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“*You’re in a world of chaos*”: Experiences accessing HIV care and adhering to medications after incarceration

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Abstract

Most HIV-infected inmates leave prison with a suppressed viral load; many, however, become disconnected from care and non-adherent to medications during reentry to community life. In this secondary data analysis of focus groups ($N = 6$) and in-depth interviews ($N = 9$) with 46 formerly incarcerated HIV-infected people during reentry, we used an inductive analytic approach to explore the interplay between individual, interpersonal, community, and structural factors and HIV management. Participants described barriers and facilitators to care engagement and adherence at each of these 4 levels, as well as a milieu of HIV and incarceration-related stigma and discrimination. The constellation of barriers and facilitators created competing demands and a sense of chaos in participants’ lives, which led them to address reentry-related basic needs (e.g., housing, food) before health care needs. Interventions that simultaneously address multiple levels, including augmenting employment and housing opportunities, enhancing social support, and reducing stigma, are needed.

Keywords

HIV; health care access; incarceration; medication adherence; stigma

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In the United States, HIV prevalence among incarcerated persons is three to five times higher than that of the general population (Baillargeon et al., 2010; Westergaard, Spaulding, & Flanigan, 2013). Seventy-five percent of HIV-infected inmates begin treatment while incarcerated, and approximately 55% to 59% have suppressed viral loads upon release (Baillargeon et al., 2009; Stephenson et al., 2005). However, many HIV-infected inmates have difficulty sustaining adequate disease management during reentry. For example, in Texas only 5.4% of HIV-infected inmates filled prescriptions for antiretroviral therapy (ART) within 10 days of release, 17.7% within 30 days, and 30% within 60 days (Baillargeon et al., 2009). In other studies, only 20% to 54% of inmates enrolled in an HIV clinic within 1 month of release (Baillargeon et al., 2010; Wohl et al., 2011). Disruptions in care and poor adherence lead to higher HIV-related mortality, poorer HIV-related outcomes, and resistance to HIV medications in recently released individuals (Rosen, Schoenbach, & Wohl, 2008; Springer, Friedland, Doros, Pesanti, & Altice, 2007). Release from prison has been associated with an increase in viral load (Stephenson et al., 2005), which can result in ongoing HIV transmission if individuals engage in HIV-related risk behaviors (Rosen et al., 2008; Springer et al., 2007). Understanding facilitators and barriers to linkage to HIV care and adherence to treatment post-release is critical for reducing HIV-related morbidity and mortality and preventing transmission within the communities to which these individuals return (Spaulding et al., 2009; Stephenson et al., 2005).

Several barriers and facilitators influencing access to care and medication adherence by formerly incarcerated HIV-infected individuals during reentry have been identified in the literature. Barriers identified in studies of former prisoners include strained interpersonal relationships (Baillargeon et al., 2009), return to impoverished neighborhoods (MacGowan et al., 2003), dual stigma of incarceration and HIV (Alexander, 2012), and inaccessibility of housing (Alexander, 2012; Baillargeon et al., 2009; Katzen, 2011; Stephenson et al., 2005), transportation (Katzen, 2011; Stephenson et al., 2005), insurance and employment (Alexander, 2012; Baillargeon et al., 2009; Katzen, 2011), as well as issues with mental illness and substance abuse (Springer, Azar, & Altice, 2011). Social support from case managers and personal motivation have been identified as facilitators that promote HIV management by improving ART adherence (Alexander, 2012; Katzen, 2011; Springer et al., 2011; Woods, Lanza, Dyson, & Gordon, 2013). Although researchers have identified these barriers and facilitators, it remains poorly understood how these factors interact and influence each other and, ultimately, affect an individual's success in adhering to HIV care. We examined the interplay of factors across these multiple levels and their impacts on engagement with care and adherence to ART among formerly incarcerated persons during reentry.

Methods

Study Design

We conducted a secondary analysis of formative, qualitative data, including in-depth interviews (IDI) and focus groups (FG) with formerly incarcerated men and women with HIV, collected to inform development of imPACT (Individuals Motivated to Participate and Adhere to Care and Treatment), a comprehensive intervention to help incarcerated people

with HIV engage in HIV care and adhere to ART after release (Golin et al., 2013). The institutional review boards at both The University of North Carolina at Chapel Hill and Texas Christian University approved all study procedures before study initiation.

Recruitment and Study Population

Recruitment fliers were displayed in HIV clinics, HIV outreach centers, and substance abuse treatment centers in order to passively recruit participants. Researchers also used database systems in HIV clinics to identify individuals who had previously provided consent to be contacted for participation in research studies. Our secondary data analysis included data from 12 female and 34 male, formerly incarcerated persons with HIV, residing in two states in the southern United States. At the time of the interviews, all participants were accessing HIV care. We summarized demographic features of all study participants in Table 1. Table 2 lists demographic information for each IDI participant to illustrate the diversity of life experiences of the individuals in this study. FG participants shared demographic profiles similar to those participating in IDIs.

