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The experience of re-infection among people who inject drugs  
successfully treated for hepatitis C

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## ABSTRACT

**Introduction:** Highly effective direct-acting antiviral (DAA) agents have changed the landscape of hepatitis C virus infection (HCV) treatment and have become more available to people who inject drugs (PWID) over the past several years. Although many achieve a sustained virologic response (SVR), a small proportion will become re-infected. This study examined experiences of re-infection among participants in Project HERO, a large multi-site treatment trial designed to test alternative treatment delivery models for DAAs.

**Methods:** Study staff conducted qualitative interviews with twenty-three HERO participants who experienced reinfection following successful treatment for HCV. Interviews focused on life circumstances and experiences with treatment/re-infection. We conducted a thematic analysis, followed by a narrative analysis.

**Results:** Participants described challenging life circumstances. The initial experience of cure was joyful, leading participants to feel that they had escaped a devalued/stigmatized identity. Re-infection was very painful. Feelings of shame were common. Participants with fully developed narratives of re-infection described both a strong emotional response as well as a plan for avoiding re-infection during retreatment. Participants who lack such stories showed signs of hopelessness and apathy.

**Conclusion:** Though the promise of personal transformation through SVR may be motivating for patients, clinicians should be cautious about how they describe the “cure” when educating patients about HCV treatment. Patients should be encouraged to avoid stigmatizing, dichotomizing language of the self, including terms such as “dirty” and “clean.” In acknowledging the benefits of HCV cure, clinicians should emphasize that *re-infection does not mean failed treatment*; and that current treatment guidelines support retreatment of re-infected PWID.

**Keywords:** Hepatitis C; DAAs; Qualitative research; Re-infection; Narrative analysis, PWID

**Highlights:**

- The experience of re-infection with HCV has been little studied
- Our narrative study of PWID suggests reinfection can be psychologically devastating
- Patients who lack developed reinfection narratives may be especially vulnerable
- Physicians must avoid stigmatizing language in managing re-infected patients

## 1. Introduction

People who inject drugs (PWID) are disproportionately affected by hepatitis C virus infection (HCV) (Ryerson et al., 2020). Clinical guidelines recommend HCV treatment for all infected persons (AASLD-IDSA, 2019). Highly effective direct-acting antiviral (DAA) agents have changed the landscape of HCV treatment and have become more available to PWID over the past several years. Many of these patients successfully achieve a sustained virologic response (SVR) (Chou et al., 2019). However, a minority become re-infected after being cured (Hajarizadeh et al., 2020).

Several qualitative studies investigating the experiences of PWID who have been treated for HCV find that achieving SVR can have a powerful psychological impact (Batchelder et al., 2015; Lafferty et al., 2020; Madden et al., 2018; Williams et al., 2019). Participants describe a radical transformation of their sense of self following cure—a shift from the diseased, stigmatized, “dirty” self, to a “clean” identity free from disease and shame. What happens, then, when a person becomes re-infected?

To our knowledge, our study is the first to describe lived experience of PWID who become re-infected with HCV. Understanding experiences of reinfection in this group is important for several reasons. First, participants may provide clues to potentially modifiable influences on reinfection, including gaps in care and socioeconomic factors such as housing problems and food shortages. Second, meanings and emotions—such as shame and hopelessness—may contribute to worsening substance use and reduce motivation for retreatment. Understanding these sequelae may help care providers to do more to reduce these painful experiences.

## 2. Methods

The HERO (“Hepatitis C Real Options”) study is a randomized pragmatic trial designed to evaluate the effectiveness of two delivery models for treating PWID with HCV (NCT02824640). Seven hundred fifty-five HCV-infected PWID were recruited from 10 opioid treatment programs (OTPs) and 15 community-based health centers (CBCs) in 8 communities across the United States and randomized to either patient navigation (PN) or modified directly observed treatment (mDOT) over 12 weeks of once-daily oral treatment with sofosbuvir/velpatasvir. Of those initiating treatment, 74.2% achieved SVR (Litwin et al., 2019). This study, a qualitative exploration of participant experiences with HCV reinfection, is a component of the HERO Implementation Study, a multi-site process analysis aiming to examine contextual factors influencing the implementation of the HERO study (Damschroder et al., 2009).

