

## RESEARCH ARTICLE

# “I got so much on my plate”: Understanding care discontinuity for HIV and HCV among formerly incarcerated persons

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## Abstract

**Objective:** To explore barriers to care continuity among formerly incarcerated persons with HIV and/or hepatitis C.

**Data Sources and Study Setting:** We draw on data from semi-structured interviews conducted in 2018–2019 with 30 formerly incarcerated persons and 10 care providers. Data were collected across two clinics in Baltimore, Maryland, and Washington, D.C.

**Study Design:** We recruited participants using a combination of nonprobability sampling techniques. Participants completed closed-ended questionnaires and took part in semi-structured interviews related to treatment barriers and incentives.

**Data Collection/Extraction Methods:** Interviews were transcribed using Express Scribe software and transcriptions were open coded using NVivo 12 software. An iterative process was used to relate and build upon emergent themes in interviews.

**Principal Findings:** Our study illuminates both internal and external barriers to care continuity. The most common external barriers were system navigation and housing instability. Internal barriers consisted of overlapping issues related to mental health, substance use, and feelings of shame and/or denial.

**Conclusion:** An overarching theme is that formerly incarcerated persons with HIV and/or HCV are grappling with numerous challenges that can threaten their health and health care. These barriers are cumulative, intersecting, and reciprocal.

## KEYWORDS

hepatitis-C, HIV, justice-involved populations, mental health, substance use, treatment discontinuity

## What is known on this topic

- There is considerable overlap between segments of the US population that are hard-hit by incarceration, as well as by infection with HIV and HCV.
- Incarceration can disrupt treatment for those with HIV, and those who have been incarcerated are less likely to adhere to care.

## What this study adds

- Examination of specific external and internal barriers to the continuity of care among justice-involved persons with HIV and/or HCV.

- The most common barriers identified were system navigation, housing instability, mental health/substance use, and psychological states related to shame and denial.
- An exploration of how continuity of care can be disrupted for those with HCV, as well as those with HIV.
- A two-sided account from both care providers and formerly incarcerated individuals regarding challenges adhering to, or providing, treatment for HCV and/or HIV.

## 1 | INTRODUCTION

Incarceration can worsen existing health problems, increase the risk of developing new health problems, and introduce complications with respect to accessing or adhering to treatment.<sup>1-3</sup> However, correctional facilities “can serve as important sites for detecting infections and initiating treatment” as well.<sup>4</sup> In particular, prisoners exhibit relatively high rates of infectious diseases such as HIV and Hepatitis C (HCV). HIV and HCV are life-threatening infections that are overrepresented in correctional populations.<sup>5-7</sup> Despite high rates of both conditions, testing and treatment in correctional facilities is inconsistent,<sup>8</sup> as is linkage to care post-release.<sup>9</sup> While incarceration may result in short interruptions in treatment, interruptions for HCV or HIV may result in the development of viral resistance, making subsequent treatment more challenging. Interruptions can also worsen symptoms and increase the risk of viral transmission.<sup>10</sup>

When individuals are processed into and out of jail, health care needs inevitably follow. Although inmates have a constitutional right to health care,<sup>11</sup> this service is not the principal function of jails and prisons. Jails are especially less equipped than prisons and do not test for, or treat, all ailments. Jails also experience rapid turnover rates, creating “a much narrower window in which to diagnose HIV, initiate or continue antiretroviral therapy (ART) for HIV and link individuals to care using pre-release planning.”<sup>12</sup> Transitions into and out of jail or prison are particularly problematic.<sup>13</sup> Although prisons and jails must legally treat persons with HIV, it may be days or weeks before an incarcerated individual is prescribed an ART regimen.<sup>14</sup> Upon release, approximately 75% of former prisoners with HIV do not access their ART within 3 months.<sup>15</sup> In the case of HCV, new medications make HCV readily curable in an incarcerated setting, but prison-based treatment is not typically mandatory and is rarely available in jails.<sup>16</sup>

