The Burden of Hepatitis C in the Injection Drug User Population

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Introduction

Hepatitis C virus (HCV) is estimated to affect about 130 million people worldwide, but determining the actual incidence of HCV infection is complicated by the asymptomatic nature of the disease. Asymptomatic individuals do not physically manifest the disease but still have the potential to transmit the disease to others, and chronically infected persons face the risk of developing advanced liver disease, cirrhosis and hepatocellular carcinoma.[1]

As HCV is most efficiently transmitted through large or repeated percutaneous exposures to blood, transfusions represented the main method of transmission before the virus was identified in 1989 and improved screening techniques were implemented in 1990.[1,2] Transfusion-associated transmission of HCV has essentially been eliminated in most of the developed world, due to risk reduction measures such as screening blood donations and potential donors.[3] Transmission via injection drug use is now the predominant mode of transmission in these countries, accounting for 60-75% of infections.[2]

This paper explores the reasons for the prevalence of Hepatitis C in the injection drug user (IDU) population. As IDUs represent a socially marginalized sector of the population, we must consider how stigma interacts with historical, socioeconomic, cultural and institutional forces to contribute to the current epidemiology. Syringe-sharing is a known method of transmission,[4] and therefore efforts to reduce the incidence of HCV infection in the IDU population have included health promotion campaigns and programs that provide sterile drug injection equipment.[5,6] However, there is limited evidence to support the effectiveness of needle and syringe programs (NSPs) in preventing HCV transmission. Lack of evidence in support of these programs does not necessarily mean that NSPs are ineffective. Also, observational studies are limited by their susceptibility to bias because NSP attenders, as a self-selecting group, may engage in other behaviors that lower their risk of becoming infected, as compared to non-attenders. Furthermore, it is ethically problematic to conduct randomized trials, because a control group would not be able to benefit from an intervention that has face validity.[7] Still, it is important to consider how stigma might impede the ability of IDUs to access services like NSPs. Furthermore, antiviral therapy for HCV exists, but treatment has historically been offered only in a limited manner to IDUs.[8] Ultimately, a socio-psychological analysis conducted through the framework of stigma will inform both treatment and prevention efforts to address the prevalence of HCV in developed countries.

The Framework of Stigma

Drawing upon research in both psychology and sociology, Link and Phelan define stigma as "exist[ing] when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them." [9] Their definition captures how any sort of difference, once imbued with social value, can be transformed into a label that is accompanied by concrete forms of inequality.

Labeling arises when certain human differences—for example, race or sexual preferences—are deemed to carry social significance, as though they provide means to gain insight into the nature of individuals with such characteristics. The next step in the construction of stigma is negative stereotyping, through which demarcated human differences are linked with a set of undesirable characteristics. The label loses its innocuous nature; it becomes a tool to devalue the labeled individuals and leads to social discrimination.[9]

According to Morone (1997) and Devine et al. (1999), these value-laden labels subsequently promote the separation of an "us" from a "them."[9] This drive for separation can be better understood as a mechanism to protect the self, "a highly pragmatic, even tactical response to perceived threats, real dangers, and fear of the unknown."[10] But the process of protecting "us" consequently excludes "them," so that those who are devalued experience status loss and discrimination. This exclusion is the point where social stigma translates into concrete forms of inequality. Link and Phelan observed that stigmatized groups often have disadvantaged socioeconomic profiles, such as low income, poor psychological well-being and unstable housing status.[9] These social and economic factors may make disadvantaged populations more likely to engage in behavior that is stigmatized,[11] thus reinforcing the stereotype and augmenting the inequality that these populations already face.

Thus, both the origin and self-reinforcing nature of stigma serve as a critical framework to first understand how IDUs are marginalized and then identify the complex forces that perpetuate the prevalence of Hepatitis C in this population. This same foundation of understanding may also provide insight into developing effective interventions to address such prevalence.

