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Commentary

Priorities and recommended actions for how researchers, practitioners, policy makers, and the affected community can work together to improve access to hepatitis C care for people who use drugs

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ABSTRACT

It is estimated that 6.1 million people with recent injecting drug use (PWID) are living with hepatitis C virus (HCV). Although HCV-related morbidity and mortality among PWID continues to increase, the advent of direct acting antiviral (DAA) HCV regimens with cure rates > 95% provides an opportunity to reverse the rising burden of disease. Additionally, given evidence that opioid substitution therapy and high-coverage needle and syringe programs can reduce HCV incidence by up to 80%, there is an opportunity to reduce HCV transmission with increased coverage of harm reduction services. However, there are significant patient, provider, health system, structural, and societal barriers that impede access to HCV prevention and care for PWID. The International Network on Hepatitis in Substance Users (INHSU), in collaboration with the Australasian Society for HIV, Viral Hepatitis, Sexual Health Medicine (ASHM), Harm Reduction International, the Canadian Network on Hepatitis C, Canadian Research Initiative in Substance Misuse, the National Viral Hepatitis Roundtable, Médecins du Monde and CATIE, held a roundtable discussion prior to the Harm Reduction Conference in Montreal, Canada on 13th May 2017 to discuss how to improve HCV prevention and care for PWID. Over 100 international researchers, practitioners, policy makers, advocates, and affected community members came together to discuss shared priorities for action, develop actionable next steps and to create partnerships to enable application of priorities. This paper highlights the key priority areas identified by participants including: enhancing global coverage of harm reduction services; addressing punitive drug policies; ensuring access to affordable HCV diagnostics and treatment; improving the evidence-base for HCV prevention, testing, linkage to care and treatment; implementing integrated HCV programs; advancing peer-based models of HCV care; and tackling social determinants of health inequalities for PWID. This paper also highlights the recommended actions for each priority identified by the participants from this roundtable.

Introduction

It is estimated that 71.1 million people are living with chronic hepatitis C virus (HCV) infection globally (The Polaris Observatory, 2017), including an estimated 6.1 million people with recent injecting drug use, representing 8.5% of people living with HCV (Degenhardt

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et al., 2017; Grebely et al., 2018). There is also a large, but unquantified, number of chronic HCV infections among people with a history of injecting drug use (PWID) (Hajarizadeh, Grebely, & Dore, 2013). Due to an aging population and low treatment uptake, HCV-related morbidity and mortality among PWID continues to increase (Hajarizadeh et al., 2013). However, with the advent of direct acting antiviral (DAA) HCV regimens with cure rates > 95%, there is potential to reverse the rising burden of disease (Dore & Feld, 2015).

In 2015, there were 1.7 million new HCV infections globally, with 23% occurring among PWID (WHO, 2017b). Given evidence that opioid substitution therapy (OST) and high-coverage needle and syringe programs (NSP) (adequate needles/syringes to cover all injecting episodes) can reduce HCV incidence by up to 80% (Degenhardt et al., 2010; Hagan, Pouget, & Des Jarlais, 2011; MacArthur et al., 2014; Platt et al., 2016; Turner et al., 2011; van den Berg et al., 2007), there is an opportunity to reduce the transmission of HCV infection with increased coverage of harm reduction services.

The World Health Organization (WHO) has set an ambitious goal to eliminate HCV as a major global health threat by 2030 (WHO, 2017a). WHO targets include reducing new HCV infections by 80%, reducing the number of HCV deaths by 65%, increasing HCV diagnoses from < 20% to 90%, and increasing the number of eligible persons receiving HCV treatment from < 10% to 80% (WHO, 2017a). Given an estimated 39% of PWID globally are living with HCV (Grebely et al., 2018), it is critical to focus on enhancing prevention, testing, linkage to care and treatment for PWID to achieve the WHO goals. However, there are significant patient, provider, health system, structural, and societal barriers (Grebely, Oser, Taylor, & Dore, 2013; Harris & Rhodes, 2013; Wolfe et al., 2015) that impede access to HCV prevention and care for PWID (Alavi et al., 2014; Iversen et al., 2014, 2017).