Prior research suggests a number of factors that may threaten the continuity of care in this population. For example, incarceration is an established risk factor for homelessness and housing instability.<sup>17-18</sup> In turn, housing instability is a known risk factor for discontinued health care among those with HIV or HCV.<sup>19-20</sup> High rates of mental illness and substance use are also well-established among correctional populations. One study of incarcerated persons found that 70% of current prisoners had a drug or alcohol disorder, and among these, 59% displayed clinically significant symptoms of depression.<sup>21</sup> High rates of mental health and substance use disorders are also evidenced among persons with HIV or HCV. Almost 50% of persons with HIV experience psychiatric symptoms, 19% have symptoms of drug or alcohol dependency, and 13% have both mental health and substance

use problems.<sup>22-23</sup> In a sample of prisoners receiving treatment for HCV, Maru and colleagues found that 16% reported past psychiatric hospitalizations and 28% reported receipt of psychiatric medication.<sup>24</sup>

Because interruptions in treatment can result in the development of HIV viral resistance or failure to achieve HCV cure, ensuring continuity in care is essential for those who begin treatment while incarcerated and transition back into the community, as well as for those incarcerated during the course of their treatment.<sup>25-26</sup> In the current study, barriers to care continuity were investigated via in-depth interviews with 30 formerly incarcerated patients with HIV and/or HCV and 10 health care providers who work with this population.

## 2 | DATA AND METHODS

Thirty patients were recruited with a history of HIV and/or HCV and a history of incarceration from two clinics in Baltimore, Maryland, and Washington, D.C. Patients were eligible to participate if they had been released from prison or jail within the last 3 years. Ten care providers were also recruited from these clinics. Providers were eligible if they had worked at either clinic for at least 6 months. All participants were 18 years of age or older.

Clinic #1 was a harm reduction organization drop-in center with embedded on-site medical services. Clinic #2 was a university outpatient infectious disease clinic serving 3000 patients with both HIV and HCV. A combination of nonprobability sampling techniques was employed, including snowball, convenience, and purposive sampling. Patients were recruited via flyers placed at either clinic in common areas for patients to view. In addition, clinic staff at both locations assisted with communicating the opportunity to patients and scheduling them for interviews. Providers were recruited mostly through snowball sampling techniques. Providers communicated the opportunity to coworkers and suggested other providers we may want to interview. Interviews were conducted between 2018 and 2019.

Participants completed a background questionnaire before the interview, which was used to collect sociodemographic information and other pertinent background information, such as the job titles of our providers and incarceration history. Then, each participant took part in a semi-structured interview with one or two members of the research team. Interviews ranged from 30 to 90 min and were conducted in private rooms at either clinic. Researchers used an interview guide composed of open-ended questions to structure the interview. Participants were asked how they felt about their health overall and about their feelings and experiences toward treatment—before,

during, and after incarceration. At the end of the interviews, patients were asked to complete another short questionnaire to assess additional factors such as recent substance use and history of trauma. Depressive symptoms were also collected at this time and were based on responses to a shortened 9-item version of the Center for Epidemiological Studies Depression Scale (CES-D).

The research was approved by the University of Maryland-College Park Institutional Review Board and the Human Research Protections Office of the University of Maryland Baltimore. All participants provided informed consent and received a \$30 gift card to a local pharmacy.

## 2.1 | Analytic strategy

Interviews were transcribed using Express Scribe software, and transcriptions were coded using NVivo 12 software. Two members of the research team open-coded transcriptions to identify common themes. Open coding refers to the process of identifying, naming, categorizing, and describing phenomena found in the text.<sup>27</sup> The process was iterative, meaning there was a back-and-forth between data collection and analysis. Researchers discussed emergent themes throughout the data collection period and delved deeper into themes as they emerged. Dominant themes were defined as the ones discussed by the most participants, but these themes also aligned with the most number of references. Given the subjective and iterative nature of qualitative data analysis, coding was conducted both independently and interdependently. Two coders independently coded and met periodically to compare and discuss interpretations of transcript content. Comparisons of themes were similar across coders, including which ones were most prevalent. Axial coding was also used to examine how themes related to each other and to create subthemes. This method was used to determine which themes should be subsumed under a single overarching theme as well.

The survey content was analyzed using Stata 12 software. The research team developed a codebook for survey items. Some items were already numeric (e.g., age), but many needed to be transformed into numeric values, such as scaled responses from “Never or rarely” to “most or all the time” to values ranging from 0 to 3. In a few cases, patients were unsure of how many times they had been incarcerated, and would give an answer such as 10–15 times. In these cases, the average or median was used (e.g., 12.5). Descriptive statistics were calculated using Stata. We calculated percentages for categorical variables and the mean and standard deviation (SD) for continuous variables to describe participants.