Data Collection

Two interviewers conducted six FGs ($n = 37$ participants across groups) and nine IDIs with individuals who were eligible but unable to attend an FG due to transportation challenges. Both IDI and FG guides focused on participant initiation of and attendance to clinic visits and adherence to ART recommendations. All data collection was conducted in private rooms at HIV clinics, HIV outreach centers, and substance abuse treatment centers from December of 2010 through May of 2011. Four IDIs were conducted over the phone. Participants received a 25 USD gift card for their participation. On average, IDIs lasted approximately 1 hour, and FGs were 2 hours. Researchers redacted all personal information and verified all IDI and FG transcripts from digital audio recordings.

Data Analysis

We used an inductive approach to conduct data analysis (Miles, Huberman, & Saldana, 2014). Two researchers read all of the transcripts line-by-line and developed a matrix listing themes they identified in the transcripts. The researchers then developed a preliminary codebook consisting of topical codes based on questions from the interview guide (e.g., “medical care facilitators”) and inductive codes based on themes identified in the transcripts (e.g., “individual challenges”). The first author read all transcripts a second time to develop the final codebook and coded the transcripts using ATLAS.ti.v.7. The first author then drafted an analytical memo to summarize each code, which facilitated systematic identification of emergent themes in the data (Saldaña, 2012). During review of memos, we noticed that barriers and challenges occurred across multiple levels – individual, relational, structural – and decided the Social Ecological Framework (SEF) was an appropriate framework to guide additional analyses of the relationships of themes across these levels (Saldaña, 2012; Sallis, Owen, & Fisher 2008). We eventually chose to use the SEF to structure presentation of the findings because it fit well with our findings. The SEF was useful because it acknowledges that there are multiple levels of influence on behaviors (individual, interpersonal, organizational and community, and structural), and that these

levels of influence interact within and between each other to influence health outcomes (Sallis et al., 2008).

Steps were taken throughout this iterative analysis process to enhance study rigor and trustworthiness of findings (Lincoln & Guba, 1985). During the coding and analysis process, the research team discussed emergent ideas in bi-weekly meetings. Engaging multiple researchers with diverse training and understanding of the study population helped to reduce the influence of bias and enhance credibility of the findings (Shenton, 2004). Triangulation, in the form of inclusion of data collected via different methods from multiple sites and contextualization of emergent themes within the context of an existing theoretical framework, enhanced the transferability of the findings (Shenton 2004). Finally, the first author kept a detailed audit trail of analysis activities, emergent themes, and analytic memos throughout the process to ensure consistency in analysis processes and techniques across time (Morrow, 2005), steps which enhanced the dependability and confirmability of the results.

Results

We report results in four sections. In the first section, we describe individual experiences as prison staff made arrangements to connect participants to post-release care. Next, we describe post-release experiences that posed challenges for HIV management. Third, we describe perceived facilitators of HIV management post-release. We conclude by describing, in the fourth section, the overarching influence of stigma on participant transitions from prison to community. Throughout these sections, we present themes across the different levels of the SEF. The location of themes within different levels of the SEF is depicted in Figure 1. For each section of the results, we discuss how individual level factors may interact with factors at other levels to affect HIV-infected former prisoners' access and adherence to care.

Connection to Care Before Release

Participant abilities to achieve continuity of care upon release were influenced by two major factors, one occurring at the individual and the other at the community level of the SEF: (a) Prior knowledge and experience, and (b) Institutional influence.

Individual level: Prior knowledge and experience—While incarcerated, individuals could rely on institutions to schedule examinations, fill prescriptions, and provide adherence support; upon release, they were responsible for their own HIV management. Those who received HIV care before incarceration more easily reconnected to care post-release, as explained by one man who had a provider before his incarceration: “I didn’t have a problem. Like I said, I think that my doctor was one of the first people I called, said, ‘I’m out.’ And she immediately made an appointment for me” (FG 2). Another man in FG 4 also asserted that his previous experience navigating the medical and insurance systems facilitated his ability to make an appointment with his preferred primary care provider:

You have to know how to maneuver around ... they gave me a doctor, ... but...I went in and change my PC (primary care provider), and called (insurance

company] ... and said I wanted [physician's name] for my PC doctor, went and signed some papers, this was prior to my appointment, this was a month and a half before my appointment because when I seen the little record thing and seen that they didn't have her name on there, they won't pay for it if it isn't her name on it, so I started the ball rolling long before my appointment ... (FG 4)

This individual was informed and preemptive; he knew to review his paperwork in advance of his first post-release appointment to ensure his ability to visit and pay for his preferred provider.

For others, navigating HIV care post-release was stressful and overwhelming. One man, who was diagnosed in prison, explained:

If you're looking for a guy who's been locked up 10 years but he's been living with the virus and he's been getting his medication, do you really expect him to come out here and function...? I mean, make appointments, take medication... (FG 1)

Determining the extent to which this participant's challenges resulted from a limited understanding of how to navigate the medical system or a limited sense of agency due to prison staff managing his HIV care for several years is difficult. Additionally, navigating the medical system was a formidable barrier for individuals diagnosed while incarcerated because they lacked experience accessing HIV care in their communities.

