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Engagement in the Hepatitis C care continuum among people who use drugs

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Abstract

Despite high rates of Hepatitis C virus (HCV) infection among people who use drugs (PWUDs), access to the HCV care continuum combined with the receipt of medications for addiction treatment in primary care settings remains suboptimal. A qualitative study was conducted among adults admitted for inpatient detoxification for opioid use disorder (OUD) in New York City (n=23) to assess barriers and facilitators with HCV prevention, screening, treatment, interactions with primary care providers, and experiences with integrated care approaches. Study findings yielded six major themes related to HCV care. Major gaps persist in knowledge regarding HCV harm reduction strategies, voluntary HCV testing services, and eligibility for HCV treatment. Treatment coordination challenges reinforce the importance of enhancing linkages to HCV care in key access-points utilized by PWUDs (e.g., emergency rooms, specialty addiction treatment settings). Peer networks combined with frequent patient-physician communication were elicited as important factors in facilitating linkage to HCV care. Additional care coordination needs in primary care settings included access to integrated treatment of HCV and OUD, and administrative support for enrollment in Medicaid, subsidized housing, and access to transportation vouchers.

Keywords

Hepatitis C; opioid use disorder; primary health care; drug users

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INTRODUCTION

The annual incidence rate of Hepatitis C infections (HCV) has doubled in the last decade and associated with the worsening opioid epidemic and rise of injection drug use (IDU). (Zibbell et al., 2018) Numerous risk factors have been attributed to transitioning to IDU and perpetuating transmission of HCV among individuals with opioid use disorder (OUD), including limited access to harm reduction services, specialty addiction treatment, or primary care services, exposure to actively using peers encouraging shared syringes and drug preparation equipment, and limited knowledge regarding HCV.(Fisher, Cahill, Broyles, Rorke, & Robinson, 2018; Young, Havens, & Leukefeld, 2010) Pegylated interferon (pegIFN) plus ribavirin were previously recommended for the treatment of HCV. Challenges to broader uptake of pegIFN included limited treatment eligibility, acceptability, and treatment-related adverse events.(Shiffman, 2004) However, the availability of novel direct-acting antiviral therapies (DAAs) has transformed the management of HCV.(Arora et al., 2011; Diseases & America; Mitruka et al., 2014; Morris et al., 2017; Norton et al., 2017) Importantly, DAAs offer vastly improved tolerability and shorter treatment courses enhancing the potential for high adherence and cure rates compared to older interferon-based therapies.(Kowdley et al., 2014)

Optimizing access to the HCV care continuum among people who use drugs (PWUD) combined with the receipt of medications for opioid use disorder (MOUD), including buprenorphine and extended-release naltrexone, in primary care settings offers an effective and patient-centered approach to reducing the burden of HCV.(Butner et al., 2017; Grebely, Hajarizadeh, & Dore, 2017) Despite these advances, serious gaps in the provision of HCV care persist among PWUDs at every step along the HCV care continuum, including testing, linkage to care, uptake and adherence to treatment, and viral suppression.(Diseases & America; Grebely et al., 2017). These findings parallel prior studies describing routine exclusion of HCV-infected drug users from interferon-based treatment despite the low incidence of reinfection with HCV.(Zanini, Covolo, Donato, & Lanzini, 2010) Limited referrals to HCV treatment among providers have been attributed to concerns regarding the risk of reinfection due to substance use, fears of poor adherence, and treatment coordination challenges.(Barua et al., 2015; Grebely et al., 2008) In addition, states offering Medicaid coverage for DAAs frequently restrict reimbursement for medications based on prescriber type and among PWUD despite revisions to expert and federal guidelines stipulating for treatment of HCV in this population.(Barua et al., 2015)

At the patient level, the perception of HCV as a benign infection relative to HIV disease has been cited as an ongoing barrier to HCV treatment.[12–14] Moreover, credible fears of invasive procedures (e.g., liver biopsies), concern for toxicities related to Interferon treatment, cost, perceived stigma related to drug use, and inadequate information regarding treatment options also serve as potent barriers to engaging with HCV care. (Grebely et al., 2008; Mehta et al., 2008; Swan et al., 2010; Treloar, Rance, & Backmund, 2013) More recent findings since the approval of DAAs by Skeer and colleagues (2016) documented concerns about stigma, cost, and limited referrals for screening and treatment among HCV-infected young adults.(Skeer, Ladin, Wilkins, Landy, & Stopka, 2018) Similar results among HCV-infected patients in the Veterans Affairs system highlighted treatment coordination

challenges and concerns about coverage for HCV treatment.(Tsai et al., 2017) Among patients initiated on DAAs for HCV, limited information regarding medication side effects and adherence strategies contributed to increased anxiety and dosing errors.(Evon, Golin, Bonner, Grodensky, & Velloza, 2015)

