

Understanding Barriers to Hepatitis C Virus Care and Stigmatization From a Social Perspective

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A large body of literature emphasizes the relationship between stigma and adverse health outcomes and health access measures. For people living with hepatitis C virus (HCV), stigma is a defining feature given the association of HCV with the socially demonized practice of injection drug use. However, there is little literature that specifically examines stigma as a barrier to HCV care and treatment. This review argues that the relationship between the person living with HCV and their health worker can work to ameliorate the effects of stigma. We draw on an emerging literature that examines the positive association between a patient's "trust" in their health worker and outcomes such as increased healthcare utilization and reduced risk behaviors. We investigate a growing body of health services research that acknowledges the importance of stigma and demonstrates ways to build positive, enabling relationships between patient, health worker, and health setting.

Keywords. hepatitis C; injection drug use; stigma; trust; clinical encounter; patient-doctor relationship.

Hepatitis C virus (HCV) remains a clinical and public health challenge worldwide. Engaging people with HCV in care and treatment has been identified as key to ameliorating the growing disease burden and social costs related to HCV [1]. However, treatment uptake rates remain low despite advances in treatment [2]. One defining characteristic of the experience of living with HCV—stigma—has not been systematically explored as a barrier to HCV care. This review examines conceptual elements of stigma and illustrates its effects, drawing on empirical evidence. The discussion focuses on contemporary HCV healthcare models that are working explicitly to acknowledge and challenge stigma by emphasizing the importance of building trusting relationships between patients, health workers, and their clinics.

UNDERSTANDING STIGMA

There are many ways in which to understand stigma [3]. A core concept is the notion of a "spoiled" or "discredited" identity that attracts stigma [4]. Stigmatized people are typically labeled by others as undesirably different and consequently subject to exclusion, rejection, blame, or devaluation [5]. The stigmatizing process is inherently social in that a stigmatized identity is one that is understood to have breached the rule of society. Stigmatizing, and therefore devaluing, a person or act is the means by which the social body controls and contains threats against its order and values [3]. The notion of stigma may be delineated into "enacted" stigma (incidents of negative judgment or action) and "felt" stigma (fear of such judgment or action) [6]. The "medically unwarranted nature" of the adverse social judgment (against person or health condition) is another, typical feature of health-related stigma, as is the potential impact of stigma on social and health policy [5]. Other authors remind us to focus on the social processes of stigma, noting that stigma is intrinsically linked to expressions of power and control and to the maintenance of social order [7].

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WHY DOES STIGMA MATTER IN HEALTH?

Stigma has a direct detrimental influence on mental and physical health. There is a broad literature examining the association between illness-related stigma and various aspects of physical and psychological health, quality of life, impact on families and carers, the uptake of care and treatment, and increased risk of disability and advanced disease [8–10].

Stigma is an essential consideration in any examination of HCV [11, 12]. The experience of stigma and discrimination has been a defining feature for those living with HCV and is inextricably linked to its association with injection drug use [13–16]. People are stigmatized because of both HCV (an infectious agent) and injection drug use (breaching social conventions). Levels of stigma perceived by people who inject drugs (PWID) can persist even when drug use is reduced or ceased [17].

As with other stigmatized health conditions, the stigmatized status of HCV has had an adverse impact on the prevention of its transmission; on treatment-seeking, uptake, and adherence; and on quality of life [18–23]. A study of mood and adjustment to illness among 87 patients awaiting treatment for HCV in Ireland, examined various physical and mental health measures [18]. The impact of stigma was associated with a wide spectrum of health outcomes, from poor adaptation to illness to presentation of psychiatric disorder. Similarly, in a study undertaken in the United States, >50% of clients with hepatitis attending a hospital-based liver clinic reported stigma, with associations found between stigma and mental health symptoms, reduced quality of life, and difficulty coping [24].

The qualitative literature has documented and explored the experience of HCV-related stigma in detail. Participants report concerns about being stigmatized by family members or intimate partners [20], by the general public [24], and most particularly, via healthcare settings. The healthcare setting is the most commonly reported site for people with HCV to experience stigma. For our purposes, the healthcare setting represents a particularly important context of culture and power to explore HCV-related stigma. The literature clearly documents the roles that “enacted” and “felt” stigma play in undermining public health and clinical efforts to engage those living with HCV in care and treatment, as people will resist engaging with health services to avoid future experiences of stigma. The following quotes demonstrate the varying experiences of stigma within the healthcare setting:

I know how I answer his question is going to determine how I'm going to get treated in this town. I could lie and get treated well, or I could tell the truth and get treated like shit . . . I said “through intravenous drugs.” And his whole demeanor towards me completely changed. [25]

You just feel a little uncomfortable . . . like they think

(they'd) rather be seeing some old lady with a broken ankle or whatever . . . it's something that I've done to myself. It's like “if you do that sort of thing, this is what you get.” [25]

Because of being an ex IV [intravenous] user I have always found it very hard to get treatment from many doctors and they are very hesitant to have you in their surgery. More support is necessary, especially from the medical profession, with a little human kindness and not this feeling of “its the cross a user has to wear, its fully self-induced, therefore no support/sympathy.” [26]

STIGMA-REDUCTION STRATEGIES: THE CLINICAL ENCOUNTER AND TRUST

A key writer in the stigma field suggests that for interventions to be effective, they need to work with, rather than against, existing structures [27]. The clinical encounter is the social structure often cited by people with HCV as the key site of stigmatization [28, 29]. Examining the ways in which patients and clinicians interact, and the exercise of power within such interactions [3, 30], is a central research priority.

