

# Medical Anthropology

## Cross-Cultural Studies in Health and Illness

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/gmea20>

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**To cite this article:** Joshua Burraway, Bailey Helbert, Julie Schexnayder, Terry Knick, Rebecca Dillingham & China Scherz (2022): Reliving it All Over Again: Uncanny Temporalities of Injection Drug Use and Hepatitis C Diagnosis in Southwest Virginia, USA, *Medical Anthropology*, DOI: [10.1080/01459740.2022.2110090](https://doi.org/10.1080/01459740.2022.2110090)

**To link to this article:** <https://doi.org/10.1080/01459740.2022.2110090>



Published online: 09 Aug 2022.



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## Reliving it All Over Again: Uncanny Temporalities of Injection Drug Use and Hepatitis C Diagnosis in Southwest Virginia, USA

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### ABSTRACT

Clinicians typically view the intersection between hepatitis C and injection drug use in terms of simultaneity – with transmission occurring via shared needles – or sequentially – with some states requiring that people stop using drugs prior to treatment. Yet, for patients, the connection between substance use and HCV infection can follow a more complex temporal pathway. In this article, we explore the non-linear temporality of “reliving” as it shapes HCV illness experience, its complex intersection with injection drug use, and the barriers patients face as they reckon with existing healthcare system responses and treatment modalities.

### KEYWORDS

Diagnosis; narrative; rural injection drug use; temporality; hepatitis C; USA

Epidemiologists and clinicians typically view the intersection between Hepatitis C Virus (HCV) infection and injection drug use in terms of simultaneity – with transmission occurring in moments of needle sharing – or sequentially – with many states requiring that people stop using drugs prior to treatment (National Viral Hepatitis Roundtable 2020). Some have also suggested that clearing an HCV infection may result in the adoption of a less “chaotic lifestyle” through an “epiphany effect” (Innes et al. 2015). Yet, while these dynamics are present for some people, these linear or “sequential” temporalities do not capture the full story. Drawing on the earlier work of other scholars on the social, structural, and existential dynamics of diagnosis (Jain 2013; Kleinman 1988; Krug 1995; Martin 2007), we argue that the social consequences of a diagnosis are tangled up in narrative processes of self-making that disrupt stable separations between past, present, and future. For many patients involved in our research on HCV treatment in Southwest Virginia, the moment of HCV diagnosis produced a sudden enmeshment of two chronic diseases in their daily lives. While new direct-acting antiviral (DAA) medication promised a future self, free of HCV, the confirmation of the virus in their bloodstream effectively dragged a past self back into their present, forcing people already in recovery to reckon with traumatic, buried, forgotten, or unwanted parts of their personal history. This experience, what we describe as “reliving,” can be understood as a rupture in the normative rhythm of everyday life or, in narrative terms, the re-intrusion of a self-story that had, for the sufferer, been previously understood as finished and strategically left behind.

In these experiences of reliving, there is an overture into the uncanny. Popularized by Freud (2003 [1919]), the uncanny gestures to the return of the repressed, forgotten, or ghostly – to the way the strange and the familiar coalesce in unsettling ways. The uncanny blurs temporal boundaries between past, present, and future, revealing how subjectivity and identity are thrown into disarray as people reckon with the complex and often unpredictable impacts of disease, diagnosis, and treatment.

Often deployed in situations where embodied experiences of illness and psychological distress coalesce with stories of loss, separation, and cultural rupture, the uncanny has been a way for anthropologists to examine forms of haunting that permeate experiences of suffering and therapeutics (Varley and Varma 2018). Such ideas reflect a broader “spectral turn” in anthropology, with many drawing on Derrida (1994) concept of “hauntology” to interpret the emergence of ghostly forces in everyday life; forces that give life to what is otherwise unspeakable or unbearable (Good 2012, 2019). These uncanny traces also reveal relations between individual psychological experience, therapeutic culture, and the political conditions.

The ghostly traces in the Appalachian corner of Southwest Virginia are of a different ontological register, not so much supernaturally charged as pharmaceutically. The US National Center for Health Statistics estimates that 932,364 people in the US died from drug overdoses between 1999 and 2020 (Hedegaard et al. 2021). This number rose to over one million in 2021 (Ahmad et al. 2021), making it clear that this trauma did not end with the reformulation of OxyContin (Ciccarone 2019). While Virginia has a lower overdose rate than many other states, the overdose death rates in the counties included in this study are among the highest in the country (Virginia Department of Health 2022). For those who avoid or survive overdosing, there are blood borne infections circulating that leave people dependent on an austerity weakened healthcare infrastructure that is poorly equipped to manage complex patients living with multi-morbidities.

