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“Like I Have No Choice”: A Qualitative Exploration of HIV Diagnosis and Medical Care Experiences while Incarcerated and their Effects

Alexandra H. Kutnick, Ph.D.¹, Noelle R. Leonard, Ph.D.^{1,2}, Marya V. Gwadz, Ph.D.^{1,2}

¹Center for Drug Use and HIV/HCV Research, NYU Global College of Public Health, New York University, New York, NY, USA

²Silver School of Social Work, New York University, New York, NY, USA

Abstract

It is estimated that one in six Black and Latino adult persons living with HIV (PLWH) spend time in correctional institutions each year. Yet after release, PLWH of color evidence poor HIV health outcomes across the HIV care continuum. This study, guided by an ecological approach and Critical Race Theory, sought to understand the lived experiences of socioeconomically disadvantaged PLWH of color who received an HIV diagnosis and/or medical care while incarcerated, and the ways in which those experiences influenced engagement in medical care after release. Drawn from a larger study in Brooklyn, NY, in 2013-2016, a subset of 28 participants who received in-depth qualitative interviews were purposively sampled for a secondary analysis of participants who received an HIV diagnosis and/or medical care while incarcerated. Using an Interpretive Phenomenological Analysis, we found participant's experiences were shaped by longstanding mistrust of the medical establishment. While incarcerated, lack of autonomy, substandard medical care, and poor social support exacerbated medical mistrust and avoidance of HIV medical care long after release. Engagement in HIV medical care and treatment were also impacted by a dynamic interplay of factors including substance use, prolonged periods of denial, poverty, and repeated bouts of incarceration. Given that experiences of HIV diagnosis and medical care while incarcerated have long-ranging, adverse effects, we argue that a better understanding of the ways in which PLWH of color experience HIV diagnosis and medical care while incarcerated may serve to inform intervention efforts within correctional institutions to improve HIV health outcomes.

Keywords

HIV care continuum; Critical Race Theory; medical mistrust; incarcerated populations; Interpretive Phenomenological Analysis

Introduction

The epidemics of mass incarceration and HIV infection are inextricably linked. The prevalence of HIV among those in correctional institutions is 3.5 times greater than it is for the general population.¹ An estimated one in six (persons living with HIV) PLWH in the U.S. spends time in a correctional facility each year,² the vast majority of whom are socioeconomically disadvantaged people of color.^{3,4} Further, PLWH of color are overrepresented in correctional institutions largely because U.S. drug enforcement policies result in disproportionate arrests, prosecutions, convictions and sentences for drug offenses for Blacks and Latinos compared to whites.⁵⁻⁶

Given the high incidence of HIV among incarcerated populations, the Center for Disease Control (CDC) recommends routine opt-out HIV testing of all individuals who enter a correctional facility as well as receipt of HIV medical care and antiretroviral therapy (ART) for those found to be infected with HIV or who present as HIV-positive upon arrival.^{3,7} Thus, correctional institutions are uniquely positioned among HIV medical care settings to provide care along each step of the HIV care continuum, namely HIV testing, diagnosis of HIV, linkage to HIV medical care, retention in regular HIV medical care, prescription of ART, and sustained adherence to antiretroviral therapy (ART) resulting in viral suppression.^{7, 8} In fact, in a systematic review across 92 studies and 15 states examining HIV care before, during and after incarceration, Iroh and colleagues (2015) found that PLWH's HIV health outcomes improved while incarcerated at every step of the HIV care continuum, even exceeding national averages. Yet post-release, these outcomes plummet and dip below national averages at every step of the care continuum.⁹

Maintaining HIV health outcomes for PLWH after leaving correctional institutions is critical for individuals and as a public health strategy for preventing forward transmission of HIV infection. Accordingly, a large body of research has documented the development of systems for linking former inmates to HIV medical care upon release.⁹⁻¹² A recent systematic review identified some successes with these interventions yet also found significant variability in their efficacy. Notably, women, African-Americans, and those with substance use disorders, are the least likely to benefit from existing interventions to link PLWH to HIV medical care after incarceration.¹³

Medical Mistrust

The asymmetry in medical knowledge and power between medical providers and patients inherently places patients in a vulnerable position particularly in the face of disease or illness.¹⁴ An overall sense of trust in the medical establishment serves to mitigate this sense of vulnerability and engenders expectations of the way in which medical providers deliver care. However, many people of color, particularly Blacks and Latinos, have high levels of mistrust in the medical establishment that profoundly influences their engagement in medical care.¹⁴⁻¹⁷ This mistrust is strongly rooted in historical medical abuses of people of color and reinforced by present-day realities of significant health disparities^{14,17-19}. While medical mistrust has been conceptualized in a wide variety of ways, in the main, it refers to mistrust of medical providers, systems, and treatments and exists on a spectrum ranging from a belief

that medical providers and/or systems do not prioritize patients' best interest to a belief that providers and systems are actively engaged in rendering harm.^{14-15, 18-19}

The social stigmatization and political context of the 30 year old HIV epidemic coupled with the stark, disproportionate burden of HIV infection, morbidity, and mortality among people of color amplified a profound mistrust of the medical establishment and the formation of conspiracy theories among many people of color.^{18,19} Mistrust in official sources of medical information about the origins, transmission, prevention, and the safety and efficacy of treatments of HIV have been found to be a potent barrier to engagement in medical care among across the HIV care continuum.^{15, 17, 20-22} A systematic review of African Americans' beliefs about HIV medical care by Gaston and Alleyne-Green (2013) found that experiences of racism, conspiracy beliefs, and the quality of provider relationships significantly impacted engagement in HIV medical care for a number of diverse samples of African-Americans. Further, medical mistrust is associated with a low levels of readiness for ART and poor medication adherence among Black and Latino PLWH.^{21,22}

