginal Health and Medical Research Council of NSW Human Research Ethics Committee (1253/17).

## Results

Semi-structured in-depth interviews were completed with 32 participants. Sixteen participants had tested HCV RNA positive (indicating chronic HCV infection) at their most recent test;  $n = 14$  tested RNA negative; and  $n = 2$  were awaiting test results. The average age of participants was 40 years, with women accounting for 25% ( $n = 8$ ) of those interviewed (male mean age: 41; female mean age: 39). The participant cohort is slightly older than the mean age of all inmates (34 years of age; men and women) in custody in NSW at 30 June 2016 (ABS, 2016). Eight male and three female participants had previously undergone interferon-based HCV treatment with cure. One male participant had previously commenced interferon-based treatment but had been unable to complete the therapy due to adverse side effects. Participants had served a median of 4.5 years in prison (men

5.5 years; women 3.5 years) of their current sentence. Half of the cohort was recruited from two maximum security prisons, likely raising the median time served. Participants reported a wide range of injecting histories and time since injection (one participant reported he had not injected in nearly three decades, while another participant disclosed having injected the day prior to interview). The most commonly reported drugs injected whilst incarcerated were methamphetamines, cocaine, and opioid substitution therapies (e.g. Subutex). Fourteen participants were receiving OST while in prison (11 men, 3 women), either methadone ( $n = 12$ ) or buprenorphine ( $n = 2$ ).

The mean age of initiation to injecting drug use was 22 years (men: 19 years old; women: 24 years old). While slightly more than one-third of participants reported currently injecting drugs in prison (men: 33%; women: 38%), this may be under-reported due to participant desire to present a certain 'image' of themselves (Tourangeau, Rips, & Rasinski, 2000), or hesitancy to disclose illicit drug use for fear of implication (despite the interviewer explaining her status as independent of custodial authorities).

A number of concerns were raised by participants regarding the effectiveness of HCV treatment scale-up to achieve prevention effects in the prison setting. Specifically, participants described concerns about risk of HCV reinfection in the absence of primary prevention, such as prison NSPs. Additionally, prisoner movement – whereby new prisoners (either from community or another prison not participating in the study) join injecting networks – was raised as a concern for risk of HCV reinfection. There was a general perception that TasP could not be maintained long-term without additional, complementary harm reduction interventions.

### **Elimination = treatment + prevention**

The elimination of HCV was consistently perceived by participants as an outcome requiring both treatment *and* prevention in efforts to reduce or eliminate transmission among incarcerated people who inject drugs. Participants warned of the inevitability of reinfection, with one participant describing TasP efforts as 'pointless'. Concerns of reinfection were inextricably linked to ongoing risk practices, particularly around injecting drug use.

There's no point getting on [treatment] if you're still going to use drugs, because eventually you're going to contract it back again, so it's just pointless doing it really. (Male, maximum security, HCV negative)

Well a needle exchange would be one way of stopping it [HCV] once everybody's got rid of it. They are talking about eradicating it totally out of the system. I think that's about the only way, with treatment as well. (Male, maximum security, HCV negative)

So this program, what you're trying to do is nulling the numbers down, when really it's sort of just delaying a losing battle. (Male, maximum security, HCV positive)

### **Prison needle syringe programmes (PNSPs)**

PNSPs were the most common recommendation to support TasP efforts. PNSPs were overwhelmingly recommended by

participants as a prevention strategy for reducing transmission of HCV in the prison setting, with one participant describing the lack of provision of NSP as 'negligent'.

Like I say, if they ever do look at the proposal for needle exchange, that's obviously going to help. If guys are not sharing needles, they are not spreading the disease. Its just common sense really, isn't it? (Male, maximum security, HCV positive)

[C]orrections will not even think about it or go there and I think it's negligent of them a bit you know, because, really, the [HCV] virus is spread through jails. (Female, HCV positive)

Support for a PNSP was not uniform, however. One dissenting voice drew upon the argument that such programmes also encourage drug use, while also suggesting that sharing would continue regardless.

I would've said clean syringes, like a syringe program, but that just encourages drug use really in a way. You know the more syringes there are they're going to use them. Still people are going to share, but it will minimize the sort of ... [So what you are saying is that people would still share syringes if there was a needle syringe program?] Yeah. [...] Well rather than coming over to get a new one, if they haven't got one there and there's a shot sitting in front of them and there's three persons there, they're not going to run up and get a new syringe, they'll just use that one. [...] So they're still going to be sharing needles, that's probably just some ongoing thing. It's dealing with human behaviour I suppose, drugs, yeah. (Male, maximum security, HCV negative)

### **Injecting networks and TasP efforts in prison**

The interplay of prisoner movement and the micro-cultures of injecting networks (such as inclusion through long-time associates) were raised as a significant concern for the feasibility of TasP in prison. Participants described concerns regarding prisoner movement resulting in (re-)introduction of HCV into prisons that had already completed treatment. Prisoner movement has been shown to have direct consequences on the transmission of HCV within the prison population (Bretaña et al., 2015). Amid prisoner movement, the absence of prevention strategies was perceived as an inevitable risk of (re-)infection amid a transient population. Injecting culture specific to drug user networks in the prison environment was identified as a risk factor, as network members often share unsterilised injecting equipment (Lafferty, Rance, & Treloar, 2018). The comments from the participants below illustrate the challenges of prisoner movement and the subsequent implications for TasP efforts in the context of reinfection.