Community level: Institutional influence—Although the pre-release procedures employed by jails and prisons vary across counties and states, almost all of our participants described policies designed to facilitate continuity of HIV management upon release. For those who received HIV care before incarceration, prison staff scheduled appointments for them with their former HIV providers. For those not previously connected to care, institutions made appointments at the local health department or a community health center. One man described the benefits of a system in which the prison sent records to the health department:

[The health department] do the examinations and they [the health department] do write off to the prison medical system and retrieve your records. So once your records come on the outside, they know what's going on with you while you were inside [prison]. (IDI 8)

Participants also received up to 1 month's supply of HIV medications upon release (the exact amount varied by institution). Almost half of participants reported that obtaining an ART prescription from a community medical provider before that supply ran out was a key determinant of their adherence. Notably, several participants ran out of medications due to long wait times for appointments for HIV care. One woman recalled:

They did [give me a medicine supply to take home with me], but the [clinic name] said they couldn't get me in for what, about a month and a half, when I had got out ... And I said, "I'll be done run out of medicine by then." (IDI 5)

This participant requested and received additional medications from the nurse at the prison facility to prevent a lapse in adherence. Many others, however, were unable to see a provider despite their efforts, as described by one man:

I gave up for 3 years because I got tired of fighting the system to try to get them [medications], and I just said to heck with it. Three years I didn't take them, and that's just the way it is. (FG 4)

This quote reflected the strong influence of institutional factors, such as not being able to get appointments or medications, on care and treatment experiences post-release.

These examples reflected the interaction between community and individual level factors that affected connection to care. Specifically, the success of prison systems to facilitate continuity of HIV care post-release was contingent upon an individual's ability to make and keep provider appointments before running out of medication as well as their previous knowledge and experience navigating the health care system.

Challenges to HIV Management During Reentry

Challenges participants experienced integrating back into their communities also hindered HIV management. From participant discussions of these challenges, we identified five subthemes across multiple levels of the SEF: (a) Substance use, (b) Housing, (c) Transportation, (d) Enrollment in insurance and safety net programs, and (e) Competing demands.

Individual level: Substance use—Several participants “partied” post-release, which involved drinking and illicit drug use. The reasons participants gave for partying included celebrating newfound freedom, reconnecting to social networks, or distracting oneself from the stresses of reentry. Some participants prioritized partying over HIV management and eventually lost motivation to access HIV care or adhere to their medications. One man recalled, “I stayed high all the time. I wasn't thinking about taking 'em [medications]. And every time they make me an appointment, I would call and cancel it until the point I just stopped going and stopped taking medicine” (FG 2). Even when the HIV care system in the community tried to maintain contact with the patient, substance use was a strong deterrent to engagement in care. Other individuals intended to take their medications but forgot when intoxicated, as described by this male participant,

The difficult part came when I fell back into using drugs, okay? And I would forget all about taking the medication because I would be so high off the drugs that it would, you know, I would forget to take the doggone medication, you know. (FG 3)

Some individuals did not adhere in the presence of those with whom they partied. One man confronted this challenge in his house where others gathered to use drugs,

I kinda' didn't take 'em because in my house, I stayed in a two-bedroom apartment, I had a bunch a people in getting high all the time. I didn't want 'em to see what the pills were because, yeah, it got on there in the little writing, “HIV.” (FG 2)

These individuals viewed the disease as stigmatizing and were wary of potentially disclosing their HIV status by taking medication in the presence of others. A few continued to access medical care while non-adherent, such as one woman from FG 2: Interviewer: “So you were still going into see her [the physician]?” Participant: “Yeah. And I told her, ‘I’m drinking. I’m smoking. I ain’t got time to take no medicines.’” Overtime, several individuals who partied experienced adverse health effects due to non-adherence or interactions between HIV medications and other substances.

Community level: Housing—Most individuals were released with few resources, into impoverished communities, and their incarceration histories limited housing options. One man described how homelessness made adherence a challenge: “Like I said, when you first get out, some of us don’t have nowhere to go, and you got nowhere to put your medicine” (FG 3). Homelessness also made it difficult for prisons to connect individuals to care before release, as one woman described, “If I had a stable residence that I was going to, so that way I could’ve had a set appointment already made for me [by the prison]” (IDI 5). Several participants disliked living in community shelters because limited privacy resulted in unintentional disclosure of serostatus. One man also expressed a fear that living in shelters could heighten his risk of becoming ill:

... when people do get out [of prison] with nothing, instead of putting them in these shelters, because that’s why I stay sick, when you’re around 250 people, and all of them are off the street, and they all come in there with all kinds of different things, God knows what, and your immune system is already low ... (FG 4)

Participants faced both social and health risks due to limited housing options post-release that created barriers to adherence.

Community level: Transportation—For many participants, limited access to transportation significantly impeded both reentry and HIV management. One man released into an urban location described this challenge:

Yes [transportation] was an issue, it was a big issue, it was one of the number one issues ... the main thing when I walked out of that door was, how do I get home, how do I get to this place, okay when I get to this place, I’ve got to go back here to get a referral to go back there, ... coming out of the jailhouse, you have to get home, and then you have to get to these [other places], because when they let you out, it’s not at 8 a.m. in the morning when everything is open right around the corner. (FG 6)

Many returned to communities far from an HIV clinic, and those without access to transportation faced difficulty accessing medical care. One man recalled, “So my problem was getting someone to take me up to [city name, for clinic appointments] which is nearly a hundred miles away” (IDI 8). Thus, participants missed appointments or received care from local clinicians who may not have previously seen them. While transportation was a barrier to accessing medical care, some participants received transportation support from case managers, as illustrated below.