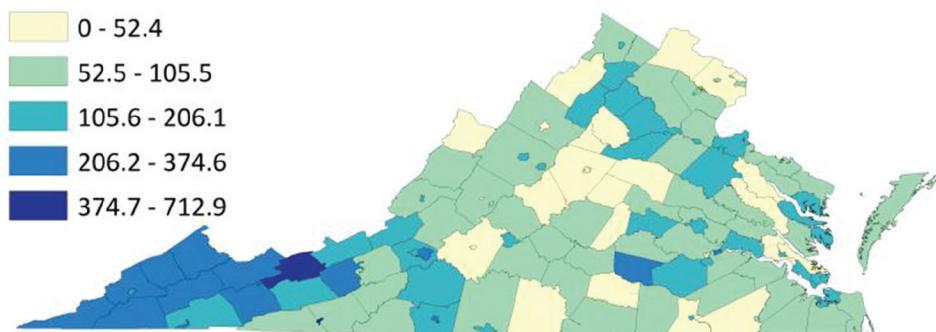
The former coal-mining towns of Appalachia are also haunted by the related history of coal-mining injury and associated violence, endemic marginalization, and chronic unemployment.<sup>1</sup> This history is a microcosm of America’s tragic history with its own lands and peoples, the coal mines laying waste to workers and the natural environment to provide the fossil fuel that historically sustained America’s ecologically catastrophic economic engine (Anglin 2002; Batteau 1990; Scott 2010; Stewart 1996). These contradictions, mark Appalachia as an “uncanny place where the American paradigm of economic development is haunted by the specter of failed progress, precisely in the heart of American national space.” (Scott 2010, 138).

Typically, Western clinical medicine does not treat these kinds of uncanny ghost stories as especially useful in the context of patient care and treatment, especially for clearly biological diseases like HCV. Medical anthropology, on the other hand, has sought to emphasize patient stories – ghostly or otherwise – as a means of making sense of human suffering, offering a biographic and sociocultural context for illness experiences that can inform therapeutic strategies (Kleinman 1988).

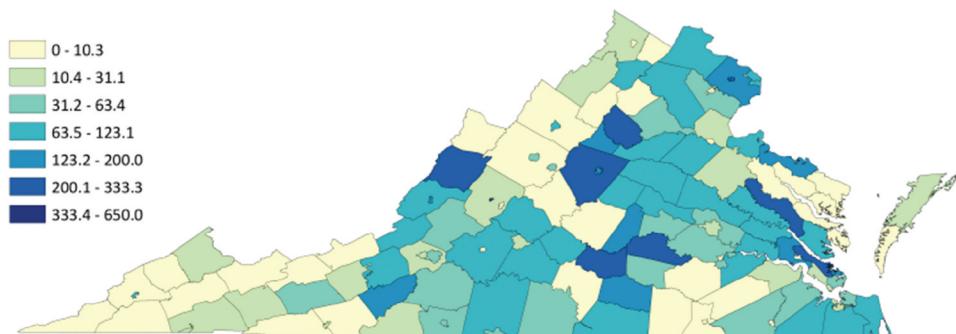
In this article, we explore how the non-linear temporality of “reliving” can, in certain cases, lend an uncanny quality to the HCV illness experience. We argue that this reveals a more complex intersection between HCV treatment and injection drug use. Practitioners treating people with HCV who have histories of injection drug use need to be aware of the struggles that patients may be facing as they remake their worlds and selves in the face of their diagnosis. In making this case, we echo earlier recommendations (Kleinman and Benson 2006) concerning the importance of incorporating emic understandings of patients’ lifeworlds into the structures, routines, and practices of clinical work; likewise, it speaks to the importance of transforming HCV treatment policy to allow this process to occur outside of sub-specialty clinics.

## Treating HCV in Southwest Virginia

In Virginia, HCV and injection drug use are clustered in the rural Southwest region (See [Figure 1](#)), while the clinical infrastructure to support HCV treatment is located three hundred miles northeast, in the more affluent, urbanized parts of the state where this treatment typically occurs in specialty clinics including gastroenterology and infectious disease (See [Figure 2](#)). In rural Southwest Virginia, high levels of economic deprivation, unemployment, lack of health insurance, and historically ineffectual therapeutics have intersected with escalating drug use to produce the ideal conditions for HCV to spread within communities of people who use drugs (Hamilton White et al. 2021; Havens et al. 2013; Schalkoff et al. 2020; Zibbell et al. 2015, 2018).



**Figure 1.** Reported hepatitis C per 100,000.



**Figure 2.** Hepatitis C treatment prescriptions per 100 new hepatitis C diagnoses. Virginia Department of Health Office of Epidemiology (2016).

At present, opioids, including OxyContin, heroin, buprenorphine, and fentanyl, are used alongside other substances, including methamphetamine (Cicero et al. 2020). Many counties in this region remain underserved by Medications for Opioid Use Disorder (MOUD) programs which utilize buprenorphine-based medications to help people with opioid use disorders (Topmiller et al. 2020), but policy changes have led MOUD programs to expand. Likewise, a 2017 law has allowed for comprehensive harm reduction services in Virginia, including syringe service programs. Yet, accessing these services can still require extensive travel in rural regions without public transportation (see Surratt et al. 2020).

