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Understanding facilitators and barriers of direct-acting antiviral therapy for hepatitis C virus infection in prison

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Summary

Hepatitis C virus (HCV) infection is a major public health concern. Globally, 15% of those incarcerated are HCV-antibody positive (anti-HCV). Even where HCV treatment is available within prisons, treatment uptake has remained low. This qualitative study was conducted to understand the barriers and facilitators for the delivery of HCV treatment in prisons from the perspectives of prisoners. This is important to inform health messaging for HCV treatment within correctional institutions. Thirty-two prisoners (including eight women) with a history of injecting drug use participated in this qualitative study. Participants were equally recruited across four correctional centres (n = 8 per site). Overall, 16 participants (50%) had chronic HCV at their most recent test, and two participants were awaiting test results at time of interview. Structural (eg proximity of health clinic) and patient-level (routine and motivation) factors were viewed as facilitators of HCV treatment within the prison setting. Structural (eg risk of reinfection) and social (eg lack of confidentiality and lack of social support) factors were perceived as barriers to prison-based HCV care and treatment. In conclusion, to increase HCV treatment uptake, prison-based programmes should implement (or advocate for) patient-centred treatment approaches that protect privacy, provide social support, and promote access to clean needles and substitution therapy to protect prisoners from reinfection.

KEYWORDS
health messaging, hepatitis C, hepatitis C treatment, prison, prisoner health

1 | INTRODUCTION

Hepatitis C virus (HCV) is a major public health concern with 71 million people (1.0% prevalence) having chronic HCV infection globally.[1] HCV is a blood-borne virus (BBV) and, in high-income countries, is predominantly transmitted through sharing of injecting equipment.[2] Recent global estimates suggest that among people who inject drugs (PWID), 52% are anti-HCV positive and 58% have a history of incarceration.[3] Among the Australian prisoner population, 22% of those incarcerated are anti-HCV positive,[4] with 58% of prisoners reporting a lifetime history of injecting drug use.[5] Even where HCV treatment is available within prisons, uptake has traditionally remained low.[6]

Recent therapeutic advances have transformed the management of HCV infection, through direct-acting antivirals (DAAs), which are once daily oral medications with cure rates of 95% or greater, and minimal side effects.[7] DAAs became widely available under universal healthcare within Australia in March 2016 for adults with chronic HCV, irrespective of liver disease progression, incarceration or

Abbreviations: BBV, blood-borne virus; DAAs, direct-acting antivirals; HCV, hepatitis C virus; NSW, New South Wales; OST, opioid substitution therapy; SToP-C, Surveillance and Treatment of Prisoners living with hepatitis C; TasP, treatment as prevention.

injecting drug use.[8] This unrestricted access has afforded the potential to significantly change prevalence and transmission nationwide (both in the community and in the prisons). In addition, due to the short treatment duration (8-12 weeks), DAAs have the capacity to greatly enhance HCV treatment scale-up in the prison setting where prisoner movement (between prisons and to/from the community) is frequent.[9]

For treatment scale-up efforts to be successful, it is necessary to understand prisoners' perceived benefits and barriers to prison-based treatment. Patient, provider, health system, structural, and social barriers and facilitators to HCV treatment in the community have been well documented. At the patient level, barriers can include lack of transport to medical appointments,[10] limited knowledge of HCV treatment, incarceration, unstable or inadequate housing, and family and employment responsibilities.[11-13] Communication difficulties and limited knowledge may limit provider abilities to deliver HCV treatment.[14] Health care systems, including cost of care, can be prohibitive for HCV treatment access in the community, particularly for those experiencing complex issues requiring comprehensive care.[12] Structural barriers may include challenges in navigating health care.[15] Stigma related to injecting drug use and HCV present a common social barrier to HCV care and treatment.[14,16] However, facilitators and barriers to the new DAA treatments in the prison setting have yet to be explored.[17] Knowledge of barriers and facilitators to HCV care for people in prison can inform tailored health messaging to better engage prisoners in testing and treatment.[18]

It is widely recognized that prisoners should have equal access to healthcare in prison as that available in the community. Both international and Australian policies and guidelines stipulate that the human rights of those in custody, particularly in regard to healthcare, should be comparable to rights available in the community.[19-22] However, it has been argued that greater standards of healthcare must be provided in prison to achieve equitable public health outcomes in prison as compared to the community.[23,24] This paper explores prisoners' perspectives of facilitators and barriers to HCV treatment uptake in the prison setting. This is important to inform communication and messaging strategies for HCV treatment scale-up within correctional institutions, ensuring that prisoners receive equitable care to that which is available in the community. In New South Wales (NSW), the prisoner health system is delivered by the Justice Health & Forensic Mental Health Network within the Ministry of Health, while the custodial authority, Corrective Services NSW, is under the jurisdiction of Department of Justice. This allows administrative independence between corrections and justice health, allowing for prisoners' health information, such as HCV and injecting history, to be kept confidential from Corrective Services.