Structural level: Lack of enrollment in insurance and safety net programs—For several individuals, lacking health insurance or financial assistance created an obstacle to accessing HIV medications or medical care, as demonstrated by this exchange.

Interviewer: Yeah, so what's the major obstacle for you seeing a doctor?

Participant: They're worried about money...

Interviewer: It's money....

Participant: It's money, it's insurance, and I have none, I have nothing, because like I said, when I stepped out [of prison], I [had] lost everything I had. (FG 4)

A few individuals suggested that having health insurance or financial assistance would enable them to access higher quality care. Further, participants found HIV management difficult when they lacked housing, food, or employment. Safety net programs, such as Medicaid, or those offering supplemental income or food assistance, were a critical source of support for this population. Other sources of support included multiple clinics and HIV Outreach Service Providers offering case management, transportation assistance, housing assistance, and mental health services, but the availability of such services varied substantially from county to county, with some, often more urban, counties having more services available. Several participants, however, experienced what felt like burdensome paperwork and “red tape” (IDI 1), “had to fight” (IDI 4), or applied several times to enroll in these programs. Individuals also described restrictions (e.g., not living with their children) that resulted in rejected applications; however, other unnamed factors, such as low health literacy, may have also influenced participants' experiences. Challenges enrolling in programs reduced access to medical care, as described by one man who disengaged from care for 4 years post release:

If I'd have got Medicaid I would have went ahead through with [seeing a physician], but they did not – there was – they told me there was no way I could – there was two ways I could get Medicaid, either my kids are staying with me in the same household or I'm disabled. (IDI 1)

He further explained that he felt he had to choose between not working or receiving other financial support, which would enable him to qualify financially for Medicaid but prevent him from earning an income for his non-medical needs:

So my thing is I don't want to just sit around that house not doing nothing when I could be out at least trying to work because, you know, I have to [buy] hygiene items for myself, toothpaste, lotion, deodorant, and I can't get that because in order for me to get Medicaid or food stamps, first thing they ask me is, “Are you receiving any money from anybody?” And if I say my father gives me money, then they was going to deny it. So it's like a no-win situation. (IDI 1)

Because they were unable to enroll in health insurance or safety net programs, some participants felt they had to choose between caring for their health or meeting other basic needs.

Structural level: Competing demands—Participants explicitly described facing competing demands between HIV management and needs related to reentry; many felt overwhelmed. One participant described the situation: “In other words, in prison you’re in a controlled environment. They let you out, you’re in a world of chaos, no transportation, no meds, no home, no phone, just go” (FG 4). Several individuals focused on finding housing, work, or reestablishing relationships with family and friends, which distracted them from taking HIV medications. One man reflected, “So I’d say the hardest part is remembering every single day. ‘Cause now I’m out in the world; I’m trying to find a job. I’m running around. I’m doing this and this and it’s like I can sometimes forget” (IDI 9). Despite valuing his health, the stress of managing other aspects of his life made it difficult to focus on adherence. Some participants chose not to adhere because side effects adversely affected the ability to meet other responsibilities, as exemplified by one male participant: “[I’m] a supervisor of a group home on the weekends under the table, of course. And I don’t take my medication while I’m at work because I don’t wanna’ be drowsy or whatever” (FG 2).

These experiences suggest that when individuals experienced the competing demands of HIV management and attending to reentry-related needs, they often met reentry needs first. Altogether, several of the barriers to reentry experienced by former inmates occurred within their communities or were structural and, for those who also experienced individual level challenges with substance use, the ability to overcome structural and community-level barriers while managing HIV was further complicated.

Facilitators to HIV Management During Reentry

In addition to these challenges, participants also described experiences that supported HIV management post-release. We identified three key facilitators: (a) Focusing on HIV management, (b) Support from individuals, and (c) Support from community programs and organizations, each occurring at a different level of the SEF.

Individual level: Focusing on HIV management—Several participants emphasized personal responsibility for their health and focusing on HIV management as facilitators to HIV management and overcoming reentry-related challenges, as illustrated in this exchange: Interviewer: “Was there anything hard about keeping doctors’ appointments for your HIV care?” Participant 5: “No, you gotta’ stay on top of it, I do.” Participant 1: “It’s where your priorities are at” (FG 5). For a few, the experience of incarceration motivated prioritization of HIV management upon release, as described by one man, “So I was like I need to keep doing what – doing the things to my body that the prison was doing for me as far as keeping me, I guess, healthy and keeping my immune system infection-free” (IDI 6). His motivation to maintain his health prompted him to seek medical care when he was first released from prison and to take his medications at the same time he received them while incarcerated to prevent missing a dose. Other participants focused on HIV management because they valued their lives. These sentiments seemed particularly strong among female participants, for example:

Interviewer: ... What prompted you to go see [the physician]?