The International Network on Hepatitis in Substance Users (INHSU) is an international organization dedicated to scientific knowledge exchange, knowledge translation, and advocacy focused on hepatitis C prevention and care among people who use drugs. In collaboration with the Australasian Society for HIV, Viral Hepatitis, Sexual Health Medicine (ASHM), Harm Reduction International, the Canadian Network on Hepatitis C, Canadian Research Initiative in Substance Misuse, the National Viral Hepatitis Roundtable, Médecins du Monde and CATIE, INHSU held a roundtable discussion prior to the Harm Reduction Conference in Montreal, Canada on 13th May 2017 to discuss how to improve HCV prevention, testing, linkage to care and treatment for PWID.

This roundtable discussion was held as part of a Symposium entitled "Integrating care for drug use and HCV infection among people who inject drugs" which included plenary presentations based on the themes "Linkage to HCV prevention and care in drug and alcohol settings" and "Key components of successful models of HCV care for people who inject drugs" (see Supplementary Materials for the Program). Following these presentations, over 100 international researchers, practitioners, program managers, harm reduction experts, policy makers, advocates, and affected community members came together in roundtable discussions to identify key priority areas from the morning sessions. Meeting participants were then organized into multi-stakeholder groups to discuss and develop actions for each priority area (see Supplementary materials for the Roundtable Discussion Guide).

The seven key priority areas for improving HCV care for PWID identified by meeting participants were; enhancing global coverage of harm reduction services; addressing punitive drug policies and criminalization of drug use; ensuring access to affordable HCV diagnostics and treatment; improving the evidence-base for HCV prevention, testing, linkage to care and treatment; implementing integrated HCV prevention and care programs; advancing peer-based models of HCV care; and tackling social determinants of health inequalities for PWID.

This paper highlights the challenges faced in each priority area (including a literature review of evidence to provide context for each priority area) and potential recommended actions to address these barriers. This paper is novel in that it is informed by roundtable discussions between a wide range of stakeholders, summarizes the key priorities and recommendations developed through those roundtable discussions, and seeks to facilitate knowledge transfer; capturing and distributing knowledge to ensure its availability for future users.

Enhancing global coverage of harm reduction services

OST is effective for the management of opioid dependence (Mattick, Breen, Kimber, & Davoli, 2014; Mattick, Breen, Kimber, & Davoli, 2009) and has been shown to prevent HCV infections (Platt et al., 2018). A combination of OST and high coverage needle and syringe programs (NSP) can substantially reduce HCV incidence (Platt et al., 2018). NSP and OST coverage varies greatly between countries (Larney et al., 2017). There are many settings with good harm reduction services, including moderate or high coverage of both OST and NSP. However, according to WHO indicators (< 100 needle-syringes distributed per PWID per year; < 20 OST recipients per PWID per year), coverage is most often low and less than 1% of PWID live in countries with high coverage NSP and OST (Larney et al., 2017).

Low-threshold, comprehensive harm reduction services provide an opportunity to access health care in an environment that is targeted, tailored, supportive and trusted (Grebely, Dore, Morin, Rockstroh, & Klein, 2017; Harris, Rhodes, & Martin, 2013; Treloar, Rance, & Group, 2014). In many settings, people who inject drugs may not engage in care due to previous stigma and discrimination from providers through past encounters with the health system (Calabrese et al., 2016; Guise, Rhodes, Ndimbii, Ayon, & Nnaji, 2016; Harris & Rhodes, 2013; Heath et al., 2016; McCutcheon & Morrison, 2014; McKnight et al., 2017; Terlikbayeva et al., 2013; Wilson, Brener, Mao, & Treloar, 2014). In a study from Thailand, 26% of PWID reported avoiding health services, with verbal abuse, having been refused medical care, and having experienced previous barriers to accessing health care as major reasons for avoidance of healthcare (Heath et al., 2016). By embedding HCV care into existing harm reduction frameworks where PWID are already accessing services (such as programs dispensing OST, NSPs, and supervised drug consumption rooms), a greater number of people accessing these services are likely to be linked into care (Grebely, Dore et al., 2017). The expansion of services offering harm reduction (including overdose prevention) to improve the health of people who inject drugs is critical, particularly given the increase in deaths due to opioid overdose that have been observed in countries such as Canada and the United States (Fischer, Vojtila, & Rehm, 2018; Jalal et al., 2018). However, this comprehensive service approach relies on increased implementation of harm reduction services globally.