A lot of people come through the remand centre, so if someone gets out, gets hep C again and then comes back, it sort of defeats the purpose, you are just going to be chasing your tail, you'll never catch it, you've just got to sort of do what you can. [...] Treatment as prevention, they figure if they can treat everybody, then it stops anybody else getting it. That's not going to happen. It's just pure and simply not going to work. [...] Too many people in and out, in and out. (Male, maximum security, HCV positive)

I know they are trying to eradicate it, but I think that's going to be very, very hard to ... it sort of like needs to go righto, "let's

not even start the program", ... they have to do [treat] the whole system, then start everybody at once you know what I mean? [...] because the boys that are taking tablets [HCV treatment], they're still going to use you know what I mean? No matter what, they're still going to use. So if they've done the course [HCV treatment] and cleared it, then you get someone who comes in and you've known them for years and "oh yeah, how you going mate?" He's got it [HCV] and the next minute, everybody that's already been cleared [treated], they're just all been re-infected and they're all going to start re-infecting themselves you know what I mean, so that's the logistics behind trying to, you know what I mean? (Male, maximum security, HCV negative)

## Discussion

This study explored prisoners' perceptions of TasP in the prison setting. Participants identified multiple challenges of HCV TasP efforts. Prisoner movement was described as a public health barrier to TasP efficacy, as well as the social behaviours of injecting drug use among people who inject drugs in prison. Risks of (re-)infection were attributed to prisoner movement following prison-wide treatment scale-up amid a lack of primary prevention measures, such as PNSPs.

In line with principles of disease elimination provided in the literature (Dowdle, 1998), prisoner participants perceived TasP as unlikely to be effective in the absence of access to harm reduction measures, such as PNSPs. One participant described treatment as 'pointless' for prisoners continuing injecting drug use following treatment completion. This suggests that the perceived likelihood of (re-)exposure may act as a disincentive to access treatment in the first place, thereby further limiting the prospect of a successful TasP intervention. However, scale-up of HCV treatment at the Lotus Glenn Correctional Centre in Far North Queensland, Australia, has decreased HCV prevalence from 12% to 1% despite no increases in access to harm reduction strategies (Bartlett et al., 2018).

The majority of participants were firmly in favour of PNSPs and some argued strongly about the current discrepancy in service provision between community and prison. These findings speak to the value that people who inject drugs place on protecting their health, and to the strong emotional responses that a HCV diagnosis can evoke. In studies conducted in the community and in prison, being diagnosed with HCV can generate feelings of anger, shock and embarrassment (Fraser & Treloar, 2006; Harris, 2009; Treloar, McCredie, & Lloyd, 2015). Such findings further underline prisoners' commitment to and preference for sterile equipment to avoid such exposure.

People at risk of contracting HCV in prison, i.e., prisoners with a history of injecting drug use, identified concerns about treatment scale-up efforts in the absence of harm reduction and prevention measures. Likewise, participants at risk of HCV re-infection provided a number of suggestions for improving treatment scale-up efforts and inhibiting risk of re-infection. The study reflects long-stay prisoner attitudes to HCV TasP regarding its potential futility due to the perceived high likelihood of re-infection. There needs to be reconsideration of policies which affect the health of prisoners (such as

the prevention of blood-borne virus transmission), including a reconsideration of the adequacy of existing prevention measures, particularly in light of current TasP efforts.

This paper focuses on the responses of prisoners regarding feasibility of TasP in the absence of primary prevention measures. It should be noted that a number of additional harm reduction strategies and policy implications not raised by participants would likely hinder HCV transmission in the prison setting and may support TasP efforts. These include reductions of prisoner movement, particularly to/from prisons implementing HCV treatment scale-up, increased access to OST (Dolan et al., 2016; Martin et al., 2015), and drug law reform to reduce the criminalisation and subsequent incarceration of people who inject drugs (Bruggmann & Grebely, 2015; Hughes & Stevens, 2010).

To our knowledge, this is the first exploration of prisoners' perceptions regarding strategies to eliminate HCV in the prison setting in this new DAA era of treatment. It is important to note that SToP-C, the larger study from which this sub-study was conducted, is undertaking efforts to epidemiologically evaluate whether prevention can be achieved through therapeutic intervention (i.e. TasP) in the absence of primary prevention strategies. The research reported on in this paper gives testimony to prisoners' perceptions of proposed health interventions (treatment scale-up sufficient to achieve TasP) which directly affects them. While TasP efforts were valued, participants ultimately perceived such efforts would not be successful long term in the absence of increased harm reduction and prevention measures.

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