

Hepatitis C: How the Relational Context of Disease Shapes Stigmatization

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Abstract – Individuals infected with Hepatitis C virus are often stigmatized, a situation shaped through unique socio-political, economic, physical and linguistic factors. Socio-politically the association of Hepatitis C with injection drug use and the pervasive stigma present in not only the general population but within the health care system marginalizes patients. Patients often feel as though they are to blame and treatment will be “rationed”. The economics factors affecting those with Hepatitis C serve to further limit access to treatment. Underscoring these factors is a unique linguistic discourse that draws on the language of biomedicine, obscuring the experiences of individuals affected with this disease. Finally, the physical setting of Hepatitis C treatment can further entrench the stigma, and subsequently health care access. Physical spaces play into the power dynamic, even with well-intentioned treatment strategies such as locating Hepatitis C treatment within opiate substitution clinics. As nurses it is crucial to be aware of and address the full relational context of a disease in order to minimize stigma and enhance equitable treatment. Strategies to help nurses act relationally and advocate for the best interest of clients are presented in this paper.

Keywords: Hepatitis C, Relational context, Stigma, Injection drug use, Nursing

Introduction

Hepatitis C is a blood-borne virus first isolated in 1989 (Butt, 2008) that results in chronic infection in up to 200 million people globally (Wendt et al, 2014). It is estimated to infect 242,500 individuals in Canada (Public Health Agency of Canada, 2012). The Hepatitis C virus (HCV) is spread through unprotected sex, sharing injection drug use materials, unclean tattoo and piercing equipment, blood transfusions and transmission from mothers to fetuses. Up to 70% of new infections in the developed world occur among people who inject drugs (PWID) (Butt, 2008). Hepatitis C is a highly stigmatized disease (Butt, Patterson & McGuinness, 2008) and it has been shown to be strongly associated with drug use, Aboriginal ethnicity, unstable housing and HIV infection (Grebely et al., 2009) all of which also are associated with stigma. The intersectionality of the stigmas associated with these groups, along with the unequal distribution of who becomes infected, leads to poor outcomes, beyond the consequences of the physical disease for infected individuals. This paper will examine the relational context of Hepatitis C and examine how socio-political, physical and linguistic factors shape the associated stigma. Nursing interventions that improve outcomes for clients by addressing issues at the intrapersonal, interpersonal and contextual levels will be explored.

Stigmatization of Chronic Infections Diseases

Chronic infectious diseases have historically been seen through an “us” and “them” lens. In the past, individuals with diseases such as leprosy and tuberculosis were seen as “dirty” or “unclean” and afflicted individuals were isolated, for example in leper colonies and sanitariums (Williams, Gonzalez-Medina & Le, 2011). These individuals were effectively shunned from society. Much of this isolation was initially justified as a protective measure to isolate “carriers” and protect the public; however, the stigma often becomes entrenched. Even when a cure becomes available the social stigma remains (Williams, Gonzalez-Medina & Le, 2011). More recently, people with HIV/AIDS have faced similar stigma. Cogan and Herek (1998) describe four conditions that lead to a high level of stigmatization associated with infectious diseases; disease where it is perceived that it is the individual’s responsibility for having contracted it, diseases that are contagious and place others at risk, diseases that are not thought to have a cure and diseases that are visible to others. With the exception of the last criteria, all of these apply to Hepatitis C.

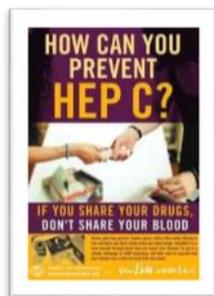
Placing the Blame on Individuals

Much of the stigma surrounding Hepatitis C is rooted in its strong association with people who inject drugs. Meeting Cogan and Herek’s first criteria, it is often assumed that the burden of acquiring the disease lies with the individual. The majority of public health campaigns target people who

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inject drugs (PWID) with posters such as Figure 1.

Figure 1. How Can You Prevent HEP C Poster



Caption: Figure 1 features a poster that says ‘How Can You Prevent HEP C?’ at the top, a picture of two hands exchanging a needle in the middle, and the statement ‘If you share your drugs, don’t share your blood’ at the bottom.

Retrieved From:
<http://harmreduction.org/hepatitis-c/hepatitis-tools/how-can-you-prevent-hep-c/>

While the poster here attempts to adopt a harm reduction view by avoiding the “just say no” message, it still employs a very individualistic approach and place personal responsibility for contracting the disease on the individual. Posters such as this one can add to stigma by sending the message that individuals are ultimately responsible for acquiring the infection. As nurses it is crucial to examine the messaging put forward in public health campaigns and advocate for wording that minimizes stigma and avoids further marginalizing vulnerable populations.