Globally, the prevalence of HCV far exceeds that of HIV among people who inject drugs (Degenhardt et al. 2017). However, HCV has received less attention from epidemiologists, public health specialists, and medical anthropologists. Without treatment, HCV infections can lead to potentially fatal conditions such as cirrhosis or liver cancer. Fortunately, recent developments have resulted in treatment options that are more effective, less invasive, and more tolerable than what was previously available, opening up new possibilities for HCV treatment.

Yet, access to HCV treatment is often limited among people who inject drugs. This is especially true for those from low-income rural areas, where access to healthcare facilities and specialized treatment can be extremely limited. Rural healthcare facilities are often lacking in resources, clinical knowledge, and the experience required to manage injection drug use and related health problems (Bourgeault et al. 2006; Harris and Rhodes 2013; Harrold and Jackson 2011; Panelli et al. 2006; Schranz et al. 2018). Relatively small numbers of patients dispersed across a wide geographical area also make providing specialized services in rural areas costly, and it can become difficult to justify the overheads, administration, and equipment costs (Hanlon and Skedgel 2006). Furthermore, communities face challenges

recruiting and keeping hold of specialized health professionals (Clark et al. 2002; Walker et al. 2020). Limited public transportation options seriously hinder access to forms of specialized care, such as HCV treatment (Arcury et al. 2005; Basu and Mobley 2007; Huttinger et al. 2004; Pieh-Holder et al. 2012; Syed et al. 2013; Wolfe et al. 2020). Accessing care in a small, closely knit community can also prompt concerns regarding confidentiality, anonymity, and stigma (Baker et al. 2020), especially given the cultural stigma around issues like HCV infection. Historically, these issues were compounded by requirements that patients abstain from drug or alcohol use to qualify for treatment. This study, however, did not require abstinence in order to qualify, reflecting recent policy changes.<sup>2</sup>

## Methods

The CHIME (Conquering Hepatitis C via Micro-Elimination in Southwest Virginia)<sup>3</sup> study was designed to counter these disparities by using a collaborative telehealth care model linking physicians and specialist care providers at academic medical centers in Central Virginia with local primary care providers (PCPs) in southwestern Virginia. In collaboration with the Virginia Department of Health, the CHIME study team was able to provide access to HCV treatment with DAAs at no cost, a process that was greatly facilitated by the expansion of Medicaid in January 2019.<sup>4</sup> The team used video communication technologies to connect patients with specialists and while also training local providers in the skills required to deliver HCV care in their communities. The collaborative model also featured bidirectional referrals from and to comprehensive harm reduction (CHR) programs and clinics providing medication for opioid use disorder (MOUD) (Sherbuk et al. 2020).

The study's qualitative component analyzed the sociocultural, psychological, and experiential aspects of HCV illness – of which there has been surprisingly little investigation within the social sciences (Hopwood and Southgate 2003). This sparsity of research is particularly true in the context of the relatively new DAA treatment modalities, which continue to exhibit surprisingly low uptake (Spradling et al. 2021). As other health scholars have noted (Falade-Nwulia et al. 2020; Sacks-Davis et al. 2020), these therapeutic improvements will struggle to ease HCV-related morbidities until they are aligned with a more nuanced understanding of how HCV is experienced in the context of a patient's daily life.

The ethnographic work described in this article was part of this wider mixed-methods study designed to monitor and evaluate care outcomes for patients at each step of the HCV care cascade (testing and diagnosis; deciding to get treatment; access to treatment; determining condition of the liver; medication prescription; taking medications; HCV cure) after the implementation of a collaborative care model (Sherbuk et al. 2020). 62% of the 123 participants in the CHIME study were enrolled in MOUD programs at the time of treatment, although this was not a prerequisite. The remainder were using substances at the time of treatment or had no history of substance use. Surveys administered before and after HCV treatment assessed each patient's quality of life, mental health, physical condition, emotional state, chronic liver disease outcomes, and substance-use history. The data was collected over a 19 month period, from May 2019 to December 2020.<sup>5</sup>

The ethnographic data on which this article is based was collected over two three-month periods, from June 2019 to August 2019 and June 2020 to August 2020. Here we aimed to provide a comprehensive and descriptively rich understanding of the HCV illness and treatment experience. All study participants were offered the opportunity to participate in the ethnographic portion of the study, and their ultimate involvement in the ethnographic portion of the project was determined by their willingness to participate. 21 people participated in the ethnographic portion of the project: 13 women and 8 men. Their average age was 41, and they were all white and resided in rural communities. 16 were simultaneously receiving MOUD and 16 were on Medicaid. Ethnographic data collection involved audio recording interviews, taking detailed narrative field notes and life histories, and engaging in more extensive interactions with a smaller subset of four research participants in the context of their everyday lives, including in their homes, on car journeys, out shopping, and at medical appointments (Emerson et al. 2011; Groleau et al. 2006; Reeves et al. 2008). Josh Burraway

carried out the majority of this work. Given the small sample size and short time frame, the ethnographic portion of this study has certain limitations, and further research would be needed to explore the generalizability of these uncanny experiences of reliving. Future research might also explore whether similar dynamics play out in urban populations, or in populations with different demographic characteristics.