We conducted in-depth qualitative interviews with PWUDs at high risk for, or infected with HCV, to identify the complex interplay of social and environmental factors that influence engagement along the HCV care continuum and are vital for informing future HCV treatment related policies and interventions in primary care settings.(Rhodes & Treloar, 2008) Notably, we elicited participants' knowledge and beliefs related to HCV infection, factors that shape PWUDs' understanding and beliefs of the current DAA treatment regimen, and explored strategies that may facilitate engagement along each step of the HCV care continuum.

MATERIALS AND METHODS

Study Design, Setting, and Participants

Eligible participants included adults 18 years of age and older admitted to inpatient detoxification at Bellevue Hospital in New York City for opioid use disorder. In-depth interviews were conducted between January and February of 2018. Bellevue Hospital is a tertiary referral center affiliated with the New York City Health and Hospitals network offering subsidized care to mostly Medicaid and uninsured patients. Participants received a roundtrip transportation voucher for participation in the single-session interview. The New York University School of Medicine Institutional Review Board approved the study protocol. Purposeful sampling was aimed to identify possible issues specific to participant demographic characteristics (e.g., age, housing status, criminal justice involvement, insurance access) and HCV knowledge, testing, and treatment experiences. Patients who reported engagement or exclusion from various phases of the HCV care continuum were oversampled to elicit a wide range of clinical experiences.

Data Collection and Analysis

All interviews were conducted by the study team (CC, BT, SS) in a private room in the inpatient detoxification unit lasting approximately one hour. A baseline quantitative survey was administered including demographic and clinical characteristics (i.e., opioid use history, past medical and psychiatric history, healthcare utilization, HIV-HCV screenings). The qualitative interview guide utilized open-ended questions based on an extensive review of the literature and addressed several broad topics pertaining to experiences and perceptions of: 1) HCV prevention and safe injection strategies; 2) HCV screening; 3) HCV treatment; 4) interactions with healthcare staff coordinating HCV care; and 5) factors that may enhance engagement to the HCV care continuum for individuals with opioid use disorder.

Interviews were recorded and transcribed by the study team and analyzed using content analysis and a grounded theory approach. The Dedoose online platform facilitated coding and analysis of themes. All transcripts were reviewed line-by-line reading by the study team highlighting major topics that provided the basis for the codebook. The study team met

weekly to discuss study findings, resolve differences in coding, and facilitate an iterative process of data analysis based on formative qualitative research methods.(Creswell & Clark, 2017) Per constant comparison methodology, iterative modifications to the codebook based on emerging themes were used to maximize inter-reviewer consistency. The grounded theory approach utilizes the constant comparison method, which relies on studying individuals, identifying ‘incidents’ or phenomenon or experiences of interest that are coded to relevant concepts or categories, and finally integrating categories into a ‘coherent explanatory model’ of how participants conceptualize their lived experiences.(Taylor & Bogdan, 1984) These multiple stages allow researchers to inductively generate theory based on raw data rather than utilizing existing theoretical frameworks to explore socially-shared meaning among individuals and how it influences their actions.(Creswell & Clark, 2017) The study team conducted multiple iterations of the constant comparison method by returning to the data throughout analysis until reaching saturation and unable to elicit any further themes from the data.

RESULTS

Demographic and background characteristics of the sample

The sample of 23 participants were mostly male (78%), with an average age was 44 (minimum 21, maximum 62), African-American (n=8) or Hispanic (n=6), and enrolled in Medicaid (n=19) or were uninsured (n=4). Past month IDU was common (78%) and most required detoxification from alcohol (61%) and/or benzodiazepines (30%) in addition to opioids (100%). Among respondents receiving HCV testing in the preceding 12 months (n=20, 87%), nearly two-thirds were diagnosed with HCV (65%, n=13/20), and three participants received HCV treatment (i.e., Interferon, DAAs) (23%, n=3/13). Four of the thirteen participants diagnosed with HCV were also positive for HIV.