While incarceration places individuals in a dependent and vulnerable position, this vulnerability may be exponentially heightened for people of color receiving HIV related medical care in a correctional facility and profoundly impact their level mistrust in health care providers and systems.²³ Yet with the exception of an early study that found incarcerated individuals have higher levels of mistrust in health care providers relative to community samples,²⁴ there is a dearth of research examining medical mistrust among individuals with a history of incarceration, and none to our knowledge examining the experience of PLWH of color receiving HIV testing and treatment while incarcerated. The present study aims to fill this important gap by eliciting the perspectives of PLWH of color regarding their experiences receiving an HIV diagnosis and/or medical care while incarcerated and the ways in which these experiences may have influenced their engagement in HIV medical care after release. Guided by an ecological approach which views experiences as embedded in multiple contexts.²⁵ This qualitative study is further informed by Critical Race Theory, a trans-disciplinary theoretical framework that aims to expand the discourse about complex racial concepts by eliciting the lived experiences of people of color.²⁶⁻²⁷

Methods

The present study is a secondary analysis of qualitative interviews from a larger study and draws on qualitative interview data with 28 Black and Latino adults living with HIV who received an HIV diagnosis and/or HIV medical care while incarcerated. Data collection for this study took place between 2013 – 2016 in Brooklyn, NY. The study received ethical approval from the New York University Langone School of Medicine Institutional Review Board.²⁸

Brief Description of the Larger Study

The larger study used respondent driven sampling (RDS)²⁹ in a well-defined high-risk area (HRA) within Brooklyn, the borough in New York City with the highest heterosexual HIV prevalence at the time of the study. Eligibility criteria included: age 18-60 years; sexually

active (vaginal and/or anal sex) with at least one opposite sex partner within the previous year; reside in the designated HRA in central Brooklyn; Black or Latino race/ethnicity; comprehension of English or Spanish; and not actively psychotic based on a standard screening instrument.³⁰

All participants engaged in a quantitative, structured baseline assessment lasting 60-90 min on socio-demographic and health history variables including incarceration history and HIV health characteristics. Following all other study activities, a total of (N = 68) semi-structured, qualitative interviews were conducted in-person, and lasted approximately 60-90 minutes. Participants signed informed consent for all study activities and were compensated \$30 plus funds for round-trip local transportation for the quantitative assessment and qualitative interview. The larger study procedures and outcomes have been described elsewhere.^{28,31-33}

Eligibility Criteria for the Present Study

The present study drew on transcripts from a subset of those who received qualitative interviews in the larger study. We included those: 1) who were HIV-infected, confirmed through HIV testing or medical documentation; and 2) reported receiving HIV medical care, including a diagnosis of HIV, while incarcerated within the criminal justice system. We determined this second criterion as follows: Participants were identified as ever having been incarcerated by the following item in the quantitative baseline assessment: “*Have you ever been held in a detention center, jail, or prison for more than 24 hours?*” In order to ensure that participants’ experience of incarceration occurred since being infected with HIV, we screened participants using the following question from the qualitative interview: “*Since testing positive for HIV, where have you received HIV medical care, including HIV medical care following HIV-testing? Probe: While incarcerated?*”. Based on these criteria, a total of 28 participants were included in the present study. (See Figure 1 for an overview of the sampling frame).

Qualitative Interview

The qualitative interview followed a semi-structured guide that aimed to elicit participants’ perspectives on their experiences of receiving an HIV diagnosis and/or HIV related medical care while incarcerated. These questions were embedded in a larger interview about participants’ experiences of their HIV diagnosis and history of engagement in HIV medical care. Grounded in an ecological framework, the interview guide sought to explore individual and contextual influences on participants’ experiences (i.e., substance use, relationship with healthcare providers, access to medical care, HIV stigma, and medical mistrust). Interview questions included main questions and probes, and the interviewers were encouraged to attend to emergent themes. Interviews were audio-recorded and professionally transcribed verbatim. All identifying information was removed from the transcripts and only pseudonyms are presented.

Interviewing Team and Positionality

The qualitative interviewing team was comprised of six female masters and doctoral-level research study staff from diverse racial/ethnic backgrounds (Black, White, Latina, and

Asian), all trained in qualitative interviewing methods. Positionality challenges related to gender, race/ethnicity, power, socioeconomic status, and privilege were intentionally addressed throughout the data collection process through regular supervision and training.

Qualitative Data Analysis

Interpretative Phenomenological Analysis (IPA)³⁴⁻³⁵ was the qualitative analytic approach used for this study, as IPA is committed to exploring how people make sense of their own experiences and emphasizes the context where this meaning-making occurs.³⁴ In keeping with IPA's idiographic approach, each interview was first analyzed individually,³⁵ which allowed for the inductive development of themes first within and then across interviews. The next stage of data analysis involved looking for patterns across cases. This process was lengthy, involved many iterations and was guided by Smith and colleagues (1999)'s analytic approach³³ including the following techniques for cross-case analysis: (1) *abstraction*, where one puts similar themes together and then develops a new name for the cluster; (2) *subsumption*, where an emergent theme itself becomes a master theme as it draws other related themes towards it; (3) *polarization*, where one examines transcripts for oppositional relationships; (4) *numeration*, where one examines the frequency with which a theme is supported; (5) *function*, where themes are examined for their function and finally; (6) *contextualization*, where the contextual elements within a narrative are identified. Each of these techniques were used to varying degrees, and themes were depicted in the narrative when they were deemed primary when discussed by numerous participants.