Participant: I had to get my refill. That's my life right there. I have to live. I take my medication, two pills, every night with some kind of food so that I make sure I don't get sick to my stomach or get diarrhea or stuff like that. I take my medication. (FG 1)

As previously described, individuals experienced several barriers to adherence and accessing care upon release; these experiences, however, illustrated that internal motivation and focusing on health facilitated adherence and access to care by providing individuals with the drive needed to overcome some community and structural barriers to HIV management.

Interpersonal level: Support from individuals—Almost half of our participants received tangible support from others, including family, friends, and neighbors. Several participants received reminders from family members, roommates, or significant others, which helped them adhere to ART. One man described interactions with his fiancé, “My fiancé calls me, she says, ‘It’s time to take your medicine.’ I go, ‘Okay thank you,’ and I get on up” (IDI 4). Another participant recalled support from his neighbor and family when he became extremely ill:

I got sick, and my neighbor lady at this little apartment complex I lived in got my emergency number out of my wallet who called my sister here, who called my sister in [state], who called the hospital I was in ... She talked to the hospital and they said ‘yeah, he’s this, this, this, and that’ after I got out of the hospital, I left [state] to live with her, when I got off the plane, she had found four AIDS doctors within 25 miles of her house, that she could take me to or have United Way do it. (FG 4)

The experiences described above demonstrated how support from others could increase adherence and save lives.

Community level: Support from community programs and organizations—A few participants participated in ART adherence programs or substance abuse recovery programs in their communities, which facilitated adherence by helping them build HIV management skills, overcome addiction, and find peer support. One man explained,

First it started out where we had just a men’s group where we called each other and, “You take your medicine? You take your medicine?” We had a little buddy system ask, “You take your medicine today?” and it helped a lot that somebody else was concerned to ask me. (FG 2)

In addition to serving as a reminder, peer support cultivated in recovery groups helped participants feel like someone else cared about them and their livelihoods, which in turn, helped maintain motivation to adhere to their medications.

Some individuals received services through community organizations and institutions that facilitated access to medical care. Participants seemed to rely heavily on the local health department for care, and several described positive interactions with the providers, which helped them stay engaged. Some received charity care through local hospitals or through participation in research studies. Case managers, rehabilitation center staff, and home health

providers were other important sources of support. Several participants received help from these individuals to find housing and transportation, schedule provider appointments, and enroll in safety net programs. One man described: “[Name] makes sure I was able to make the appointments here. She’s a health care home provider and I called her today to get me an appointment and she makes all of my rides and they pay for everything” (FG 3). Another participant received case management for his reentry needs: “Yeah because there are a lot, see there are other benefits to going to [agency name], there’s a lady there that gives you clothes and bus vouchers, and referrals and things, and these are things you need...” (FG 5). Some participants who used case management before incarceration resumed it upon release. Others received instructions from prison facilities upon release to retain case management for assistance connecting to HIV care. Notably, some reported difficulty initiating services due to high agency caseloads and burdensome paperwork required to receive services.

Participants also took advantage of federal programs specifically for people with HIV that helped them meet their reentry-related needs. One participant enrolled in a program enabling her to find a nice apartment:

But my apartment I found was on the higher end of what they typically pay. But if you find an apartment within that range, they could potentially pay your rent and all your utilities. The only contingency is you must be HIV-positive. It’s through the Ryan White Act. (IDI 2)

She later described how support from this program in finding a secure, stable place to live ultimately provided her a safe location to store her medications and take them in private.

Stigma, a pervasive influence—In addition to the previously described barriers and facilitators that fell within the different levels of the SEF, one overarching barrier that cut across levels was stigma. At the interpersonal level, some participants’ family members made them feel inferior by using their serostatus or incarceration histories as weapons in arguments. Stigma experienced at the interpersonal level also made it difficult to find housing, as described by one man:

Well, I got tired of sleeping in my car; I got tired of going places and people turning me down because of the fact that they knew that I was HIV positive. Even my own mother was weary of me and she would be like, “You can’t stay here.” And when she gave me something to drink it was in a plastic cup and paper plates. And, “Don’t sit here in this chair, you sit over there,” and all this kind of stuff. (FG 1).

Experiences with stigma strained participants’ interpersonal relationships and made them wary of disclosure, which limited opportunities to receive social support. Furthermore, stigma experienced at the interpersonal-level interfered with HIV management for those who felt judged by medical providers for being formerly incarcerated and HIV infected. One man explained, “I don’t like really having to explain myself and the reasons why and then him [the physician] giving me the side look like I was like trash almost or disposable or ‘You’re one of those patients’” (FG 2). In several cases, experiencing stigma made individuals reluctant to interact with their providers in the future, and anticipating stigma from providers resulted in missed appointments, as described by another man:

My first doctor, I hated her because she had accused me of – one of my neighbors was mad with me, so they [the neighbor, called my doctor and told her] that I was abusing my life partner. And [my doctor] came out and asked me and I told her, “No. All I did was drink and stuff. And I had never touched anyone.” And then she [the physician] kept running and going on that, “If you try to hide it... I’ll have the police – have you evicted.” And so I hated her [the physician]. So I would not go to the doctor because I didn’t want to deal with her. (FG 2)

This participant’s interactions with his provider made him feel stigmatized, which kept him from returning to HIV care. Patient-provider dynamics were especially influential for those lacking health insurance because their options for choosing another provider were limited.