Following transcription, field notes and interview transcripts were thematically coded so as to locate particular patterns and themes within the data set. (Glaser and Strauss 2017). Once the study team identified a set of themes, we returned to analyze the complete narratives of those individuals who provided the richest data on particular themes and with whom the study team had developed the deepest and most enduring connections. The case studies put forward in this article were chosen because they capture the theme of “reliving” in particularly powerful ways. That said, it is important to note that the heterogeneity in HCV experience across the study cohort was such that “reliving” was just one emergent experiential theme within our data. Indeed, there were a number of patients whose diagnosis, treatment and subsequent cure constituted the final step in what they took to be their broader recovery narrative. This diversity of experiences, we argue, does not diminish the value of “reliving” as an analytical category. On the contrary, it confirms the extent to which ethnography is able to generate forms of knowledge that resist reductionism and instead bring life to the irreducibility and infinite diversity of the human condition (Mattingly 2019).

### **Things have a way of catching up with you**

For some, HCV diagnosis emerged as an unanticipated inflection point that forced them to confront a new reality marked by an uncanny sense of temporal disturbance. The case studies presented in this article focus on three people who exemplified this experience of disruption. Like the majority of the study cohort, these people had a history of substance use and were already enrolled in substance-use treatment when they were screened for HCV. Which is to say that they received their positive diagnosis at a time they identified as a recovery period which they saw as juxtaposed with their previous history of substance use.

#### ***William***

William’s house, located at the beginning of a dead-end road that runs into a now defunct coal mine, sits on the edge a once prosperous mountain town, the remnants of this bygone era – its bank, its grocers, its cinema – reduced to hollowed-out ruins, swallowed up by fire, presumed to be an arson. When Josh asked William why anyone would want to burn down these places, he shrugged his huge linebacker shoulders, “Something to do, I guess,” hinting at the conflagration of unemployment, boredom, and social obsolescence that has gripped many mining towns in the region. William himself hadn’t been able to work for some time, work injuries and a chronic lung condition had led him to seek disability insurance from the federal government, the outcome of which had been held up in bureaucratic limbo for years. His primary role was now as a caregiver for his partner, Jean, who had had a stroke 12 years before. Even after more than a decade of physical therapy, Jean still couldn’t make it more than a few steps without a wheelchair and needed help with everything from cooking, to getting dressed, to bathing. Both she and William had long-term histories of injection opioid use, mostly with one another, and both enrolled in a MOUD program two years before William’s diagnosis, on the recommendation of their primary care provider, who is local to the area and has been William’s family doctor since he was a child.

Despite his history of injection drug use, William’s HCV diagnosis came as a surprise. While at the hospital having a sore on his hand examined, William suffered a heart attack and was rushed into emergency surgery. His bloodwork revealed the HCV infection, along with some major kidney dysfunction. While the boundaries between these diseases may be diagnostically discrete, in

William's experience, they were anything but, as his doctors chose to delay his next cardiac surgery until his HCV had been treated and his liver evaluated. Once he was back at home, it was the HCV diagnosis – more than his heart failure or his kidney issues – that weighed most heavily on him, not because he was symptomatic, but because he worried about infecting Jean.

It makes me think different about the things I do, especially around my old lady . . . If I cut myself or something like that, cooking her food. It makes me think twice about being around her . . . It makes you live your life differently. It makes you not do certain things that you used to do. You probably can't catch it after drinking after somebody. It's not the kind I got. There's a lot of different kinds of it. Still, I don't want anybody really drinking after me now, where before, I didn't really even think about it.

Almost a year passed after his diagnosis before William sought treatment. When our study started, William's doctor convinced him to enroll in the telehealth program and begin treatment for his HCV. When he initiated the process and began receiving his first doses of medication, the prospect of being cured of HCV visibly lifted his mood, as he assumed that this would remove the final barrier between him and his heart surgery. In this period, he contemplated the possibility of a brighter, healthier future where he would have the physical strength to secure some work, save a bit of money and travel with Jean, who had never left Virginia. However, by the time he had completed treatment, his breathing difficulties, combined with his weight issues and ongoing kidney problems meant that, even with his HCV cured, his surgery remained on hold – as did the more hopeful future he had imagined with Jean.