A defining element of relationships between clients and healthcare professionals is trust. A growing body of literature notes that trust between client and clinicians is essential for effective therapeutic encounters. Trust affects numerous important health-related behaviors, including willingness to seek care/use health services, uptake and adherence to treatment, quality of interaction between patient and doctor, patient disclosure, and behavioral change [31]. In this sense, trust is interpersonal, a quality of the relationship between individual client and health worker. Nonetheless, it is also important to consider trust at the system level, that is, the extent to which clients trust both the health system and the range of other social systems that govern modern life [32]. Thus, we recognize that a client's trust in their health professional may be related not only to their experience of and subsequent extent of trust in other parts of the health system (perhaps unrelated to HCV care), but also to other social systems (the judicial system, child protection, employment, welfare, and so forth) [33, 34].

The link between trust in one's clinician and health-related behavior is important. A study of 374 PWID, recruited in the United States [35], explored why some participants used services available to them and others did not. Factors that were independently associated with increased healthcare utilization were trust in physician, not experiencing depressive symptoms, being human immunodeficiency virus (HIV) positive, and having health insurance. Underlining the greater importance of attitudinal rather than demographic variables in explaining healthcare utilization, the authors urge health policy makers

and clinicians to attend to factors such as trust when formulating decisions about services for vulnerable populations.

In France, the risk practice of distributing or “passing on” used injection equipment for others to (re)use was examined in a sample of 224 HIV/HCV-coinfected participants [36]. This cohort demonstrated that a reduced likelihood of distributive sharing was associated with trust in one’s physician. The authors suggest that building a trusting relationship with a physician allowed clients to shift from seeing themselves as only a drug user to seeing themselves as a legitimate patient. This positive shift in identification was suggested as, in turn, promoting attention to other health-related issues, such as the reduction of injection risk practice.

A recent qualitative study examines the association between stigma, patient–doctor relationships, and a “rationed expectation” of access to HCV treatment [37]. The case of “Peter” is explored in detail. Peter had tried unsuccessfully for 10 years to access HCV treatment. He notes his expectation that access to HCV treatment for PWID would be rationed (or absent) and also draws on his personal experience of a 10-year relationship with a doctor that did not result in treatment and also failed to develop his general literacy of hepatitis C treatment.

I’d built up, from chatting to other people and stuff, that treatment for hepatitis was rationed, they didn’t treat i.v. users. I got a lot of feedback: “you don’t want to bother because they’re not going to treat you” and my experience was the same as well: I hadn’t been treated.

He was literally saying “Look, you’re never ever going to be treated here”. That’s what he was telling me, but he wasn’t telling me directly. . . .It was a way of saying it without saying it. . . because he couldn’t say it because he’d get into trouble if he said it, wouldn’t he? That’s why I think he tolerated me all those years, because he had to, if you see what I mean. But he had made up his mind the first or second or third time we had met. . . .He was in control. I was meant to be the submissive patient. . . .I had to keep my mouth shut, and you know, I wasn’t a productive member of society. That’s what I felt. I wasn’t someone who was going to make a difference to society, you know. He had more important patients than me, that’s what I felt.

Peter was finally offered treatment when he sought care with another doctor in another hospital. There, Peter noted, he “never felt uncomfortable there. There was no judgement at all” and the staff remembered him from month to month. The authors emphasize that the positive therapeutic relationship developed in the second site was experienced as exceptional and that throughout their qualitative data, access to HCV treatment was met with gratitude rather than with any strong expectation of a right to treatment.

This emerging body of literature underscores the primacy of trust between client and health worker (and health system) when considering ways to minimize the negative impact of stigma on HCV care. Below, we briefly outline various models of care for HCV. Evaluations of these models have shown that the design of care has paid particular attention to understanding the ways in which stigma is produced by social institutions (including and especially healthcare) and developed strategies to promote and build trust among its intended clients.