2 | METHODS

Availability of, and access to, DAAs has created an opportunity to assess the feasibility of treatment as prevention (TasP) in prison. Mathematical modelling has shown that treatment scale-up at even moderate levels (4-8/100 PWID per year), in combination with primary prevention programmes, including access to sterile equipment and opioid substitution therapy (OST), has the potential to provide considerable TasP benefit, with declining HCV prevalence and incidence.[25,26] The Surveillance and Treatment of Prisoners living with hepatitis C (SToP-C) study is evaluating the feasibility and effectiveness of TasP across four prisons in New South Wales.

Participants were recruited from the four correctional centres (eight participants from each site) involved in the SToP-C study, including three men's prisons (two maximum and one minimum security) and a women's medium/minimum security prison. Participants were purposely selected to provide comparable representation of those living with HCV and those not currently living with HCV. Research nurses conducted the preliminary recruitment of participants by informing participants of the qualitative study with an offer of enrolment. A list of prisoner identification numbers of those who agreed was provided to the interviewer; names were withheld to ensure anonymity. The interviewer attended each study site where confidential interviews were completed face-to-face in a private room, separate from correctional personnel. Written informed consent was obtained prior to commencing interviews. Participants were able to withdraw from the study at any stage without impacting their involvement in the broader SToP-C study or relationships with any of the organisations directly or indirectly involved in the study (including Corrective Services NSW). Participants were remunerated with AU$10 into their prisoner bank account following completion of the interview as compensation for their time.

All participants reported a history of injecting drug use. Sixteen participants were HCV RNA detectable (meaning they had chronic infection); 14 participants were HCV RNA undetectable (of whom seven had previously completed HCV treatment); and two participants were awaiting results at time of interview. Eleven participants (eight men and three women) had previously completed interferon-based therapy with a sustained virological response (equivalent to cure); three had spontaneously cleared a previous infection. One participant had previously commenced interferon-based therapy but discontinued prior to treatment completion due to adverse effects.

Participants were asked about knowledge of HCV risk, including harm reduction and prevention mechanisms in the correctional setting, perceptions of HCV treatment in prisons and concerns of re-infection following treatment scale-up. This analysis focuses on understanding the perceived barriers and facilitators for the delivery of HCV treatment in prison in contrast to community-based treatment.

Interviews were audio-recorded. Interview transcripts were corrected and then de-identified. QSR NVivo 11 qualitative software was used to code the transcripts. A preliminary coding framework was developed in consultation among the authors and informed by the interview schedule. A second round of coding was completed using latent thematic analysis[27] to identify benefits and barriers to prison and community-based treatment within a health messaging framework grounded in authenticity, developed by Petraglia[28] and contextualized to HCV by Winter and colleagues.[18]

Ethics approvals were sought and obtained from the following research ethics committees: Justice Health & Forensic Mental Health Network (G621/13); Corrective Services NSW (qualitative sub-study approval on 5 April 2016); and Aboriginal Health and Medical Research Council of NSW (1253/17).

Results are presented noting participants' gender, HCV status and treatment history. All previous treatments refer to interferon-based therapies. Participants currently on treatment were receiving DAA therapies through the justice health authority; as at the time of interview, the SToP-C study had not yet commenced the treatment scale-up phase. Participants living with chronic HCV, but not currently receiving treatment, were scheduled to commence treatment in the coming months.

3 | RESULTS

Thirty-two adults in prison with a history of injecting drug use participated in semi-structured in-depth interviews (n = 24 men; n = 8 women). The median age of initiation to injecting drug use was 22 years; the median age at interview was 40 years. Fourteen participants were receiving OST.