Priorities for action include:

1 Increase advocacy work, particularly focusing on addressing stigma and discrimination against PWID within health care settings and in the broader community;
2 Advocate for governments and funders to increase financial support of harm reduction services (including overdose prevention);
3 When implementing harm reduction services, provide education to practitioners on best practices for ensuring dignity and respect for service users.

Addressing drug policies and criminalization of drug use

Punitive drug policies and criminalization of drug use have many unintended implications for HCV prevention and linkage to care for PWID (Csete et al., 2016; Wolfe, Carrieri, & Shepard, 2010; Wood et al., 2010). Punitive drug law enforcement not only inhibits access to harm reduction services, such as NSPs, through fear of arrest but also increases the number of PWID in prison where the incidence of HCV infection is high and access to OST, NSP and HCV treatment is largely non-existent (Champion et al., 2004; Cunningham et al., 2017; Dolan

et al., 2016; Larney et al., 2013). If PWID do not fear risk of arrest or stigma they are more likely to access health care, including HCV prevention, care and treatment (Dolan et al., 2016). However, it is critical to acknowledge different legal, political, social and cultural circumstances with respect to drug policy globally (Csete et al., 2016; Lancaster & Ritter, 2014; Ritter, Livingston, Chalmers, Berends, & Reuter, 2016; Stevens & Zampini, 2018). Irrespective of these global differences, strategies to enhance HCV elimination and improve drug user health will require changes in drug policy to facilitate enhanced prevention (both for HCV and overdose) and treatment (for HCV and drug dependency more broadly) (Grebely, Dore et al., 2017).

Priorities for action include:

1 Countries should consider drug policy reforms, including the decriminalization of non-violent drug offenses such as drug use and/or possession, and provide alternatives to imprisonment for PWID;
2 Countries should develop policies and laws that decriminalize the use, possession and distribution of sterile needles/syringes (thereby permitting NSP programmes);
3 Countries should reduce barriers to, and stigma around the delivery of OST and overdose prevention (e.g. naloxone) for people who are opioid-dependent in the community and prison.

Ensuring access to affordable HCV diagnostics and treatment

The implementation of effective, wide-spread, HCV awareness and care programs relies on access to affordable diagnostics and treatment. Currently, only a small fraction of patients have access to treatment globally, and high prices of HCV diagnostic tests and DAAs are identified by communities as a major barrier to HCV care (Treatment Action Group, 2015).

There is a need to ensure broader access to a variety of HCV testing and diagnosis platforms which may offer low-cost solutions (including dried blood spot testing, HCV core antigen testing, rapid diagnostic HCV antibody testing, and finger-stick HCV RNA assays) (Grebely, Applegate, Cunningham, & Feld, 2017).

High list prices of DAA therapy have led to treatment restrictions set by governments and insurance companies (Barua et al., 2015; Marshall et al., 2018a; Ooka, Connolly, & Lim, 2017). However, prices for DAA therapies in many countries have reduced substantially, due to competition between pharmaceutical companies, payer negotiations and greater access to generic therapies, thus facilitating broader access to DAA treatment (Marshall et al., 2018a, 2018b).

Actions to increase the number of HCV care programs through affordable diagnostics and treatment include:

1 Focus on further simplification of diagnostics to reduce the number of HCV tests required to diagnose chronic HCV infection and facilitate treatment scale-up globally;
2 Ensure broader access to a variety of HCV testing and diagnosis platforms which may offer low-price solutions;
3 Ensure access to affordable treatment by negotiating lower prices for DAAs or using Trade-Related Aspects of Intellectual Property Rights (TRIPS) flexibilities such as compulsory licenses to allow procurement of low cost generic DAAs (Treatment Action Group, 2015).

