Hepatitis C stigma and discrimination in prisons

Stigma is when a person or a group of people is judged negatively because of a characteristic they possess, or are assumed to possess. Discrimination often follows stigma, when the person is treated differently because of this negative judgement.

When considering the stigma that can arise in a prison-based hepatitis C program, it's important to recognise several intersecting characteristics that can be sources of stigma:

- Stigma regarding having hepatitis C: it's a serious, transmissible infection which others may fear acquiring.
- Stigma regarding injection drug use: hepatitis C can be transmitted through injection drug use, and poor community understanding about substance use disorders can lead to negative moral judgements about the character of people who inject drugs.
- Stigma associated with incarceration: there is stigma associated with spending time in prison.
- Stigma associated with other attributes or experiences: there is stigma associated with other characteristics such as experiencing poverty, being gender and sexuality diverse or being from a culturally and linguistically diverse background.

Internalised stigma may also impact people in prison. This happens when social attitudes about these groups become part of a person's understanding of themselves and their sense of self-worth.

Taken together these aspects of stigma can make it harder for someone to put themselves forward for care, and can create barriers to getting access to the services people need.

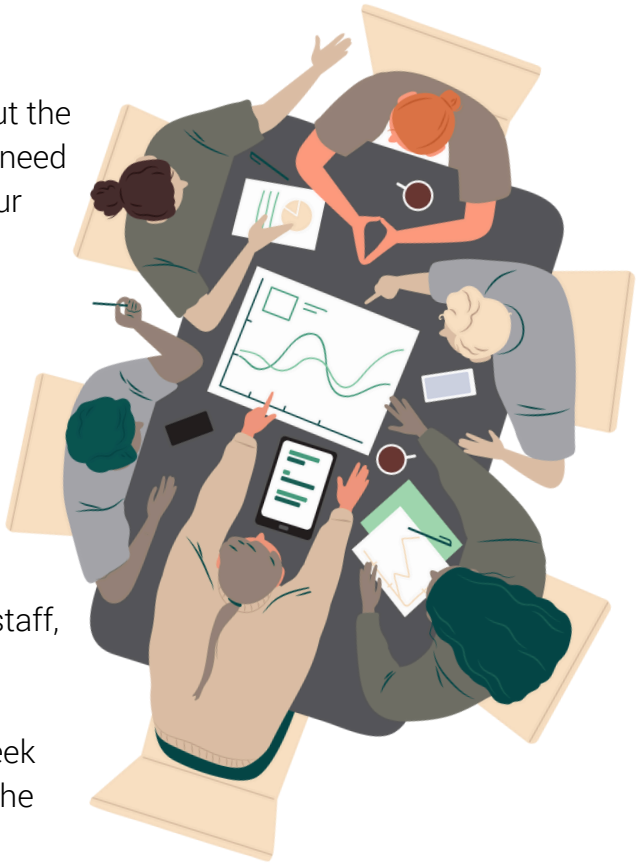
> *The thing that we also did was to do with the stigma and discrimination. So that's also between inmates and guards. So everybody's stigmatizing a patient, but that happens outside in this society too, it's the same thing. But it could be a little bit rougher in the prison setting. So we have witnessed people getting the positive test, and then they were kicked out from the cell, because the inmates, they did not want them there. Or they had to sleep [on] the floor...*
> *- Interview participant, high income country*
> *Walker et al. 2024*

The effect on advocacy

When advocating for hepatitis C programs in prison, you may encounter some stigmatising beliefs. For example:

- There may be a reluctance to offer healthcare to people in prison, believing that they should experience hardship in prison due to the crimes they committed
- Decision-makers may want to make hepatitis C treatment conditional on a person abstaining from injection drug use, even though this is not a prerequisite as treatments remain highly effective regardless of abstinence and people should not be precluded from accessing healthcare due to drug use
- Getting support for provision of harm reduction services such as opioid agonist treatment or needle and syringe programs can be challenging because they may be perceived as 'enabling' injecting drug use

Advocates may experience resistance without explanation but the underlying cause may be these stigmatising beliefs. You will need to be able to identify these beliefs and respond to them in your advocacy work.



The effect of stigma in prisons

Inside prisons, stigma and discrimination associated with hepatitis C is prevalent , and this can be a barrier to treatment initiation for people in prison. For example, having hepatitis C may mark individuals as injection drug users leading to consequences such as social isolation from other people in prison, additional disciplinary attention from staff, and/or potential for targeted drug screening. Individuals who experience stigma and discrimination, or are worried about stigma, can feel that it is too risky or potentially harmful to seek hepatitis C care. Consequently, individuals may miss out on the opportunity for testing and treatment during incarceration.

In addition, healthcare and custodial staff may have negative attitudes towards people who inject drugs. They may also question whether people in prison deserve access to testing and treatment, and may hinder access to health care services during incarceration. Finally, custodial staff may also be fearful of acquiring hepatitis C at work and the risk this may pose to them and their families.

