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## “Hepatitis C treatment turned me around:” Psychological and Behavioral Transformation Related to Hepatitis C Treatment

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### Abstract

**Background**—Hepatitis C (HCV) is a significant public health problem that primarily affects current and former substance users. However, individuals with a history of substance use are less likely to have access to or engage in HCV care. Psychological and behavioral barriers prevent many HCV-infected individuals from initiating or engaging in HCV treatment. This study aimed to investigate the psychological and behavioral experiences of current and former substance users receiving HCV treatment within a combined methadone and primary care clinic in the United States.

**Methods**—We conducted 31 semi-structured qualitative interviews with opioid-dependent adults enrolled in an integrated HCV treatment program within a methadone maintenance clinic in the Bronx, NY. We used thematic analysis, informed by grounded theory, and inquired about perceptions of HCV before and after initiating HCV treatment, reasons for initiating HCV treatment, and the decision to participate in individual versus group HCV treatment.

**Results**—Participants described psychological and behavioral transformation over the course of HCV treatment. These included reductions in internalized stigma and shame related to HCV and addiction, increases in HCV disclosure and self-care, reductions in substance use, and new desire to help others who are living with HCV.

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**Contributors:** Abigail Batchelder and Alain Litwin designed the interview guide and integrated initial feedback from Shadi Nahvi and Julia Arnsten. Abigail Batchelder conducted the interviews and developed the coding system. All authors provided feedback on the coding system. Deena Peyser and Abigail Batchelder reviewed and coded the transcribed interviews. Abigail Batchelder analyzed the data integrated iterative feedback from all co-authors. Abigail Batchelder wrote the manuscript and all co-authors provided substantive feedback and final approval.

**Conflict of Interest:** none.

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**Conclusions**—Integrating HCV treatment with methadone maintenance has the potential to create psychological and behavioral transformations among substance using adults, including reductions in HCV- and addiction-related shame and improvements in overall self-care.

### Keywords

Hepatitis C; injection drug use; methadone maintenance; shame; internalized stigma

## 1. INTRODUCTION

An estimated 3.2 million individuals in the U.S. are currently living with Hepatitis C (HCV; Center for Disease Control and Prevention (CDC), 2014). People who use substances comprise over 60% of all HCV-infected persons in the U.S. (Metts et al., 2014), with an estimated HCV prevalence between 70–90% among those who have injected substances (CDC, 2014; Hagan et al., 2008; van de Laar et al., 2009). However, individuals with a history of substance use are less likely to have access to or engage in HCV treatment. Despite evidence that substance users do not significantly differ in HCV treatment adherence or sustained virologic response from non-substance using HCV patients, system-, provider- and individual-level barriers contribute to limitations in HCV treatment access, initiation, and engagement (Harris and Rhodes, 2013; Papadopoulos et al., 2010).

Social factors, including stigma related to HCV and substance use, act as system- and provider-level barriers to HCV treatment (Butt, 2008; Harris and Rhodes, 2013; Lekas et al., 2011; Sgorbini et al., 2009; Swan et al., 2010; Treloar et al., 2013; Zickmund et al., 2003, 2012). Health-care settings, in particular, are frequently associated with HCV-related stigma and discrimination by current and former substance users (Harris and Rhodes, 2013). In a review of 21 studies, Paterson suggested that perceived stigma associated with HCV is often rooted in practitioners' negative attitudes about injection drug use and substance users (Paterson et al., 2007). Perceived stigma within healthcare settings and from specific providers may prevent substance users from accessing, initiating, or completing HCV treatment (Afdhal et al., 2013; Marinho and Barreira, 2013; Treloar et al., 2013).

Perceived stigma has been associated with internalized stigma, which can exacerbate emotions such as shame and embarrassment, and can also reduce self-care behaviors (Treloar et al., 2013; Vogel et al., 2013). HCV- and substance use-related stigma have been associated with reluctance to disclose HCV status, initiate HCV treatment, and engage in HCV care (Astone-Twerell et al., 2006; Evon et al., 2013; Paterson et al., 2007; Zickmund et al., 2003). While the side effect profiles of interferon-based treatment for HCV likely prevented some HCV-infected individuals from initiating HCV treatment, the advent of lower side effect burden HCV treatment options has reduced individual-level barriers related to side effects (Wei et al., 2014). However, psychological barriers, such as perceived and internalized stigma, remain challenges to initiation and completion of treatment for HCV-infected substance users (Evon et al., 2013).