His breathing continued to trouble him to the point that even small movements around the house were exhausting and William found it more and more difficult to care for himself and for Jean. Reflecting on his situation, William dwelt on the HCV diagnosis as the defining point where his health embarked on its current trajectory. He did not blame the virus for his other health problems, but rather saw it as a reminder of what he put his body through during his years of substance use. Hepatitis C, bundled up as it is with his multitude of other co-occurring health issues, is “the price I’ve paid for the life I used to lead. I tried to leave it behind, we did leave it behind. But these things have a way of catching up with you.”

This uncanny sense of his former life catching up with him and disrupting his visions of the future is manifest in his HCV diagnosis. The fact that, even after its cure, the diagnosis still played on his mind demonstrates how certain diseases can possess a kind afterlife. In using the concept of the uncanny – a “class of the frightening which leads back to what is known, of old and long familiar” (Freud 2003 [1919], 124)–to examine William’s experience of HCV diagnosis and its subsequent treatment, we can better understand where it fits in the broader story arc of his life as both a person and a patient. In particular, it helps us think with greater nuance about the way he experiences HCV as something “fateful and inescapable” (*ibid*) that has taken control of him, stunting his future possibilities even as it no longer resides within him.

### **Melissa**

Melissa and Josh were sitting in the clinic following her initial telehealth appointment for her HCV treatment, making small talk over his British accent and cracking jokes. One of his jokes got her, and she laughed, her hand moving over her mouth as a kind of reflex. She apologized, a sheepish look dawning over her face. “I’m just really insecure about my teeth because he busted them in” –he, being her former husband, whom she’d married when she was just 17. “That’s the first thing he wanted to do. He didn’t want me going out.” By the time she was in her 20s, Melissa’s husband had been subjecting her to an unrelenting regime of emotional and physical abuse, destroying her self-confidence to the point where she barely left the house for fear of what he might do. One day, after Melissa roused him from a nap, he flew into a rage and beat her almost to death.

It was going on for over two hours. I crawled over to the neighbor’s house. My shirt was full of blood, they told [my family] that you need to come down there. We don’t know if she’s alive or not cuz where he hit me in the back of the head, I’ve still got the dent. He hit me so hard. It knocked me completely out. And when I was out, he was beating my face in and that’s how I passed out. When I woke up six or seven days later, that’s how I got my

disability. I got my disability in one week after they looked at my hospital record. I didn't even have to go in front of the judge . . . That's how bad. In here was black. Inside my eyeballs, they were black . . . It was that bad. So, they put me on Percocet and stuff like that or Oxies or whatever.

After three years of being prescribed opioid analgesics following this horrifying ordeal, her clinicians eventually withdrew her prescription without offering her any kind of effective tapering schedule. Following some major withdrawal episodes, Melissa used what little money she drew from her disability benefits to source OxyContin and Percocet from the black market. Prone to major mood swings owing to her schizoaffective disorder and still enduring the traumatic effects of her husband's abuse, illicitly sourced prescription opioids like OxyContin became her primary coping mechanism and means of escape. It wasn't until she was in her late forties that she was finally able to find a recovery program that worked for her, a combination of counseling and MOUD.

In her mid-fifties, Melissa's went to her MOUD provider with complaints of severe stomach pain and tested positive for HCV. Her diagnosis threw her into a state of mortal panic, confusion, and self-recrimination. She became flooded with memories not just of her ex-husband's abuse but also of the things she went through during the most self-destructive period of her opioid usage, blaming herself for "putting [herself] through that predicament." These cycles of self-blame continued throughout her treatment, often amplified by schizoaffective episodes and periods of acute memory loss that left her feeling unsafe, afraid, and anxious, sometimes causing her to physically barricade herself within her own home.

At the same time, however, seeking and undergoing treatment was an empowering experience for Melissa. Supported by her new partner, Melissa felt like she had reclaimed a kernel of agency in her life.

I didn't know what to do. I felt like I was dirt. When I first got diagnosed, I was like, 'Oh my God.' Then after I found that I could get treated, it helped me a whole lot. And then to get treated for it, that was just the icing on the cake . . . I want to live. I want to see my grandkids. I don't do drugs no more cuz I want to watch my grandkids grow up.

When Melissa was diagnosed, the specter of death loomed large: "My first thought was that I was gonna die – I've come all this way and now it's gonna kill me." This thought that having only just reclaimed a "livable" life (Butler 2009, 23), Melissa should suddenly find herself facing death was deeply disorientating. This specter appeared as a symptom of her traumatic history, of which her substance use was itself a symptom. While her stomachache might have brought her to the doctor in the first place, any physical pain associated with her HCV diagnosis paled in comparison to the psychological pain she suffered at the uncanny intrusion of this former self into the life she had since built. Indeed, while the treatment was pharmaceutical in nature, there was also the sense of it almost as a kind of exorcism: a casting out of the uncanny ghosts haunting her present so that she might finally claim the futurity her drug-free present promised.