Overall, participants indicated support for the notion of accessing HCV treatment in prison. Structural and patient-level factors were viewed as facilitators of HCV care and treatment whilst incarcerated. The prison setting was considered to offer simplicity of access, and individual benefits such as opportunity for self-improvement. Structural and social factors were perceived as barriers to prison-based treatment. The enclosed social setting of prison was perceived to hinder treatment uptake for fear of involuntary disclosure of HCV status to others, particularly within communal injecting networks. Others highlighted community-based treatment as affording opportunity for social support from family while undergoing treatment, as well as better access to prevention measures. HCV reinfection was raised as a concern whereby some participants suggested timing treatment close to the anticipated release date in an attempt to minimize the re-exposure window between HCV cure and release from prison. There were strong similarities among participant responses across gender, security classification and treatment history. Below we present the structural facilitators and barriers to HCV care and treatment in prison, as well as the patient-level facilitators and social barriers as perceived by prisoners either living with HCV or at risk of HCV.

3.1 | Facilitators to prison-based HCV care and treatment

3.1.1 | Structural

Prison-based treatment was perceived to circumvent barriers to HCV treatment which may be encountered in the community, such as distance from health care services and associated transport issues. The "boxed-in" environment of prison was viewed as a facilitator for treatment, with one participant highlighting the loss of his driver's license hindering access to community-based care options.

> You know the clinic is two hundred yards from where we are living and on the outside if you've got to go to the hospital and if you haven't got transport, people just tend not to, because they're running around, so yeah in here, we are a boxed-in environment and you are going to get things happening. (Male, HCV undetectable, previously treated with cure).

> Everything is just close for you in here. You don't have to worry where you're going or how to get there. Like I've lost my license … Where I live … I'm far away from everything, so if I haven't got a car … it takes me an hour to get to the hospital, so that would be the only inconvenience, like transport getting there. (Male, HCV detectable, currently on treatment)

> Because you don't have to go travel all over the countryside to see a nurse or get your blood test, it's all in one place. (Female, HCV detectable, previously treated and since reinfected)

Prison health clinics were viewed as providing on-site and around-the-clock medical support. In this regard, the justice health system provided within the Australian prison environment was perceived as advantageous, countering community-based concerns of distance to clinics, modes of transportation and subsequent barriers to access.

3.1.2 | Patient-level

Patient-level factors seen to enhance treatment uptake in the prison setting, included motivation and time. Participants described incarceration as an opportunity for self-improvement, "to better" oneself, including in relation to HCV treatment. For these prisoners, their sentence was viewed as a facilitator for addressing health issues, enabling people to return to community better—or healthier—than when they went into custody.

> Because you've got access to it [treatment], you don't have to pay for it and you are trying to better yourself. You're trying to make yourself healthy and on the outside, you put things off, you're not in prison. (Male, HCV undetectable, previously treated with cure)

People who experience high rates of recidivism often have complex life circumstances.[29] The characteristics associated with the lifestyles of people in contact with the criminal justice system can be a deterrent

to accessing health care when in the community. Life in the community was described as presenting time-intensive competing priorities, which may not be conducive for accessing or adhering to HCV treatment. By contrast, the removal of community distractions and the availability of downtime in prison were viewed as favourable for prison-based treatment, with some participants highlighting the structured and routine lifestyle within prison as conducive for accessing health care and undergoing HCV treatment.

> Once they're outside a lot of people don't stop to think about that sort of stuff [HCV treatment], it's too much going on out there. (Male, HCV undetectable, previously treated with cure)

> If they are in here, they've got time on their hands so it's easier. … Other responsibilities, then they might have a drug habit on the outside or they might not have accommodation, they've got big problems you know what I mean, so then [treatment's] just on top of that. (Male, HCV detectable, previously treated and since reinfected)

3.2 | Barriers to prison-based HCV care and treatment

3.2.1 | Structural

The high prevalence of HCV among the prisoner population was considered by participants as a barrier to prison-based HCV treatment. Participants reflected on the health risks (ie risk of HCV reinfection) associated with continued drug use following curative HCV treatment. These risks were considered in combination with social and environmental factors of injecting networks and prevention access in the prison setting. There are currently two BBV prevention measures available to prisoners in NSW correctional centres: Fincol, a bleach alternative, and OST.[30] There are no needle syringe programmes available within Australian correctional centres.[31] Other participants suggested timing HCV treatment completion to coincide near the time of release as a strategy for minimizing the period in prison where they may be at risk of reinfection. The participants below suggest that community-based treatment may be more beneficial due to access to clean injecting equipment, thereby reducing risk of reinfection following treatment completion.

