

# Medical Writers' Circle

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a series of articles  
written by medical  
professionals about  
the management  
and treatment of  
hepatitis C

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## Stigma<sup>2</sup>: Hepatitis C and Drug Abuse

**H**epatitis C virus (HCV) is the most common chronic blood-borne infectious disease in the United States, with nearly 4 million people infected<sup>1</sup>. In addition to the physical challenges HCV presents, this illness carries with it a stigma that negatively impacts the quality of life for infected individuals. Some of these negative consequences include reduced self-esteem, diminished mental health, less access to medical care, and fear of disclosing a positive status, with the latter often resulting in limited social support at a time when it is sorely needed<sup>2,3</sup>. This disease-related stigma is also likely to contribute to hesitancy on the part of some medical providers to treat people infected with HCV.

In attempting to understand such stigma, it is useful to refer to Goffman<sup>4</sup> who has written extensively on the subject. He, along with other researchers, has developed a list of attributes for those diseases that have the greatest level of stigma. Included in this list of attributes is that: (a) the disease is progressive and

incurable, (b) the symptoms cannot be concealed, (c) the public is not adequately informed about the disease, and (d) a person with the disease is perceived to be responsible for having it<sup>4-6</sup>. Using this list of attributes, Herek<sup>7</sup> argued that HIV is one of the more highly stigmatized illnesses, because it possesses each of these attributes. Certainly, the very same argument can be made with regard to HCV. First, HCV is a progressive disease, and current pharmacological therapy (a combination of pegylated interferon and ribiviran) does not successfully clear the virus in all individuals who complete treatment. Second, although HCV can remain asymptomatic for decades, the most severe consequences of the virus are often difficult to conceal<sup>8</sup>. Third, community awareness of HCV is unfortunately quite low. Even many health care providers and substance abuse treatment staff who frequently interact with those dealing with HCV-related issues have little knowledge about the virus and remain unaware of the true impact and implications of the disease<sup>9,10</sup>. Fourth and finally,

many people who have HCV infection are judged to be immoral and are blamed for having the disease. The "blame" and "immorality" associated with HCV is primarily a result of the fact that most cases of infection now occur through the sharing of contaminated injection drug use equipment. In fact, injection drug users (IDUs) constitute nearly two-thirds of those with new HCV infections<sup>11</sup>.

The implicit connection between HCV infection and drug use causes HCV-positive people to often be viewed as having made poor choices: that is, they are seen as having "chosen" to engage in illicit and dangerous behaviors that resulted in their contracting a serious illness. Subsumed under the label of "drug user," these individuals are deemed immoral and tainted. Notably, this debilitating stigma impacts HCV infected people regardless of how they actually contracted the virus, whether through contaminated blood products, the reuse of unsterilized equipment, accidental needle prick, through sex, or through the use of injection drugs during a sea-

son of life that has long since past. What's more, people who contracted the virus via drug injection and continue to use drugs are marginalized and discriminated against on the basis of their drug use as well as their HCV status. This "double" discrimination leads to social isolation, stress, and increased barriers for individuals who need to access critical HCV education, testing and medical care and support<sup>12</sup>.

Also troubling is that this "double stigma" occurs among drug users who are addressing their addiction by attending a substance abuse treatment program. This disturbing fact was illustrated through in-depth interviews with staff and clients at 11 drug treatment programs throughout the United States conducted by the STOP HEP C project. This project, funded by the National Institute on Drug Abuse (NIDA), examined what drug treatment programs are doing for their clients concerning HCV. During an interview at one of the participating programs, a client unwittingly raised the specter of this "double stigma" when he referred to HCV as the "junkie disease." Many other clients at these programs raised the issue of this dual stigma, reporting that even though they were addressing their addiction and complying with the rules of recovery, they were still experiencing discrimination from practitioners outside of the treatment program. While the 2002 NIH Consensus Statement on hepatitis C<sup>13</sup>

clearly states that drug users should not be denied HCV treatment solely on the basis of their addiction, medical providers who have not been trained in the addictions field are unlikely to understand that drug users can often benefit from HCV treatment. In fact, a number of HCV-positive clients who participated in the STOP HEP C project described occasions in which practitioners in the community discriminated against them because of their drug use history. One client in a residential program was referring to his primary care physician when he said:

*"He (her primary physician) said 'You don't qualify, I mean it's people like YOU.' And I said 'people like me?? What?? Drug addicts??' ... He said 'they won't take you; you're not a candidate (for the HCV treatment).'"*

