

MENTAL HEALTH AND HEPATITIS C

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SECTION

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PSYCHOSOCIAL ISSUES AND HCV

Introduction

Having the *hepatitis C virus (HCV)* raises many questions and concerns. With the diagnosis comes information about a chronic and often progressive disease that may lead to significant complications. Treatment is indeed possible and increasingly successful, but it can be cumbersome and may lead to significant side effects.

Yet, concerns about HCV go beyond medical questions about the disease and its treatment. Hepatitis C is a liver disease caused by a virus that is typically transmitted parenterally, meaning through blood products or contaminated needles or surgical instruments. All these seemingly simple facts affect the lives of many patients infected with HCV. There is guilt by association. Suffering from a blood-borne illness, an illness affecting the liver, carries a stigma.

There is the concern about passing the virus to others. Patients themselves or others may shy away from personal contact, fearing that the disease might spread. And then there is the experience of a disease and its treatment that drains energy as if invisible forces were at work, not allowing patients to meet expectations.

Such problems can cause patients to feel alone, isolated, and rejected from their much-needed social support system. Several recent studies have focused on the social implications of HCV. This section will present an overview of the effects HCV can have on patients' social support systems. It is our hope that:

- Recognizing these problems will function as the first step toward solving them.
- Reading about such difficulties may help some patients prepare for future challenges or to see that they are not alone in their experiences.

Problems in Close Personal Relationships

The social implications of HCV can be very important to patients. The significance was effectively shown in a study by Coughlin and her team where they found that the level of social functioning for female patients with HCV was the best predictor of patients' psychological well-being and overall mental health.¹ Yet what remains more elusive in the published literature are the specific social challenges that patients with the HCV diagnosis face. Given the lack of available information to provide these details, we will draw on our own investigations on social issues affecting patients with HCV and place these in the larger context of the medical literature. We will especially focus on the voice of the patients themselves and the concerns they express.

We conducted a large study interviewing several hundred patients with HCV seen in a university-based *hepatology* clinic.²⁻⁴ We asked about the effects of their disease on their interactions with others. Nearly half of these patients noted that having HCV had resulted in a significant strain or actual loss of at least one relationship.⁴ They reported problems with sexual partners (17%), family members (16%), and friends (12%).⁴ Nearly 1 in 10 of the patients had lost contact with more than one person in their lives due to the disease.⁴ As one man expressed, "When I got here [to the clinic] they told me I had hep C and then, when I was honest about it and told a girlfriend. I no longer had a girlfriend."

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Patients often used powerful language to describe their isolation after the diagnosis, employing terms such as “lepers” and “hermits.”² “When I first found out, I always felt dirty, like someone who had leprosy or something.” Interestingly, it was not just the people around those with HCV who shied away from close contacts. A small number of patients saw themselves as a potential cause of harm, with 7% noting that they themselves had limited their social interactions.⁴ One man mentioned that he was too concerned to interact with others. “I’m constantly aware of being around people in my surroundings, because you don’t want to give it to anybody else. So it kind of plays with your mind a little bit. I was really depressed at first because it felt like you were just unclean or you [could] contaminate them. I got isolated from society and kind of stayed by myself.”

Stress and Concern, and the Erosion of Social Support

In discussing the loss of social support, patients explained various reasons for the toll HCV had taken on their relations. Surprisingly often, it was the physical symptoms and consequences of the disease itself and its treatment that had caused the difficulties. About one-quarter of patients described stressful situations where family members worried about their health, or where they themselves worried about being able to stay healthy for their loved ones.⁴ One woman noted that, “my relationship with my daughter has changed as well, because, after I found out, she got pretty angry with me. I think it’s just because I was so sick.”

A professor of nursing shared a similar experience in her narrative account of her infection and successful treatment for HCV.⁵ Dr. Jana C. Saunders wrote that, “my HCV illness was very difficult for both of my daughters. While they never told me about all their concerns until after I had completed the treatment, they now tell me they were afraid I would not survive the treatment or the disease. I could tell by their physical and emotional distancing from me, they also had a hard time coping with my new disease.”⁵ Such accounts exemplify the extent to which HCV and the side effects of treatment can affect patients’ lives.