Historical Underpinnings

The marginalization of IDUs can be traced back to the policy of drug prohibition. In the United States, one of the first federal laws against opium smoking was enacted in 1887,[12] and stringent drug prohibition policy continues today.[13] MacCoun and Reuter (2001) find such policy grounded in moralist perspectives, guided both by legal moralism and legal paternalism. The former proposes that drug use is intrinsically immoral and therefore should be banned. The latter seeks to prevent the harm that drug users can inflict on themselves and their families.[14]

These moralist arguments are evident in historical efforts to establish the global prohibition of common drugs, such as opiates, cannabis, stimulants and psychedelics. The preamble of the United Nation's Single Convention on Narcotic Drugs of 1961 clearly outlines the agendas of the parties involved: "*Concerned* [emphasis in original] with the health and welfare of mankind… *Recognizing* that addiction to narcotic drugs constitutes a serious evil for the individual and is fraught with social and economic danger to mankind, *Conscious* of their duty to prevent and combat this evil."[15] In this statement, the frequent use of "evil" demonstrates the fundamental moral concern surrounding the abuse of narcotic drugs. Furthermore, the document outlines that this evil not only threatens the individual user, but also constitutes a “social and economic danger to mankind,” calling on the legal paternalist view for action. As a result, the convention finds international coordination necessary to bring about effective measures. While the convention is beneficial in impelling global cooperation, its moral overtones may alienate IDUs and are liable to be amplified by legislation.

It is therefore important to consider how a continuation of stringent policy of drug prohibition in the United States has contributed to the marginalization of IDUs in this country. The United States’ 1967 “Report of the Task Force on Narcotics and Drug Abuse of the President’s Commission on Law Enforcement” reflects a moral concern similar to that of the United Nation’s Single Convention and communicates the domestic approach to combating drug use:

> We have built our drug control policies around the twin judgments that drug abuse was an evil to be suppressed and that this could most effectively be done by the application of criminal enforcement and penal sanctions… Thus the addict lives in almost perpetual violation of one or several criminal laws.[13]

Again, the reference to “evil” is telling of the justification for the criminalization of drug use. Such criminalization was solidified by President Nixon’s declaration of the War on Drugs in 1971, which bolstered the role of legislation in drug control; in the 21st century, the attitude toward drug prohibition remains largely punitive.[13]

Taken together, these responses to drug use, especially in the United States, reflect a moral battle that has become dominated by legal implements. Yet it is worrisome how the process of criminalizing drug use contributes to the stigmatization of drug users. In the context of Link and Phelan’s definition of stigma, the label of “drug user” is deemed to carry social significance because it means someone who has committed a moral transgression and may therefore present a danger to society.[9] The moral concerns impelling drug prohibition are certainly valid; however, labeling drug users as criminals may result in discrimination that is counterproductive to efforts that address their drug use and, consequently, risk of HCV infection. This glimpse of drug prohibition policy, as exemplified by contemporary legislation in the United States, elucidates the roots of the marginalization of IDUs, which may ultimately provide insight into the high prevalence of hepatitis C in this population.

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Social Networks of IDUs

Drug prohibition has created a subculture of illicit drug users that is in conflict with mainstream society. The response of IDUs to the hostile environment constructed by their larger society reveals many unintended consequences of drug prohibition, ranging from how IDUs sustain the drug practice that marginalized them in the first place to how they develop networks of survival and support. Link and Phelan note in their definition that ostracized groups are often economically disadvantaged.[9] Thus, there is an economic impetus for IDUs to form social networks in order to pool limited resources or obtain drugs or drug-injecting equipment. The formation of these “convenience networks” is additionally spurred by the difficulty of acquiring drugs, due to the criminalization of drug use.[4] Without stable resources of their own, individuals within these networks may engage in unsafe injecting practices, such as sharing needles. It is also important to consider the power imbalance in these networks. For example, individuals who have fewer resources to share are often left to inject with used equipment, placing them at higher risk for disease.[16]

In line with their disadvantaged socioeconomic profiles, IDUs also rely on each other to fulfill basic needs. Studies have found that IDUs share such commodities as food, shelter and clothing, establishing a pattern of reciprocal assistance.[17] The convenience network, which can first emerge as a source of acquiring drugs and fulfilling other needs, develops into a community that provides social support; sharing drugs and other resources becomes a reaction to the communal struggle that this marginalized population faces daily.