Low uptake of Treatment

Stigma is increased in diseases where a cure does not exist. Despite an effective treatment existing for Hepatitis C, uptake is very low (Grebely et al., 2009). Current treatment for hepatitis C is an antiviral called ribavirin along with peginterferon α (Wendt et al., 2014). While treatment has a good success rate, both physical and psychiatric side-effects are common. Side effects can include hematological changes, flu-like symptoms and profound depression (Sheppard & Hubbard, 2006). Many individuals do not view treatment as a viable option for them, or do not feel that they have access to treatment.

Reluctance or inability to access treatment is partly due to the fact that stigma exists not only in the general public but has been found to be pervasive among healthcare providers (BC Centre for Disease Control, 2011). Individuals have reported rejection by healthcare professionals and a large number of demands placed on individuals before they are given the “privilege” of treatment (Rhodes, Harris & Martin, 2013). Power dynamics play a crucial role and physicians are seen as powerful and as having the authority to decide to whom to dole out treatment. In the case of Hepatitis C, injection drug use was initially a contraindication to treatment in many places and individuals were denied care until they could be abstinent (Rhodes, Harris & Martin, 2013). The following quote by a patient describes the struggle to access treatment:

I’d get so fed up and sort of try to work out what’s going on. He would come up with ridiculous things and one of them was depression, you know, another was to stop injecting. But they were half-hearted, if you know what I mean. It was like he had decided he wasn’t going to treat me and I should have cottoned on earlier. (Peter) (Rhodes et al., 2013, p.1030)

It is evident that although objectively there is a treatment for Hepatitis C, to many individuals it is not accessible, thus Hepatitis C can be experienced more as a fatal, incurable disease, the third criteria Cogan and Herek (1998) associate with a high rate of stigma.

Linguistic Discourse: Hepatitis C compared to HIV

The linguistic discourse around hepatitis C and particularly the contrast with the linguistic discourse of HIV/AIDS is very interesting and highlights some key differences between the stigma related to these two diseases. Despite the fact that HIV and hepatitis C are both chronic blood-borne disease their social context has evolved very differently. AIDS activists played an early role in advocating to shift the discourse of HIV from one of purely biomedicine to a broader discourse examining social, political and cultural issues as well. Hepatitis C by contrast has not seen the same level of activism (Körner & Treloar, 2006).

A 2006 paper examining the discourse in editorials of four major medical journals found an exclusive reliance on biomedical language in the case of Hepatitis C (Körner & Treloar, 2006). Individuals with hepatitis C were only seen as “subjects” “patients” or “participants” in clinical trials and described as things to be acted upon. The HIV editorial content of medical journals goes beyond merely listing patients as “subjects” but includes articles discussing policy change and advocating for better methods of delivery of care. The discourses include social justice and ethics as well as biomedical discourses. It could be argued that this is because HIV has a longer history than Hepatitis C, but Hepatitis C was discovered in 1989. For the 10 year anniversary of the discovery of HCV there were no articles looking back and no articles addressing where we have come from. This is a stark contrast to HIV media. (Körner & Treloar, 2006).

This focus on biomedical discourse is evident in the popular media as well as medical journals. Using Google to compare the top 10 news headlines for Hepatitis C we see a similar pattern. Hepatitis C headlines focus almost entirely on drugs and the language of biomedicine. There is a significant lack of focus on the people who suffer. We see no articles looking at harm reduction, personal stories or advocacy. In contrast, the top 10 headlines for HIV involve

articles looking at harm reduction, awareness and many more focused on individuals, along with some articles from a more biomedical standpoint (Table 1).

Impact of Physical Location on Power Dynamics

The physical location of how and where diagnosis and treatment services are situated can have a significant impact on both access to treatment and the stigma of Hepatitis C. Hepatitis C treatment includes weekly injections of peginterferon α and clinics are only open certain hours, generally typical workday hours. For individuals that do not operate on a regular 9-5 schedule, or those that have work commitments during this time, missing physician appointments and subsequent withdrawal of treatment may result. It has been suggested in the literature that tying hepatitis C diagnosis and treatment to opiate maintenance programs may improve access to services by offering a sort of “one stop shop” (Rance, Newland, Hopwood & Treloar, 2012).

