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Exploring drug users' attitudes and decisions regarding hepatitis C (HCV) treatment in the U.S

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Abstract

Individuals with a history of injecting drugs are at the highest risk of becoming infected with the hepatitis C virus (HCV), with studies of patients in methadone maintenance treatment programmes (MMTPs) reporting that 60–90% of intravenous drug users (IDUs) have the virus. Fortunately, HCV therapy has been shown to be effective in 42–82% of all patients with chronic HCV infection, including IDUs. While the decision to start HCV therapy requires significant consideration, little research exists that explores the attitudes of drug users toward HCV therapy. Therefore, this paper examines how drug users perceive the treatment, as well as the processes by which HCV-positive individuals examined the advantages and disadvantages of starting the HCV medications. Interviews were conducted with 164 patients from 14 drug treatment programmes throughout the United States, and both uninfected and HCV-positive drug users described a pipeline of communication among their peers that conveys largely negative messages about the medications that are available to treat HCV. Although many of the HCV-positive individuals said that these messages heightened their anxiety about the side effects and difficulties of treatment, some patients said that their peers helped them to consider and/or initiate HCV treatment. Gaining a better understanding of drug users' perceptions of HCV treatment is important, because so many of them, particularly IDUs, are already infected with HCV and may benefit from support in addressing their HCV treatment needs. In addition, currently uninfected drug users will likely remain at high risk for contracting HCV and may need to make decisions about whether or not to start the HCV medical regimen in the future.

Keywords

hepatitis C; substance abuse; drug treatment programmes; medical treatment

"...most people who have hepatitis C, they're not worried about...contracting it or how to avoid contracting it. They've got it...They're worried about, number one, what the treatment protocol includes."

-- male, MMTP

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Background

Hepatitis C virus (HCV) is a blood-borne infection that is reaching epidemic levels in the U.S. (Alter & Moyer, 1998; Centers for Disease Control and Prevention [CDC], 1998; Garfein, Vlahov, Galai, Doherty, & Nelson, 1996; Hagan et al., 2001; Thomas et al., 1995). Fortunately, recent advances in the treatment for HCV have resulted in pharmacological therapy that is successful in clearing the virus in approximately half of all individuals (with rates as high as 82% for certain groups) who complete the "gold standard" medical regimen, a combination of pegylated interferon and ribavirin (National Institutes of Health [NIH], 2002; Pearlman, 2004a, 2004b; Teo & Hayes, 2004; Zeuzem, 2005).

Although most new cases of HCV infection occur among IDUs, historically the HCV treatment regimen was not always recommended for active drug users (NIH, 1997). However, in 2002, NIH reviewed the most recent developments in HCV research and updated the Consensus Statement Guidelines for HCV Treatment. Reacting to several studies that suggested that IDUs respond as successfully to the current HCV therapy as patients without a history of injection drug use (Backmund, Meyer, Von Zielonka, & Eichenlaub, 2001; Dalgard et al., 2002; Schaefer, Heinz, & Backmund, 2004; Sylvestre, 2002), NIH expanded the Consensus Statement to recommend that potential candidates for treatment include active IDUs, as well as people currently taking methadone (NIH, 2002).

While these new recommendations are an encouraging development in addressing the treatment needs of chronically-infected drug users, an HCV-infected individual's decision to start the drug regimen is complicated by a number of factors. For instance, once chronic HCV infection is confirmed, individuals need comprehensive medical testing to determine the appropriateness of starting treatment (NIH, 2003). In addition, researchers have pointed out the need to utilise a collaborative team approach to successfully treat people with a history of substance abuse for HCV that relies on the input of a number of health care providers, including primary care physicians, HCV specialists, psychiatrists/psychologists, social workers, and drug counsellors (Edlin, 2002; Sylvestre et al., 2004). Yet, many HCV-positive drug users are likely to have difficulty obtaining comprehensive evaluation and care from a multidisciplinary team of medical providers, as this population often has limited access to health care services (Bae, 1997; Chitwood, McBride, French, & Comerford, 1999; Contoreggi, Rexroad, & Lange, 1998) and people with HCV are more likely to be uninsured or have publicly-funded health care (NIH, 2002). Given the large number of medically uninsured drug users in this country and the high cost of HCV medications (\$15,000 or more for a full course of treatment in the U.S.), many infected individuals have to apply for financial assistance programmes funded by pharmaceutical companies to pay for treatment (Schering-Plough, 2006). Some studies have also identified patient level barriers to the use of health services among people with substance abuse histories. For instance, research conducted with people living with HIV/AIDS found that individuals' decisions to take or not to take antiretroviral treatment were influenced by their perceptions about the treatment and alternative therapies, spirituality, and desire to avoid adverse side effects (Kremer, Ironson, Schneiderman, & Hautzinger, 2006). However, few studies have explored HCV-positive drug users' attitudes about HCV pharmacological therapy or the decisions they make when contemplating HCV treatment. Therefore, using qualitative data collected from 164 drug users across the U.S., this paper will present their perceptions of the HCV medicine regimen and those influences that contributed to some individuals' decisions to either initiate or avoid HCV treatment.