Research teams at HERO sites around the country recruited participants whom they knew to have become re-infected. The study recruited a convenience sample of 24 participants. Recruitment was challenging, since re-infected patients often dropped out of the study and could not be reached for follow up. Research staff usually made more than one attempt to contact each participant. Following an informed consent process, participants were interviewed by phone or in person. In some cases, local research staff interviewed participants in person; in other cases, patients were interviewed by members of the implementation evaluation team via telephone. A qualitative interview guide examined life circumstances and context, experiences with the HERO study, circumstances leading to re-infection, the experience of re-infection, and plans for seeking retreatment. Interviews lasted approximately 30–45 minutes. Interviews were audio recorded and professionally transcribed. Participants received an honorarium of \$25. The Institutional Review Board at Albert Einstein College of Medicine approved the study.

Analysis began immediately with the first transcript received. Recruitment efforts continued until it became clear to the implementation team that new transcripts were no longer generating important themes and insights—a turning point known as data saturation.

In keeping with standard qualitative analysis approaches, the analysis proceeded in several steps. The first two authors included a psychologist and a medical student who conducted the interviews. A potential source of bias was the first author's assumption that reinfection would be a devastating experience for our participants. This was related to a previous interview study with HERO participants that explored the powerful experience of HCV cure. Next, we reviewed transcripts and created a provisional coding scheme. This scheme was applied to an initial subset of the data by the first and second authors. The coding scheme was then revised and reapplied to data segments in iterative fashion, until both authors judged it to be sufficiently parsimonious and comprehensive. Study staff uploaded the data into NVivo, a qualitative data analysis program that facilitates the rapid thematic organization and retrieval of qualitative data. The second author then coded the data in NVivo. The first author examined the coding reports generated by the program. In a final step, they merged some new codes, deleted some, and added others.

We first conducted a descriptive analysis, examining broad themes in the data such as life situations, treatment experiences, and the experience of reinfection. In a second, comparative phase, we examined differences in re-infection narratives across the sample, using Labov's narrative analysis framework (Labov, 2008).

According to Labov, the major purpose of any narrative is to assert the narrator's right to hold the stage—to justify his/her story. Central to his framework is the notion of the most reportable event (MRE). The MRE is the “so what?”—the event that justifies the story. The MRE has several possible characteristics: anomaly, valence, emotional impact, irony, or moral implications. Through comparative analysis, we identified two groups. The larger group (about three-fourths of the sample) had an organized re-infection story to tell—characterized by a typical MRE. The other group did not. We explored differences between the experiences of these two groups.

### 3. Results

#### 3.1 Participant characteristics

The sample included twenty-four participants. The average age of participants was 36.3 years. Sixty-three percent had a high school diploma/GED or less. Sixty-two percent were male, 80% were White, and 20% Hispanic. Thirty-three percent were employed. Thirty-three percent were securely housed.

#### 3.2 Life circumstances

Participants described histories of drug use, trauma, homelessness and violence. Several reported having to steal or exchange sex to get money for food or drugs:

I've been homeless for the past seven years. . . I just got a car this week, so I was sleeping in back of McDonald's. I'm starving. I don't have money. I have no income, and I'm just fucked in every way. [For food]—I steal it. . . I go into the store, and I find fruit and things like that that I don't have to cook.

*When you miss coming here to get your methadone, those are the days [that you use drugs]. Could you walk me through one of those days? Yeah, um, wake up, realize we missed the clinic, I prostitute to get the money we need, and we go see the dealer.*

In the context of these very difficult life circumstances, drug use relieved stress and suffering:

*I mean getting high just means all my problems go away for a little while. . . it's like digging yourself out of a hole with a teaspoon, [but] it just makes all my problems go away. . .*

Many participants described a sense of emptiness and a lack of connection to other people. Drugs helped some feel more alive and connected:

*I can't communicate with people anymore. I can't be the person that I am. . . I get scared, I get nervous. I don't want to talk to people. I don't want to do anything. If I'm forced to go in public when I'm not high, I just want to get it done and go home.*

For many of our participants, shame and despair were an integral part of their life experiences.