Although this might seem like a reasonable plan, a qualitative study conducted in Australia argued that this can in fact further cement the stigmatization of individuals already experiencing marginalization (Rance et al., 2012). The authors argue that the majority of research focusing on this concept relied on examining individual characteristics and ignored consideration of the cultural and contextual set-up of clinics offering opiate substitution therapy (OST). This study is based on the work of Michel Foucault, a post-structuralist from France. Foucauldian analysis focuses on the spatial and the idea that “analysis of power is also the analysis of spaces” (Rance et al., 2012, p.247). Many opiate substitution clinics have strict guidelines about attendance and Rance et al (2012) show that individuals fear that accessing HCV treatment at OST clinics may interfere with their ability to access their opiate substitution therapy. They fear that missing their appointments due to being sick from HCV treatment will mean they continue to be labeled as “junkies” who are “non-compliant” and further stigmatized. One individual describes it as follows:

The first month [of HCV treatment] when you're really sick. That would be the only problem, where you don't want to go out anywhere ... Until you can get better and then you can start going in to get [methadone] yourself ... (Male, 47 years) (Rance et al., 2012, p.250)

In addition, the services of a Hepatitis C specialist are usually physically located in large urban centres. Having to live close to one of these centres or travel for treatment can limit housing choices and options particularly for individuals already facing poverty and poor housing.

The Role of Nurses

As nurses it is crucial to address these issues at the

intrapersonal, interpersonal and contextual levels. Intrapersonally, nurses must be aware of their own views and beliefs towards, hepatitis C, infectious diseases and people who inject drugs. It is important to understand even with not knowing full details of a person's situation we can effectively support individuals by being with them as they experience difficulty. For Hepatitis C this may mean being with individuals when they receive a diagnosis to hear their worries and concerns about what this means to them and how they see themselves. During a course of treatment it may mean finding ways to provide comfort when individuals are experiencing difficult side effects, particularly the psychological side effects which are often said to be worse than the physical side effects. Additionally, it means having compassion for life circumstances that may make it difficult for individuals to follow a treatment regime.

Finally, nurses must act systemically. We must advocate for those with hepatitis C and assist them in advocating for themselves. Neale (2008) conducted a study with people who were homeless and used drugs, which they referred to as “homeless drug users” (HDUs) examining hepatitis C in the context of social exclusion. She emphasizes that the “experts on HDUs with HCV are obviously HDUs with HCV themselves” (p. 433). When looking at the discursive change that has occurred during the history of HIV/AIDS, it is evident that AIDS activists were able to learn the language of biomedicine and use this to gain credibility and make their voice heard in a system set up to favour a medical model (Körner & Treloar, 2006). Activists were able to bring their views into the clinical trials and the world of medicine. Hepatitis C needs to benefit from the same partnership between governments, community groups, activists and the health care system (Körner & Treloar, 2006). As nurses we can play a key role in this partnership. In addition, we need to be actively involved in research and expand publications to include discourses other than those from a biomedical model and to include that of social justice and ethics. Only by addressing issues at all three levels, intrapersonal, interpersonal and perhaps most importantly the contextual systemic issues, can we hope to reduce the number of individuals suffering from hepatitis C infection.

Table 1: Top news headline from a Google search on February 9 2014.

Hepatitis C	HIV
Gilead posts higher profit, strong hepatitis C drug sales	Crackpipe vending machines installed in Vancouver to curb spread ...
Hepatitis C: New Drugs Effective Yet Expensive;	AIDS Early HIV Cure
Experimental treatment cures Ottawa wrestler of hepatitis C	Trial of pill to prevent HIV could lead to rise in promiscuity, scientists ...
New drug Sovaldi heralds the end of hepatitis C in Britain	Flirting with danger: HIV storyline in Emmerdale - involving the old ...
Rs.7.5 crore to tackle hepatitis-C in Kashmir villages	UBC student Hayley Pipher to swim 10K for HIV awareness
UPDATE 2-Gilead posts higher profit, strong hepatitis C drug sales	Uzbek Girl Grows Up In The Shadow Of HIV
Maker Of \$1000 Hepatitis C Pill Looks To Cut Its Cost Overseas	Bionor Pharma: Vacc-4x Could Be The First Functional Cure For HIV
Hepatitis C investigation at Brantford General Hospital	Eliminating Paediatric HIV, Men Should Play a Part
Hepatitis C transmission confirmed at BGH	Manyara region plans to cut HIV prevalence
Drug approval delay condemning Hep C patients to death	Anxiety affects cognitive skills in midlife women with HIV

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