Methods

The qualitative data presented in this paper were collected during interviews with patients conducted at 14 drug treatment programmes throughout the U.S. (seven programmes were

located in New York, while one programme was located in each of the following states: Maine, Arizona, California, Kentucky, Texas, Washington and Florida). In total, 62 patients completed

Arizona, California, Kentucky, Texas, Washington and Florida). In total, 62 patients completed an individual face-to-face interview with the project researcher and 102 patients participated in a focus group interview format. The number of patients that participated in the individual interviews at each programme ranged from 4–8 and averaged 5 individuals, while 5–13 patients (8 on average) participated in the focus group interview at each programme. These individuals were seeking addiction treatment at either: 1) an outpatient or residential programme that did not provide medication to treat drug dependence; or 2) an outpatient methadone maintenance treatment programme (MMTP).

The Study Sample

The majority of the patients were male (63%) and identified as heterosexual (89%; as compared to 6% bisexual and 5% lesbian/gay). Most patients ranged in age from 20–39 years old (47%) or 40–59 years old (52%). In addition, almost half of the patients reported that they had never been married (46%), while 44% were legally/common law married and 10% were divorced, separated or widowed. Twenty-seven percent of the patients identified as African-American, 29% Hispanic, 60% non-Hispanic White, 3% More than one race, 7% Other, and 3% American Indian/Alaskan Native (total % greater than 100 due to more than one answer choice). When asked to report the highest grade of school they had completed, 31% reported that they had not received a high school diploma or equivalent, 36% said they had completed high school or equivalent, 22% reported some college but no degree, and the remaining 11% had either an Associate's or Bachelor's degree.

On average, participating methadone patients were significantly older than the non-methadone patients (44 years old vs. 37 years old; P.001) and had a significantly higher percentage of female patients (48% female patients vs. 29% female patients; P=0.012). The participating patients' education level at the programmes also varied significantly depending on treatment modality. In the non-methadone programmes, 38% of the patients did not complete high school and 23% had education beyond high school. This was the case for 22% and 46% of the methadone programmes in the sample did not differ from one another with respect to race/ethnicity, marital status and sexual orientation.

Data Collection Procedures

The interviews were conducted in confidential settings at each location. Recruitment for the interviews was conducted by designated staff at each programme, and all participating patients went through informed consent procedures. Being HCV-positive was not used as an eligibility criteria for recruitment, and patients were reminded that any disclosure of HCV status during the interview was voluntary. However, a substantial number of individuals did disclose their HCV positive sero-status to the researcher. Interviewees were asked a wide range of questions about HCV and their perceptions of any existing HCV services at their respective programmes. Those individuals who voluntarily disclosed their HCV-positive status were also asked to share their experiences related to living with the virus, including treatment concerns.

Data Analysis

All but 5 of the interviews were audio-recorded. In the 5 instances where patients did not consent to this process, they allowed the researcher to take written notes. All of the audio-taped and written interview data were transcribed verbatim and subsequently coded and analysed using ATLAS. ti software (Scientific Software Development GmbH). The analysis process included the development of primary and secondary coding structures, which were analysed both individually and within larger coding networks. The analysis conducted to determine statistically significant differences in demographic characteristics of the patients included t-

tests for continuous variables and chi-square tests for categorical variables. Results are reported at the.05 level, or less.