We assessed validity using Yardley's (2008) guidelines³⁶ for ensuring validity in qualitative research, which is recommended for assessing validity within an IPA approach.³⁷ The full analytic team comprised of two data analysts, one of whom was also an interviewer, and senior research staff, including the PI and Co-I, who formed an "interpretive community". The analytic team engaged together in an iterative data analytic process guided by Yardley (2008),³⁶ namely meetings to discuss the most frequent and resonant themes, relationships among codes, and their explicit and underlying, latent meanings. Methodological rigor of the analysis was maintained through an audit trail of process and analytic memos and periodic debriefing with the larger research team, which included experts in HIV testing and treatment, HIV-stigma, criminal justice-involved populations and social and economic inequities. Data were analyzed with the assistance of Dedoose software,³⁸ for qualitative data analysis.

Quantitative Measures in the Baseline Assessment

Sociodemographic characteristics.—Using a structured instrument, the following were assessed through self-report using single item questions with open-ended items and coded responses: age; race; gender; educational attainment; employment status; relationship status; family composition; financial insecurity (i.e., unable to pay for necessities in the past year); health insurance; past and current housing instability (that is, whether has ever been homeless and is currently homeless); **Incarceration history**, including lifetime and recent incarceration (ever incarcerated and if so, whether incarcerated in the past year) as well as times incarcerated over the course of one's lifetime.

Problematic drug and alcohol use were assessed for lifetime and recent use, through the Texas Christian University Drug Screen (TCU Drug Screen) and Alcohol Use Disorders Identification Test (AUDIT) measures. The TCU measure has nine items and is coded dichotomously with yes/no responses and established cut-off values for problematic levels of drug use.³⁹ A sample TCU item is: “Did you try to control or cut down on your drug use but were unable to do it?” ($\alpha = 0.91$). The AUDIT, a self-report screening instrument developed by the World Health Organization (WHO)⁴⁰ to assess problematic alcohol use, is a 10-item measure with a 5-point likert scale. A sample AUDIT item is: “How often during the last year have you failed to do what was normally expected of you because of drinking?” ($\alpha = 0.89$). Both the TCU and AUDIT are widely used assessment instruments for PLWH populations.⁴¹

Medical Mistrust was assessed through the seven-item Medical Mistrust Index (MMI).⁴² The MMI assesses mistrust of healthcare organizations as opposed to mistrust of individual healthcare providers. It is coded on a 5 point likert scale, ranging from “Strongly Disagree” to “Strongly Agree”. A sample MMI item is: “Patients have often been deceived or misled by healthcare organizations” ($\alpha = 0.92$).

HIV health characteristics were assessed through self-report using single item questions with open-ended items and coded responses. The variables assessed included: years since HIV diagnosis; as well as HIV disease progression biomarkers, specifically current CD4 count and HIV viral load. For the quantitative data, data were analyzed using descriptive statistics including counts, percentages, means, and SDs. All quantitative analyses were conducted in the R statistical computing environment.

Results

Sample Characteristics

As shown in Table 1, participants in this sample were mostly male (60.8%), were 47 years old, on average ($SD = 7.12$ years) and primarily Black (78.6%). Most of the participants had children (96.4%) and were married or in long-term relationships (92.9%). In terms of socioeconomic characteristics, the vast majority of participants (92.9%) were unemployed, and three-fourths (75.0%) of participants were unable to pay for basic necessities in the past year, an indication of extreme poverty. In terms of incarceration histories, most participants had extensive involvement with the criminal justice system, as they had been incarcerated in their lifetimes an average of 8.19 times ($SD = 6.64$), and 17.9% had been incarcerated in the past year. Further, the vast majority of the participants who comprised the sample (96.4%) met criteria for lifetime histories of problematic drug and alcohol use based on AUDIT and TCU criterion.

Regarding medical mistrust, as shown in Table 2, based on the MMI index, there was a lot of variability in participants' current attitudes towards healthcare organizations and whether they trust healthcare organizations. Notably, 50% ($n = 14$) of participants endorsed the statement: “When healthcare organizations make mistakes, they usually cover it up.” Further, 46.4% ($n = 13$) of participants endorsed the following items: “You’d better be cautious when dealing with healthcare organizations” and “Patients have often been

deceived or mislead by healthcare organizations”, suggesting that many participants in the sample struggled with mistrust of the medical establishment. Further noteworthy is the fact that the MMI Index asked about trust in healthcare systems in general, and did not ask specifically about mistrust in healthcare systems in correctional institutions.

Regarding the HIV health characteristics of the sample, the participants had been living with HIV for 14.14 years (SD=8.01) on average and 60.7% were diagnosed with HIV while incarcerated. Further, 67.8% (n = 19) reported currently being on ART. In terms of self-reported CD4 count, participants reported an average of 482.57 cells/mm³ (SD = 341.83) with a range of 1- 1,249. Of the 28 participants in the sample, 39.3% (n = 11) reported being virally suppressed. Data is also shown in Table 3.