On a fundamental level, these networks satisfy the desire of IDUs for mutual understanding.[18] Therefore, the “convenience network” becomes a “comfort network.”[4] Within these “comfort networks,” syringe sharing becomes normalized as part of the social experience; network members serve as role models for injection practices, which can be impressed particularly upon younger injection drug users and thus perpetuated through the network.[16] In addition, the IDU subculture may represent the only communal source of resources and relationships for these individuals, who are otherwise excluded from mainstream society.[18] As a result, the desire for empathy through sharing resources, even needles, may trump an interest in safe injecting behavior.

These networks provide insight into why IDUs may engage in unsafe injection practices even when they have access to sterile syringes. Programs that provide sterile injection equipment for IDUs have been central to strategies aimed at reducing the spread of blood-borne viruses.[6] Underlying this harm reduction measure is the philosophy that individual choice represents the sole determinant of IDU behavior.[4] Yet, the economic drive to form IDU networks and the social importance of these networks are examples of influences other than individual choice in controlling injection behavior; these networks represent social constructions that have become impenetrable to the agency of the individual.[19] Therefore, access to sterile syringes in and of itself may not be an entirely effective measure to prevent syringe sharing and the consequent risk of HCV transmission.

The external pressures of mainstream society may further facilitate HCV transmission through IDU networks. The rigorous laws central to the American policy of drug prohibition can increase the movement of individuals within these networks. Different individuals from different groups can then come into contact with each other, thus facilitating the spread of HCV among networks.[18] The spread of HCV may therefore be seen as an unintended consequence of drug prohibition and the subsequent methods of legal enforcement, as IDUs who are marginalized participate in networks that increase their risk of infection.

Cultural Pressures of Larger Society

An additional problem is that IDUs, even as they are embroiled in their own subculture, are still held accountable to the cultural values of mainstream society. In Western culture, the perceptions of individualism, responsibility and health have intertwined to yield several notable consequences. One is that the rational individual is seen as capable of, and therefore responsible for, maintaining his own well-being. However, a less positive corollary is that the individual thus bears the blame for an illness that he or she is supposed to have been able to prevent, such as a sexually transmitted disease.[5] Citizens who do not fulfill their duty of self-care to themselves and, ultimately, to their society face judgment and stigmatization.

Before the early 1980s, IDUs were viewed as incapable of such self-regulation and care; the extremely addictive nature of drugs was thought to trump their intrinsic capacity for rational decision-making. However, this attitude shifted during the HIV/AIDS era, as the rise of neoliberalism promoted the development of harm reduction strategies. IDUs today are expected to engage in the same process of self-regulation that non-stigmatized citizens do.[20] However, it is important to consider how stigma may hinder IDUs' ability to engage in such processes.

Health promotion campaigns rely on individual IDUs to minimize the risk of disease transmission associated with drug use.[5] Framing the individual IDU as active in HCV prevention is supposed to be empowering, conferring resilience and the possibility of redemption. At the same time, though, IDUs who do contract HCV are seen as having neglected their duty to care for themselves and also now represent a danger to others. This compounded stigma can be seen in the account of one IDU with chronic Hepatitis C (CHC): "Not only are you a druggie and all that this implies, but [it is assumed that because you have CHC] you don't care about other people because you shared needles."[21] The judgment that this individual faces for sharing needles exemplifies the tension between IDU subculture and mainstream society. A certain degree of moral judgment is warranted, if it can effectively discourage IDUs from continuing to engage in risky behavior. Nonetheless, it is important to remember that syringe sharing may be normalized within IDU networks, whether due to limited resources or perhaps to build a sense of community. Because mainstream society is often insensitive to the economic and social motivations underlying the practice of reusing injection equipment, it imposes stigma that may hamper IDUs' attempts to engage in self-determination.

Stigma constitutes a burden of the disease of hepatitis C, as individuals internalize feelings of shame. To avoid further ostracism, IDUs may try to keep their infection a secret and refrain from seeking help, a response that can preclude them from accessing necessary healthcare services for treatment.[2] Moreover, if these IDUs are still involved in unsafe injection behaviors, they can spread HCV to others.

