

Silence and Stigma: The Hepatitis C Virus (HCV) Epidemic

by

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The Problem

The Hepatitis C virus (HCV) is the most common, chronic blood borne disease in the United States, far surpassing HIV in prevalence, yet is largely culturally invisible. Over four million Americans and approximately 250 million people worldwide are chronically infected with this potentially life threatening virus. Despite the magnitude of the catastrophic social and health consequences of HCV, we have done little to address the issue, largely due to an association of HCV with injection drug use. While persons who inject drugs (PWID) are a high risk group for acquisition of this virus, the stigmatization associated with this particular route of transmission taints the socio-political perspective of this disease as a whole, which enables public health and policy-makers to largely ignore a growing epidemic.

Persons with HCV experience a significant stigmatization and reduction in quality of life for both physical and mental health. The health conditions related to chronic HCV infection range from mild symptoms to significant extra-hepatic symptoms including liver disease and hepatocellular carcinoma. Liver disease associated with chronic HCV is the number one predisposing factor for liver transplants in the United States. The mortality associated with HCV-related liver disease is approximately 12,000 per year, rapidly approaching yearly deaths due to HIV/AIDS in the United States. By 2019 these numbers will triple, costing an estimated \$10.7 billion in direct medical expenses. Given these dire socioeconomic and health consequences, we ask: Why is the social problem of HCV virtually ignored, limiting public and private funding for HCV research, education, and treatment, and hindering diagnosis and disease prevention?

The Research Evidence

The largest groups of persons affected by HCV are disadvantaged and marginalized populations, including homeless people, PWID, people of color, and those who are incarcerated. Imprisoned populations experience a 30 percent prevalence of HCV, while services are meager and potentially stigmatizing. People commonly assume that HCV infected inmates entered prison already infected despite a lack of research regarding incarceration-based transmission (for example, prison-based tattooing).

While HCV does affect a variety of persons in the United States, the prevalence rate of chronic infection is significantly higher among persons of color than among whites. PWID are particularly susceptible to HCV infection due to direct percutaneous exposure to infected blood. Transmission of HCV is ten fold more efficient than HIV. Consequently, rates of HCV among PWID are estimated at 90 percent in those who have been using IV drugs for at least five years. PWID are stigmatized by both the general public and non-injection drug users. In sociological terms this *double failure* to conform to societal norms disenfranchises individuals who are in an addictive process that is already marginalizing and dehumanizing. It is the marginalization and dehumanization of PWID, and the misperception that all persons living with HCV have engaged

in injection drug use, that perpetuates insufficient public health funding and poor policy-making regarding the HCV epidemic.

Numerous studies indicate persons infected with HCV experience discrimination in healthcare and employment. The perception that all persons who have HCV have contracted this disease through injection drug use suggests that all persons living with HCV are medically high-risk. Indeed, health care providers may not take on HCV+ patients as they are afraid they will “sink their practices” or be too multi-need in nature. In addition, persons diagnosed with HCV often undergo profound detrimental changes in their personal identities and social interactions. The stigma surrounding HCV is related to confusion with HIV/AIDS, correct or incorrect presumptions of illicit drug use, promiscuity, and general fear of communicable disease transmission.

Perpetuating ignorance in relation to this social problem exacerbates the stigmatization and fear of the issue. It is abundantly clear that awareness about HCV is low across various sectors of the population. Researchers find that knowledge about HCV among PWID is much lower than knowledge concerning HIV, an especially alarming finding considering the significantly higher rates and ease of transmission of HCV in the population. Even those who provide professional services to at-risk populations may have inadequate knowledge. More than half of employees at several U.S. drug treatment programs could not correctly answer one quarter of the questions regarding HCV knowledge, suggesting systematic misinformation. In addition, only slightly more than half of primary care residents surveyed knew how to properly treat HCV. Sixty-six percent of primary care residents recommended vaccinations for uninfected persons; yet, no vaccine exists for HCV.

Because HCV is stigmatized due to perceived routes of transmission, there is a lack of overt political will behind this disease. State and federal policy makers largely ignore the epidemic, which leads to limited federal funding for HCV detection, prevention, treatment, and education. Congress appropriated a paltry \$17.6 million for fiscal year 2007 to the Centers for Disease Control’s Division of Viral Hepatitis to prevent and track all viral hepatitis in the United States (not only HCV). Federal legislation to address this epidemic has failed in Congress three years running. The scant funds that are provided to support Adult Viral Hepatitis Coordinators in most states and a few large cities do not support testing or educational programs.

In the 21st century, no one in the United States should have to die of HCV-related liver disease. Projections suggest that by 2019 approximately 22,000 people will die annually from liver disease if more is not done to ameliorate the spread of the HCV virus. Stigma, transmission-related myths, and ignorance perpetuate insufficient knowledge of HCV. Inadequate health care policies maintain poor HCV related health outcomes among the most marginalized in society. Social justice cannot be served until this public health epidemic is addressed with equal economic, political, and policy rigor to that of purported threats, such as the avian flu, SARS, West Nile Virus and other unrealized U.S. epidemics.