## 3 | RESULTS

### 3.1 | Participant characteristics

The sample consisted of 30 patients and 10 care providers. Twenty-two participants (5 providers, 17 patients) were recruited from clinic

**TABLE 1** Demographic characteristics of sample<sup>a</sup>

|                                       | Patients (N = 30) | Providers (N = 10) |
|---------------------------------------|-------------------|--------------------|
| Age                                   | 45 (11.6)         | 49 years (8.6)     |
| Sex                                   |                   |                    |
| • Cis-Male                            | 19 (63)           | 5 (50)             |
| • Cis-Female                          | 3 (10)            | 3 (30)             |
| • Transgender or gender nonconforming | 8 (27)            | 2 (20)             |
| Race                                  |                   |                    |
| • White                               | 3 (10)            | 3 (30)             |
| • Black                               | 26 (87)           | 6 (60)             |
| • Other                               | 1 (3)             | 1 (10)             |

<sup>a</sup>Numbers represent mean (standard deviation) or the number of participants (% of sample).

1, and 18 participants (5 providers, 13 patients) were recruited from clinic 2. The providers represent a diverse group of positions, including two medical doctors, one case manager, two community health workers, two clinic coordinators, two social workers, and one phlebotomist.

Table 1 displays the background characteristics of participants. Patients were predominantly Black (87%) and male (63%). Eight patients identified as transgender or gender nonconforming (27%). Providers were mostly Black (60%), with 50% of providers identifying as male, 30% as female, and 20% as transgender or gender nonconforming. The average age of patients was 45 and the average age of providers was 49.

Table 2 displays the selected characteristics of patients. Only 13% reported being currently employed. The average number of times incarcerated was also 13. The majority of participants reported recent substance use and a history of various traumatic events. For example, nearly half reported being shot or stabbed, and 70% reported being robbed at some point in their lives. Further, 40% of formerly incarcerated participants reported using a serious drug such as PCP, heroin, and/or cocaine in the past 30 days. Respondents also reported elevated symptoms of depression. A cut-point of 10 has been used in studies of the general population to indicate the presence of depressive disorders.<sup>28–29</sup> The average score in our sample was 10.5, and 14 out of 30 participants reported symptoms greater than 10 on the scale.

### 3.2 | Interviews

Interview data reveal an array of intersecting processes that affect continuity in care among our sample. Out of 40 participants, 38 discussed specific issues that affected care continuity, either talking about their own experiences (patients) or what they observed (providers). In total, there were 321 references to this overarching topic. We categorized our findings under two broad themes: *external* versus *internal* barriers. While external barriers refer to structural obstacles that are either exogenously imposed or encountered by formerly incarcerated persons (e.g., systems navigation), internal barriers refer

**TABLE 2** Selected characteristics of patients ( $N = 30$ )<sup>a</sup>

| Variable   | Mean or %   |
|--|-------------|
| In a relationship (%)                            | 7 (23.3)    |
| Have children (%)                                | 14 (46.7)   |
| Currently employed (%)                           | 4 (13.3)    |
| # Of times incarcerated (mean, sd) <sup>b</sup>  | 13 (19.2)   |
| • 1–5 times (n, %)                               | 6 (20)      |
| • 6–10 times (n, %)                              | 5 (16.7)    |
| • 11–15 times (n, %)                             | 5 (16.7)    |
| • 16+ times (n, %)                               | 13 (43.3)   |
| Years since diagnosis with HIV of HCV (mean, sd) | 14.4 (9.97) |
| • 0–5 years                                      | 7 (23.3)    |
| • 6–10 years                                     | 6 (20)      |
| • 11–15 years                                    | 5 (16.6)    |
| • 16+ years                                      | 12 (40)     |
| Substance use past 30 days (n, %)                |             |
| • Alcohol  | 19 (63.3)   |
| • Cigarettes                                     | 26 (86.7)   |
| • Heroin   | 5 (16.7)    |
| • Cocaine  | 9 (30.0)    |
| • Methamphetamine                                | 0           |
| • Marijuana                                      | 12 (40)     |
| • Pcp  | 4 (13.3)    |
| History of trauma (n, %)                         |             |
| • Death of parent                                | 23 (76.7)   |
| • Death of sibling                               | 13 (43.3)   |
| • Shot or stabbed                                | 14 (46.7)   |
| • Beaten up                                      | 22 (73.3)   |
| • Sexually assaulted                             | 9 (30)      |
| • Robbed   | 21 (70)     |
| • Parent incarcerated                            | 10 (33.3)   |
| • Seen someone shot or stabbed                   | 24 (80)     |
| • Exposed to domestic violence                   | 16 (53.3)   |
| • Physically abused by parent                    | 16 (53.3)   |