Several strategies have been suggested to ameliorate or address barriers to HCV care among substance users. Harris and Rhodes concluded that combination intervention approaches are needed to address social barriers to HCV treatment (Harris and Rhodes, 2013), including

combining HCV treatment with opioid substitution therapy. Settings that provide accessible information about HCV care and treatment, including curability, may also reduce stigma related to HCV and substance use (Chen et al., 2013; Marinho and Barreira, 2013; Rance and Treloar, 2014). Other authors have suggested that nonjudgmental and accepting interpersonal relationships (Treloar et al., 2013), as well as cultures that facilitate peer support (Galindo et al., 2007; Norman et al., 2008; Rance and Treloar, 2014), are needed to address and reduce barriers to HCV treatment.

The innovative HCV treatment program at Albert Einstein College of Medicine's Division of Substance Abuse has established a model of HCV care that has been providing integrated HCV treatment along with methadone maintenance and primary medical care for over 10 years. While similar programs have emerged in Australia in recent years (Treloar et al., 2013), the Einstein program provides substance users in a low-income, urban, U.S. setting with accessible HCV treatment information, and has cultivated a nonjudgmental culture by fostering peer educator support and offering on-site HCV treatment options (Litwin et al., 2005, 2009; Roose et al., 2014; Stein et al., 2012).

In this study, we sought to elucidate the experience of substance users who had undergone HCV treatment within the integrated HCV treatment program at the Einstein Division of Substance Abuse. This study builds on existing literature by providing an in-depth analysis of the experiences of substance users who have engaged in HCV treatment within a longstanding, urban program that prioritizes peer involvement and maintaining a nonjudgmental culture.

## 2. MATERIAL AND METHODS

### 2.1 Setting

The multidisciplinary integrated HCV treatment program at Einstein's Division of Substance Abuse has been previously described (Litwin et al., 2005, 2009; Stein et al., 2012). Briefly, the program provides HCV pharmacotherapy and related services along with comprehensive substance abuse treatment and medical and psychiatric care (Stein et al., 2012). Through this model, patients have the opportunity to participate in group or individual HCV treatment (Litwin et al., 2005, 2009; Stein et al., 2012). Group treatment involves weekly provider-led treatment sessions, which includes review of side effect management and adherence strategies, administration of interferon injections (when applicable), brief physical examinations, and meditation exercises. Those who opt for individual HCV treatment have access to both HCV treatment providers and peer educators. Through the peer education program (Roose et al., 2014), trained peers participate in on-site and off-site activities, including co-facilitating group treatment, escorting patients to liver biopsy appointments (when applicable), and initiating HCV educational events, such as clinic and community outreach. All participants interviewed for this study had the opportunity to participate in either group or individual HCV treatment, interact with peer educators, and work towards becoming peer educators themselves.

## 2.2 Participants

Between June, 2011 and March, 2013, we interviewed a convenience sample of methadone-maintained patients who had initiated HCV treatment in the Einstein Division of Substance Abuse. Eligibility criteria included having initiated treatment since March 2009 and no longer being on treatment. Providers informed the 60 patients who had initiated HCV treatment during this time period about the study, and interested individuals had the option to contact study staff directly or provide verbal consent to allow themselves to be contacted by study staff. All 60 patients agreed to be contacted by study staff, and all were called. The first 31 to be reached were scheduled and interviewed. One additional patient did not show for two scheduled interviews. The Einstein Institutional Review Board approved this study.

## 2.3 Interviews

Study participants were interviewed for 45–90 minutes in a private room at their methadone clinic. Interviews were conducted by a qualitative interviewer (AB) who was not providing substance use or HCV treatment. The interview focused on participants' perceptions of HCV, their experiences initiating and undergoing HCV treatment, HCV medication adherence, and substance use. Participants received \$25 in cash.

## 2.4 Analysis

Our analytic approach followed Braun's six steps of qualitative thematic analysis (Braun and Clarke, 2006), and included elements of grounded theory (Glaser and Strauss, 1967). Interviews were conducted until thematic saturation was achieved. Initially, two co-authors listened to and read all interviews to identify general themes. Open coding identified a list of themes, and a working coding tree was developed. We then iteratively refined and finalized the coding structure. Ultimately, each transcript was double coded by two co-authors (AB and DP), and discrepancies were brought to the team for discussion.