*I'm constantly thinking about what I could have done because I feel like I fucked up and I should have done a lot better with my life.*

Many participants articulated self-loathing:

*There are times where I wonder why the fuck am I here? Because I should be gone. There's a lot better people out there that are dead that are way better than me as a person, have way better moral value and done way better things in their lives and they're dead. They [might have injected just] that one time. And like I do this shit every day, you know what I mean?*

### **3.3 Motivation to seek treatment**

The high cure rate from the new generation of DAAs was one factor that led participants to seek treatment. Many participants described getting treatment as something positive that they could do for themselves.

*Was it something that you were excited about once you heard about the opportunity to get treated? Yeah, absolutely. Definitely. It made me feel confident. Something that I could at least better my life somehow, you know.*

Eliminating the shame and stigma of disease was a major motivation.

*When I first found out that I had it, like the first time I had it, I was crying. I felt dirty. I was like, "This is disgusting." Like I never had it, never heard [about] it, like, you know what I mean? Like I just felt gross.*

*Can you tell me more about the stigma [of HepC]? Oh, it's just the way other people look at you, you know? . . . They don't look at you like you're a king or a queen, you know what I mean? They look at you like you're a scumbag.*

### **3.4 Experiences with the HERO study**

Asked whether the HERO study staff might have done more to help participants avoid re-infection, none could provide any suggestion. Participants invariably felt that they had only themselves to blame.



*With the re-infection, is there anything that our team could have done differently to help [prevent that]?* No, it was me, it was myself, you know, that did it, you know. . . I was the one that up, you know. It was me, myself.

As we have noted, all participants in this sub-study had successfully completed HCV treatment and achieved SVR. Many participants described their joy when they discovered that they were cured.

I was just like; I couldn't believe it. I could not believe it. I was like. . . I had just been cured almost of like cancer.

As other studies have shown (Batchelder et al., 2015; Williams et al., 2019), participants found the cure to be a powerful, transformative experience. Many spoke of a “new beginning”.

Knowing that at the end of these 12 weeks I was going to not have that in my system anymore and I was going to have like a clean palette, was something to look forward to. And when I did complete the 12 weeks and I got my blood work back I felt happy. I felt refreshed, you know, like a new beginning.

### 3.5 Re-infection narratives

We used an analysis strategy proposed by Labov (Labov, 2008) to examine differences in the structure of re-infection narratives across participants, focusing on the MRE in each story. As described above, the MRE is the “so what?”—the event that justifies the story. The majority of participants in the sample seemed eager to tell their re-infection story. Most of these stories focused on a central, core MRE—an ironic, surprising, or upsetting proximal cause of re-infection.

For most, the MRE was associated with strong emotions—mostly shame and sadness. Relapse itself created strong feelings of self-disgust:

I felt like such a piece of shit, like how stupid just for a few hours of relief you totally re-infected yourself, you put yourself in a situation to get really sick again.

Shame and disappointment also arose in the context of *failed effort*—perhaps the loss of that longed-for clean self that has been described in the literature on HCV cure (Batchelder et al., 2015; Williams et al., 2019)

So I found out after a year that I had got re-infected. And that was like kind of like heartbreaking for me at the same time because I worked so hard to cure myself or get cured. Being re-infected was devastating to me.

Several worried that HERO study staff would be disappointed or upset when they learned that the participant had become re-infected.

And then I was like I found out I was re-infected, and I was like felt so ashamed because I was doing so good up until that point. And then to see the people that are curing me and, you know, it was kind of like it was definitely embarrassing at the time.

In several stories, the cause of re-infection was the return to the “people and places” that trigger drug use. Most participants had made many efforts, despite their lack of resources, to remove themselves from the social and physical contexts in which they were using drugs. Re-infection occurred when they ended up back where they started. After all their efforts, there was irony here:

[The year after I got cured] I had my own apartment. But that ended up not working out good with the landlord, so I had to go back to my mother's house. [At my mother's house I was in a *trap neighborhood*.] Trap neighborhoods are like where you can go out into the neighborhood and there's no safe direction, you know what I'm saying? And that's when things kind of went downhill.