Overview

Study findings illuminated six major themes related to HCV care, including limited knowledge of HCV, benign perceptions of HCV infection, persistent barriers to HCV screening, limited access to HCV treatment, misperceptions regarding available HCV therapies, and generally positive experiences with DAAs for HCV. Among respondents eliciting concern for high-risk behaviors (e.g., needle-sharing, unprotected sex) and HCV infection, access to HCV testing and treatment for HCV were often limited due to cost, inability to locate or receive referrals for screening or treatment services, and physician preferences to not initiate HCV treatment.

Limited knowledge and benign perceptions of HCV infection

Participants’ sources of information regarding HCV infection, prevention, and treatment strategies were mostly limited to HCV-infected peers and family members. Underscoring gaps in knowledge regarding high-risk behaviors leading to HCV seroconversion, several interviewees were baffled by the cause of their HCV infection: “I don’t even really fully understand Hep C. You get that from needles?” The lack of experienced symptoms following infection with HCV combined with deferred treatment for HCV by physicians

further reinforced benign perceptions of HCV infection or delays in obtaining HCV testing (see Table 1).

Gaps in knowledge regarding HCV prevention and safe injection practices were underscored by respondents' limited utilization of syringe exchange programs or retail pharmacies offering free syringes, or addiction treatment services to reduce the risk of HCV infection. One participant recalled cleaning shared syringes with tap water rather than using bleach:

“The crazy part is I was with a girl who told me she had Hep C. In the midst of my addiction, I still shared a needle with her. That’s the insane part of this disease that I actually knew she had it. I cleaned it out the best I could but I didn’t bleach, and that’s when I accumulated Hep C.”

Experiences with HCV screening

Although respondents expressed concern for contracting HCV during episodes of sharing syringes or unprotected sex, testing for HCV was often limited to routine admissions to emergency rooms, inpatient detoxification, or criminal justice settings:

“I definitely was concerned a lot of times [for HCV]. My boyfriend got tested positive for Hep C, and I thought that’s it. I have to have it. How can I not have it? We’re having unprotected sex at this point, doing drugs together. When I first went into detox, they told me I tested positive and I thought, of course.”

Nonetheless, experiences with HCV screening were generally positive and suggestions for improving access to HCV testing included mobile vans:

“I am not gonna go to no building and get tested [for HCV] because I don’t have the time for that. If that mobile van is sitting out there, and they telling me that’s what it’s for, I will go in there. It will ease my consciousness.”

However, the frustration recounted by some participants following a positive HCV test may be attributed to the limited awareness by patients of the availability of DAAs, inadequate post-test counseling services, and limited linkage to HCV treatment. One participant recalled the moment he was notified of his positive HCV diagnosis that precipitated anxiety, confusion, relapse to heroin:

“I got tested in there [rehab]. I remember the day they tell me I was positive. I tell them I was gonna die that day. I left the rehab and everything. I started using drugs and then prison again.”

Another participant shared a harrowing experience of a false positive test in an inpatient detoxification program that was then refuted by repeat tests in her residential treatment program:

“It was a quick detox place. Not to be rude but they didn’t know [about HCV]. They said ‘didn’t you know, your situation? You know, right? You know you’re positive [for HCV], right?’ I was like, maybe because of my boyfriend? Then, I went to the next place [residential treatment] and they told me I wasn’t positive, and I said test me again. I don’t believe it. They did it again, and they said you are not.”

Suggestions for streamlining and reducing the anxiety surrounding HCV testing included integrating rapid HCV tests in healthcare settings and circulating HCV testing sites via public health campaigns:

“It would be good if you guys did testing here [in detox]. If you had the instant testing, people could come in here, and just ask people if they want it or not? Do instant testing like the HIV/AIDS program through NYC health. The instant testing is so comforting. Its anxiety provoking for a minute but then it’s not since you know you’re in a facility. You have people you can talk to and give you support.”