Results

The HCV peer pipeline: The fear of treatment side effects

One major theme that emerged consistently throughout the experiences of the drug users in this study is the significant role that their peers appear to play in shaping their perceptions of the HCV medicine regimen and, for HCV-positive individuals, their decisions concerning whether or not to initiate treatment. Many of the patients described a pipeline of communication among their peers that appears to heighten anxiety about the difficult side effects that result from treatment. Most patients said that this communication tends to be overwhelmingly negative toward the pharmacological treatment. As one patient put it, "...everything that I had heard about treatment itself was negative [--male, MMTP]." The degree of negative feelings expressed toward the treatment was at times extreme, as exemplified by the individual who asked, "Has there been a study to show that the...side effects of the treatment are worse than the disease itself?...Because I've talked to all the people that went through the treatment... It's worse than not having the treatment at all [-- male, Residential Programme]."

Many individuals in this study said they had previously experienced at least one friend or family member who had gone through the treatment. One woman shared her perception of her peers' treatment experiences:

...how I did not test positive for HIV and Hep C, I do not know... But I watched too many people get sick...And then I watched the effects of the treatment and how that impacted people's lives...Um, which was incredibly invasive. Yeah. It's not an easy treatment, that's for sure...I watched people get incredibly depressed...sicker in some ways than they [were before the treatment]...it was awful. [-- female, Residential Programme]

Many of the self-identified HCV-positive individuals reported that they were discouraged away from treatment because of the negative things they had heard about the medications. One patient said:

People are scared stiff about going on the treatment. They've heard all these horror stories. And you get all this misinformation. So, more people I think, um, don't even pursue [treatment] any further because they've heard all the horror stories. [-- male, MMTP]

One HCV-positive individual noted that it was precisely this fear that was keeping him from moving forward with treatment:

Because I guess, from what the people were [saying], there was a person going through [HCV treatment] right now; and then there was a person that went through it and is in remission, or whatever. [They were saying that the treatment is] gonna make you really, really sick, really sick.... And that scares me, because I'm a wimp...I don't feel sick now, so why would I want to do that?...That's what scares me. [-- male, MMTP]

Even for some of the patients who were currently being encouraged to start treatment by a physician, the reports from their peers about the arduousness of the treatment influenced their decision to put it off. One individual said, "*I kinda backed away from the medication because I learned more by heresay than they said with the awful side effects and*..*I shoulda stuck with my doctor*..*.Like they scared me off*...*Yeah, the rumors* [-- male, hospital-based Residential Programme]." Another woman had already gone through all of the medical evaluation

procedures with her doctor, including a liver biopsy, to determine if she was an appropriate candidate for treatment. She told the researcher that her physician had already prescribed the medication (about 6 months prior to the interview), but she wouldn't start them because she still feared the side effects.

Other Reported Influences on Patients' Decisions to Avoid/Forego Treatment

In addition to the negative messages communicated among peers about the side effects of the treatment, HCV-positive individuals identified other factors that reportedly resulted in their delaying their efforts to consider and/or seek treatment for their infection.

Delayed HCV symptoms: "Hey, I feel fine..."

Some patients were not considering their treatment options because they did not believe that their infection was having a big enough impact on their health to warrant much concern. For instance, one individual said he wasn't actively pursuing any assistance for his HCV infection, "...well because [my HCV] doesn't... Yeah, I don't feel like I have it [-- male, MMTP]." In describing how they reacted to their HCV diagnosis early on, other patients said that the lack of any symptoms that they could associate with the virus minimized their concern about the need for further medical assessment. One woman said that she didn't think it was important to deal with her HCV when she was initially diagnosed because, "I didn't get sick from it or anything [-- female, MMTP]." When asked if he had pursued any medical monitoring when he was first diagnosed with HCV, another patient said, "I didn't really think about it...I was physically super strong...I had been all my life [-- male, MMTP]."