Within their communities, participants were stigmatized due to their incarceration histories, which adversely affected the ability to meet needs related to reentry. One man described his experience looking for work:

And the two jobs that I’m qualified for, they turned me down. They turned me down talkin’ about, “You’ve got a felony on your record.” But yet the two people that they hired for the job, neither one of them stayed there 30 days. But I had the experience that they didn’t have. But you wouldn’t hire me because I’ve got a record. (FG 3)

At the structural level, participants described policies prohibiting former prisoners from applying for needed support. One man lamented the difficulty of expunging his record for a fresh start, “So I’m just sorta’ in the pipeline now. They say you need to have the felony removed, but nothing’s never removed” (FG 2). Another man attributed high recidivism rates in formerly incarcerated persons to structural discrimination and stigma within his community:

I’m a G-grade felon, I can’t never get food again; can’t never get food stamps. And they be trying to figure out what keeps people going back to prison. If you can’t never get food stamps, and ain’t too many gonna’ hire you if you commit a felony. ... And you might just be dealing with a misdemeanor but it doesn’t matter; they don’t want you around, ‘cause they scared of you. (FG 3)

Participants in our study often met reentry-related needs before focusing on HIV management. Societal stigma and resulting discrimination heightened existing barriers of competing demands to meet reentry-related needs and delayed participants’ abilities to achieve the stability necessary to turn their attention to HIV management. This was especially true for participants who lacked support from others to help them overcome barriers and connect to resources. A few participants described peers who desired to return to prison because the barriers to reentry and HIV management were too difficult to overcome.

Discussion

We explored the interactions between factors influencing engagement in care and adherence in formerly incarcerated men and women with HIV through the lens of the SEF. The degree

to which participants could meet both their HIV management and reintegration needs varied and, often, structural and community level factors largely beyond their control substantially hindered or aided the ability to manage the virus. The majority of individuals faced challenges connecting to care during reentry despite prisons having relatively strong systems in place to link individuals to HIV care post-release. Those who had some individual or interpersonal level support, including previous experience, a devoted case manager, or a strong internal drive to manage their HIV, generally experienced fewer challenges. Upon release, participants experienced many competing demands, and their experiences of interactions between the barriers and facilitators across multiple levels influencing these demands made their lives feel chaotic. Some participants were both motivated to conduct HIV management and had the support and resources necessary to act on these motivations. Others wanted to manage their HIV but faced barriers across different levels of the SEF, such as addiction (individual level; Springer et al., 2007) or lack of housing and transportation (community level; Alexander, 2012; Katzen, 2011; Stephenson et al, 2005), which interfered with disease management, findings consistent from research on underserved HIV-infected populations who cycled in and out of HIV care (Parker & Aggleton 2003). We also found that some participants lacked the social support and resources to both successfully reenter society and manage their HIV. Overarching all of these experiences was a context of stigma related to both HIV and incarceration, which also served as a barrier to care and adherence. Our study design (with mixed gender focus groups) did not allow exploration of gender differences in reentry experiences, however, given the vast literature describing differences in health care seeking behaviors between women and men (Galdas, Cheater, & Marshall, 2005), this topic may warrant future research.

One of the most salient structural level barriers to care and treatment was the inability to enroll in health insurance and federal safety net programs during reentry, which limited access to quality health care in our sample, findings which support prior research (Baillargeon et al, 2009; Katzen 2011). This barrier was complicated at the individual level by participants who anticipated experiencing stigma from health care providers, which further reduced access to quality care. These findings suggest the importance of providing formerly incarcerated HIV-infected individuals with education and support to facilitate self-advocacy and successful navigation of the medical system. In addition, providing sensitivity training for health care providers working with this population may be useful. Nationally, about one third of prisons do not provide Medicaid enrollment support prior to release (Rosen et al., 2014). Providing HIV-infected inmates with support to enroll in Medicaid (Teitelbaum & Hoffman, 2013) before release would facilitate continuity of care after release, as well as provide individuals with the ability to find providers who meet their needs.

The Patient Protection and Affordable Care Act (ACA) provides several structural level opportunities to increase access to and quality of care. Under the ACA, up to 57% of inmates released annually would be eligible to enroll in Medicaid or receive federal tax credits to help purchase insurance through state and federal health insurance exchanges (Cuellar & Cheema, 2012). Formerly incarcerated people with HIV, however, will only benefit from these opportunities if they purchase insurance through exchanges or reside in a

state that has expanded Medicaid. Data collection for our study took place prior to passage of the ACA; because our participants resided in the U.S. southeast, a region where only 1 state (Arkansas) of 11 has chosen to expand Medicaid (The Henry J. Kaiser Family Foundation, 2014), most will not benefit from Medicaid expansion. However, provisions in the law providing substance abuse counseling, increasing funding for mental health home care visits, expanding reliance on use of medical homes, and providing incentives to increase the use of electronic medical records should increase the quality of health care accessed by this vulnerable population, regardless of state residence (Teitelbaum & Hoffman, 2013).