### Brenda

Brenda's mother walked out of the house when Brenda was only four. The next time Brenda saw her mother, she was seven, and her mother had a new partner in tow. In the meantime, her father had remarried, locking Brenda into what she described as a "Cinderella situation," her new stepmother favoring her own children over her and regularly subjecting Brenda to excessive punishments. So, when the opportunity to spend some more time with her own mother emerged, Brenda was only too happy to escape from her father's house. Her mother's new boyfriend, however, had an edge to him and was prone to outbursts that could be violent. One day, while her mother was out and Brenda was in his care, her mother's partner molested her. Brenda, only 10 years old at the time, never told anyone about the assault, and has yet to disclose the event to her family. As a teenager, Brenda discovered she was attracted to girls. This became another secret she tried to hide from her family, paranoid about the shame and recrimination it might bring her. Brenda describes "trying like hell to turn [herself]

straight," the mounting psychological distress of this sparking a downward mental health spiral that manifested in bulimia and depression. At 17, Brenda came out as gay and began a relationship with a girl a couple of years younger than she. After the girl's parents learned of the relationship, the mother called the police and successfully pressed charges against Brenda for statutory rape. Passed between various jails across Virginia for the next four years, Brenda was raped in prison by an inmate after her charges were disclosed, she suspects, by the guards. During this period her grandmother – with whom she was extremely close – also passed away.

Even with tragedy compounding on top of tragedy, Brenda didn't begin using drugs until she left prison, eventually being introduced to drug use by a woman she'd met while she was incarcerated. Her time out of prison was brief, as she was soon picked up in a bust after trying to sell drugs to an undercover officer in her hometown. It was back in prison where Brenda met her now-fiancée. Perfect running partners, the two of them used and scored together once they were released, during which time Brenda overdosed and violated her parole. It was during this last eight-month stint in prison that Brenda – the feeling of that near-death moment still clear in her mind and body – decided to stop using, and the court ordering her to attend rehab once her sentence ended. It was a couple of months into rehab that Brenda was diagnosed with HCV following a routine blood test. Though she knew there was always a risk of contracting it, that it arrived in the midst of her most extended period of recovery felt like a kick in the teeth. She said, "When I found out I had Hep-C I kind of thought of myself as sick and like nasty . . . I felt ashamed of my blood, my own body."

The experience was especially jarring for Brenda because, having cemented her place in a Narcotics Anonymous program and making steady progress through the steps, she felt like she had "become a different kind of person"—a process of self-transformation that was forcefully interrupted by the diagnosis. After successfully completing HCV treatment, Brenda was trying to look ahead and rebuild her life. Still, even with her HCV gone, the imprint of that period of her life remained stubbornly adhered:

I would really like to work with addicts as well but there's always my past that will have a little control of that, just from past charges and stuff like that so it would just be a work in progress of what I can and can't do.

In Brenda's situation, we gain a glimpse into one of the other central aspects of the Freudian uncanny, the feeling of lacking a sense of home. The original German word—*unheimlich*—from which the uncanny comes, translates literally as "not homely." The feeling of shame that accompanied her unexpected diagnosis was experienced as a kind of estrangement from the embodied self that she had been steadily cultivating. Her blood and body felt alien, no longer *home* to the person she was committed to becoming. In Brenda's case, the professional home she felt that she belonged in – as an addiction counselor – was also kept out of her reach by her past charges, fostering a collapsing sense of the future that threatens the patterns of meaning and possibility that her new identity had conferred upon her up to this point in her recovery.

## Uncanny bodies

For William, Melissa, and Brenda, their HCV diagnosis was more than the naming of a disease. Rather, it was an interruptive (Mattingly 2014; Vigh 2008; Zigon 2007) event that modulated the trajectory of their self-narratives, the "reliving" of their former selves unsettling their ongoing stories about who they were, where they were going, and where they had come from. Their experiences resonate with observations made by Gary Krug, whose work among people with HCV infection in Australia dates back to a period when the prognosis and treatment options were far less certain. Krug's argument, that people with HCV "are confronted with new, unanticipated descriptions and predictions that carry with them implications for actions, life plan and their own internalized self-images" (Krug 1995, 304) seems as relevant now as it did then. Indeed, evident in all three accounts is this sense of disruption

that occurs when a carefully rehabilitated self that has emerged from years of emotional, physical, and psychological labor is suddenly blind-sided by the unannounced intrusion of a former self. These patient stories are characterized by such uncanny experiences.

Instead of emanating from within the unconscious mind however, as the psychoanalytic model might have it, the uncanny return of the long alienated “addicted self”—understood by these three patients as a kind of polluting force – emerges from within the body – contained within in the biological marker of the blood – its emergence forcing the person to re-negotiate their relation to the world.