<sup>a</sup>Numbers represent mean (standard deviation) or the number of participants (%).

<sup>b</sup>Percentages do not add up to 100 because one participant had missing data for # of times incarcerated.

to psychological, social-psychological, or behavioral impediments (e.g., mental health). Notably, these barriers can act both independently and interdependently to impede care.

### 3.3 | External barriers

#### 3.3.1 | System navigation

Difficulties with system navigation were identified by many of our participants as a barrier to their own care or the care they provide.

Systems included governmental, correctional, and health care systems. These difficulties resulted in the interruption of treatment through communication breakdowns, lack of information sharing, or by necessitating time-consuming or cumbersome processes. For example, HCV-treatment-receiving patients experienced difficulty in accessing medicine when admitted to jail or prison. As one care provider explained:

“We started giving out client cards that say ‘I’m in treatment. I need my medicine.’ People at the jail still ignore them. [Patients] tell me flat out—‘Yeah they took my drugs away. I couldn’t take my Hep C medicine.’ And Hep C is one of those where you can’t miss doses.”

Participants explained that it could take a week or more for jails to administer the required pharmacotherapy. Difficulties accessing medicine were echoed by patients:

“We would request for help [and] it would take days or when we would write things, it would take days for them to even respond and I just felt like I’m in this alone. It’s just like, I’m going to have to get released to get the help that I want. You know, and it wasn’t just me in there. It was a couple of us that was going through the same thing.” (30-year-old Black transgender person).

Another interruption was common when individuals were released. As one social worker explained, sometimes the person is still recorded as being incarcerated.

“When you get out, someone on the jail’s end has to change [the person’s status] so that then you can use [Medicaid] in the community again and it becomes community medical assistance. And oftentimes that’s a struggle because that doesn’t happen ... So, we can’t get their meds for them, because it’s still saying that they’re in jail. So, the pharmacy can’t fill medication for someone who’s still in jail, right? Even though they’re standing right here in front of you...”

Trying to locate patients upon release can also be challenging. A social worker explained that, “It’s trying to find them... find a person who has no phone who was just released from prison.” While the care continuum may be hampered by glitches or breakdowns in the systems themselves, returning prisoners are grappling with numerous hurdles upon reentry, including finding housing, food, and money. As such, running the gauntlet of governmental, correctional, and medical systems upon release may be especially daunting and difficult. One participant lamented that when she was released from jail, “They was telling me...I wasn’t approved for this, I wasn’t approved for that, just wait, just wait...” (50-year-old Black female). Our interviews indicated

that system navigation disrupts ongoing treatment for HIV and HCV, hinders the ability to start or re-start treatment, and absorbs time for formerly incarcerated persons and staff members attempting to meet their needs.

### 3.3.2 | Housing instability

Many participants interviewed related housing difficulties to treatment non-adherence. Our research suggests that housing is a formidable barrier for three reasons: (1) it is perceived as an immediate survival need above and beyond medical treatment, (2) it raises issues in terms of storing and taking medication, and (3) it makes patients more difficult to contact. With respect to the first issue, participants noted that when someone is homeless, being able to adhere to treatment takes a backseat to this more immediate problem. As one formerly incarcerated patient who was currently homeless relayed:

“It’s hard out there. And then you get problems, you try to get out one situation, get into another situation, medicine ain’t adding up... I don’t wanna be in the cold, I don’t wanna take two pills, fuck them two pills. I gotta get out this cold.” (50-year-old Black male).