Implementation of integrated HCV prevention and care programs

Testing, diagnosis and treatment for HCV infection remains suboptimal globally (Bruggmann et al., 2014; Lazarus, Sperle, Spina, & Rockstroh, 2016; Liakina et al., 2015; Saraswat et al., 2015). Efforts to improve this will require models of care that address specific components of the HCV care cascade.

A model of care broadly describes the way that health services are delivered. It includes “where” services are offered, “what” services are offered, “who” delivers the services, and “how” these services are delivered. For HCV care among PWID, this includes the setting where services are offered, which can include tertiary-care hospital-based clinics, drug treatment services, community health centres, general practice or primary care practices, prisons, needle and syringe programmes, supervised consumption rooms, pharmacies and others [7]. The range of services offered within a specific model of care can include testing for HCV and other infections (either on-site or offering testing with off-site referral), liver disease assessment, HCV assessment by a practitioner, and DAA treatment. A model of care might offer specific components of the cascade (with partnering and referral to other services) or will provide all services as “one-stop-shop”. Who delivers services can vary, depending on the complexity and training required for an assessment, with task-shifting considered where appropriate. How these services are then delivered defines the model of care.

A significant component of successful HCV models of care is the concept of meeting people where they are. Integrating HCV care into settings where PWID are already accessing services is important (Bruggmann & Litwin, 2013). Such arrangements build trust through a non-judgmental approach and can alleviate pressure on the healthcare system by providing co-located interventions.

Actions to increase the number of integrated HCV prevention and care programs include:

1 Expand knowledge exchange and dissemination of research on integrated care models to enhance care for PWID (not just HCV), including models in low and middle-income countries (e. g. create conferences that incorporate multiple stakeholders, create a centralised list of agencies implementing successful models, create an online repository for sharing successful HCV education materials, advocacy projects, briefings, and research);
2 Make health services available, accessible and acceptable to PWID, based on the principles of medical ethics, avoidance of stigma, non-discrimination and the right to health (United Nations Office on Drugs & Crime, 2017);
3 Ensure service coverage estimates include: OST, NSP, HIV testing, linkage to care, and treatment (cascade of care) and HCV testing, linkage to care, and treatment (cascade of care);
4 Build national multidisciplinary working groups to bridge siloes and develop a virtual community of providers able to share best practice;
5 Educate and empower community-based practitioners to provide HCV treatment in a range of settings where PWID access services (including primary care, drug treatment, NSP, supervised drug consumption rooms, homelessness services, prisons);
6 Improve data collection and dissemination on successful programs that can be used to drive policy change and increase funding for integrated programs.

Advancing peer-based models of care

There are examples in the literature of the fundamental role that peer workers play in the ongoing support of people prior to, during and following DAA treatment. Peer workers utilize their lived experience to inform their work and peer-based models of care receive a high level of patient acceptability and can be an effective way of creating trust between services, healthcare providers and patients (Alavi et al., 2013; Crawford & Bath, 2013; Grebely et al., 2010; Keats et al., 2015; Mason et al., 2017; Musgrove, 2011; Norman et al., 2008; Rance & Treloar, 2012; Roose, Cockerham-Colas, Soloway, Batchelder, & Litwin, 2014; Stein et al., 2012; Sylvestre & Zweben, 2007; Treloar et al., 2015). However, the literature in this area is still emerging and some challenges have been identified as to the successful implementation of peer worker programs.

There has been discussion in the literature about what constitutes a peer and the degree of control a peer or a peer organization has over the design and implementation of a peer support program (Crawford & Bath, 2013). In research evaluating a trial of peer supported HCV

treatment, led by a peer organisation, what appeared important in the definition of "peer" was that clients of the service recognized the peer worker as being in the "same predicament", even with acknowledgement that "everybody who's a user or, or whatever, don't have exactly the same stories, but there's that camaraderie, and just that no judgment" (Treloar et al., 2015).

While it is important to focus on what facilitates effective relationships between clients and peer workers/peer supporters, research from the UK demonstrates limitations on peer work imposed by the organizational environment (Bonnington & Harris, 2017). For example, services may offer limited support to the peer worker program and drug and alcohol services which operate within recovery or abstinence frameworks, may place limitations on who can be a peer worker.