For patients like these, their perceptions that HCV was not negatively affecting their health appears to have minimised their desire to medically evaluate their chronic infection and/or consider whether or not the medications could help them avoid future disease-related complications. One individual said that the manner in which the health care provider who tested him for HCV reportedly downplayed his test results kept him from considering further medical treatment at the time of his diagnosis:

[The person who tested me] said, don't worry about [the fact that you are HCVpositive]. You're not sick now, so don't worry. That was about a year ago. And I'm thinking of suing that guy. Because here now a year later I'm on the cusp of, you know, cirrhosis. [-- male, MMTP]

Viewing HCV through an HIV lens

Other individuals said that the degree of concern they ascribed to dealing with the medical implications of HCV after finding out they were infected was impacted by their relative fear of contracting HIV. The vast majority of patients agreed that there is much less awareness about HCV and said that a diagnosis of HIV is still considered an imminent death sentence among many drug users. Patients admitted they were much more worried about getting HIV than HCV, and a surprising number of them also expressed how they had felt a sense of extreme relief when they had been diagnosed with HCV instead of HIV. Some of these patients said that these feelings had led them to underplay the potentially serious long term consequences of their HCV infection, which in turn, led them to believe that there wasn't necessarily any need to medically evaluate their disease. One patient shared her experience:

I'll tell you one thing...how I found out about hepatitis C is...I was tested for AIDS... And the doctor called me in, and I thought, oh, my God...he's gonna tell me [I have HIV]. And he told me, well, you don't have AIDS; but you've got Hep C...I didn't know anything...You know, I thought, thank the Lord! I was happy. I was overjoyed. And then a few years later, I find out that, hey...You die from this, too. [-- female, MMTP]

Patients also suggested that many health care provider practices tend to reinforce the idea that HIV is the more serious disease. For example, one man said that because the HIV testing that he received at his programme was accompanied by mandated comprehensive pre- and post-test counseling, while the HCV testing that he received was not, he was left with the impression that HIV was a much bigger concern. His test results ultimately came back positive for HCV, but he explained why he didn't pursue his treatment options at the time of his diagnosis, "*They don't [take HCV seriously], so I don't take it seriously…I don't think there's nothing wrong with me…I just think I got a disease, like a flu in my body* [-- male, MMTP]."

Reported Influences on Patients' Decisions to Explore/Initiate Treatment

Increased HCV knowledge encourages treatment considerations

Consistently across programmes, HCV-positive patients explained how the more they learnt about their disease, the more open they became to considering their HCV treatment options. In particular, patients said that once they understood the link between their HCV infection and their specific health problems, they reprioritised their need to consider treatment. When asked when it was that she became concerned about treating her HCV, a patient responded:

When I noticed when...I'd come here and then I'd go out, home. And my feet were starting to swell up a little bit; but I didn't think of it. I thought it was water retention. Then I noticed that I started becoming disoriented and lethargic. And I was getting real bad dizzy spells where I'd fall down. And then I fell down so bad that...I ended up in the hospital. And that's what [the doctor] said, well, the hepatitis finally kicked in...Full force. [-- female, MMTP]

One HCV-positive patient said that he opted for treatment because the symptoms of his HCV infection were becoming increasingly difficult to tolerate:

Being tired all the time...I was always tired, sore. Um, I didn't function at work. Um, seemed like, um, you know, three, four hours I'd have to be taking a nap...And the aches and pains got to the point where it just, it was unbearable. [-- male, Residential Programme]

Another patient acknowledged that the peer pipeline initially influenced him to avoid treatment, but then explained why he finally decided to start the medications:

...because a couple of people...they told me a lot of negative things about going on [the medications]. And you know, I was debating; but... I was getting sicker and sicker. And I said, to hell with it. I'm going for it. [-- male, MMTP]

Some individuals who were still struggling to decide whether or not to start treatment wanted more education, particularly information about the potential long-term consequences of untreated HCV and the pros and cons to treatment. For example:

At that time it was like, alright I got it and you know, I just knew so many people had it, so it wasn't, it didn't play a big deal. But at this time I have a concern for it because I see people who have it that get really sick...[I know that my HCV is] gonna get worse. So at this time I'm trying to soak up knowledge...because I don't know...I hear things from other people...about liver biopsies, I don't have a clue, you know. So at this point I'm just trying to seek out ways [to learn more]. [-- male, Outpatient Programme]

But look, treatment works for some people

While the fear generated by the peer pipeline about the difficult side effects of treatment reportedly served to discourage many HCV-positive individuals from starting the therapy, other patients noted that peers could alternatively have an encouraging effect on individuals who were still considering taking the medications. For those patients that had come into contact with peers who had successfully undergone the treatment and cleared the virus, or had heard of such cases, this knowledge appears to have offered some counterbalance to the negative communication about treatment and encouraged them to weigh the advantages of pharmacological therapy. A patient explained:

Yeah, most of [what people say about the medications is] negative. But the positive thing is that, obviously, it's there; because it works on some people...or you wouldn't go through the torture of going through it. [-- female, MMTP]

Talking about the role his peers played in his own decision to take the medication, one patient said:

But to be quite honest, I knew I had [HCV] for a long time. But I didn't know exactly how fatal it was until my friends kind of filled me in on it...That's the whole reason I started seeking treatment, is because I talked to people in this program who had it. [-- male, MMTP]

Some individuals, like the following patient, credited their HCV-positive peers with helping them successfully seek treatment, namely by linking them up with a knowledgeable medical provider whom they could trust:

And I realized that a lot of people were getting this thing [HCV] and it was killing people. And I had it, so...and I was just like her. I had problems with doctors...My first doctors paid no attention. They didn't care. And I finally, through my friends, I found a doctor who has helped me... [-- male, MMTP]

Still other patients who were currently contemplating treatment expressed their desire to talk specifically with their peers who had first-hand experience with the treatment. One patient said, "…*I haven't met anybody who did interferon…I would like to speak to somebody that already did the treatment [because] like I don't know what to expect…* [-- male, hospital-based Residential Programme]" Another patient imagined the benefits of discussing the pros and cons of taking the medication with a peer that had successfully undergone treatment:

I would love to come up to [someone who has successfully undergone treatment] and say, look, I'm starting this. What more can I expect of this?...Would there be any changes [in my body] on my medication, how I'm gonna be feeling...And if she had been through it...and she's got cured from it...I would like to know how and what things to do. [-- male, Residential Programme]

Discussion

The findings highlighted in this paper offer important insight into the perceptions of drug users toward the HCV medication regimen and some of the factors that reportedly facilitated or impeded HCV-positive drug users' decisions about whether or not to begin the pharmacological therapy. A peer pipeline of communication was described that largely underscores the negative aspects of the pharmacological therapy for HCV and reportedly raises anxiety about the adverse side effects of the medications. HCV-positive patients also identified several other issues that led to the perception that their disease was not serious enough to require medical intervention, including the inability to associate their chronic HCV infection with any symptoms and a limited understanding of the potential serious health implications of chronic liver disease. Patients also indicated that the widespread belief among their peers that HIV is

a more serious and deadly disease than HCV functions to minimise providers' and drug users' concerns about the implications of HCV infection. On the other hand, infected individuals also described several factors that encouraged them to consider and/or initiate treatment, including: (1) increased knowledge about their own symptoms and the potential long-term impact of HCV on their health; and (2) contact with peers who had successfully undergone treatment for their HCV infection.

The fact that peers, in particular, reportedly played a large role in shaping patients' decisions about HCV treatment initiation or avoidance has several implications. First, to the extent that peers are providing HCV-positive individuals with information about HCV, it is important to increase drug users' knowledge about the disease. This is important because studies suggest that many drug users lack basic knowledge and maintain a variety of misconceptions about the virus (Best et al., 1999; Davis & Rhodes, 2004; Dhopesh, Taylor, & Burke, 2000; Evans, Stotts, Graham, Schmitz, & Grabowski, 2004; Heimer et al., 2002; Kwiatkowski, Fortuin, Corsi, & Booth, 2002; Rhodes, Davis, & Judd, 2004; Stein, Maksad, & Clarke, 2001; Walley, White, Song, Kushell, & Tulsky, 2003). Therefore, successful efforts to provide drug users with up-to-date information about the virus and chronic infection may serve to minimise the degree to which misinformation is spread among peers, while fostering peer exchanges that share accurate, constructive HCV-related messages. Second, avenues that promote opportunities for HCV-positive drug users to interface with their peers should be explored (e.g., HCV support groups).

The findings presented in this paper should be interpreted with some measure of care because the experiences of the individuals who participated in the research may not be representative of all drug users. In addition, all of the patients were enrolled in a drug treatment programme when they were interviewed, which may have had a unique influence on their perspectives. For instance, the fact that discrimination did not play more prominently in the patients' attitudes toward HCV medical therapy may be because they were recruited through a drug treatment facility and thus were possibly more hesitant to openly criticise health care providers and/or the medical system. Furthermore, people who were in fact HCV-positive, but unwilling to disclose their status to the researcher, may have identified alternative and/or additional influences on their decisions to start or avoid treatment had they been questioned about it. Finally, it is not possible for the authors to determine the extent to which HCV treatment was medically necessary for the infected patients that we interviewed.