Fatigue and Misunderstanding can Affect Social Networks

One of the major physical symptoms affecting relationships was *fatigue*. Unfortunately, fatigue is a prevalent symptom of HCV infection and a common side effect of antiviral treatment. In a study of patients who had never been treated, 86% described fatigue as a symptom.⁶ In our study, participants described the effect fatigue had had on their lives. Whether caused by the HCV disease or its treatment, this symptom had become a real burden on relationships for 14% of patients.⁴ In addition to having strained relations with his wife and children, one man explained, “The relationships with friends have pretty much died out, too. I have a few friends that I keep in contact with...Basically I do not have any good relationships with anyone.”

Patients associated fatigue with lower social support. In our study it was associated with many symptoms, both mental (*depression*, anxiety) and physical (mobility, ambulation, body care and movement).⁴ Similarly, Hilsabeck and colleagues reported that poor social functioning was the biggest predictor of fatigue.⁷ This study raises the interesting question of whether there can be a two-way association between fatigue and social support where poor support worsens physical symptoms or their perceived effects on patients, which in turn, further reduces social support.

In addition to the physical manifestations of hepatitis C disease, the public comprehension of the disease posed a source of relationship problems. Patients encountered individuals who demonstrated a complete lack of understanding of HCV. This in turn affected their social interactions.⁴ For example, when asked about changes in relationships, one man noted, “Don’t have any. Lot of stress. Extreme amount of stress. Because they don’t want to take time to read. They don’t want to take time to listen to what you got to say....I didn’t know nothing about this until I started reading on it.” Other patients noted that family and friends did not believe they were physically limited by HCV as they did not appear classically “sick.” This led to accusations that HCV was not a “real” disease, like cancer or heart failure, and that instead the patient must be pretending to be ill.⁴

Employment and Financial Issues and the Straining of Social Support

The diagnosis of HCV and its effects on physical and psychological health also negatively affected patients' ability to meet professional expectations. In our own treatment study, nearly a third of our patient sample had experienced difficulties in the work environment.⁸ Such problems at work, especially when it resulted in a demotion or even the frank loss of work, resulted in turmoil for patients and their social lives. One man and his wife described the emotional and social impact of losing a job due to HCV. "I used to be able to work and do things on my own and I don't feel like it. I'm not able to do anything like that anymore. So I feel kind of low, more than I'm use to. And this female [turning to wife] would go to work every day and bring home a paycheck. It's kind of a drag on me and makes it even tougher on her...and the little ones feel it also."

Although our studies have found employment to be an area of major stress for patients with HCV and their families,^{2,4,8} little in the published literature has helped to shed light on this phenomenon.⁹ Minuk in his study of expressed concerns of HCV patients reported this problem,¹⁰ as did Hopwood and Treloar in their qualitative study of patients' experiences in undergoing antiviral treatment.¹¹ However, more work is needed to clarify the stressors that HCV patients face in the work force and the effect it has on their social lives and health.

A related concern emerges from the financial problems patients experience, which can add to their already significant emotional stress.⁴ Patients stated they were often supporting treatment costs out-of-pocket, and the rising level of debt from treatment helped to further strain familial relationships. Such experiences became especially difficult when patients faced a job loss caused by their HCV. One woman explained that she had been fired for absences incurred due to her disease. When asked to describe what the effect of the disease had been, she explained, "Tremendous! I had to quit my job. I am a single parent raising four kids, two of which are teenagers. It's hard. I cannot work full-time and parent. I had probably the best job I ever had. I had to give it up in March because it was either work full-time or parent. And I am not about to give my kids up." These findings are supported by Zacks and colleagues who found that 66% of HCV-positive participants expressed concern over their financial security.¹²