It is important to examine further the conflict between the morals of IDUs and mainstream society.[22] While it is not unreasonable to expect the former to share the individualist values of the latter, it is necessary to heed how stigma can hinder the ability of IDUs to carry out such values. Link and Phelan remind us that stigmatized groups are often socioeconomically disadvantaged.[9] However, expectations of individualism, especially as related to health, assume that IDUs can act appropriately on social and economic capital to reduce the risk of HCV transmission.[20] As contracting HCV is seen as a failure to fulfill expectations of individualism and thus warrants moral judgment, IDUs experience stigma that unnecessarily compounds the stigma they already face as drug users. A later section of this paper will discuss how to develop strategies that move away from placing the responsibility of treatment and discontinued transmission of HCV entirely on the individual IDU.

Institutional Barriers in the Healthcare Setting

Even if IDUs are able to surmount the patient-side barriers to seeking HCV treatment, they soon encounter provider-side barriers in the healthcare setting. These barriers are worrisome because practitioners not only make decisions that directly impact the well-being of patients[23]—which, in the case of HCV-infected patients, involves addressing the biological consequences of the virus on the body—but also have the potential to incorporate caregiving into their relationship with their patients and lessen the stigma that these patients face from other parts of society. [24]

In 1997, the National Institutes of Health (NIH) recommended, in its consensus statement on the management of hepatitis C, that illicit drug users not receive treatment until they have discontinued drug use for at least six months.[25] Likely underlying these treatment guidelines were concerns about poor adherence to treatment, side effects of treatment and HCV reinfection. As HCV treatment entails a rigorous course of antiviral therapy, there may have been doubts that IDUs were able to fulfill this serious commitment. The severe psychological side effects of treatment do present a legitimate concern to patient well-being, especially since drug use is often associated with poor mental health, yet this too often prevents patients from being assessed for their capability to tolerate and benefit from treatment.[8] In addition, successful treatment and clearance of the virus does not confer immunity,[26] and current drug users may easily reacquire HCV. However, it is important to question how much weight was given to economic considerations in the development of these guidelines. While it is important to ensure that funds for healthcare are spent efficiently, the NIH guidelines seemed like a blanket statement dictating drug use as a contraindication to treatment. HCV treatment may indeed be more successful for patients who have discontinued drug use.[27] However, the guidelines did not distinguish between individuals who are unwilling to discontinue drug use and those who are willing but simply do not have the resources (such as access to drug treatment programs) to do so.[8] While such a distinction may be difficult to make, especially in the clinical setting, these guidelines may have precluded a dialogue between physician and patient about how to discontinue drug use.

The 1997 NIH treatment guidelines were ultimately problematic because IDUs constitute the majority of current and new HCV infections in the United States. As the various concerns about initiating HCV treatment for IDUs were codified into guidelines, such policy essentially turned a blind eye to the sector of the population that faces the highest burden of this disease.[8] Bureaucratic policies are certainly necessary in a healthcare system, from guaranteeing a baseline quality of service to ensuring that funds are spent most efficiently. However, the rigid HCV treatment guidelines did not sufficiently acknowledge the barriers that drug users face when seeking to discontinue drug use. As a result, the guidelines created another barrier to accessing the resources that could reduce the prevalence of hepatitis C among IDUs. Exemplifying the theory of social suffering, [28] the healthcare bureaucracies designed to alleviate suffering instead perpetuated the prevalence of hepatitis C in the population most vulnerable to the disease. Fortunately, the NIH guidelines were revised in 2002, as will later be discussed in more detail. Nevertheless, it is important to keep in mind how vestiges of the initial guidelines may persist in how physicians practice medicine with drug-using patients.

Stigma impinges on the trust that is integral to the patient-physician relationship and detracts from the basic requisite of caregiving as a moral experience.[24] This cycle of mistrust and lack of cooperation may find its origin in the interactions between patients and physicians, and if either party has negative experiences with the other, it then expects similar experiences in future interactions.[23] For example, a physician may have had a few patients who are known to be IDUs with Hepatitis C. If these patients miss appointments or deviate from prescribed treatment regimes, the physician may be averse to providing similar resources to other HCV-infected IDU patients. Such patients who encounter a lack of support upon interacting with the healthcare system may then be reluctant to seek help in this environment. Suspicion and frustration thus become typified between individual actors.[19] Once codified into guidelines, such as the 1997 NIH treatment guidelines, mistrust translates into discrimination on the institutional level. As physicians deliver these treatment guidelines, we can see how the healthcare setting itself contributes to the epidemiology of HCV infection observed in the IDU population.