While we did not identify a “magic bullet” that seamlessly kept individuals adherent and in care post release, social support, through institutions and personal networks, was instrumental in helping HIV-infected individuals manage their disease and the reentry process, a finding supported by the literature (Alexander, 2012; Katzen, 2011; Woods et al., 2013). These findings underscored the importance of (a) connecting HIV-infected inmates to resources to address reentry needs, such as housing, employment, and substance abuse treatment, and (b) reinforcing social support systems prior to release, to facilitate continuity of care post release. Community organizations offering disease management programs and resources to help individuals access medical care were also crucial. These findings provide evidence for the usefulness of community-based reentry models that address several levels of the SEF by integrating case management, community support, health care, and access to employment, transportation, and substance abuse resources for this population (Woods et al., 2013).

Finally, many participants described a heavy burden of incarceration-related stigma and some recalled experiences with HIV-related stigma. Experiencing HIV- or incarceration-related stigma heightened barriers to reentry by making it more difficult for participants to meet needs related to securing housing and employment. Striving to overcome these heightened barriers delayed participants’ abilities to turn their attention toward establishing care with a trusted provider and interfered with the ability to adhere to a medication schedule. These findings were consistent with existing theories that describe both anticipated and enacted stigma experienced by HIV-infected individuals (Earnshaw & Chaudoir, 2009; Parker & Aggleton, 2003) and provide support for implementation of interventions focused on reduction of HIV-related stigma within communities (Sengupta, Banks, Jonas, Miles, & Smith, 2011), as well as the development of interventions to reduce stigma due to incarceration at the community and structural levels. Further, it is likely that some participants in our study experienced an enhanced burden during reentry due to the compounded effects of HIV- and incarceration-related stigma (Reidpath & Chan, 2005); however, the extent to which participants experienced layered stigma was not discernible from these data and merits exploration in future studies.

This study has limitations. The experiences reported here may not reflect the experiences of formerly incarcerated people with HIV who never engaged in care post-release, as all participants were enrolled in HIV treatment at the time of this study. Participants may have provided socially desirable responses, as it was known that the interviewers were developing an intervention to support access to HIV care. Furthermore, some participant responses may

have been colored by recall bias, as the length of time since last incarceration was long for some participants. Despite these limitations, the findings give care providers, researchers, community practitioners, and policy-makers rich information that could be used to develop interventions to help formerly incarcerated people with HIV improve HIV management post release.

Conclusion

HIV-infected inmates facing prison release experienced competing needs between HIV management and meeting reentry needs, and they often first met reentry related needs. Those with resources, including social support and experience with navigating care systems, were more easily able to overcome individual and contextual barriers to HIV management. Structurally, the ACA provides opportunities to help this population access quality health care. Interventions seeking to augment social support amongst family and friends of formerly incarcerated HIV-infected individuals and reduce HIV- and incarceration-related stigma in HIV care providers and potential employers and landlords, should facilitate continuity of care for this population.

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Key Considerations

- Most HIV-infected inmates leave prison with a suppressed viral load; many, however, become disconnected from care and non-adherent to medications during reentry to community life.
- HIV-infected inmates facing prison release experienced a sense of chaos in their lives due to competing needs between HIV management and meeting needs related to reentry (e.g., housing, food), and they often worked on reentry-related needs first.
- Barriers and facilitators affecting HIV management occurred at individual, interpersonal, community, and structural levels.
- HIV-infected inmates facing prison release, who possessed resources, including social support and prior experience navigating health care systems, were more easily able to overcome individual and contextual barriers to HIV management.
- Interventions that simultaneously address multiple levels, including augmenting employment and housing opportunities, enhancing social support, and reducing stigma are needed to facilitate continuity of care within this population.