Overview of Qualitative Findings

We found that participants’ experiences of HIV medical treatment within correctional institutions markedly impacted their trust in mainstream medical providers and HIV treatment, and served as a lens through which health behaviors and health care choices were made long after release. Two overarching multi-faceted themes emerged from our analyses. First, we found a unique constellation of factors associated specifically with the experience of being incarcerated, including: (1) the lack of autonomy; (2) medical care experienced as substandard; and 3) poor social support which amplified feelings of stigma. These factors appeared to compound upon each other and exacerbated experiences of mistrust of the medical establishment, particularly mistrust of ART, which in turn, contributed to difficulties maintaining engagement in HIV medical care after release. Second, we found that substance use played a pivotal role in complicating participants’ experiences of HIV-related medical care. In particular, we found that for most participants, lengthy periods of denial of HIV status were mutually reinforced by the synergistic effects of substance use, poverty and its consequences, and repeated bouts of incarceration and, all of which, taken together, compounded medical mistrust and derailed participants’ engagement in HIV medical care after release. Below, we unpack these themes that emerged regarding experiences of HIV diagnosis and HIV-related medical care within the criminal justice health care system, and elucidate the long-ranging adverse effects these experiences had on participants’ health and well-being after their release.

Unique Constellation of Factors Associated with Incarceration and their Compounded Effects

Lack of Autonomy.—We found that the lack of autonomy that is characteristic of incarceration challenged the HIV medical care experiences for participants in our study, and reverberated in their health care choices after release. In particular, we found that participants who received their HIV diagnosis while incarcerated were especially affected by the lack of autonomy they experienced during such a traumatic and vulnerable time as an HIV diagnosis. Participants diagnosed with HIV while incarcerated described their experiences of both HIV-testing and diagnosis as harsh and coupled with a lack of agency regarding their ability to obtain information and make informed decisions about their healthcare. Participants commonly noted they did not feel empowered to ask questions about the process of HIV testing, nor about the implications of an HIV diagnosis on their health.

For example, Joseph, a 52-year-old man who had been incarcerated twice, recalled his experience of being diagnosed with HIV while incarcerated as follows:

“[In prison], the nurse first saw me because they tested me, the swab first. Then they called me back to inform me they needed blood. But I didn’t know what for, I mean I felt, I really felt confused, I didn’t know what was going on. But just went along because I didn’t have no choice.”

Further, after Joseph tested positive for HIV while incarcerated he was prescribed HIV medication to treat his HIV disease within the prison healthcare system.

“When I first started taking the meds in prison, the nurse told me, oh, you’re probably going to be used to it in a couple of days, like the side-effects, and it being okay, but it was more like years. They just say anything to get you to do what they want.”

Joseph describes feeling coerced into getting tested for HIV and once diagnosed with HIV experienced a sense of resignation as to his lack of ability to make decisions about his health care. These experiences left Joseph not only with mistrust of his particular medical providers within the prison healthcare system, but also fostered his suspicion of the HIV medications he was prescribed.

In addition, as with Joseph, it is noteworthy that not one of the participants in the sample mentioned the process of being consented for HIV-testing, nor alluded to any pre- or post-test HIV counseling when describing their experiences of HIV testing and diagnosis while incarcerated. In New York State, where all of the participants were incarcerated, HIV testing is voluntary and must be offered to every inmate at the time of their initial medical evaluation in the correctional facility and includes a process of informed consent and medical treatment, if found positive.⁴³

Furthermore, when participants were asked to describe what factors may have facilitated their successful engagement in medical care after release from prison, the vast majority of participants in the study invoked the critical importance of maintaining their autonomy to decide whether or not to engage in HIV medical care after release. For example, Helen, a 49 year-old woman who had been incarcerated five times asserted the following regarding her decision to take HIV medication after her release:

“I’m a grown person. I can make my decision, I don’t want to—I don’t want to. I have a choice to say yes or no.”

Experiences of Medical care as Substandard.—Our analyses demonstrated that in addition to experiencing a lack of autonomy in the context of receiving HIV medical care while incarcerated, the majority of the participants also viewed HIV medical care within the prison healthcare system as substandard. Many participants described HIV healthcare experiences where providers failed to educate them about their HIV disease and available medical options, as well as neglected to appropriately inform them about what treatment involved. For example, Jose, a 55-year-old man who was incarcerated once, contrasted his

experiences of HIV medical care within the prison health care system to HIV medical care experiences outside of prison, as follows:

“You know, I went to jail, did two years, but as you get older, you get wiser you know. I don't wanna die in jail, I'm 55 years old. [Chuckles] I got friends that died in jail from the virus too. They don't treat you well in jail. They don't give you the right treatment. Out here there is a better treatment then there.”

Jose further articulated how feeling uncared for within the prison healthcare system led to suspicion about the effectiveness of the HIV medication treatments among his friends. Jose attributed his friends' deaths from AIDS to their decision to abstain from HIV medications they could not trust, as he stated the following:

“Because, I got friends that died of AIDS in there, you know. They wasn't taking there medicine because they didn't know what it was. [It's] hard in there [in jail], no one cares about you.”

Moreover, a theme that emerged among a number of the female participants in the sample, was that their husbands' experiences of substandard HIV medical care while incarcerated greatly affected them as well. For example, Lily, a 50 year-old woman who had been incarcerated three times and who contracted HIV from her husband after he was diagnosed with HIV while incarcerated, recalled the following:

“And that's when I started crying. I said, oh my god. I always protected myself but you know, my husband was in and out of jail. And one time when he came out of jail, he had a bunch of medication he hadn't taken' cause he didn't know how to read no English. And there was a list, and I read it. Carlos is diagnosed with AIDS, and the medication, blah, blah. How many times a day. A whole bunch. But my husband, he didn't know what was going on, couldn't read no English, and didn't do nothing with those medication.”