Suggested Solutions

Through an analysis of the social network of IDUs, the cultural pressures of larger society and the institutional barriers in healthcare settings, we can see that stigma not only affects the experience of IDUs who are infected with HCV but also perpetuates the prevalence of hepatitis C in this marginalized population.

To alleviate the suffering of the IDUs currently infected with HCV, policymakers must take the lead by countering the institutional constraints that prevent HCV patients from receiving treatment and care. While healthcare practitioners are the ones who interact directly with patients, they are limited in their ability to combat the stigma that has been codified into treatment guidelines.[23] Past treatment guidelines in the United States represent an unfortunate consequence of the "iron cage" of rationality, [29] whereby bureaucratization and rationalization take too much precedence over individual decision-making.

Encouragingly, research on rates of adherence, side effects and risk of reinfection in the IDU population has begun to guide policy change. The 1997 NIH guidelines that decree that cessation of drug use should precede treatment of HCV infection reflected an artificial boundary on the role of medicine, a "practice of sanitizing [sic] people in order that they become acceptable patients for specialist physicians."[30] These divisions promote mistrust in the patient-physician relationship that may be found at the root of those blanket guidelines. However, in 2002, the NIH decided that IDUs be offered treatment on a case-by-case basis and that "active injection drug use in and of itself may not be used to exclude such patients from antiviral therapy."[31] Such changes not only mitigate the suffering of those currently infected with HCV, but also expand the perception of the patient from someone who seeks purely medical treatment to someone who also requires social support.

Such comprehensive support can be found in models of treatment that simultaneously address both HCV and drug use. These models can be additionally effective by recognizing how poor mental health and other infectious diseases may be comorbid with HCV in the experience of an IDU. In the United States, there are already several such initiatives underway. For example, the Substance Abuse and Mental Health Services Administration is developing curricula on how to combine drug treatment and hepatitis management strategies.[32] Ultimately, providing patients with a multidisciplinary team of healthcare and social support can best ameliorate the experience of HCV for IDUs and lead them to end drug use.[33] Here, individual practitioners can take the initiative to promote trust in their relationship with their patients by setting a common goal of improved health. For example, physicians can clearly vocalize a commitment to giving their patients the best treatment possible, as long as patients reciprocate with a desire to discontinue drug use.

To provide long-term solutions to the problem of hepatitis C in the IDU population, we must look further upstream and consider how the marginalization of IDUs places them at greater risk of HCV infection. The earlier discussion of IDU social networks, which first develop out of "convenience" and then evolve into sources of emotional support and communal understanding, elucidates the limited nature of individual control over injection behavior. Rather than subscribing to the prevailing mentality of penal action and trying to dissolve these networks, public health officials may instead consider how these networks can help disseminate information about safe injection behavior.[16] As social norms within a network play a key role in health behaviors, individuals within it can be trained as peer health educators to change the norms of injection behavior. For example, they might encourage their peers to seek access to sterile syringes through needle and syringe programs. By helping each other to gain access to more resources, they can connect through a common goal of improving health and, perhaps in the future, ending drug use.

Stigma is interwoven with the socioeconomic, cultural and institutional forces that conspire to aggravate the suffering of HCV-infected IDUs and perpetuate the prevalence of the disease in this population. However, it is promising that an awareness of this stigma can inform healthcare policy change and public health initiatives that leverage the social networks of IDUs, to ultimately alleviate suffering and address the current epidemiology.

Conclusion

In developed countries, the prevalence of hepatitis C in the IDU population constitutes not only a high burden of disease but also an issue of social justice. A biosocial analysis through the framework of stigma affords an understanding of how various large-scale forces act together to contribute to the observed epidemiology. With such an understanding, developed countries would be poised to design and implement effective measures to ameliorate the suffering of IDUs infected with HCV and fight against the persistence of hepatitis C in this marginalized population.

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