## 3. RESULTS

Thirty-one adults (mean age = 51.3 years) were interviewed. Twenty-six had completed treatment and 5 discontinued. Two thirds of the sample (n=21) was male. Seventy-one percent (n=22) self-identified as Hispanic and 13% (n=4) as African American or Black. All participants were enrolled in Medicaid. Twenty-three percent (n=7) of those interviewed were co-infected with both HIV and HCV, and all had chronic (rather than acute) HCV. Approximately half (n=14) had participated in group HCV treatment.

We first describe participants' initial internalized stigma related to HCV, prior to initiating HCV treatment. Then, we describe participants' stated reasons for initiating HCV treatment and their reasons for engaging in group versus individual HCV treatment. Finally, we describe the pervasive themes of psychological and behavioral change or "transformation" that participants reported over the course of HCV treatment. These included reductions in internalized stigma, increased willingness to disclose HCV-status, reductions in substance use, increased self-care, and a desire to help others with HCV.

### 3.1 Initial Stigma Related to HCV

Prior to beginning treatment, most participants described reluctance to disclose their HCV diagnosis due to perceived stigma and self-conscious emotions, such as embarrassment and shame.

“I didn’t want nobody to know at first... I was embarrassed to let people know that I have Hep C,”

(Participant 1).

“At the beginning, I didn’t want nobody to know that I was on Hep C medication, ‘cause I didn’t want nobody to look at me like I’m sick, you know?”

(Participant 9).

Several participants explained that their hesitance to disclose their HCV status was because of the relationship between HCV and substance use.

“[HCV] brings up feelings like, ‘oh, man, you used to get high, you’re no good,’”

(Participant 18).

### 3.2 Reasons for Initiating HCV Treatment

Participants described initiating HCV treatment both to treat HCV and to initiate lifestyle changes. Some participants described initiating HCV treatment because of a desire to engage in recovery, or as a way to develop healthier habits.

“I couldn’t stay out there no more doing heroin for the rest of my life. I knew I couldn’t do it... That was the main reason [I started HCV treatment]. I knew I had to change my lifestyle. I knew I had to change,”

(Participant 17).

Others described anticipated behavioral and psychological changes associated with HCV treatment.

“I did it because I knew I had to. I needed to do it. For me that’s being responsible. After being on drugs for like 40-some odd years, responsibility was something that I didn’t really know anything about. But I saw a way to work on that, being responsible,”

(Participant 17).

### 3.3 Participation in HCV Group treatment

Multiple participants described feeling that group HCV treatment helped maintain their engagement.

“If it wasn’t for the other peers talk[ing] about how they felt or about how I could beat the Hep C, I wouldn’t have the strength to keep going,”

(Participant 9).

“You could hear other people with what they’re going through...the effects they’re going through and you could express your feelings too. It just works out better than just one on one talking to the doctor,”

(Participant 15).

“That group became so close; it was surprising. We got so honest about things and we started using [it] like a therapy group,”

(Participant 12).

Participants who did not participate in group treatment also described benefitting from the social support associated with the integrated HCV treatment program.

### 3.4 Changes During and After HCV Treatment

All participants described experiencing changes or “transformations” in their psychology and behavior over the course of HCV treatment. Most participants described a reduction in their experienced stigma and shame associated with HCV and substance use. For many, this change or transformation manifested in changes in willingness to disclose HCV-status, changes in substance use and self-care health related behaviors, and in their desire to reach out to others living with HCV.

**3.4.1 Psychological changes**—All participants described psychological changes during and after participating in HCV treatment. Several participants explicitly described valuing or caring for themselves more after undergoing HCV treatment.

“At first I didn’t want to take care of myself. I didn’t care about myself. I didn’t care how I looked, how I dressed. Today, I care how I look, how I dress, what people think of me, how they see the way I’ve changed,”

(Participant 18).

Other participants described a change in their ability to regulate their emotions and be present for themselves.

“Before I used to just get pissed off and give up. I haven’t given up on myself since [treatment],”

(Participant 12).

Another participant described a new sense of hope after learning her HCV viral load was undetectable.

“I’m feeling good because now I got hope for [a] long life, I’m feeling good because I am undetectable. I got one opportunity now for [a] longer life for doing something much better.”

(Participant 16).

**3.4.1.1 Recovery from internalized stigma and shame:** Several participants explained how the process of undergoing HCV treatment resulted in changes in feelings of shame related to past behaviors.

“Everything I did during my addiction—I am not ashamed of it because I’m doing something to change,”

(Participant 22).

**3.4.1.2 Psychological changes related to group treatment:** The majority of participants who engaged in group treatment described peer support as extremely influential in their treatment.