Fear of Transmitting the Virus and the Effect on Social Support

Another common concern voiced by 25% of our study participants was the fear of potentially transmitting HCV.⁴ Although the current literature indicates that the likelihood of spreading HCV through casual or sexual contact is low, patients and their family, friends, and coworkers remained concerned.¹³ In one study, patients indicated a substantial change in sexual behavior due to the disease, with 20% of participants saying that they kissed less frequently and 27% noting that they engaged in less sexual intercourse.¹² In our own study, 20% of patients spontaneously stated that they worried about possibly infecting sexual partners and family members.⁴ A patient shared the stress he experienced in his relationship: "From the very get-go of knowing I had this, the changes were that my wife was more scared...All of a sudden she wanted to use protection and I was like, why, we have been married twenty years and you don't have it. I do."

Another isolating aspect of the disease came when patients chose to limit contacts in order to avoid any potential spread of disease.⁴ In our interviews, patients agonized over the hope of ever finding a partner if they were not currently in a stable relationship. This concern was reflected in the statement by one young man, "[HCV] is hard on friends. It's hard on families, and extremely hard on relationships. That's one of my major concerns right now. Suppose I meet somebody and we hit it off pretty well. It's like, well, do I tell them I have hep C? I feel you should tell them right away instead of going on with something and getting along and saying 'I have hep C' and 'oh, oh,' you know? Because whenever you mention a blood virus the first thing that comes to people's mind is *HIV*." These findings are consistent with results published by Zacks, with 19% of participants reporting that they were less likely to date due to HCV disease.

Perhaps more surprising, 1 in 6 patients mentioned fears related to transmission through casual contacts with friends and/or children.⁴ "My family's aware of [the HCV] and I've become super protective of them. Not a total quarantine, of course, but we practice very strict hygiene rules."

Our results have been corroborated by others. In a study by Minuk and colleagues, patients listed transmitting the virus

to family members and to others as two of the biggest stressors related to their HCV diagnosis.¹⁰ Additionally, in a study of HCV and attitudes toward blood donation by Waldby and colleagues, patients with HCV were described as viewing their blood as a danger that they needed to protect others from.¹⁴ Finally, the study by Zacks also found that participants changed behavior by especially limiting exposures to their body fluid, by not sharing a drinking glasses (45 %), towels (35 %), and not preparing food for others (14 %).¹²

Lifestyle & Emotional Difficulties and Social Support

Having a liver disease and adhering to treatment recommendations often requires significant lifestyle modifications. *Abstinence* from drug and *alcohol* often changed interaction patterns with friends and acquaintances. In our study of patients undergoing antiviral therapy, 22% of the participants admitted having difficulties in eliminating all alcohol or illegal substances from their daily routine.⁸ To remain compliant with treatment recommendations, patients felt the need to restrict their contact with family and friends in social situations that traditionally involved alcohol, such as going out to a bar or restaurant. One man shared his experience saying, “I don’t go out as much. Since this is a liver disease, I hardly drink. I do slip occasionally because, hey, it is a good time. I have got friends that are social and relationships are built around hitting the bars and talking and having a good time, maybe seeing some music. So, while I still go out, I don’t drink as much and, frankly, it is not as exciting as when you don’t have a few drinks. So those relationships have changed.” Others who had lived a life involving alcohol or drugs also experienced difficult challenges as they felt compelled to change their social circle. One man described the progress he had made but also the struggles he experienced in re-orienting his social life. “My friends have really changed to where I used to have a bunch of drinking buddies.... A lot of those buddies are gone.”

The emotional problems caused by HCV and/or its treatment also worsened interpersonal relations. A study by Lang and her colleagues found that for patients who had never experienced treatment, irritability was the second most prominent symptom (behind fatigue).⁶ One in five patients in our study felt their temper had led to deteriorating relations with friends and family members.⁸ “My wife said that I’ve been moodier. There’s been swings towards raising my voice to the children and to her maybe.” The isolating impact of the emotional irritability was revealed by one man who noted, “I think I’ve withdrawn a lot more. I’ve been a little testier, harder to get along with those I’ve maintained contact with. The close ones have gotten the worst of it, unfortunately.”