As described above, Lily had only surmised that her husband had been diagnosed with HIV because of paperwork and unused HIV medication she found after he was released. Further, Lily described her husband as having received substandard HIV medical care while incarcerated where he did not receive basic, yet critical health education such as dosing schedules of prescribed HIV medication regimens that he could understand. Consequently, Lily believed that as a result of the substandard HIV medical care her husband received while incarcerated, he left prison unable to manage his HIV disease.

Poor Social Support.—Findings indicated that inadequate social support while incarcerated was widespread for participants in our study, and operated in conjunction with the above-described factors to impair participants' abilities to successfully engage in medical care. We found that poor social support primarily stemmed from two reasons: 1) participants socially isolated themselves due to fear of HIV stigma and discrimination; and 2) participants had limited contact with their closest support systems. In fact, participants described HIV stigma as pervasive within criminal justice institutions, and reported that while incarcerated, stigma exacerbated their social isolation, distress and lead to their avoidance of HIV medical care. For example, Louis, a 46 year-old man who had been

incarcerated five times recalled how as a result of HIV stigma, he would not disclose his HIV status to anyone in prison nor engage in HIV medical care:

“In prison I didn’t tell no-one. Don’t take no medication. Because I don’t want to tell nobody because the discrimination part that comes with it, you know what I mean, and I won’t be I comfortable with that. Better not to tell no one your business.”

In addition, because of the way medication is dispensed in prison, taking HIV medication was particularly fraught and lead participants to further socially isolate themselves, as Helen described:

“I wanted to be treated just, you know, the same as anybody else. Because, in jail, everyone knows that you taking medication... you can see that people look at you kind of different. I would walk by sometime, and everyone talking, and whispering, and looking. And, I know they talking about it, about my being HIV positive. So I kept to myself. I am not going to be treated that way, you know. No I am not.”

Furthermore, because participants were separated from their closest support systems while incarcerated, they missed vital social support in managing the emotional implications of receiving a diagnosis of HIV, including dealing with the implications of the disease process and challenges associated with treatment. For example, Clark, a 45-year-old man who had been incarcerated ten times and was diagnosed with HIV while incarcerated recalled his experiences of social isolation in prison, and its consequences, as follows:

“You know, when I go to jail, I don’t have nobody. Nobody to talk to about it [HIV infection] or to help me out with meds. I’m walking around— no mom, no brothers and sisters, no cousins, you know, that was real hard. ”

Participants’ experience of social isolation and HIV stigma while incarcerated was not only commonplace, but also detrimental, as poor social support often lead to avoidance of HIV medical care. Furthermore, the effects of social isolation while incarcerated are nested within an overall context of medical mistrust, as described above. Hence, it is notable that none of the participants described having supportive relationships with medical providers while incarcerated that could have potentially buffered the effects of stigma they experienced. Rather, it was only after release from incarceration, that any of the participants described establishing trusting and positive relationships with providers that facilitated their ability to get educated about HIV, accept their diagnosis, and learn to manage their disease. For example, Sarah, a 45 year-old woman who had been incarcerated five times and was diagnosed while incarcerated, recalled the following:

“Like—it was like right after I was diagnosed, and they didn’t educate you that much in jail. So, whatever bits and pieces you heard was like, basically, bits and pieces you heard. I didn’t become—start getting educated till I came home and I got with the doctor I like, and so that was my opening to knowing some things, and learning how to accept this virus and take my medication.”

Prolonged Denial of HIV Status

Results of our analysis revealed that the vast majority of participants in this sample struggled with acceptance of their HIV status. In particular, we found that those participants who received their HIV diagnosis while incarcerated experienced particularly lengthy periods of denial of their HIV status, ranging from 3 to 23 years, which especially challenged their post-release HIV medical care. For example, Darren, a 44 year-old man who has been incarcerated six times and who was diagnosed with HIV while incarcerated five years prior to his interview, relayed the following:

“What entered my mind when they say it, I don't believe it. they say it's true, I don't believe it and I am going to keep living my life, been living my life and it worked for me to this day. It has been working for me, still never been hospitalized, no complications. So no medicine, none of that.”

Darren did not believe his HIV diagnosis when he received his test results while incarcerated, and five years later continues to struggle with this belief, as his experience of his health stands in contrast with this knowledge. Essentially, Darren trusted his own experience more than he trusted the medical information he was provided and as a result did not believe he needed to be treated with antiretroviral medication.

Further, Shirley, a 55-year-old woman who was diagnosed with HIV while incarcerated and has been incarcerated five times in total, described her own lengthy process of denial as follows:

“Well, actually—I actually found out in '90 when I was on Riker's Island [where she was incarcerated], but, you know, they didn't really tell me what was going on, and it go (in) one ear and out the other, so when I got out, I did many, many, many, many, many, many drugs and really didn't care, really didn't believe it, until this year [in 2013]. ”

Shirley experienced a particularly long period of denial following her HIV diagnosis while incarcerated. She reported that her medical providers within the criminal justice system failed to fully inform her about what was going on while she was diagnosed and that she was unable to cognitively or emotionally process her diagnosis. In addition, Shirley emphasized how following her release, her substance use reinforced and compounded her denial, a theme that emerged in this study that will be explored in greater detail below.