Certainly, many other factors besides those examined in this paper are likely to influence HCV treatment initiation among drug users. For example, drug users continue to face discrimination from some medical providers who frequently treat them with distrust and disrespect (Chitwood, Sanchez, Comerford, & McCoy, 2001; Crofts, Louie, & Loff, 1997; Day, Ross, & Dolan, 2003; Edlin et al., 2001; Stephenson, 2001; Treloar, Hopwood, & Loveday, 1996; Zickmund, Hillis, Barnett, Ippolito, & LaBrecque, 2004). Also, despite the recent changes to the NIH guidelines regarding HCV treatment, many health care providers have historically been concerned that drug users treated for HCV might have a high risk of re-infection, low treatment compliance, and/or drug relapse (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Golub et al., 2004; Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Hauser et al., 2002; Milby et al., 1996; Osher et al., 2003). In fact, recent research conducted by Morrill et al. (2005) found that primary care physicians tended not to treat patients with a past history of substance abuse for their HCV infection. Other studies conducted in both the U.S. and abroad reveal that IDUs, in particular, face discrimination in the health care setting that can result in barriers to HCV treatment. For instance, people who are prescribed methadone are less likely to receive liver transplants or HCV pharmacological therapy in the U.S. (Edlin, 2002; Koch & Banys, 2001). In studies conducted in Australia, HCV-positive drug users most frequently identified the health care setting as a source of HCV-related discrimination (Hopwood, Treloar, & Bryant,

2006) and HCV-positive clients reported less satisfaction with their health care experiences than HCV-negative clients who received services at the same treatment facility (Brener, 2006). Finally, people with a history of IDU are less likely to receive referrals to specialist liver clinics and have a lower chance of receiving antiviral therapy than non-IDUs (Cullen, Kelly, Stanley, Langton, & Bury, 2005; Doab, Treloar, & Dore, 2005; Gifford et al., 2005; McNally, Temple-Smith, & Pitts, 2004; Stoove, Gifford, & Dore, 2005).

In addition, the fear of the adverse side effects reported by HCV-positive individuals in our research is a realistic response to the limitations of the treatment regimen for this disease, because the side effects of the HCV medications can be severe and hard for patients to tolerate (Schiffman, 2004; Ward et al., 2004). For instance, all of the patients in a qualitative study (n=19) conducted in Australia reported that they had experienced side effects while on HCV treatment, including depression, anxiety, heart problems, headaches, fatigue, and difficulty sleeping (Hopwood & Treloar, 2005). While the side effects can often be managed medically (Sylvestre, 2003), many of the uninfected drug users in this study said that they have witnessed peers and/or family members struggle with the difficult side effects. For this reason, it is not surprising that they reported that they view the HCV medications with a large measure of apprehension.

Encouragingly, several promising new treatments for HCV are being tested for their effectiveness and tolerability (Swan, 2004). The development of an improved medication for HCV with fewer and less severe side effects should alleviate some of the existing barriers to treatment uptake. In the meantime, improved education efforts that target those individuals who are most at risk and can provide better access to appropriate and sensitive medical evaluation services should be encouraged. Furthermore, because the patients in this study said that peers played an important role in their own treatment considerations, future studies should evaluate the impact of interventions that promote positive peer exchange, such as HCV peercounseling models and/or speakers' bureaus. Ultimately, past and/or current drug users who are considering taking the medical therapy will likely require support to medically evaluate their HCV disease status, weigh their treatment options, and put the necessary social and economic resources in place to help get them through the treatment. Also, finding an effective channel to educate patients about strategies for managing the side effects may make more individuals who are eligible to receive HCV treatment actually consider starting the regimen. Given the large number of undiagnosed and untreated persons with HCV, ongoing research to examine the information sources and decisional processes that drug users employ regarding HCV testing and treatment is especially pertinent. Such knowledge can be instructive to both health care and drug treatment providers who wish to help their HCV-positive patients overcome obstacles to HCV treatment uptake.

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