Overcoming stigma and discrimination

Addressing stigma and discrimination starts with education. Education should seek to address all areas of stigma, covering topics such as:

- The facts about hepatitis C transmission in prison
- The importance of testing, treatment and prevention in prison
- The nature of substance use disorder and injection drug use in prison

Incarceration or participation in drug use should not be a reason to deny people health care. People in prison have a right to health care which is equivalent to that in the community.

All stakeholders at all levels of the sector should be targeted for education, including people in prison, healthcare and custodial staff, as well as organisational, departmental, and ministerial staff. By addressing each area, you can help to inform stakeholders and overcome the judgements that lead to stigma.

Understanding hepatitus C in prison

People tend to fear transmission of hepatitis C virus, and this leads to stigma. It is important to educate people on various routes of transmission (not only through sharing injecting equipment but also through fights involving blood, sharing tattooing equipment, toothbrushes, razors etc), noting that there is no risk unless blood is present. While there is no risk of acquiring the virus by simply sharing a living space with a person with hepatitis C infection, or by interacting with them in everyday life in the community, the high prevalence of hepatitis C infection, the crowded physical environment and the sometimes violent interactions in the prisons makes them high-risk environments. This highlights the importance of having both staff workers and people in prison on board with testing, treatment, and prevention in prisons.

Education should emphasise safe injecting practices as well as information regarding hepatitis C, namely that treatment is simple and effective. If a person does acquire hepatitis C infection, it can be treated and cured.

Understanding substance use disorders

There are many reasons why people start and continue to inject drugs, and common societal judgments tend to question why the person does not 'try harder', suggesting that it is a matter of choice, intention or willpower. Individuals may continue to inject drugs due to the complex interplay of social factors, mental health issues, the management of physical or emotional pain, lack of access to effective treatment and support services or personal choice regarding their own drug use. Overcoming stakeholder resistance to the idea of a prison-based hepatitis C program may mean addressing a lack of understanding about why people continue to inject drugs, or you may find that some people want to insist on abstinence as a condition for entry into the hepatitis C treatment program.

It is important to emphasise that hepatitis C treatment is equally effective irrespective of whether a person is currently using injecting drugs, and there are no drug interactions with the antiviral medications that would require abstinence as a condition. People can also be retreated many times with DAAs if they become reinfected.

Harm reduction approaches can complement a hepatitis C treatment program. These approaches seek to minimise the associated harms by:

- Providing safer alternative drugs to reduce injection drug use – such as opioid agonist treatments like methadone or buprenorphine
- Providing easy access to sterile injecting equipment to reduce sharing – through prison needle and syringe programs

When you can educate stakeholders on the reality of substance use disorders, it is possible to move past the 'right and wrong' judgements associated with injection drug use, and move towards a non-judgmental and rights-based approach that reduces stigma.

Treating hepatitis C in prisons

The stigma of incarceration has many layers, but when considering advocacy, one attitude you may encounter is a resistance to spending money on services for people in prison, rooted in the belief that they do not deserve such 'special treatment'.

Far from being 'special treatment', the time spent in prison provides an opportunity to reach a group of people who have far higher rates of hepatitis C infection, and typically have far less access to healthcare outside prison. It's an opportunity to provide treatment in a structured environment where the person can complete a course of treatment that lasts 8-12 weeks and has a greater than 95% success rate in curing hepatitis C. This benefit goes beyond health improvements for the individual – it is also important for the community, helping to reduce the burden of disease and ongoing transmission, and to meet WHO goals for elimination of this virus. Reducing hepatitis C infection in prison also makes for a safer work environment for those who work in prisons

When a person is imprisoned, their punishment is deprivation of liberty – their rights to choose how to spend their time and where they stay are taken away. Additional punishments like restricting access to healthcare is a breach of basic human rights. The United Nations has set Standard Minimum Rules for the Treatment of Prisoners (the Mandela Rules) requiring the provision of healthcare that is equivalent to what the person could get in the community.

When advocating for prison-based hepatitis C programs, you may need to reinforce both the individual-level, prison-level, community level- and national benefits of treating people in prison, and remind stakeholders of the need to offer equivalent standards of healthcare.

Eliminating hepatitis C

The goal of hepatitis C testing, treatment and prevention interventions is to improve health outcomes for people in prison, as well as to eliminate the virus and reduce the overall burden of disease. This can only happen if communities apply all available tools to identify, treat and prevent hepatitis C. Withholding treatment because of stigma and judgement is counter-productive to this goal. This negative approach ensures that the virus will continue to circulate.

Even when drug use is criminalised within a community or society, it can be useful to redirect discussions about the 'right or wrong' of drug use to instead focus on the benefits to individual and community health. People who inject drugs and people in prison should not be deprived of healthcare. Additionally, reducing the risk of hepatitis C transmission makes the environment safer for people in prison, as well for healthcare providers and custodial staff, and helps to reduce long-term costs to health systems.

When advocating for prison-based hepatitis care, it can be helpful to focus on the big picture of eliminating hepatitis C, including from the prison environment. This sets aside arguments about whether individuals are 'deserving' and instead looks to solve the problem of hepatitis C in an environment that offers opportunities for successful interventions.

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