Some formerly incarcerated participants did not feel comfortable disclosing their illness to others. This inclination led them to avoid certain housing situations where hiding their medicine would be an issue. A clinic coordinator noted that sometimes patients avoid returning home because they “just don’t want their parents to know.” Another relayed a story about a client who lived with her grandmother after being released. The client tried to hide her HIV status, but her grandmother found out and told her she had to leave. Homelessness also presents logistical challenges to taking medication. One community health worker described:

“I think honestly the biggest challenge to our patients is housing. I think we can really do a great deal of damage to HIV if we could house some of the individuals who are positive. They don’t have places to keep their medicine. As a community health worker I had clients who literally slept in a tent in the dead of winter and I was doing home visits to a tent.”

Another participant who was currently not adhering to treatment explained that his medication was stolen while he was in a homeless shelter and that he planned to get back on track once he found a place to live:

“Staying at the shelter, got my stuff stolen. I was pissed off... just got my stuff stolen, I got my medication stolen. I just got out, so I said once I get situated in my place, go back to work, going to get this, you

know, get back into the program, you know, and get it taken care of.” (59-year-old Black male).

Importantly, many believed that they must figure out housing first or “get situated” (e.g., housing, money) before focusing on their health care, relating back to the first theme.

Finally, housing instability creates problems on the side of care providers in terms of contacting patients who have stopped showing up for appointments or for known patients who have been released from jail and have not returned to the clinic. One provider noted, “If it’s someone who is, has no phone, or is relatively homeless, it’s harder to kind of find out where they’ve been and get in touch with them.” This same participant noted that often the clinic staff tries to locate the individual, but such efforts can be limited and difficult. If patients do not have a stable address, place of employment, or a contact number on file, it leaves staff with few options.

## 3.4 | Internal factors

### 3.4.1 | Mental health and substance use

Most participants (providers and patients) discussed the role that mental health and addiction played in their treatment adherence. As one provider noted, “A lot of my patients also have either diagnosed or undiagnosed mental illness. Oftentimes they self-medicate.” Moreover, two patients specifically mentioned depression as the reason they self-medicated and another explained the contribution of these issues to her HIV care cascade after release from jail:

“I was taking my medicine, but then after I came out [of jail], it was like rocky, you know?... It was on again, off again, taking it, not taking it. I mean...when you sick you don’t, you know, the last thing you think about is some medication even though you know you sick, because you trying to get that pain off of you. That’s the thing, you’re trying to get the pain off.” (49-year-old Black female).

Importantly, our data suggest that mental health issues and drug use disrupt HIV and HCV treatment. For example, one participant with HCV discussed how being out on the street and dealing with depression and drug addiction distorted their reality and memory.

“They be times where my depression sit on me so hard that I don’t wanna get up and move or do anything or eat or anything. Or my mind could just be racing so much or I be doin’ so much and moving around so much like it’d just skip my mind to do it. And there’s been times when I’ve been up for like four days and still don’t take the medication. Not [that I] would fall

asleep, but I mean just rippin' and runnin' for four whole days and would forget to take my medication.” (28-year-old Black transgender person).

Similarly, some explained that drug addiction affected their mindset with respect to taking care of their health. One patient said he was “focused on getting high instead of [his] health,” (54-year-old Black male), and another remarked that “the drugs came before everything” (34-year-old Black transgender person). One participant explains why he went 9–10 years without treatment for his HIV or HCV:

“I was out in the street doing drugs. No time when I go see the doctor. I am sitting up here with stuff up my nose. Like ‘I will see him later’ [laughs].” (46-year-old Black male).

Another patient described his battle to maintain his health while also dealing with drug addiction as “a non-stop war between the crack, coke, whatever—anything” and explained that his attempts to take drugs and take care of his health were not possible: “There's just no balance.” Finally, a patient noted, “once you get that [drug] issue out of the way, then you can start trying to maintain your medication” (50-year-old Black male). Importantly, as with housing, there was a perception among participants that drug addiction was an issue that needed to be taken care of *before* they could focus on HIV/HCV treatment.

### 3.4.2 | Denial, avoidance, and shame

Feelings of denial, avoidance, and shame were paramount in our interviews. Although these psychological states and processes were initially coded as independent categories, axial coding revealed that they were inexorably connected. Since they most often related to each other in our data, they were considered part of an overarching theme. Many participants pointed to these feelings—either experiencing them or observing them in the case of providers—when discussing discontinuity in care. To be sure, there was substantial overlap between discussions of these psychological states and substance use. In fact, some participants explicitly discussed their drug use as a means of avoiding feelings or symptoms related to HCV or HIV.