The Contribution of Substance Use

One of the most widespread themes that emerged in this study was the pervasive, negative influence of substance use on participants' lives. As described above, the vast majority of the participants in this study had histories of substance use disorders. We found that the mechanisms through which substance use adversely influenced participants' experiences of HIV diagnosis and medical care within the prison health care system were numerous and complex. Chief among them were: (1) substance use leading to increased criminal justice involvement and repeated bouts of incarceration; and 2) substance use compounding denial of HIV status and exacerbating avoidance of medical care after release. For example, Clark described how after a long, non-linear struggle with substance use, it took him many years,

many different experiences of incarceration, HIV testing, periods of denial, and reckoning with his HIV diagnosis before he was able to begin to successfully engage in HIV medical care.

“So I think maybe-maybe the first time [I tested for HIV]—the first time maybe was around 1998-1999 at Riker’s [where he was incarcerated], or then like 2000-2000 or something, then the second time maybe was around 2005 or 2006 something like that while I was at Riker’s again. And that’s when I really start[ed] thinking about it, but I still didn’t really. I went to the doctor and stuff and then I didn’t go back. And then I started back using [drugs] again and that’s where that I stopped taking my (HIV antiretroviral) medication. I am clean now and go to the doctor... but it’s still hard.”

Further, we found that for many participants, struggles with substance use intersected with a host of other difficulties including repeated bouts of incarceration, child welfare involvement and HIV diagnosis that compounded their challenges with managing their health and well-being. For example, Donna, a 49 year-old who has been incarcerated nine times, recalled how she received her HIV diagnosis while incarcerated:

“When I first found out I was positive, I was pregnant actually. I had a baby and uh she was premature by one month. They tested the baby and she was HIV positive and I have it. I lost um the baby, you know. She went into foster care and then eventually got adopted. I really lost custody because I went to jail and he (her partner) went to jail. I think if I was out, I would’ve got on the program. I would’ve got her back—you know what I’m saying? But that-that jail time, that’s what really messed it up for me.”

Certainly Donna’s experience of her HIV diagnosis while incarcerated was difficult, as she attributed the loss of her infant to the child welfare system as due to her being incarcerated and unable to access substance use treatment. Notably, child-welfare involvement as a result of incarceration due to substance use was a frequent experience described by the female participants in this study. Further, Donna described a number of years where following her diagnosis she also experienced homelessness as part of a vicious cycle of substance use and repeated bouts of incarceration she struggled with, as she recalled:

“I was homeless. I was on the street. I slept on roofs. I, you know, going back and forth to jail. There was a period of a few years after finding out [my HIV status] where I was going to jail, back and forth, and that’s not the place to be. It’s depressing. Jail is really depressing, you know. And every time you turn around you’re going back there. I was using [drugs] and going back and forth to jail.”

Moreover, in addition to Donna, housing instability was an issue for many of the participants in the study, and contributed to many participants’ difficulties with successfully engaging in HIV medical care. For example, Clark described how as a result of subsidized housing regulations, his court-mandated substance use treatment caused him to lose his housing, which not only caused him distress, but also lead to difficulties managing his health, as follows:

“The last time I had got arrested the judge wanted to put me in like a long-term [substance use treatment] program. But I was like how can I go on a long-term program and keep my apartment? I had friends and stuff that when they went to [a long-term] program, they lost everything because they had Section 8 [federal housing subsidy]. So I didn't want to lose my Section 8. But I did. Ain't got nothin now that I'm out. And I get stressed out really, because how much I want my own house, you know. Hard to take care of myself, like with my meds now [without my own house], you know ”

Like many participants in the study, Clark faced enormous obstacles to successfully managing his HIV disease, including complex structural barriers associated with substance use treatment, housing, incarceration and poverty that left Clark with little autonomy and increased stress.

Certainly, for the participants in this study, understanding the significance of the experience of being diagnosed with HIV/and or receiving HIV medical care while incarcerated requires an appreciation of the larger context where participants reside. As described, the context for the participants in this study is one of severe socioeconomic disadvantage where frequent incarceration, substance use, homelessness and medical mistrust are pervasive, and severely complicate participants' ability to successfully manage their HIV disease.

Discussion

The present study explored the experiences of a highly vulnerable sample of PLWH of color who received an HIV diagnosis and/or medical care while incarcerated and continue to struggle with maintaining positive HIV health outcomes after release. We used an in-depth qualitative methodology to elicit the perspectives of PLWH of color with histories of incarceration and found that participants' experiences of HIV medical-care while incarcerated were influenced by a complex and dynamic interplay of factors at all levels of the social ecology.

Our findings indicated that all participants in our study experienced a heightened level of vulnerability and powerlessness receiving HIV medical care while incarcerated which, to varying degrees, appeared to affect their level of medical mistrust and their health status months and years after release. Importantly, we found that participants' experiences with correctional medical providers did little to engender trust in the veracity of their diagnosis of HIV or the necessity, safety, and potential outcomes of the treatments provided by these providers and may have hardened their medical mistrust once they were released. Further, these experiences appeared to drive participants' need to maintain a strong sense of autonomy about their health care choices after release, for many, to the detriment of their health. While participants' responses on the quantitative measure of present-day mistrust of medical systems yielded some variability in the level of mistrust, many participants were quite ambivalent about engaging in HIV-related medical care or firmly decided not to engage in care despite the consequences to their health. These beliefs were reflected in their health care status as only 19 of 28 participants in the sample were on ART, and of those, only 11 were virally suppressed.