Another client spoke about a dentist who refused to treat her because she told the provider that she was HCV positive and in drug treatment. Interviews with staff at these programs also underscored the stigma associated with their HCV-positive clients, and a number of staff noted that they were aware of the discrimination their clients face when dealing with providers in the community because of their substance abuse issues. One staff person at a methadone program said that negative attitudes among providers toward HCV-positive drug users,

*"...kind of shuts the doors for*

*many of our patients for access to [HCV] treatment..."*

Even within the treatment program, many clients who identified as HCV-positive associated feelings of "embarrassment" and "shame" with their disease. This further decreased their sense of self-worth and self-esteem, preventing or delaying many of them from disclosing their serostatus to the treatment staff. In addition, clients were concerned that having their HCV positive status disclosed would result in alienation by their peers. Further compounding the problem, some clients told us that they had specifically avoided using available HCV services at their drug treatment programs in order to keep their status unknown, while still others described staff who seemed unknowledgeable and apathetic about their HCV-related concerns. These latter clients interpreted the staff's behavior as evidence that the staff did not care or did not have the time to deal with HCV-related issues<sup>14</sup>. As one client put it, "the staff just don't give a shit about us."

What makes testimonies like these so regrettable is the fact that drug treatment programs are among the few places where underserved clients have access to information about HCV and to HCV-related services<sup>15, 16</sup>. The good news is that some clients had positive experiences with staff at their programs who they believed genuinely cared about them and were committed to help-

ing them with their HCV-related concerns, even advocating for them with medical providers in the community. Some clients related how the medical staff was helpful in explaining their symptoms and helping them with the side effects of the HCV medications. Another client told us how she felt cared for by the nurse who repeatedly reminded her to make the necessary medical appointments to deal with her HCV. She said:

*"... And I feel it from her that it's not nagging... It's actually genuine... she cares. Yeah, that she genuinely cares about me. Which is, you know, it's strange because you don't always get this kind of support from your own family... You know, to get it from somebody. So, I appreciate it."*

As a result of these findings, the STOP HEP C project was funded by NIDA to create, implement, and evaluate an HCV training for drug treatment program staff. The training provides comprehensive information about HCV, as well as: a) the importance of having staff advocate with community providers on behalf of clients who need HCV-related medical services; b) the likelihood that clients taking HCV medications will experience difficult emotional and physical side effects; c) the importance of communicating with clients about HCV in a way that motivates and supports them, while decreasing their feelings of denial and/or resistance; and d) drug treatment staff's potential role in supporting

and offsetting the stigma and discrimination that clients are likely encountering in addressing their HCV concerns. Staff who have participated in the training have indicated that it has improved their understanding of the difficulties that their clients face, and enhanced their competence to convey HCV information to clients and to support them with their HCV-related issues.

Whether within or outside of the drug treatment program, the discrimination and devaluation of identity associated with HCV-related stigma does not occur naturally. Rather, these effects are created by individuals who, for the most part, generate the stigma as a response to their own fears. Interventions to reduce stigma are crucial for improving care, quality of life, and emotional health for people living with HCV. Studies show that stigma can be reduced through a variety of intervention strategies including increasing knowledge about the disease, counseling, coping skills acquisition, and/or increasing contact with infected or affected individuals<sup>17</sup>. As Treloar, Hopwood, and Loveday<sup>18</sup> indicate, the continued marginalization of HCV-positive individuals will not only continue to place a heavy burden on those infected with the virus, but will also obstruct efforts to address the growing HCV epidemic. It is imperative that future research examines HCV-related stigma, and develops effective strategies for overcoming negative percep-

tions of the disease. Certainly, HCV trainings that target local schools, hospitals, drug treatment programs, and other similar community organizations may help to eliminate, or at least reduce, the compounded stigma associated with HCV.

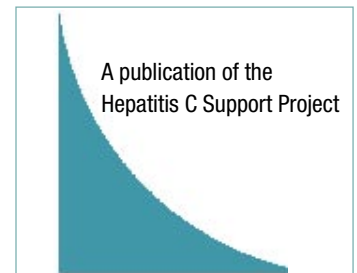
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The Mission of the Hepatitis C Support Project is to offer support to those who are affected by the hepatitis C Virus (HCV), hepatitis B Virus (HBV) and HCV coinfections.

Support is provided broadly, through information and education, as well as access to support groups. The Project seeks to serve the HCV community as well as the general public.

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