In several stories, re-infection resulted from a surprising mistake, an accident, or the malfeasance of others. For example, several participants said that they re-infected themselves by using old needles. Others told stories of being “tricked” by friends, relatives, guests, and roommates.

After we lost our place where we were staying with a friend in Mass, and there was somebody going up in our room, like using our stuff. That's the *only, only* way it could have happened.

The bottom line is what caused it was me being in that house. Someone was infected, and I didn't know it. Obviously, they don't go around telling people. I think they either used my razor or my toothbrush.

Some stories seemed to include elements of a typical “tall tale.” For example, one participant recounted how he became infected through an act of heroism—saving a life on a platform hanging thirty stories in the air.

Yeah, a guy got cut on the job. He's 30 stories in the air doing glass and the glass that we do is pressurized. . . He hit the corner of the glass and it blew up. It's like a bomb went off and cut his neck, an artery in his neck and his arm. There was mad blood. Blood was leaking down on me. I had to get up there, you know. People were scared to touch him. I was 30 stories in the air holding him. Blood everywhere.

### 3.6 Re-infection non-narratives

While the majority of participants wanted to tell their re-infection story, a small group, by contrast, showed no such interest. Interviewers had to struggle to elicit the sequence of events surrounding the re-infection experience.

*When you heard about [being re-infected], how did it make you feel?* Not good. [laughs] . . . *Can you tell me more about that?* I just felt a little discouraged, that was pretty much it. *[Can you] walk me through . . . how it impacted you when hearing that news?* Not so good news. [laughs] I don't know. [laughs] I'm not sure. *What were some of the thoughts that went through your mind?* I just felt like I went through all of that for nothing, pretty much. I don't know.

For these participants, the events that led to re-infection did not add up to a story. Their accounts lacked an MRE—“I just felt a little discouraged, that was pretty much it.” In Labov's sense, there was no story because nothing had happened.

*How did it impact you when you were told you were re-infected?* It really, it really didn't. I mean I knew when I was doing it that I was going to get it back, so I expected it. *Can you walk me through that day and your emotions?* Well, you just don't care. You know what's going to happen, but you don't care until it does. But even when it does, you really don't. You kind of put it out of your mind.

When the interviewers tried to elicit narratives, some respondents became irritable:

*How did you get re-infected? Can you walk me through it?* I don't understand the question. I keep telling you. . . I got high with her that day. That's me walking you through it. That's it. That's the bottom line. I got high with her. Know what I mean? *I hear you.* Like what do you want me to tell you? We got up in the morning, we ate breakfast, we had coffee, you know what I mean? I mean we just got high, that's it. And I got it, you know what I mean?

For these participants, the reinfection event lacked the moral or emotional salience, the irony or element of surprise, which characterized narratives in the larger group. Participants in this smaller group described little emotional reaction.

*Can you describe to me the actions and how you were re-infected in more detail?* There's nothing—I didn't feel nothing. There were no feelings to it.

Often, this numbness and apathy seemed to reflect a deep hopelessness.

I thought that I would want to try to keep it away, but I guess the addiction was just too powerful. It's been so long since I've tried to stop using.

### 3.7 Retreatment

We queried participants about their plans for retreatment, and asked if they thought they could avoid infection the second time around. The majority expressed strong motivation for retreatment and a plan to avoid a second re-infection.

*You know you can get a new treatment. I don't want to do that, but I'm letting you know—nothing like that is going to happen again. I'm not going to take chances, any chances with anything. So, what are you going to do differently?* Oh, [use equipment] one time only [and then] throw away. I got to have it where I can't have access to it again. The needle needs to go into a thing that I can't reopen or something, you know what I mean?

And I've put it out to my partner that if you want to use, and live like that, then you can consider yourself homeless and single because that is not how I am going to live.