In contrast to participants who entered a correctional facility with a previously known HIV infection, we found that those who received their initial diagnosis of HIV while incarcerated (60.7%), had an especially difficult experience with long-ranging adverse effects. Consistent with other studies,^{33,44-48} we found that many participants experienced HIV diagnosis as a traumatic stressor and reacted to their HIV diagnosis with difficulties cognitively processing any HIV education provided while incarcerated,⁴⁵ as well as with denial³² and numbing responses such as problematic substance use.^{44,46} Receiving an HIV diagnosis can be traumatic and overwhelming in the best of circumstances but incarceration likely worsens this experience due to social isolation,⁴⁸ amplified HIV-stigma,⁴⁹ loss of autonomy,⁵⁰ and substandard medical care.²² Based on these findings, clinicians who treat PLWH of color who have received an HIV diagnosis while incarcerated should be aware of and have an understanding that an HIV diagnosis can be traumatizing, particularly under the unique circumstances of being diagnosed with HIV while incarcerated. In addition, for providers within the correctional healthcare system, special considerations surrounding HIV testing and counseling should be accounted for, including ensuring pre-and post-test counseling processes promotes PLWH's autonomy.⁵⁰ Essentially, interventions that emphasize autonomy for PLWH of color, as well as appreciate and account for the challenges of doing so within a context of mistrust, are sorely needed.

Moreover, given the nexus of mass incarceration and HIV, the contextual influences in the lives of PLWH of color are critical to consider. Our findings indicated poverty and its effects were both ubiquitous and detrimental and its impact on participants in this sample cannot be over-stated. In addition, given that participants in our study were incarcerated an average of eight times over the course of their lifetimes, we view the context of incarceration as being an all too common experience for many PLWH of color, and accordingly, is a context that is crucial for future research to explore and understand. As such, using an ecologic^{24,25} and CRT framework^{26,27} proved to be useful for exploring experiences of HIV medical care while incarcerated, as they attend to salient contextual factors that affect PLWH of color's experiences such as medical mistrust.

Limitations.

This exploratory study was unable to address several key confounding factors related to experiences of HIV diagnosis and medical care within the criminal justice system, most notably evidence of resilience, gender dynamics and mental health concerns, as well as key variations in provision of HIV medical care over time and across settings such as in jails versus prison.⁵¹ Further, our purposive sampling method may limit its generalizability to the population of PLWH of color who have been incarcerated in New York State. In addition, the sample was more homogenous with respect to age, and included more Black than Latino participants than anticipated, which may limit its representativeness. Further, as a secondary analysis, saturation of themes was not reached, in particular, questions about HIV medical care and diagnosis experiences while incarcerated were embedded in larger qualitative interview which did not explicitly focus on incarceration. Relatedly, this study had a larger sample size than is typical for IPA studies (N = 28).³⁵ However, given the aims of this study, in order to develop an in-depth interpretation of the data, as well as the fact that there was variability in the quality of the interviews, the sample size was ultimately appropriate for the

present study, as there was no disadvantage evident in using all 28 available transcripts. In addition, the reliability of retrospective data and self-reported health behaviors is not known, and as with many studies of health behaviors and factors that are perceived as stigmatizing, such as substance use, incarceration and HIV itself, it is possible that social desirability factors prevented participants from fully disclosing their behaviors. Finally, the cross-sectional nature of the design does not allow for an exploration of patterns over time that could provide a broader understanding of participants' perceptions of their experiences of HIV medical care while incarcerated and its impact.

Conclusions

The present study extends the literature on the lived experience of PLWH of color receiving an HIV diagnosis and/or medical care while incarcerated, a highly vulnerable population at high-risk for poor HIV health outcomes. Our study findings highlight the way in which a complex and dynamic interplay of individual-level and contextual factors such as loss of autonomy, negative healthcare experiences and associated medical mistrust negatively affect PLWH of color who have received HIV medical care while incarcerated after release. These findings have important implications for improving HIV medical care in correctional settings.

REFERENCES

1. Maruschek L HIV in Prisons, 2001-2010. Washington, DC; 2012.
2. Spaulding AC, Seals RM, Page MJ, Brzozowski AK, Rhodes W, Hammett TM. HIV/AIDS among Inmates of and Releasees from US Correctional Facilities, 2006: Declining Share of Epidemic but Persistent Public Health Opportunity Litvintseva AP, ed. PLoS One. 2009;4(11):e7558. [PubMed: 19907649]
3. Centers for Disease Control and Prevention. HIV Testing Implementation Guidance for Correctional Settings.; 2009.
4. Scheyett A, Parker S, Golin C, White B, Davis CP, Wohl D. HIV-infected prison inmates: Depression and implications for release back to communities. AIDS Behav. 2010.
5. Blankenship KM, Smoyer AB, Bray SJ, Mattocks K. Black-white disparities in HIV/AIDS: the role of drug policy and the corrections system. J Health Care Poor Underserved. 2005;16(4 Suppl B): 140–156. doi:10.1353/hpu.2005.0110 [PubMed: 16327113]
6. Mauer M Addressing Racial Disparities in Incarceration. Prison J. 2011.
7. Westergaard RP, Spaulding AC, Flanigan TP. HIV among persons incarcerated in the USA: A review of evolving concepts in testing, treatment, and linkage to community care. Curr Opin Infect Dis. 2013.
8. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clin Infect Dis. 2011.
9. Iroh PA, Mayo H, Nijhawan AE. The HIV care cascade before, during, and after incarceration: A systematic review and data synthesis. Am J Public Health. 2015.
10. Rich JD, Beckwith CG, Macmadu A, et al. Clinical care of incarcerated people with HIV, viral hepatitis, or tuberculosis. Lancet. 2016.
11. Booker CA, Flygare CT, Solomon L, et al. Linkage to HIV care for jail detainees: Findings from detention to the first 30 days after release. AIDS Behav. 2013.
12. Liao A, Crepaz N, Lyles CM, et al. Interventions to promote linkage to and utilization of HIV medical care among HIV-diagnosed persons: A qualitative systematic review, 1996-2011. AIDS Behav. 2013.