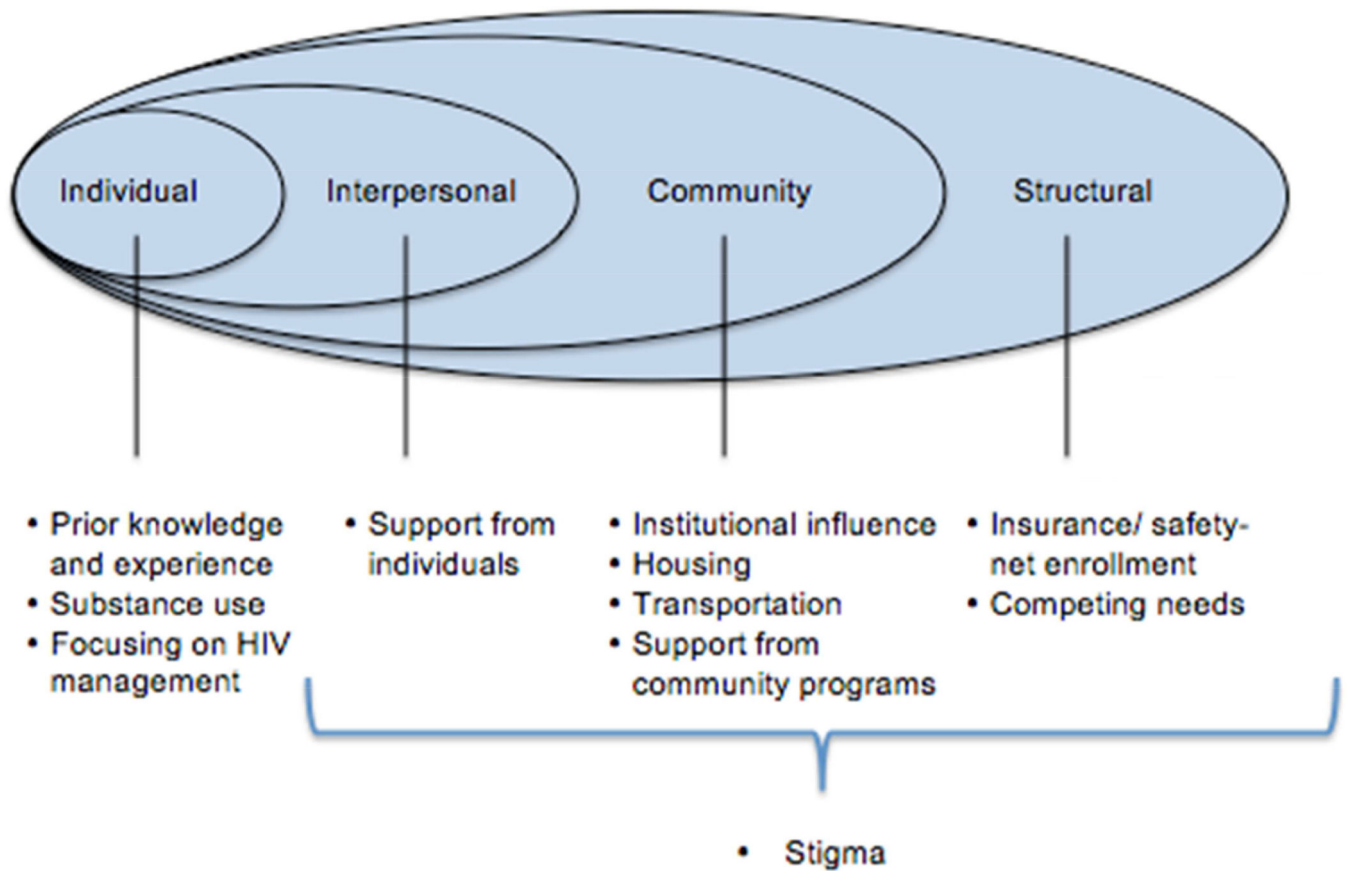


Figure 1. Factors influencing ART Adherence and engagement in care across the Social Ecological Framework.

Table 1

Demographics of Sample at Time of Interview

Characteristic	<i>n</i> = 46 (%)
<i>Race/Ethnicity</i>	
Black	39 (84.8%)
White	4 (8.7%)
Hispanic/Latino	1 (2.2%)
Multiracial	2 (4.3%)
^a <i>Average Age in Years</i>	43
Range	23 – 60
<i>Education Level</i>	
Did not complete high school	6 (13.0%)
High school diploma or earned GED	16 (34.8%)
Some college or earned bachelor's degree	20 (43.5%)
Some graduate school or earned graduate degree	4 (8.7%)
^a <i>Average Number of Incarcerations</i>	3
Range	1 – 8
<i>Length of Last Incarceration in Years</i>	
< 1	21 (45.7%)
1 – 3	10 (21.7%)
4 – 5	2 (4.3%)
6 – 10	5 (10.9%)
11 – 20	2 (4.3%)
21	1 (2.1%)
Missing	5 (10.9%)
<i>Employment Status</i>	
Unemployed with disability	18 (39.1%)
Unemployed without disability	11 (23.9%)
Worked part-time	2 (4.3%)
Worked full time	2 (4.3%)
Retired	1 (2.2%)
Missing	12 (26.0%)
<i>Relationship Status</i>	
Single	22 (47.8%)
Married	4 (8.7%)
Separated	2 (4.3%)
Divorced	6 (13.0%)
Widowed	1 (2.2%)
Missing	11 (23.9%)

^aData for participants' ages and number of incarcerations were missing for 2 participants; averages were calculated at *n* = 44.

Table 2

In-Depth Interview Participant Demographics

IDI	Age	Gender	Employment Status	Relationship Status	Education Level	Number of Incarcerations	Approximate length of last incarceration	Diagnosed during last incarceration
IDI 1	34	M	Worked part-time	Divorced	Did not complete high school	5	< 1 year	No
IDI 2	46	F	Unemployed without disability	Single	Some college or earned bachelor's degree	5	< 1 year	No
IDI 3	46	M	Unemployed with disability	Single	Some college or earned bachelor's degree	3	1 – 3 years	No
IDI 4	60	M	Unemployed with disability	Single	Did not complete high school	1	21 years	Yes
IDI 5	39	F	Unemployed without disability	Married	Some college or earned bachelor's degree	3	6 – 10 years	No
IDI 6	29	M	Unemployed without disability	Single	High school graduate or GED	3	1 – 3 years	Yes
IDI 7	43	F	Worked part-time	Single	Did not complete high school	0 (jail 5 times)	< 1 year	No
IDI 8	57	M	Unemployed with disability	Separated	Some college or earned bachelor's degree	1	3 – 5 years	No
IDI 9	33	M	Unemployed with disability	Single	Some college or earned bachelor's degree	2	< 1 year	No

Note: GED = general equivalency exam; IDI = in-depth interview.