“The group did have an effect on me. It made me think that there are people that really care, the staff and the people in the group. When I came here I had a very negative outlook on life, for so many years I worked hard, did drugs and had a bad marriage. I did some stupid things and scarred my body up with needles and fights and booze. But coming here and meeting people that had a positive outlook and dealt with treatment and were here to help me, made me feel a hell of a lot better and made my outlook on life a lot easier. It was good, it was one of the best things I ever did,”

(Participant 21).

**3.4.2 Behavioral changes—**Almost all participants described meaningful behavioral changes that began during HCV treatment. These included: becoming increasingly willing to disclose their current or past HCV-status, reductions in substance use, increases in general self-care, and a desire to help others living with HCV.

**3.4.2.1 Change in HCV disclosure:** Almost all participants described a change from initial reluctance to disclose their HCV-status to willingness to accept and share their status. One participant attributed her shift in willingness to disclose her HCV treatment to her desire to help others with HCV.

“I’m on Hep C medication and it’s working. I’m doing great with it. I changed completely and I was okay with telling anybody who wanted to hear about the medication so they could get motivated,”

(Participant 1).

Other participants described how changes in their HCV-status resulted in a sense of pride and accomplishment, which affected their willingness and openness to disclose their HCV status.

“I didn’t [disclose]--at the beginning... but then I felt proud. I felt proud to say that in a month it was undetectable,”

(Participant 9).

**3.4.2.2 Change in substance use and self-care:** For many, HCV treatment was associated with reported reductions in substance use behaviors.

“Everything changed. I stopped drug use. I stopped everything because I said if I beat the Hep C, I could beat that too. Praise God up to today, I feel so good,”

(Participant 1).

“I didn’t care about living. I didn’t care about dying. All I wanted was to get high. Today I care about not getting high,”

(Participant 18).

Another participant described several changes he experienced after HCV treatment, including sobriety and progression toward stable housing.

“I noticed that I wanted to be sober. That getting high was no more fun—a waste of time, waste of money. I can throw more energy and effort into more positive things that can reach other people in a less position than I am. Like I went through the shelter process, right now we are in transition for housing, I’m about—let’s say maybe three months away from being independent completely,”

(Participant 20).

Others described transitioning into a healthier lifestyle.

“You know I’m taking care. I’m more aware of my body now, and I take care of myself, from my weight to my diet—everything. I’m real conscious of that,”

(Participant 23).

Multiple participants described an increased sense of responsibility in their lives. They associated their increased sense of responsibility with their reduced substance use and their HCV-related accomplishments.

“With this hepatitis and being clean, when I started [HCV treatment], I guess I started being responsible. You know, making responsible decisions about my life. In that aspect, it showed me where they all connect,”

(Participant 23).

One participant explicitly linked HCV treatment to a broader life transformation.

“I like to think of it as the Hep C treatment turned me around a little bit. The whole issue of the Hep C, addressing it, that’s how I like to think of it. Saving my ass, in plain English, saving my life, you know... So, coming into the hepatitis treatment really was a big turnaround,”

(Participant 21).

**3.4.2.3 Desire to help others with HCV:** The majority of participants described a desire to reach out and help others living with HCV.

After the treatment, I felt like people need to know about this. What can I do to wake them up and let them know—come see a doctor, take the blood work, see if you have it. If you don’t have it, thank God you don’t have it, but if you do have it, there is treatment. There is hope,”

(Participant 18).



## 4. DISCUSSION

In this sample of 31 individuals receiving integrated HCV treatment within an inner-city clinic providing both methadone maintenance and primary medical care, we confirmed previous findings of negative perceptions of HCV prior to initiating treatment, including internalized stigma and shame (Butt, 2008; Harris and Rhodes, 2013; Treloar et al., 2010). The majority of participants in this study described initiating HCV treatment because they wanted both to treat their HCV, and to make larger changes in their lives. Those who chose to participate in group HCV treatment overwhelmingly described that the social support and shared experiences of group members contributed to reduce internalized stigma and promote behavioral change. Our most notable finding was that virtually all participants described psychological and behavioral transformations while undergoing HCV treatment, regardless of participation in group or individual HCV treatment. These transformations included reductions in stigma and shame associated with HCV and substance use, new willingness to disclose HCV status, reductions in substance use, increases in self-care, and a desire to help others with HCV.