Perceptions of HCV treatment

Physical and psychological sequelae (e.g., depression, psychosis) following receipt of Interferon treatment among family members and peers were shared in vivid detail and in contrast to the perceived safety of DAAs (see Table 2). Information relating to various facets of HCV treatment were typically obtained from peers rather than any healthcare providers or public health campaigns. However, one respondent described the helpfulness of monthly informational sessions led by a peer counselor in residential treatment regarding HCV and treatment:

“He [peer counselor] came monthly to Samaritan Village to talk about Hep C. I know everything about it now. That was really helpful. I know how much the treatment costs. Harvoni side effects are null, 90% success rate, vs the other [Interferon] is 50% with weekly shots. Harvoni is expensive but extremely effective.”

In addition to the benefits of receiving DAAs, some participants also reflected on the importance of abstinence from opioids, alcohol, and dietary changes to improve the health of their liver following a HCV diagnosis. One participant recalled how they: “stopped drinking, started exercising, and it [Hepatitis C viral load] became undetectable. I also took milk thistle for a long time to try and help my liver function.”

Actual experiences with HCV treatment

Despite negative perceptions of Interferon treatment among most respondents (see Table 2), one interviewee that completed Interferon reported only mild side-effects:

“They tell you it [Interferon] makes you so weak. But they started the injections, and it made me feel better. After three weeks, I didn’t feel weak anymore.”

Respondents completing DAAs didn’t recall any serious side-effects and encouraged other family members and peers with HCV to link with treatment. For many, “just the knowledge of knowing that it’s [DAAs] a cure” was cited as a major factor in seeking treatment. One participant was also gratified by the relatively short duration of Harvoni treatment:

“Basically, the treatment [DAAs] was good. Some people do get headaches, side effects, and lack of energy. I didn’t feel anything. I was practically cured in 2 weeks. It’s a three month treatment. It works so quickly. The lady told me your count is 21 from 3 million.”

Many participants described a profound satisfaction with receiving a “cure” from the virus and also ridding the stigma of a HCV diagnosis associated with PWUD:

“It was big, the blood tests telling me it was gone was such a relief. It was a stigma on my life.” Notions of completely curing a disease associated with drug use (i.e., HCV) was a significant and recurring theme among several participants and potentially reducing the threshold to also engage with primary care and addiction treatment.

Referrals to HCV treatment

Among respondents seeking HCV treatment, encounters with physicians in residential treatment, methadone maintenance, primary care, and criminal justice settings often discouraged receiving treatment due to low hepatitis C viral loads or normal liver studies. Additional barriers included incarceration, cost, active substance use, and lack of insurance coverage (see Table 3).

Respondents also emphasized the importance of receiving support for basic needs, such as housing or financial support, since such experiences could exacerbate depression symptoms, active substance use, and failure to initiate or adhere to HCV treatment. Entry into residential treatment was often prioritized by individuals as a critical “first-step” in securing housing, financial support, and addiction treatment:

“I’m trying to get into residential treatment. If not, it’s going to be difficult. I was so close to getting housing, public assistance, job training, and everything else that a case worker at this program was trying to hook me up with. But I screwed it up and they threw me out of the program. With homelessness, all bets are off. I get so depressed.”

Respondents recounted difficulties obtaining referrals to HCV treatment despite visible signs of hepatic disease. Few respondents were engaged with primary care or identified primary care as an entry point to obtaining referrals to providers offering HCV treatment. One interviewee recalled the ineffectual encounter with providers who failed to refer him to HCV treatment despite concerning laboratory and radiology findings: “Last week I was in the ER. My CK levels were high. They gave me 1 bag of IV fluids and told me to go. I knew that wasn’t enough. He [doctor] was downplaying what I had [HCV], making it as easy as possible to get me to leave. But I was homeless and a drug addict. They told me nothing about Hep C, didn’t get any follow up. They were talking out loud when the Sonogram showed liver nodules and I knew that this was cirrhosis, and they walked out.”

Successful linkages to HCV treatment often occurred informally via word-of-mouth by peers or peer counselors enrolled in residential or outpatient addiction treatment programs. Peers assisted participants in securing health insurance, shared treatment experiences with Harvoni, and described possible side-effects:

“The peer leaders did a great job informing me about how it’s [DAAs] gonna work. They gave me information on the support groups. At the time, I had straight Medicaid but I had to pick one [insurance provider]. So they were like ‘if you pick one, you might not get approved.’ So they advised me to pick Health First [a New

York State Medicaid Plan], and I did, and everything worked out. They also gave me information on the support groups. If it wasn't for them, I probably wouldn't have completed it [DAAs] by myself. I needed to be pushed at that time. I was still in early recovery.”