> Outside is better… Because girls who have undergone treatment in here, they're going to keep on using aren't they, so they are going to catch it again…. you won't get re-infected outside because you've got the needles, the cleaner needles. (Female, HCV undetectable, treatment naïve)

> I would prefer maybe to wait until I was about to get released from prison that way if I do it [treatment] then, then I get out I haven't got it [HCV] and I'll be more inclined to make sure that I always use clean syringes. (Male, HCV undetectable, treatment naïve)

3.2.2 | Social

Social factors were identified as a barrier for HCV engagement within prisons, with some participants describing the intense scrutiny of other prisoners when accessing the health clinic. This scrutiny may require prisoner-patients to provide an alibi upon return to the yard or cell if they intend to keep their HCV status confidential. This level of surveillance by their peers created a barrier for some participants to come forward for testing and treatment, for fear of unintended disclosure or being "found out," which may lead to exclusion from injecting networks.

> They could be feeling like they are in trouble if they were to come up [to the clinic] and try and do something about it [hep C] anyhow, because they'll be thinking everyone else will find out they've got hep C if they are doing the hep C program and that'll put … they might not be part of that crowd anymore. (Male, awaiting test results, treatment naïve)

Additionally, the absence of familiar social supports while accessing treatment was viewed as another barrier to prison-based HCV treatment by some respondents. Treatment in community settings offered the desired social supports for HCV engagement which were lacking for some participants within the prison setting.

> [*What would be some disadvantages about having treatment in prison?*] Probably the lack of family support, to not have family around you and friends, you know real friends, genuine friends. (Male, HCV detectable, previous treatment without cure)

4 | DISCUSSION

This paper presents prisoners' perceptions of facilitators and barriers to accessing HCV treatment in prison in the context of a treatment as prevention trial. Participants cited practical enablers of treatment access (structural) and personal incentives for treatment (patient-level). However, structural and social issues were flagged as concerns, or barriers, to HCV treatment whilst incarcerated. These included the high prevalence of HCV in prison (which was also deemed as an incentive for accessing treatment whilst in prison) combined with a lack of prevention measures—potentiality resulting in subsequent risk of reinfection following prison-based treatment.

Structural barriers to community-based HCV treatment have included environmental issues of space which inhibit a patient's ability to navigate access to care.[15] In the prison setting, geographic proximity was viewed as favourable for treatment adherence. Research in Dublin has shown that geographic distance can be a barrier to attending health care appointments for HCV treatment.[10] Similarly, a trial in NSW of HCV treatment within opioid substitution treatment services was regarded positively because of its "one-stop shop" approach.[13] Proximity and the "one-stop shop" availability of health care were identified as important aspects of convenient care for people who were incarcerated and who may have complex lifestyles in the community. In the community, people may incur travel costs and fees for doctor's visits, prescriptions and other costs associated with health care. In Australian prisons, these services are offered free of charge.[22] The strong support for prison-based HCV treatment is unsurprising in the context of material circumstances, whereby prisoners have greater access to care within the prison setting compared with the logistical and financial costs (albeit limited) of care in the community.

The routine of the prison setting was viewed as a facilitator for treatment adherence, and conversely, lifestyle within the community was raised as the biggest barrier to HCV treatment outside of prison. Lifestyle and the absence of daily routine have been found to inhibit HCV treatment within the community.[11] Once released, competing priorities may contribute to additional barriers to health care including establishing housing, adhering to parole conditions (and the time involved in attending mandatory meetings), and finding employment.[32] Prisoner entrants have identified costs, transport and distance, commitments, drug use and other barriers to seeking health care in the community during the previous twelve months prior to incarceration.[22]

Participants viewed incarceration as an opportunity for self-improvement, drawing on personal motivation in conjunction with the economic resources (access to free health care) and structural components (proximity and assurance of adherence) readily available within the prison setting. These findings reflect other research which found that people in prison were motivated to access HCV treatment as a gesture of reciprocity to loved ones on the outside[33] and desires to cure their HCV and "make a new start" upon leaving prison (34:9).