Conversely, other programs have demonstrated ways in which clients can transition to peer workers and outlined the aspects of the organizational environment required to achieve this transition (Tookey et al., 2018). Despite these examples, the impetus of DAA treatment and the health benefits to be gained for people who inject drugs requires new and innovative models of peer support that add value to existing models of care (Henderson, Madden, & Kelsall, 2017).

Actions to strengthen peer-based models of care to improve access to HCV care include:

1. Increase financial support from governments and funders for peer-based programs, and protect funding for such programmes;
2. Develop and share a series of data collection tools/guidelines to facilitate the evaluation of peer support models;
3. Develop and share a robust peer worker training program;
4. Remove criminal record checks as a requirement for hiring peers to work in health services;
5. Establish a directory of services successfully integrating peer-based models into their strategic framework as a point for networking and knowledge exchange.

Improving the evidence-base for HCV prevention, testing, linkage to care, and treatment

An expanded evidence-base has considerably improved prevention, care and treatment of HCV infection among PWID (Grebely, Bruneau et al., 2017). Over the past decade, knowledge of the epidemiology of injecting drug use, HCV, and HIV among PWID has increased, including updated global estimates (Degenhardt et al., 2017). There have also been a number of systematic reviews that have enhanced the evidence base regarding strategies effective for HCV prevention (Hagan et al., 2011; Platt et al., 2018), linkage to HCV care and treatment for PWID (Bajis et al., 2017) and DAA outcomes among PWID (Hajarizadeh et al., 2018). However, further research is needed on the optimal strategies to enhance HCV prevention, testing, linkage to care and treatment. Lastly, although there are data on HCV reinfection following HCV treatment among PWID (Aspinall et al., 2013; Cunningham, Applegate, Lloyd, Dore, & Grebely, 2015; Simmons, Saleem, Hill, Riley, & Cooke, 2016), further research is needed to define the long-term risk of HCV re-infection and factors associated with HCV reinfection (to inform re-infection prevention strategies).

Unfortunately, there are many gaps in knowledge that represent barriers to effective prevention and management of HCV among PWID. These research gaps and future research priorities have been recently highlighted in a review on behalf of the International Network on Hepatitis in Substance Users (Grebely, Bruneau et al., 2017).

Challenges to gathering quality data persist, including a lack of standardization, inconsistent indicators, and limitations in terms of how much/what information to collect. The rapid pace of diagnostic and DAA development requires that novel interventions and models of care need to be evaluated more quickly. This has made it challenging to conduct randomized studies to assess the effectiveness of new interventions to enhance testing, linkage to care and treatment. Also, there is a greater emphasis on ensuring that novel interventions and models of care are scalable, can be readily integrated into clinical practice, and will lead to improved patient outcomes (Barker, Reid, & Schall, 2016). This has led to a greater need for implementation research which includes both social science research and involvement of community.

Social research, especially qualitative research, is recommended for complex interventions in both randomized controlled trials (Craig et al., 2008) and in implementation studies (Peters, Adam, Alonge, Agyepong, & Tran, 2013) to understand how models of HCV testing, linkage to care and treatment can be optimised. Inclusion of social scientists in evaluating new models of care should be standard.

A further gap in current research is the routine involvement of PWID in evaluation research. There is growing recognition of the importance of community involvement in the preparation, execution and translation of research (Shippee et al., 2015). This recognition posits that community involvement is a means to produce research findings that are relevant to the community's concerns and priorities and to support policy of practice change that is informed, realistic and effective (United Nations Office on Drugs & Crime, 2017). Statements have been produced by national and international drug user organisations to highlight the ethical imperative to involvement of people who use drugs in research (Australian Injecting & Illicit Drug Users League, 2002; Jürgens, 2008).

While a multi-disciplinary research team, including involvement of peers, should be considered as the gold standard for evaluation or implementation research, this may not be achievable in limited resource settings resulting in an inability to appropriate evaluate models of care. This could be addressed by partnerships between research teams and drug user organisations to enhance understanding of the acceptability, impact and scalability of the new model of care.