Additional facilitators to successful entry to HCV treatment included: 1) supportive friends and family; 2) individuals who completed HCV treatment and shared positive treatment experiences with participants; and 3) fear of end stage liver disease and death. In addition, one participant who described the shock of being re-infected with HCV post-treatment due to resumption of IDU, credited his buprenorphine provider for facilitating access to DAAs once again:

“In the beginning, I thought I'm fucked and could die because of my liver. Then, the suboxone doctor told me I could have treatment [Harvoni]. I just didn't believe I can get it again.”

Barriers to retention in HCV treatment

Respondents frequently elicited frustration with linking and completing HCV treatment during periods of active substance use due to their inability to adhere to scheduled appointments, laboratory studies, or secure insurance. One respondent emphasized the importance of abstinence to accomplish basic administrative and clinical tasks throughout the course of HCV treatment:

“If you are in active addiction, it's gonna be hard for you to keep the appointments you need to. It's not like one day you walk in and they say ‘Here, drink’. It's a big process. You have to be tested once, and then they do some other tests. Then they take your information, contact your insurance company, they might call you on this day, and there's a lot involved if you're in active addiction. You're not gonna care about your disease *and* your addiction. You do things you don't wanna do. That's your priority, getting high.”

Several participants completing DAAs underscored the need for more patient-centered strategies to ensure appointment and medication adherence after initiating treatment, including frequent communication with healthcare staff and patient navigators:

“They [hepatology clinic staff] were so nice! I had my own peer leader that reminded me about my appointments, gave me metro cards, and they were on top of me. They wanted you to go back and follow-up. I still think I have to go back one more time, and check my levels again. They are really on it. Once you start the treatment, you got to finish it or you could jeopardize it.”

DISCUSSION

Study findings underscore the mechanisms by which PWUDs' encounters with the health care system negatively impact HCV care along each step of the care cascade and exacerbate health disparities. Overall, participants' narratives highlighted major gaps in knowledge regarding HCV prevention strategies, management of dormant or asymptomatic HCV infection, eligibility for HCV treatment, and access to primary care providers offering

treatment for HCV and opioid use disorder that echoed findings from prior studies conducted during the interferon-treatment era.(Grebely et al., 2008; Swan et al., 2010)

Significant gaps in knowledge of preventative and harm reduction behaviors regarding injection use emerged as a central finding, including past and current multi-person use of drug injection equipment, and syringes and cleaning syringes with water. While a number of respondents expressed a heightened level of concern regarding high-risk behaviors and their link to HCV infection, engagement with testing and HCV treatment services was markedly delayed or fragmented.

Participants attributed delays in HCV testing or linkage with treatment due to the lack of experienced symptoms following HCV infection, active substance use, limited counseling and screening for HCV in health systems, and misperceptions regarding HCV (e.g., symptoms post-infection with HCV occur in older adults). Benign perceptions or limited knowledge of HCV infection leading to delayed linkages with HCV care are aligned with prior findings among women who use drugs(Lally, Montstream-Quas, Tanaka, Tedeschi, & Morrow, 2008) and PWUD in Ireland,(Swan et al., 2010) and highlight the importance of public health interventions disseminating HCV knowledge and encouraging uptake of care. (Rhodes & Treloar, 2008) Other participants however elicited the ubiquity and inevitability around HCV infection following episodes of unprotected sex or syringe sharing practices and major gaps in safe injection practices to mitigate this risk.(Rhodes & Treloar, 2008)

Our findings reinforce the need for targeting screening, education, and treatment resources in key access-points utilized by our respondents (e.g., jails and prisons, inpatient detoxification, residential treatment programs, specialty addiction treatment settings, emergency rooms, and primary care) combined with referrals to primary care offering longitudinal care for HCV and opioid use disorder. Respondents emphasized the ease of access in community settings (e.g., mobile vans) and health systems (e.g., emergency rooms, specialty addiction treatment programs) in addition to proactive peer support and physician-patient communication as factors that may potentially enhance engagement with the HCV care cascade. Importantly, recent studies have demonstrated how modest efforts framed around the HCV care cascade model (e.g., reductions in injecting duration, screening, treatment scale-up with opioid substitution therapy and DAAs) could substantially impact relative prevalence reductions of HCV.(Martin et al., 2013; Turner et al., 2011) Lastly, the high favorability of HCV treatment with DAAs for PWUDs may serve as a critical factor in also engaging individuals with medications for addiction treatment in primary care.