In William’s case, this re-negotiation was centered around having to alter his food preparation practices and hygiene rituals so as not to compromise his care-work with Jean. In clinical circles, such fears are typically explained away as the patient’s misunderstanding of epidemiological transmission dynamics – something that can be fixed by more formal disease education (Lubega et al. 2013). Yet, as William’s persistent worry about Jean’s drinking from his glass shows, such fears cannot always be educated away. He explicitly states that he knows he cannot transmit the virus by sharing a glass, and yet the fear persists. William’s hygiene anxieties do not stem from a technical misunderstanding. Rather, they emerge from his fears over his “bioidentity” (Waldby et al. 2004); bioidentity here referring to the ways the physical body – in both its entirety and its fragments – can both support and destabilize the experience of self. The bioidentity framework was developed via in-depth interviews with patients who had tested positive for HCV and, as such, is especially instructive for thinking through the ways in which infected blood might inform a person’s embodied sense of self-identity and social relations. None of this is to say that patient education is not a vital tool in the quest to enhance the coordination and delivery of care in the context of HCV. Rather, the point we seek to make is that patient education programs would benefit when enacted in tandem with attention to narrative that would enable them to better address existential, embodied, and relational challenges their patients may encounter as they move through the care cascade.

Attending to these stories also offers insight into the ways histories and diagnoses shape relationships, treatment uptake, and future health outcomes. Melissa, for example, has struggled with her memory since she was hospitalized following the attack by her ex-husband, often forgetting things like when and how much medication she needs to take. These memory issues are amplified during the times where her mental health is frayed, such as in the weeks and months following her HCV diagnosis, where she was reliving the traumas of her past. After forgetting to take her HCV medication on a number of days, she began to fear that it wouldn’t be effective and that she’d squandered her opportunity to rid herself of the disease. Following a major panic attack sparked by these anxieties, her new partner became involved in helping her track her medication, so that she didn’t need to rely on her own memory. This kind of relational burden-sharing was crucial to Melissa successfully completing treatment. This process also formed a major part of her evolving self-story in which the trauma of her abusive marriage and subsequent opioid usage were redeemed by the intimate caregiving of her new relationship, thereby opening up a more positive sense of the future. Melissa only wished that her partner could have been part of the treatment process from the start, attending her appointments with her so that they could be briefed on the treatment regimen together. In this situation, narrative knowledge about Melissa’s life history and her relationships might have helped tailor a treatment program that mobilized her existing support network, so as to guard against the risk of memory and mental health issues impacting her medication adherence.

Likewise, William reported missing medication doses on several occasions owing to exhaustion from trying to combine caring for Jean with caring for his own increasingly fatigued body, a situation exacerbated by his ongoing hygiene anxiety. In this juggling act, taking care of Jean’s needs always won out over his own because it was the moral cornerstone of their shared world (Kleinman 2012). While these kinds of calculations are part of any domestic caregiving situation, they are heightened in contexts where both partners are coping with significant disabilities. William’s and Jean’s lives were indivisibly entwined, and yet that story was never part of the treatment conversation.

Fortunately, both William and Melissa completed the treatment and achieved a sustained virologic response. However, despite their bloodwork showing identical results, the extent to which the news affected their sense of the future could scarcely have been more different. Melissa, having survived the risk of becoming a “failed patient,” was able to move even further beyond the gravitational pull of her past self and focus on the relationships that mattered most to her, namely her boyfriend and her grandchildren. William, by contrast, faced multiple unresolved medical conditions, and these ultimately eclipsed the kind of “new beginning” future that he had initially pictured at the start of his treatment. With the virus’s elimination not precipitating a sufficient change in William’s health to allow for heart surgery, the prospect of work, financial saving and cross-country adventure melted away, leaving him stuck in the strange liminal state of being simultaneously cured but still debilitingly sick, left to brood on the ways in which he was still “reliving,” still facing the costs incurred during a life he tried doggedly to leave behind.

Brenda, whose historical baggage encompassed interlocking forms of intimate and structural violence from her earliest years onwards, also faced an uncertain future of “stuckness” that was inexorably tethered to her troubled past. Unlike William, Brenda’s desire to become a different kind of person – interrupted first by her HCV diagnosis – was held back not by her physical body, but by the ways her incarceration and drug-use have echoed through her life in the form of an indelible stain. To use Goffman’s (1961, 1986) terms, this stain, this stigma, effectively risks “spoiling” Brenda’s identity, foreclosing her ability to find future employment in her desired field and, in so doing, creating yet another rupture in her story that originates from a past self that, in spite of her recovery, continues to wield control over her.