“I was depressed and I was in denial like, ‘No.’ I guess sometimes the drug was giving me... ‘You ain't got [HIV]. You'll be ok. And just keep using me” (34-year-old Black transgender person).

Another noted,

“I use because of [my condition] too. I do not feel that... I do not want to accept the reality of it” (28-year-old Black transgender person).

However, feelings and processes of avoidance were not always discussed in relation to drug use in our sample, and as such, we treat it as a unique internal barrier. One participant explained:

“I don't want to accept the reality of it, but I have to... but every time I think of it, I quickly want it to go away. I don't want it to be the truth.” (49-year-old Black female).

Notably, this participant reported cocaine and heroin use in the past 30 days, suggesting a possible overlap with substance use for this participant as well. The fact that these psychological states impede treatment was not lost on providers. One social worker noted that it is difficult for clients to show up to the clinic because “we're a reminder of something that most of them don't want to think about.” She further explained, “We see that a lot. I think some of the folks that just kind of drop out...they just need a break, you know?” When and if patients do return, she said they frequently feel shame over lapses in treatment. A clinic coordinator corroborated these perceptions, adding that when patients miss appointments, “for a lot of them, it's shame I think”.

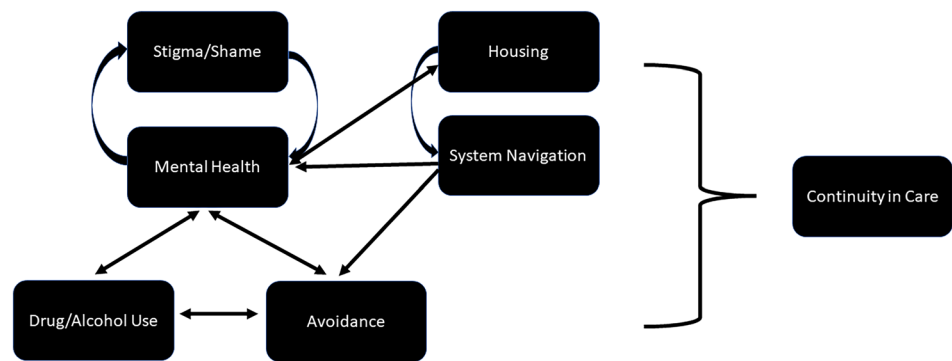
A number of patients explained that the shame and stigma of their conditions led them to either hide their medication or miss doses. For example, one participant explained that he stopped taking his medication while in prison: “I didn't want [other inmates] to know I was HIV positive, you know, cause as far as confidentiality and other inmates, you know, being in your business” (59-year-old Black male). Similarly, another described missing doses because they were hiding the medication from friends:

“I knew they wouldn't understand, so I hid my medicine. I remember one of my friends, somebody who came out and was like ‘I'm positive,’ and to see feedback they got from the people was just devastating. Like ‘don't come near me’ or like if she was to touch a pen, ‘don't touch that pen.’” (30-year-old Black transgender person).

In short, participants explained that shame, avoidance, and denial play a role in care continuity. Patients may miss appointments, hide medication, or skip treatment. Unfortunately, this avoidance can sometimes lead to more shame. Thus, it may require a great deal of support to motivate patients to return after they have taken a hiatus for these reasons. In fact, former patients in our sample identified *positive clinic staff* as the main protective factor for adhering to care in the community. When asked, “What has been helpful for you in keeping up with your treatment?”, 60% of patients remarked on how accommodating, nonjudgmental, and caring the staff were at each study site. For example, when asked why he returns to this clinic, a participant stated, “The persons. Their attitudes. There's no discrimination whatsoever.” Another stated, “they basically make me feel like they care.” Thus, the importance of a positive clinic staff and community was crucial.



**FIGURE 1** Barriers to continuity in care for formerly incarcerated persons: A conceptual model



An overarching theme in our study is that formerly incarcerated persons with HIV and/or HCV are grappling with numerous challenges that can threaten their health and health care. *These barriers are cumulative, intersecting, and reciprocal* (e.g., housing issues can harm mental health, which can increase substance use, which can worsen mental health). As the following formerly incarcerated participant remarked:

“I got so much going on right now, I got so much on my plate, I'm trying to find a place to lay my head every night, you know, somewhere to eat, you know what I'm saying?” (59-year-old Black male).