Actions to improve the evidence-base for HCV epidemiology, prevention and care among PWID include:

1 Ensure up to date population size estimates include the following criteria; people with a history of injecting drug use, people with recent injecting drug use (with clear definitions of what defines "recent"), and prevalence and incidence of HIV, HCV (including RNA testing), and hepatitis B virus (HBV);
2 Facilitate partnerships to foster research collaborations through multi stakeholder groups, including greater involvement of people with lived experience of HCV in research design and implementation and utilization;
3 Raise awareness about the importance of data in supporting advocacy efforts; work to develop policy briefs to accompany research outputs; develop a research paper highlighting population definitions, key indicators and best practices in reporting; and conduct research studies with real-world data that can offer capacity building with service providers and community.

Tackling power structures and social determinants of health inequalities for PWID

The WHO defines the social determinants of health as the conditions in which people live, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices (Solar & Irwin, 2006). The criminalisation of drug use and subsequent experience of prohibition and policing by people who use drugs (Wolfe et al., 2010; Wood et al., 2010) has resulted in an oppressed and marginalised community disproportionally affected by several health and mental health conditions, including HCV.

Drug law reform should be a key advocacy plank of the international community involved in promoting HCV care and treatment. Within that, it is important to understand the ways in which the globally punitive approach to people who use drugs shapes and interrupts daily life and imagined futures. The structural violence towards people

who use drugs embedded within systems such as housing (Bourgois, 1998), policing (Sarang, Rhodes, Sheon, & Page, 2010) and in drug treatment (Crawford, 2013), even in liberal democracies (Treloar & Valentine, 2013), have been well documented. These are deep-rooted systems that are difficult for HCV practitioners to effectively challenge and change. This does not mean that no action can or should be taken by this global network. Attention should be paid to the systems available that can be influenced to redesign systems to be more accessible and appealing for people who inject drugs.

Actions for addressing social factors leading to health inequities relating to HCV in PWID include:

1 Ensure meaningful engagement of people with lived experience of HCV and drug use in conferences and education programs; advocate for people with less power/social privilege to be at the decision-making table, on the committee, at the conference, on the speakers' panel;
2 Support community-led alternate systems/structures/programs/groups, examples include: buyer's clubs, non-formalized needle exchanges and overdose prevention activities, non-institutionalized peer support.

Conclusion

The WHO target to eliminate HCV as a major global public health threat by 2030 is ambitious. Given the considerable burden of HCV infection among PWID, people who inject drugs must be a critical partner in achieving global HCV elimination. Any efforts to address HCV elimination will require improvements in health services for people who use drugs, including OST and NSP, addressing punitive drug policies, and tackling the social determinants that lead to health inequities for PWID.

Although there are many successful models and interventions to enhance HCV testing, linkage to care, and treatment, further work is needed to adapt models and interventions built for the interferon-era to the interferon-free era. Simplifying existing models will be crucial to achieve broader scale-up, particularly in resource-limited settings. Also, further recognition is needed of the considerable knowledge and lived experience of PWID in engaging people in HCV testing and care. Collectively, there needs to be greater knowledge exchange of successful models, interventions, and strategies to enhance HCV care for PWID.

This paper summarizes a roundtable discussion among researchers, practitioners, policy makers, program managers, harm reduction experts, advocates, and the affected community to develop shared priorities for action to improve access to HCV care for PWID. This knowledge transfer process will be important for informing the planning of potential activities by a variety of stakeholders, including the International Network on Hepatitis in Substance Users.

Although DAA therapy provides an opportunity to reduce the burden of HCV-related liver disease through curative treatment, it is only through partnerships, sharing of information and creation of joint priorities for action that we will improve access to HCV care and achieve the WHO targets to eliminate HCV as a major global public health problem.

Contributors

Emma Day, Tina Broder, Sally Cruse, Melisa Dickie, Suzanne Fish, Jason Grebely contributed to the commentary concept. Emma Day and Jason Grebely wrote the first draft of the commentary. All authors contributed to the writing and review of the commentary.

Declaration of interests

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.drugpo.2019.01.012.

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