Importantly, for all three their HCV diagnosis came out the blue, moving into biological visibility through a chance bit of bloodwork only to then fade, following treatment, back into absence at the point of “cure.” Tellingly, though, what counts clinically as a cure – the absence of disease through “sustained virological response” – does not feel like absence to them. For them, HCV and its connection to their past substance use continues to leave an uncanny mark on their lived bodies. As Overend (2014) has argued, this sense of uncanny or ghostly return problematizes the clean lines between visible and invisible disease and with it the very notion of cure as it is understood in biomedical circles. To think with the uncanny concept of “reliving” is to propel oneself beyond bio-centric representations of illness, helping us to better understand and articulate the phenomenological experience of HCV in ways that biological accounts alone cannot.

## Conclusion

Deeper exploration of temporality and embodied selfhood in the context of HCV diagnosis and treatment can enrich clinical understandings of how patients confront, negotiate, and make meaning out of this complex illness. Used well, and in compliment with more standard forms of medical care, ethnographic storytelling can provide contextual and biographical depth that can help healthcare providers engage with patients not just as individual medical cases, but as complex people. Such a practice can serve as a means of cultivating trusting and empathic relations with patients.

For people who inject drugs, such forms of listening are rare, with the culture of suspicion entrapping patient and caregiver in damaging patterns of distrust and hostility (Crowley-Makota and True 2012). For such patients, attending to their stories within the treatment process can be especially transformative. The need to create space for storytelling within medical encounters is all the more important given the current debates over who can provide HCV treatment (Guss et al. 2018). Up until 2014, HCV medications could only be prescribed by or in consultation with a specialist, in part due to the complexity and toxicity of the prior regimens. Since that time, the advent of safer, less complicated regimens, more amenable to integration into primary care settings, have allowed groups like the National Viral Hepatitis Roundtable (NVHR) to advocate for policy changes that would allow primary care providers to prescribe. In 2020, 29 states, including the state of Virginia, allow PCPs to prescribe, but uptake remains slow.

There remains much work to do to change the policy for all states and to provide PCPs with the training and support necessary for them to engage in this form of treatment (National Viral Hepatitis Roundtable 2020).

This situation leaves patients struggling to access specialty clinics, navigating a complex triage process specifically designed to keep people out, rather than to pull people in. Patients must work to get a referral to get through the front door, and little room is given for forgiveness for missed appointments or missed calls. Such processes serve as barriers to care for many reasons but may be especially difficult for people who are also coping with complex forms of trauma. Further, providers of subspecialty care, located far outside of the communities most affected by HCV in Virginia, may have limited understandings of context and limited capacity for flexibility and compassion within the structure of their practice. If the kind of empathic witnessing we argue for in this article is going to occur, it will need to occur in primary care settings, in spaces that have far lower barriers to access and are more likely to provide the longitudinal care that creates space for patients to tell their stories. While William, Melissa, and Brenda were all “reliving” complex forms of suffering that resurfaced in the wake of their diagnoses, they were better able to seek treatment for their HCV because the care was provided in tandem with the office of their family doctors – not in a subspecialty clinic hundreds of miles from their homes. Williams’s doctor was someone with whom he had had a lifelong relationship and who understood the many challenges he faced. Even in such an intimate context there is room for allowing even more of a person’s story into the treatment context, but it is also true that it is here that such a shift is most likely to succeed. There have been extraordinary new advancements in treatment, but if this extraordinary power is not harnessed in tandem with a deep grasp of the contextual and experiential contours of people’s actual daily lives – a task that is most likely to take place in the office of a primary care clinician – then we will remain stuck in our current paradox where our technological ability to cure vast swathes of people is undercut by an inability to reach and treat those who need it most.

## Notes

1. As Angela Garcia (2010) demonstrates in her work in New Mexico, the intersection of historical tragedy, land appropriation, rural poverty, and overdose deaths are by no means limited to Appalachia.
2. Hepatitis C: The State of Medicaid Access. *May 2021 National Progress Report*.
3. Clinical Trial Number: NCT03876470.
4. In 2018, Virginia agreed to take part in the federally funded expansion of Medicaid (a federal and state program that aids with healthcare costs and coverage for those with limited income and resources).
5. Part of this study took place during the COVID-19 pandemic. Data collected during the June-August 2020 shifted from in-person to remote. We used telephone and video calls and remained in contact with local healthcare practitioners who were clinically active in the region.

## Acknowledgments

We first acknowledge our patients and participants who so generously shared their experiences with us. We also thank Preya Agam, Chelsea Canan, Charlene Joie Cantrell, Eleanor Sue Cantrell, Jessica Clark, Kamryn Crowder, Michelle Hilgart, Devan Kaufman, Rebecca Little, Kathleen McManus, Kori Otero, Patrice Ross, Jacqueline Sherbuk, Abigail Thornbury, and Art Van Zee. This study was approved by the University of Virginia’s Institutional Review Board IRB-HSR 21167.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

This work was supported by the National Institute of Allergy and Infectious Diseases, National Institutes of Health [grants T32 AI007046-43 and K08AI136644] and by Gilead [CHIME grant].

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