Concerns regarding reinfection risk following HCV treatment were identified as a barrier to prison-based treatment. Needle and syringe programmes are a key element of the Australian BBV prevention strategy. However, Australian prison policies currently prohibit needle syringe programmes.[31] Other participants suggested risk of reinfection could be reduced or mitigated for those in prison if they are treated close to their release date (thereby reducing time of injecting drug use following treatment completion prior to release). This suggests ongoing need to educate prisoners about ways to minimize reinfection risk.

Maintaining confidentiality while attending and returning from the prison health clinic for HCV care was identified as a concern which may result in compromised social status for those who do not readily disclose their HCV status. This is consistent with other prison research whereby prisoners have identified concerns of confidentiality as a barrier to HCV testing and treatment.[34,35] Unintentional disclosure of one's HCV status could drive targeted testing for illicit drug use via urine screening, compromise the prisoner's social standing, as well as limit their access to drug user networks in prison.[36]

These results inform the ways in which communication about HCV treatment with prisoners can be enhanced to take account of the prison context and prisoners' understandings and concerns. Health messaging must consider the economic, structural, and social contexts of injecting practices within the prison setting and practical resources available for harm reduction and prevention, without attributing blame.[18] These contexts have been shown to influence risk of HCV transmission among injecting networks in the prison setting.[36] Taken together, the findings presented in this paper suggest opportunities to tailor health messaging[28] which addresses the underlying structural, patient, social and economic circumstances associated with accessing health care in prison compared with those in the community. Prisons considering the scale-up of HCV treatment should highlight the ease of access (proximity) to medical care within correctional facilities; that treatment may be viewed as an opportunity for self-improvement whereby they can cure their HCV prior to release; and the affordability of health care whilst incarcerated (in settings where HCV treatment is affordable and available to prisoners). In the context of injecting networks, messaging could focus on bringing all members of the network forward for testing and treatment as an alternative to clandestine treatment uptake. Future epidemiological research from the SToP-C study will investigate the potential efficacy of TasP in reducing the risk of (re-)infection in prisons. If confirmed, the data would then allow better health messaging regarding participants' concerns of reinfection following HCV cure.

This study has a few limitations which should be noted. This qualitative study was conducted in prison with people with a history of injecting drug use. All participants enrolled in the study were eligible for treatment whilst incarcerated. Participants testing HCV positive were awaiting treatment commencement. As DAA treatment was anticipated to be imminent, both through the study and through standard care, some participants may have exaggerated benefits of prison-based treatment due to social desirability response bias[37]; that is, they may have felt it was in their interest to describe facilitators for treatment in prison. This study examined prisoners' perspectives of HCV treatment in the existing criminal justice system. Broader analysis, which is beyond the scope of this paper, would include perspectives of decriminalisation of drug use and alternatives for incarceration for drug-related crimes.

5 | CONCLUSION

The data reported in this manuscript can inform authentic health messaging about HCV treatment, including dialogue about treatment considerations in ways which are meaningful to people in prison. This qualitative study identified prisoners' perceived facilitators and

barriers to HCV treatment within a clinical trial (SToP-C) designed to ascertain efficacy of TasP for HCV in the prison setting. Our findings provide insights into valuable health messaging which may reduce barriers and further promote HCV treatment uptake among prisoners in the SToP-C trial, and more broadly in the prison setting. Additionally, correctional health care staff should work with prisoners to mitigate incidental disclosure of HCV status following clinic attendance.

While prison may be an opportune time to deliver HCV treatment from a public health perspective, the participants in this study provided insights to barriers which may undermine these goals/efforts, such as ongoing risks of re-infection in the prison setting. However, the findings presented in this paper suggest that people in prison living with HCV, or at risk of HCV, are responsive and agreeable to HCV treatment whilst incarcerated and that prison-based treatment offers opportunities for self-improvement.

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CONFLICT OF INTERESTS

LL, JR and CT have no conflicts of interest. JG is a consultant/advisor and has received research grants from AbbVie, Bristol-Myers Squibb, Cepheid, Gilead Sciences and Merck/MSD. ARL is a consultant/advisor and has received research grants from AbbVie, Bristol-Myers Squibb, Gilead and Merck/MSD. GJD is a consultant/advisor and has received research grants from AbbVie, Bristol-Myers Squibb, Cepheid, Gilead and Merck/MSD.

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