The Isolating Effect of Social Stigmatization

Having a liver disease, a disease most likely caused by contaminated blood or instruments, is often also associated with a value judgment. The links between alcohol, intravenous drug use, and liver disease frequently trigger reactions in others that the disease may well be a consequence of inappropriate behavior, thus casting the shadow of stigmatization over patients.

Several patient groups have been found to experience such negative stereotyping, especially those with active intravenous drug habits or mental disorders. Crockett and Gifford found that female drug users in Australia have experienced widespread and extensive stigmatization.¹⁵ This phenomenon extends beyond actual drug users and can affect individuals regardless of how HCV was contracted. In the study by Zacks, 51% of participants noted that they experienced social rejection due to their disease.¹² In our own study, 57% of participants had experienced some type of stigmatization related to HCV.²

Patients described three major reasons for feeling stigmatized.² First, they felt others confused or associated HCV with HIV/AIDS.² Some mentioned that the acronym “HCV” led to confusion. One man shared the story of being informed of the diagnosis via a letter from the blood bank where he had donated blood. “When I first found out about it from the blood bank saying I had HCV – ‘wait a minute HIV!?’ I confused it and said ‘oh no!’ and worried how to tell my wife I had this.”

Second, given the commonly perceived link between blood-borne diseases such as HIV/AIDS and sexual transmission, patients were frequently viewed as sexually promiscuous.² One woman noted, “You know, my doctor was telling me, it’s almost like AIDS. You can catch it from kissing or having sex, or using the same container, drinking out of the same milk

jug. So, it kind of scares your friends away.”

Finally, many patients were automatically seen as drug users.² One woman explained, “People don’t understand what [HCV] is about. When they hear hepatitis, they think of IV drug users. That’s what I always thought when I heard of it years ago.”

The experience of stigmatization is not trivial. It may disrupt important and close ties with family members and friends. Nearly 1 in 5 patients reported that HCV-related stigmatization had negatively affected relations with family and/or friends.^{2,4} One patient noted that she had been denied the right to see a family member. “We have to file for grandparent visitation rights. They tried to hold my disease against us, so I could not see my grandson.” Another man shared the experience of losing contact with family members. “My real daughter from a previous marriage really got farther away quick; won’t have anything to do with me any more. . . I have no idea what that was all about. She had a couple of babies there and I don’t know if she thought that I was going to contaminate the kids or what, but she hasn’t called for about two years since she found out.”

Based in part on such experiences, 18% of the persons interviewed had decided that they would not tell others about their disease in order to decrease the chance of receiving a negative reactions.⁴ However, such a lack of disclosure could ultimately result in a lessening of social support as well. One woman responded to the question of what effect her disease had had on relationships, “I don’t have any...I avoid them. In fact, I’m really cold with people. I don’t let no one warm up to me, to get close, because I don’t want nobody to know.”

As noted above, suffering from a viral infection of the liver affects the work environment. In addition to physical problems, 26% of patients shared examples of being stigmatized in the work environment due to their disease.² One woman wrote, “When I first found out and they phoned at work, it was like I had leprosy because everyone stayed away and did not talk to me...That was pretty bad.” Others noted that they had directly lost work due to prejudice and stigmatization. One man stated that he had lost multiple jobs due to stigmatization. “The next job I was terminated from I told my supervisor, because I was working handling bread trays that were 13 feet off the floor, I told my supervisor if I ever got knocked unconscious, don’t touch my blood. Less than a week later, I was in the unemployment line. The third job I got fired from I was working at [Blank] Foods and I cut my hand and they out and out told me point blank...the reason they fired me is that I have hepatitis C and I pose a direct threat.”