The small group of participants who had reacted to their re-infection with numbness and saw their re-infection as a “non-event” also expressed their intention to get retreated but reported no plans to avoid re-infection.

*What are the plans in place for you when it comes to HepC at this point?* Just to take the pills. Okay. *What pills?* The ones that I was taking before, the new ones that [Dr. X] is going to prescribe for me. She says there's another one out. *Okay. Can you tell me more about that?* I don't know about it.

## 4. Discussion

The study reported here is part of a larger study of implementation processes and outcomes in the HERO study. A convenience sample of participants experiencing SVR followed by re-infection, reported a diversity of experiences of suffering. Over half were insecurely housed, and a quarter were living on the street at the time of interview. Many reported depression, isolation, and hunger. Several resorted to stealing or transactional sex to buy food or drugs. Most lived with shame and despair due to their drug use, their life failures, and their infection with HCV. Getting “high” helped some to forget their suffering. For others, drugs increased confidence, allowing them to connect with others and take care of everyday business.

Our participants invested the cure of their HCV infection with powerful symbolic meaning: it was a way of “doing something for myself”, “a new beginning” (Batchelder et al., 2015; Madden et al., 2018). Relief from shame and stigma was at the core of this experience (Richmond et al., 2018) (Madden et al., 2018). To participants, SVR seemed to promise a repaired identity, “a chance to feel clean again”. Unfortunately, the joy and sense of promise that accompanied the experience of cure was followed by shame and despair when participants became re-infected.

Though the promise of transformation may be motivating, clinicians should be cautious about how they describe the “cure” when educating patients about HCV treatment. Patients should be encouraged to avoid stigmatizing, dichotomizing language of the self, including terms such as dirty and clean (Lafferty et al., 2020). In acknowledging the benefits of HCV cure, clinicians should emphasize that *re-infection does not imply a moral failure*. While a patient’s sense of agency and control should be supported, clinicians should also discuss the role that societal inequities and public health policy failures play in HCV infection and re-infection. Patients may need special care and support in states where policy restricts access to retreatment.

The results also suggest the importance of integrating substance use treatment and harm reduction strategies into HCV treatment. The HERO study interventions did not directly provide medication for opioid use disorder (MOUD),<sup>1</sup> or syringes. Moving forward, HCV treatment programs should actively integrate evidence-based health promotion interventions designed to prevent re-infection.

The use of a narrative analysis framework in this study helped to reveal key differences between those who remained hopeful and motivated in the face of re-infection, and those who did not. The majority of participants in this small study told detailed stories about how they perceived their re-infection resulted from an ironic turn of fate, a mistake, an accident, or the misdeeds of others. We are unable to determine the factual accuracy of these accounts—in fact, narratives in some of these stories seem to include fictional, tall tale elements. Regardless, participants with a story to tell—those who portrayed their re-infection as due to anomalous, ironic, or tragic causes—also seemed more optimistic regarding retreatment and more likely to have a detailed plan for how to avoid re-infection. Participants who did not have a story to share showed evidence of emotional numbing and hopelessness. Patients like this can be difficult to work with, but they may be in particular need of care and support. Alleviating the isolation, shame, and stigma experienced by these patients may be key to sustaining HCV infection treatment success and long-term health.

#### 4.1 Limitations

Our research has limitations. The sample cannot be assumed to be representative. Given the difficulties that local staff faced with recruitment, our sample likely differed in important ways from other re-infected participants. However, as the first study in the literature to examine experiences of re-infection, our study provides important insights into this phenomenon, with implications for clinical management.