In Christchurch, New Zealand, a nurse-led community clinic was established for people with HCV unwilling or unable to access care in other settings. Within 3 years of its establishment, the clinic had enrolled 500 clients. The clinic provided care that was highly endorsed by clients. Clinic staff were perceived as less discriminating than staff of other health services [38]. The qualitative evaluation provided further detail on the relationship between clients and clinic staff:

I mean the clinic staff members were understanding. They heard what I had to say. They didn’t look down on me. They basically talked me through it and, basically, yeah, like they supported me. When I found out I had hep C they gave me support, showed me where to go if I need any help. Showed me like the process and told me about the disease. . . .They were helpful. They were understanding. They weren’t judgmental. And they were, like they informed me about what’s happening and the course of the disease, and basically everything about it. And I mean like I like going there because basically I feel welcomed and helped, you know? And I feel being taken care of. Whereas, going to my GP was something I just dreaded. (Alvin, clinic client) [39]

I actually introduced [my mates] to the clinic. . . .So I’ve sort of just been saying, like: “There’s a free doctor there, there’s a social worker there, there’s so much, you know. . . .even if you’re sure, go over and ask them; they can tell you yeah or whether they can help you out of not, you know? And they’re never rude to you and they’re never disrespectful, you know? They don’t judge a book by its cover.” (Daphne, clinic client) [39]

Interestingly, measures taken of HCV knowledge among this population showed rates of correct knowledge (>89% indicating a correct answer on all 13 knowledge items) markedly higher than those collected from a sample of Sydney-based clients (from OST clinics and the Medically Supervised Injecting Centre in Sydney). For example, 17% of the Sydney sample could identify that alcohol can contribute to complications of HCV, compared to 97% of the Christchurch sample [40]. Moreover, the Christchurch clinic appeared to be comparatively more successful in engaging clients in HCV treatment: 60% of the Christchurch sample had seen a specialist for HCV

assessment, which was double that recorded in a sample recruited from a variety of community and health services in New South Wales (NSW), Australia [41].

In NSW, Australia, 2 models of HCV treatment have been implemented to diversify sites offering care beyond the traditional tertiary-hospital setting. One model is exploring HCV treatment provided by community-based general practitioners. Initial evaluations of this model show that patients' decisions to undertake treatment in the community were underpinned by their ongoing relationship with and trust in their general practitioner, coupled with concerns about relocating care to an unknown hospital setting [42].

A second model in NSW is exploring the delivery of HCV care via OST and community health clinics. Evaluations of this model revealed a number of reasons as to why patients were attracted to a co-located treatment model (of HCV and OST services). In part, the existence of an already established relationship with the OST clinic, along with concerns about possible negative judgments when relocating to another service, featured in clients' decisions to undertake HCV care within their OST clinic.

[The OST manager] had positive words about it . . . And for a person to take the time out and actually talk to me about it, I trusted her and I thought, you know,

“Well maybe I should give it a go.” (Tracy, 33, awaiting or initiated treatment) [43]

Peer workers have been instrumental in supporting both the establishment and daily management of HCV care services [43–45]. The quality of relationship between the client and the clinic was consistently noted as central to the clients' concerns. Participants indicated that they wanted a clinic that promoted a “humanistic, genuine, honest, non-judgmental and calm environment that considered the emotional well-being of patients” [44]. The involvement of peers worker was seen as central to engaging clients who may have had previous negative experiences of healthcare and were distrustful of health professionals. The peer worker allowed clients a safe way to engage with HCV care:

I think the fact that she has been there makes you feel that you don't have to hide anything from her. She is not judging you. She won't will she? Everything she gave us or however we carried on with our habits is something that she does know. [44]

A final model to note relates to HCV testing that side-steps the issue of identifying at-risk (and therefore stigma-attracting) groups. The US Centers for Disease Control and Prevention have advocated for a birth cohort HCV screening program, on the basis evidence that this age group comprises <30% of the total population but accounts for three-quarters of all HCV infections [46].

Targeting HCV testing to this age group was determined to be a cost-effective strategy, regardless of patient report of risk.

Although the care models featured in each of these examples may not have explicitly cited stigma as a key factor in its design and implementation, the focus on the relationship between client, health worker, and clinic was central to each. Trusting relationships were consistently recorded in evaluations of each model as critical to their operational success. The quotations we have cited, all taken from evaluations of these models, are at odds with the stigma-related quotations we presented earlier in our article. Rather than feeling unwanted, uncomfortable, or even rejected, clients at these clinics described feeling welcomed and heard, to the extent that some promoted the positive atmosphere of their clinic to their friends and peers.

CONCLUSIONS

This review urges raising and prioritizing the profile and understanding of stigma and its central role in patient decision making about “if and how” to engage in HCV care. Similarly, we have highlighted the emerging literature that addresses the role of trust in building and maintaining effective relationships between client, health professional, and health system. We need to acknowledge the potential disconnect between the lived experience of HCV and the assumptions of health professionals and policy makers. It may be that the centrality of stigma and mistrust is underestimated and receives little attention when considering how best to engage with, and attract, people living with HCV. Developing genuine partnerships with people living with HCV and consulting them on the design and operation of health services may be a first step toward establishing, modifying, or reforming health services to better address stigma as a barrier to HCV and treatment.

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