Stigmatization Within the Provider–Patient Relationship

Some patients with HCV have experienced stigmatization in the medical environment. Often the healthcare provider is the first person the patient learns the diagnosis from. The healthcare provider is also the person the patient needs to turn to in order for management and treatment of the disease. Therefore, feeling stigmatized by doctors, nurses, or other healthcare workers can have significant implications.

We studied patient perception of communication with doctors taking care of their HCV and found that 41% of the HCV patients had some type of communication difficulties with their doctors.³ This included 9% feeling directly stigmatized by their doctors, with 16% feeling that they had been abandoned by their healthcare provider either in the context of a misdiagnosis or as a result of poor care.³ Such an experience can cause frustration, as described in a comment a patient made to his wife during an interview. “Remember when we went into the emergency room? You said I have hepatitis C, and I just inhaled some *ammonia*, and they thought we were drug dealers? I was farming this fall and I took a big dose of anhydrous ammonia. Four hours of waiting because the first thing they think of is ‘he’s a meth dealer’, you know?”

Our findings do not stand alone. Grundy and his colleagues found that female HCV patients experiencing stigmatization within the medical environment held negative feelings toward their healthcare providers.¹⁶ Day, Ross and Dolan reported stigmatizing experiences among heroin users infected with HCV.¹⁷ Banwell and her group revealed similar experiences of medical discrimination amongst HCV infected lesbians and bisexual women.¹⁸ Schaefer and colleagues noted that 39% of patients in their study had experienced stigmatization and other difficulties communicating with their healthcare providers.¹⁹ Perhaps as a result, 55% of patients in the study stated that they had not told at least some of their medical

providers of their HCV diagnosis, thereby limiting the medical insight into their disease.¹⁹

Two large studies conducted by Gifford and his group determined that nearly half of the HCV infected patients rated their treatment by medical professionals as poor and attributed this to their HCV status.^{20,21} Finally, Paterson and her team described abandonment and frustration by patients, noting that those who were ineligible for treatment or who had experienced treatment failure felt they had nowhere left to turn.²²

As the doctor-patient relationship is so important to helping those with HCV adjust to and live with their disease, the question arises of why such problems exist. While no study definitively answers this important question, some data suggest that poor knowledge of HCV may contribute. Previous studies have demonstrated that primary care providers, medical residents, and other healthcare providers are often not sufficiently trained or comfortable in diagnosing and treating HCV infection. Nicklin and colleagues found widely varying recommendations for HCV-infected patients among primary care providers.²³ Similarly, Shehab and his group reported that 25% of primary care providers did not know what treatment to recommend for HCV, thereby delivering suboptimal care.²⁴ Negative attitudes that providers may hold toward *interferon-based therapy* itself (given its early low success rates and of the array of possible side effects) may further complicate this situation.^{25,26}

Studies suggest that healthcare providers may also have an aversion toward HCV-infected patients themselves.¹¹ The reasons for this stigmatizing treatment are not clearly known.²⁷ Negative attitudes may further exacerbate knowledge deficits, which can be caused by rapidly changing medical recommendations, and the complexities of managing patients with multiple psychiatric and medical conditions.²⁷ Fear of exposure to the hepatitis C virus may also lead to potentially stigmatizing behavior.²⁸

Regardless of why some healthcare providers may hold such beliefs, the ultimate result is that patients with HCV can experience problems in developing the relationships they need in order to effectively face and manage their condition.

Summary

In conclusion, this section has described some of the challenges that people living with hepatitis C may face. Hopefully, an improved understanding of the disease will lessen the likelihood of negative social stereotyping. While educational efforts should emphasize and explain appropriate precautions, they need to more specifically address unnecessary concerns about endangering others through the spread of the hepatitis C virus.²⁹⁻³¹ Such information should be easily available for healthcare professionals, patients, relatives, friends and/or others interacting with individuals living with hepatitis C.

As the powerful narratives of patients who experience the physical, emotional, and social effects of their hepatitis C disease show, educational campaigns should devote some efforts toward dispelling myths that may underlie some of the stereotyping or unwarranted anxieties patients or other have.

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