Fighting Stigma to Improve Access to Hepatitis C Care for Substance Users

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Hepatitis C infection affects an estimated 5 million individuals living in the United States (US).[1] Much of the work to identify and treat people infected with the hepatitis C virus (HCV) has targeted Baby Boomers (individuals born between 1945-1965) because of the high burden of disease in this population. Public health messaging about routine screening for Baby Boomers and television commercials depicting older adults being cured of HCV with new medications has increased awareness about HCV in this cohort (although screening rates in this population remain unacceptably low).[2] But HCV is now affecting a new group--younger individuals with a history of substance use--and it has become a major public health concern. Between 2011-2014 there was a 250% increase in the number of acute HCV cases reported in the US, and many of these are attributed to injection drug use related to the opioid crisis.[3] However, unlike the HCV epidemic affecting Baby Boomers, this new wave of HCV cases among substance users is receiving little attention. Instead, people who use drugs face significant stigma that affects their engagement in the HCV care cascade.

NVHR's upcoming webinar about stigma

On August 8th at 3 pm ET, the National Viral Hepatitis Roundtable will host a free educational webinar about stigma as a barrier to HCV services among people who use drugs. The webinar is part of the "More than Tested, Empowered" program and will feature presentations from the Urban Survivor's Union, the Atlanta Harm Reduction Coalition, and the People's Harm Reduction Alliance. These organizations will share their experiences addressing stigma by engaging current substance users and healthcare providers to share their concerns and develop strategies and solutions. To register for this event, click here.

Why the stigma?

Stigma refers to the disapproval and/or rejection of an individual because of characteristics, beliefs, or behaviors perceived to be deviant or different from accepted social norms. The stigma related to substance use is often related to moral judgements and/or the criminalization of drug use. Additional stigma may result because of the knowledge that certain drug use behaviors are associated with increased risk for bloodborne infections like HCV. Substance users are often blamed for their substance use disorders and/or other conditions associated with drug use, and are

often viewed as less deserving of treatment services. A study conducted by the Johns Hopkins Bloomberg School of Public Health found that 43% of Americans surveyed felt that substance users should not be given the same health insurance benefits as other individuals.[4] The stigma associated with substance use is pervasive and is perpetuated by misinformation and fear.

The consequences of stigma

Stigma affects substance users in various ways. It may occur as a result of substance use alone, or it can be compounded by the stigma associated with other factors including mental illness, homelessness, poverty, infectious disease, and incarceration. Some results of experiencing stigma include:

- Social consequences: Fear of being judged or rejected can lead to social isolation. Substances users may feel ashamed of their drug use and struggle with whether or not to discuss addiction concerns with others. They may feel as if they've been written off by family and friends. As a result, individuals often lack social support, hide their drug use from others, and avoid seeking help. Women who use drugs are especially vulnerable to stigma, especially if they have children or become pregnant, and may even face stigma from other substance users.

- Discrimination: Substance users may experience discrimination in many settings including employment, housing, and when seeking social services. They are often treated unfairly by law enforcement officials, who may prejudge or assume guilt because of past substance use issues.

- Mental illness: Stigma is associated with increased anxiety and depression. It can cause feelings of guilt, worthlessness, and shame which can then lead to low self-esteem and internalized stigma. This may also increase substance use as a way to cope.

- Barriers to healthcare – Substance users often experience stigma from healthcare providers who may suspect that they are being dishonest about their health history, assume that they will be noncompliant with treatment plans, or believe that they are unable to make sound decisions about their health. They may be labeled as "drug-seeking" and in some cases denied services. Even seeking services for conditions related to drug use can be a humiliating and degrading experience. As a result, substance users may not disclose certain risk behaviors, which can

inadvertently lead to inadequate care, or they may avoid seeking healthcare services altogether.

- Health policy – Policy makers often overlook the needs of substance users because of prejudices or personal bias. They may feel that the rights of people who use drugs are less important than the rights of others. This results in a lack of funding for substance use programs, a shortage of treatment services, and a perpetuation of healthcare injustice.

"In short, stigma encourages silence and inaction." [5]

Substance use, stigma, and HCV

Injection drug use is a risk factor for HCV infection. It is recommended that anyone who injects drugs (or has a history of injection drug use) be screened for hepatitis C. However, because of stigma, substance users may avoid being tested. They may not feel comfortable seeking healthcare services, or they may fear the rejection that can result from a positive test result. For substance users who are known to be HCV-positive, stigma may limit treatment services available to them. As one "More than Tested, Cured" project participant was told, "We can give you treatment, but you have to be clean." [6] Healthcare providers may not offer HCV treatment because they believe substance users will not reliably take their medications. Or they may have concerns that substance users will continue to engage in risky behaviors and potentially become re-infected with HCV. But studies show that substance users are motivated to complete treatment and successfully adhere to medication plans.[7] Additionally, post-treatment re-infection rates among injection drug users have been low.[8] Following recommendations by the American Association for the Study of Liver Diseases, many states have passed policies to remove sobriety restrictions that previously barred access to for HCV treatment.[9] Yet other programs have maintained or expanded such restrictions, demonstrating that there is more work to be done.

What can we do?

Eliminating stigma has been recognized as a national priority in both the Health and Human Services National Viral Hepatitis Action Plan and the National Academies of Sciences, Engineering, and Medicine National Strategy for the Elimination of hepatitis B and C.[5,10] Unfortunately, this is not an easy task, and it requires multiple strategies.[11-12] First, it should be emphasized that healthcare is a right of every individual, regardless of any preconceived ideas about that individual. Treatment for HCV, substance use disorders, mental health, and other conditions should be made available, affordable, and accessible for people who use drugs. Second, advocacy for the rights and dignity of people who use drugs is essential. Policy makers need to be made aware of the discrimination against people who use drugs and pressured to pass legislation to

improve access to medical and social services for this population. Third, refrain from using language that may inadvertently reinforce stigma. For example, terms like “addict” or “drub abuser” create negative labels and reduce the identify of a person to their substance use. Be mindful that the words we use matter. Finally, education is key to breaking down stigma. It reduces fear and increases understanding of the needs of people who use drugs. It can dispel misconceptions about substance use disorders. We should all encourage drug users to share their stories and urge others to listen.

For more information about HCV among people who use drugs, visit NVHR’s “More than Tested, Empowered” program website or email us at info@nvhr.org. To participate in our upcoming webinar, register here.

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