Limitations

The experiences and perceptions described by our participants may not be generalizable to other injection drug users in different localities where the availability of harm reduction services, routine screening for HCV, and access to DAAs may be different. Quantitative studies among a larger sample of participants are needed to approximate the proportion of individuals actually receiving HCV testing and treatment services. Criticisms of interferon should be interpreted with caution due to the limited number of respondents who received this treatment.

Conclusion

Engagement across the HCV care cascade remains limited due to major gaps in knowledge regarding HCV prevention strategies, symptoms following HCV infection, screening services, and eligibility for HCV treatment. Treatment coordination challenges persist and highlight the need for patient-centered approaches to enhance linkage in primary care-based treatment of HCV and opioid use disorder.

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Table 1.

Benign perceptions of HCV

Lack of experienced symptoms attributed to HCV infection	"I didn't know much about Hep C at all. HIV, I knew about. My older brother, he died from HIV. He overdosed but he had HIV so I knew a lot about it. Hep C, I didn't know much about. I never felt the effects from being Hep C positive."
Physician preference to not start DAAs	"Every doctor tells me I don't need treatment, they leave me alone. They [physicians] say well if you need treatment, let me know, I can get you into places that can help you."
Limited access to healthcare providers addressing HCV	"I don't really know where to get more information on it, where to get tested like, for Hepatitis, more in-depth information on it. About what you were saying about the enzymes, I don't know where to go that deals with that specific thing."
Misperceptions that sequelae attributed to HCV infection (e.g., cirrhosis) worsens with older age	"Treatment's not that important to me... I just heard about information people gave me about Hep C in groups: that you can get cirrhosis, your liver can get bad, and the older you are the less function."

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Table 2.

Perceptions of HCV treatments

Adverse events related to Interferon	“Everyone that I knew that was taking them shots [interferon] and was getting sick.”
	“I had a spike once (HCV viral load), but didn’t want to do IFN. It’s like liquid chemo. I’ve seen what it did to other people, it destroyed them. I didn’t want to do that.”
Mild adverse events related to DAAs	“My friend got treatment for Hep C and he got off the Hep C by taking a pill. He talked to me about it, he felt good. Sometimes you feel weird, dizzy... but it’s good, it works.”
Short-duration of DAAs	“If there is a cure, just 8 weeks of a pill, it’s a miracle pill in my eyes. They used to say it’s [HCV] incurable.”

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Table 3.**Barriers to treatment**

Normal liver function	"I was diagnosed [with HCV] in 1999 in jail in Puerto Rico. They [physicians] said my liver is all right, that my liver doesn't have that much damage to get treatment."
Low Hepatitis C viral load	"They [physicians] didn't want to start treatment since my viral load was low"
Incarceration	"Every time I go to jail again, they test you for everything. They [jail physicians] explain to me about the pills [DAAs], that when I go home, I can get treatment for that [HCV]. They don't give me treatment because it's a short time in jail."
Active drug use	"Yeah, I have a few friends that did it [DAAs] and they're cured. They good and it works. I've been wanting to get there but drugs always have been a blockage on the way of me getting there."
	"They want you to be at least 6 months clean. If you're still using needles, you're probably gonna wind up sharing it. What are you getting treatments for if you catch it again? It's definitely something you need to, get clean, stick to it, have some structure in your life, you're gonna complete this thing."
Cost of Harvoni treatment	"I don't know about the whole cost, I've heard it's [DAAs] really expensive."
Medicaid coverage	"I've had insurance problems recently. They shut it off and I had to go through this whole huge thing. I had to go to a Medicaid office several times, I had to keep calling them up and trying to turn it back on."
	"One time I went for treatment [DAAs], and they told me, my plan wouldn't cover it. I went to a doctor, and I told him, and the doctor told me 'look, to tell you the truth, these companies, this is a very expensive treatment, and some HMOs are not covering it.'