Figure 1 depicts a conceptual model of how these processes may operate, although we acknowledge that the complexity of these relationships is beyond what is depicted here.

## 4 | DISCUSSION

HIV and HCV are life-threatening infections that are over-represented in correctional populations. Incarceration can also interrupt existing treatment. Our study sheds light on barriers to care continuity in this important population, the main ones being system navigation, housing, substance use, and psychological states related to shame, denial, and avoidance. These barriers were reciprocal and intertwined. Further, for many participants, barriers were cumulative and began prior to incarceration. Incarceration further complicated their lives, introducing new challenges or exacerbating existing ones. As such, incarceration was a *risk factor* for care discontinuity in some cases but a *risk marker* in every case; that is, while incarceration may introduce or exacerbate obstacles for certain individuals (risk factor), it was consistently an indicator that an *individual is grappling with many challenges* (risk marker)—regardless of whether those challenges were introduced by the incarceration experience itself. This is an important distinction, given that an intervention focused solely on incarceration as a risk factor for care discontinuity may be less effective than interventions that tackle the myriad of issues confronting this population.

Our findings also suggest that patient navigation programs, which assist patients in navigating “a complex and often fragmented health-care system,”<sup>30</sup> may be helpful with this population. Such programs have been increasingly implemented to assist HIV-positive individuals,

with some evidence of success.<sup>31</sup> These programs have been targeted at the continuity of ART and are “patient-centered” interventions. The most common activities of patient navigators are to accompany them to appointments and coordinate appointments. Improving the experience of seeking care or benefits could also be useful, especially in terms of wait times. As argued by Seefeldt,<sup>29</sup> “waiting is an under-explored area of social stratification and domination.” Those on the lower end of the socioeconomic spectrum spend more time waiting—for instance, for public transportation, in benefits offices, in waiting rooms for appointments with case workers, etc.<sup>32</sup> Long wait times further marginalize disadvantaged populations and could lead some to give up the process entirely.<sup>33</sup> Patient navigation and assistance programs may be especially beneficial for those coming out of prison or jail, given multiple systems that must be navigated and multiple needs that must be met.

Our study is not without limitations. For one, it is important to note that our findings are based on a small non-probability sample and therefore are not generalizable to a broader population. Second, data were collected from cities where health care policies and practices may differ from other parts of the country. For example, both Maryland and D.C. were early adopters of Medicaid expansion. It is, therefore, important for future research to assess barriers to care continuity among formerly incarcerated persons living in other regions of the country. Third, formerly incarcerated persons were recruited from clinics where they were receiving care. This selection bias means that our sample does not include persons who are not receiving care for a variety of reasons. However, just as most of our participants have been in and out of correctional facilities, they have also been in and out of treatment. Their narratives, therefore, provide rich reflections of their overall health care trajectories, including factors they perceived as jeopardizing their care continuity or as helping them to adhere or return to care. Nonetheless, researchers should seek out the experiences of those who are currently not seeking care and perhaps never have or never will. Indeed, barriers for that population may be unique. Fourth, while in-depth interviewing is well-suited to understanding perceptions and first-hand accounts, we cannot conclude, based on our data alone, that the barriers identified *causally* affected treatment trajectories. This is beyond the scope of this study. However, these perceptions (especially those of patients) are vital for designing successful interventions aimed at care continuity.

In sum, our study examined barriers to HIV and HCV care continuity for criminal-justice-involved populations. Insights are based on

the first-hand experiences of formerly incarcerated persons with HIV and/or HCV, as well as care providers. The results, taken together, provide compelling information to help improve health care delivery and adherence. Sustained treatment is essential for the prevention of death and severe health complications related to HIV and HCV. Continuity in care is critical for both HIV, a lifelong condition that can be managed with medication, and HCV, which can be treated and cured in a matter of months. Given higher rates of each condition among those with a history of incarceration, and given that incarceration is associated with care discontinuity, addressing internal and external barriers to care continuity is a crucial step toward improving both correctional and public health.

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