The psychological and behavioral transformations described by participants may be associated with the unique culture of the integrated HCV treatment program at Einstein. This program offers a combined intervention, including providers who are willing to deliver accessible information about HCV treatment, potential for curability through medical treatment, peer educators, and the option to participate in group or individual treatment. By addressing both individual and social level barriers (e.g., including strategies for reducing stigma, increasing social support, maintaining regular contact with providers, and promoting medication adherence), such combined interventions may improve HCV treatment access and initiation (Harris and Rhodes, 2013).

Clinical cultures that attempt to de-emphasize power differentials between patients and providers by arming both peer educators and patients with information may ameliorate stigma within healthcare settings and reduce barriers to HCV care (Harris and Rhodes, 2013; Heijnders and Van Der Meij, 2006; Link and Phelan, 2001; Marinho and Barreira, 2013; Treloar et al., 2013). In particular, peer educators have been identified as influential in cultivating effective HCV care (Galindo et al., 2007; Norman et al., 2008; Rance et al., 2014; Rance and Treloar, 2014) as they promote patient empowerment and are able to share their lived experiences of HCV treatment (Norman et al., 2008). Further, peer educator involvement may be especially central to patient engagement when patients have had negative healthcare experiences in the past (Treloar et al., 2013). The presence of peer educators may also indicate an accepting and empowering clinic culture. Treloar et al. (2013) explain that patients receiving care in clinics with recently established peer programs reported feeling more accepted and understood, compared to patients in clinics without peer educators. The involvement of peer educators in the Einstein HCV program likely played an important role in the psychological and behavioral transformations described by the participants in this study.

The option to participate in group or individual HCV treatment in the Einstein program may further foster a culture of empowerment by enabling patients to choose the way they receive

HCV treatment. All study participants who chose group treatment reported that the support of the group helped sustain their engagement in HCV treatment and led to changes in their self-perceptions and self-care behaviors. In another qualitative study that explored a psychosocial support group for people living with HCV, participants explained that the group enabled close relationships, which fostered a safe and non-judgmental environment where participants could self-reflect, obtain social support, and feel accepted and cared for (Woolhouse et al., 2013). However, the majority of study participants in this sample reported psychological and behavioral transformations, regardless of participation in group or individual HCV treatment. Nonetheless, the option to participate in group treatment may have contributed to a supportive culture which enabled transformation. The transformation described by study participants may be associated with identity reconceptualization, from substance user to person with a curable illness. Other studies have identified associations between changes in self-perception and promotion of self-care, including reduced injection practices (Jauffret-Roustide et al., 2012). In a recent qualitative study, Rance and colleagues (2014) described identity reconceptualization among individuals who initiated HCV treatment within an opiate substitution therapy setting in Australia. The authors suggested that HCV treatment enabled patients to move from conceptualizing themselves as “addicts” or substance users to conceptualizing themselves as patients with a curable illness worthy of medical treatment. A similar process likely contributed to the psychological transformations described by the participants in this sample.

This study has limitations. We were unable to verify self-reported reductions in drug use. While we reached thematic saturation, a larger sample size may have offered additional insights. As all participants initiated interferon-based treatment, it is possible that our results are influenced by the experience of struggling with interferon side effects. Future research is needed to assess whether the psychological changes we observed remain when patients are treated with interferon-free regimens. Additionally, the convenience sample may not have been representative of all patients who were treated. Finally, the unique aspects of the HCV program at Einstein may have contributed to our results.

Despite being disproportionately affected by HCV, former and active substance users continue to face system-, provider- and individual-level barriers to accessing and initiating HCV treatment. While substance use and low levels of self-care behaviors have been cited as reasons for limiting access to HCV treatment, our results suggest that integrated HCV treatment within the substance abuse treatment setting may act as a catalyst for decreased substance use and increased self-care. The experiences described by our study participants indicate that integrated HCV treatment may address underlying psychological barriers to self-care, including internalized stigma and shame. Although we cannot state which aspects of such a program are most critical, this study evidences that integrated multicomponent HCV treatment is effective and transformative. Ultimately, clinical trials are needed to assess whether an integrated, multicomponent HCV program has the capacity to catalyze significant psychological and behavioral changes. Given the cost of new HCV treatments, many payers are excluding active substance users from interferon-free treatments. However, our results suggest that the non-virologic benefits to antiviral treatment, such as improved self-care and reductions in substance use, may be substantial.

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### Highlights

- We interviewed 31 methadone-maintained adults enrolled in integrated hepatitis C (HCV) treatment.
- Participants described psychological and behavioral transformations from treatment.
- Integrated HCV treatment may be able to reduce shame and improve overall self-care.