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## REFERENCES

- AASLD-IDSA. (2019). *Recommendations for testing, managing, and treating hepatitis C*. Retrieved March 11, 2020 from
- Batchelder, A. W., Peyser, D., Nahvi, S., Arnsten, J. H., & Litwin, A. H. (2015). "Hepatitis C treatment turned me around:" Psychological and behavioral transformation related to hepatitis C treatment. *Drug Alcohol Depend*, 153, 66-71. <https://doi.org/10.1016/j.drugalcdep.2015.06.007>
- Chou, J. W., Silverstein, A. R., & Goldman, D. P. (2019). Short-term budget affordability of hepatitis C treatments for state Medicaid programs. *BMC Health Serv Res*, 19(1), 140. <https://doi.org/10.1186/s12913-019-3956-x>
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*, 4, 50. <https://doi.org/10.1186/1748-5908-4-50>
- Hajarizadeh, B., Cunningham, E. B., Valerio, H., Martinello, M., Law, M., Janjua, N. Z., Midgard, H., Dalgard, O., Dillon, J., Hickman, M., Bruneau, J., Dore, G. J., Grebely, J. (2020). Hepatitis C reinfection after successful antiviral treatment among people who inject drugs: A meta-analysis. *J Hepatol*, 72(4), 643-657. <https://doi.org/10.1016/j.jhep.2019.11.012>
- Labov, W. (2008). Oral narratives of personal experience. In P. Hogan (Ed.), *Cambridge Encyclopedia of the Language Sciences*. Cambridge University Press.
- Lafferty, L., Rance, J., Grebely, J., Dore, G. J., Lloyd, A. P., Treloar, C., & Group, S. T.-C. S. (2020). Perceptions and concerns of hepatitis C reinfection following prison-wide treatment scale-up: Counterpublic health amid hepatitis C treatment as prevention efforts in the prison setting. *Int J Drug Policy*, 77, 102693. <https://doi.org/10.1016/j.drugpo.2020.102693>
- Litwin, A. H., Jost, J., Wagner, K., Heo, M., Karasz, A., Feinberg, J., Kim, A. Y., Lum, P. J., Mehta, S. H., Taylor, L. E., Tsui, J. I., Pericot-Valverde, I., Page, K., & Group, H. S. (2019). Rationale and design of a randomized pragmatic trial comparing patient-centered models of hepatitis C treatment for people who inject drugs: The HERO study. *Contemp Clin Trials*, 87, 105859. <https://doi.org/10.1016/j.cct.2019.105859>
- Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia. *Harm Reduct J*, 15(1), 42. <https://doi.org/10.1186/s12954-018-0248-4>
- Richmond, J. A., Ellard, J., Vallance, J., Thorpe, R., Higgs, P., Hellard, M., & Thompson, A. (2018). Achieving a hepatitis C cure: a qualitative exploration of the experiences and meanings of achieving a hepatitis C cure using the direct acting antivirals in Australia. *Hepatol Med Policy*, 3, 8. <https://doi.org/10.1186/s41124-018-0036-5>
- Ryerson, A. B., Schillie, S., Barker, L. K., Kupronis, B. A., & Wester, C. (2020). Vital Signs: Newly Reported Acute and Chronic Hepatitis C Cases - United States, 2009-2018. *MMWR Morb Mortal Wkly Rep*, 69(14), 399-404. <https://doi.org/10.15585/mmwr.mm6914a2>
- Williams, B., Nelons, D., Seaman, A., Witkowska, M., Ronan, W., Wheelock, H., Zaman, A., & Garcia, J. (2019). Life projects: the transformative potential of direct-acting antiviral treatment for hepatitis C among people who inject drugs. *Int J Drug Policy*, 72, 138-145. <https://doi.org/10.1016/j.drugpo.2019.03.015>

**Author statement**

Karasz--Conceptualization, investigation, formal analysis, validation, methodology, supervision, writing--original draft

Merchant—Project Administration, Data collection, review & editing

Singh—review and editing

Thomas—data collection, review and editing

Borsuk—data collection, review and editing

McKee—conceptualization, formal analysis, Writing—review and editing

Duryea—review and editing

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Tsui—review and editing

Litwin--Funding acquisition, resources, Writing--review and editing

**Highlights:**

- The experience of reinfection with HCV has been little studied
- Our narrative study of PWID suggests reinfection can be psychologically devastating
- Patients who lack developed reinfection narratives may be especially vulnerable
- Physicians must avoid stigmatizing language in managing reinfected patients

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<sup>i</sup> Participants in the OTP arm of the trial were receiving MOUD in these programs.