Recommendations and Solutions

Social and health services, including prevention, education, management, and research are expensive. Yet, the CDC estimated in 1998 that more than \$600 million was spent that year to support the health of persons who are acutely and chronically impacted by HCV. A decade later, the monetary and human suffering costs of societal neglect, which has led to an increase in these medical and social expenditures, far outweighs the monetary costs of taking action. In order to adequately address this pressing social issue, the following recommendations are proposed.

Research

It is clear that HCV is under studied, and there is a need for further research in biology, social science, and treatment. The following are policy suggestions to improve the state of HCV research.

- Research endeavors to understand patterns and trends related to HCV transmission are needed.
- Epidemiological and social science research that accurately estimates the prevalence of HCV and the intricacies of risk behaviors among potentially hidden populations will provide intervention specialists with more information to develop targeted primary and secondary prevention programs.
- Research agendas in the behavioral sciences must begin to address important behavioral issues.
- Research must assess social drug and sex networks that may exacerbate risk for HCV.
- Researchers should evaluate best practices regarding HCV acquisition among persons who are newly initiated into injection drug use.
- Researchers must investigate the transition from experimentation with drugs to injection drug use among youth. They should evaluate syringe exchange programs and their effectiveness in deterring the transmission of blood borne pathogens.
- Secondary prevention strategies are needed to support healthful living with HCV for marginalized persons who may not gain appropriate access to medical care.
- Drug treatment facilities should be studied as secondary HCV prevention/intervention sites.
- The efficacy of peer-education models for prevention of HCV transmission among the extremely marginalized should be explored.

Prevention

The majority of people living with chronic HCV do not know of their infection. A lack of knowledge perpetuates transmission and decreases the opportunity for individuals to take liver health preventive measures necessary to decrease the likelihood of severe liver disease. While there is no magic bullet for most blood borne pathogens, harm reduction programs that acknowledge people's current social circumstances may reduce drug and sex-related harms and can support positive health choices for marginalized persons. The following policy recommendations may help to prevent the spread of HCV.

- Testing should be accessible to all high risk persons, especially PWID, those who are incarcerated, and all persons at high risk for HCV infection.

- A new harm reduction approach to drug use and safer injection practices among PWID is needed.
- Safe syringe access and disposal programs should be available in all communities nationwide to decrease the likelihood that HCV is transmitted through sharing injection drugs.
- More accessible treatment options are necessary to prevent the health complications of HCV disease.

Education

Political disenfranchisement of PWID in the United States maintains the isolationist policies that exacerbate the HCV epidemic. It is suggested that through efforts to educate all strata of our society including medical providers, allied health care, social service providers, and the public, that a destigmatization may occur such that people infected with HCV will no longer have to die in the shadows of our communities. The following recommendations can help with HCV education.

- Launch extensive and comprehensive education programs designed for target audiences including educational messages regarding disease transmission, risk assessment, behavior modification, treatment options, and harm reduction strategies.
- Develop specific programs for healthcare providers, dentists and oral hygienists, pharmacists, persons working in substance abuse and mental health, corrections staff, and others working in social services for disadvantaged persons.
- Develop basic educational programs aimed toward the general public.
- Evaluate and assess information given to persons diagnosed with HCV to ensure persons have the appropriate knowledge to make decisions about their health.

Management

While HCV is an equal opportunity infectious disease, it is the subpopulations that are marginalized socioeconomically and morally in our society that will have the worst outcomes. Those most likely to progress with HCV-related liver disease are people on the fringes of society. People who may be infected with HIV, HBV, who consume significant amounts of alcohol, and who are marginally housed, are all less likely to be linked to a medical care system and thus, more likely to progress with HCV related liver disease. The following are policy suggestions that will help manage HCV more effectively.

- Provide access to basic health care.
- Facilitate alcohol and drug treatment (when necessary).
- Administer viral hepatitis A and B vaccines to high-risk adults.
- Make treatment for HCV available for all persons, but especially persons who are incarcerated and PWID.
- Provide accessible and integrated care structures for persons with HCV.

Key Resources

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Internet Resources

HCV Advocate: <http://www.hcvadvocate.org/>

Hepatitis Education Project: <http://www.hepeducation.org/>

CDC Viral Hepatitis: <http://www.cdc.gov/ncidod/diseases/hepatitis/index.htm>

About the Authors

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Ann Shindo is the Oregon State Viral Hepatitis Prevention Coordinator for the Oregon Public Health Division and Adjunct Assistant Professor at the Graduate School of Social Work, Portland State University. She has extensive street-based experience working with homeless young persons at risk for HIV and HCV as well as experience with incarcerated adults living with HIV and HCV. She has fifteen years of health sciences research adding to her expertise in the biopsychosocial aspects of chronic and stigmatized diseases. She is currently addressing social stigma and marginalization as it relates to living with HCV in the United States.