13. Elkington KS, Jaiswal J, Spector AY, et al. Can TasP Approaches Be Implemented in Correctional Settings?: A review of HIV testing and linkage to community HIV treatment programs. *J Health Care Poor Underserved*. 2016.
14. Graham JL, Giordano TP, Grimes RM, Slomka J, Ross M, Hwang LY. Influence of trust on HIV diagnosis and care practices: a literature review. *J Int Assoc Physicians AIDS Care*. 2010;9(6): 346–52.
15. Gaston B, Gina B. The impact of African Americans' beliefs about HIV medical care on treatment adherence: a systematic review and recommendations for interventions. *AIDS Behav*. 2013;17(1): 31–40. [PubMed: 23010941]
16. Bogart LM, Wagner GJ, Green HD, et al. Medical mistrust among social network members may contribute to antiretroviral treatment nonadherence in African Americans living with HIV. *Soc Sci Med*. 2016.
17. Whetten K, Reif S, Whetten R, Murphy-Mcmillan LK. Trauma, mental health, distrust, and stigma among HIV-positive persons: Implications for effective care. *Psychosom Med*. 2008.
18. Rumors Heller J. and Realities: Making sense of HIV/AIDS conspiracy narratives and contemporary legends. *Am J Public Health*. 2015;105(1):e43–50.
19. Ball K, Lawson M, Alim T. Medical Mistrust, conspiracy beliefs & HIV-related behavior among African Americans. *Journal of Psychology and Behavioral Science*. 2013; 1(1):1–7
20. Freeman R, Gwadz MV, Silverman E, et al. Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: a qualitative exploration. *Int J Equity Health*. 2017;16(1):54. [PubMed: 28340589]
21. Dale SK, Bogart LM, Wagner GJ. Medical mistrust is related to lower longitudinal medication adherence among African-American males with HIV. *J Health Psychol*. 2016;7(21):1311–21.
22. Gwadz M, Applegate E, Cleland C, et al. HIV-infected individuals who delay, decline, or discontinue antiretroviral therapy: comparing clinic- and peer- recruited cohorts. *Front Pub Health*. 2014;2:81. [PubMed: 25077137]
23. Hatzenbuehler ML, Keyes K, Hamilton A, Uddin M, Galea S. The collateral damage of mass incarceration: Risk of psychiatric morbidity among nonincarcerated residents of high-incarceration neighborhoods. *Am J Public Health*. 2015.
24. Thom DH, Ribisl KM, Stewart AL, Luke DA. Further validation and reliability testing of the trust in physician scale. *The Stanford trust study physicians Medical Care*, 37 (1999), pp. 510–517 [PubMed: 10335753]
25. Bronfenbrenner U, Morris PA. The ecology of developmental processes In: Damon W, Lerner RM, eds. *Handbook of Child Psychology: Theoretical Models of Human Development*. Hoboken, NJ: John Wiley & Sons Inc; 1998:993–1028.
26. Delgado R, Stefancic J. *Critical Race Theory: An Introduction*. 2nd ed. New York, NY: New York University Press; 2012.
27. Ford CL, Airhihenbuwa CO. Critical race theory, race equity, and public health: Toward antiracism praxis. *Am J Public Health*. 2010.
28. Gwadz M, Cleland CM, Hagan H, et al. Strategies to uncover undiagnosed HIV infection among heterosexuals at high risk and link them to HIV care with high retention: A “seek, test, treat, and retain” study. *BMC Public Health*. 2015.
29. Heckathorn DD. Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. *Soc Probl* 1997.
30. Susser ES, Struening EL. Diagnosis and Screening for Psychotic Disorders in a Study of the Homeless. *Schizophr Bull* 1990; 16(1): 133–145. <https://academic.oup.com/schizophreniabulletin/article/> [PubMed: 2333474]
31. Stevens ER, Nucifora K, Zhou Q, et al. Cost-Effectiveness Of Peer- Versus Venue-Based Approaches For Detecting Undiagnosed Hiv Among Heterosexuals In High-Risk New York City Neighborhoods. *JAIDS J Acquir Immune Defic Syndr* 2017.
32. Gwadz M, Cleland CM, Kutnick A, et al. Factors Associated with Recent HIV Testing among Heterosexuals at High Risk for HIV Infection in New York City. *Front Public Heal* 2016.

33. Kutnick AH., Gwadz M, Cleland CM, et al. It's a Process: Reactions to HIV Diagnosis and Engagement in HIV Care among High-Risk Heterosexuals. *Front Public Heal*. 2017.
34. Smith JA, Jarman M, Osborn M. Doing interpretative phenomenological analysis In: *Qualitative Health Psychology: Theories and Methods*. London: Sage Publications; 1999:218–240.
35. Smith JA. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qual Res Psychol*. 2004.
36. Yardley L Demonstrating validity in qualitative psychology. In: *Qualitative Psychology: A Practical Guide to Research Methods*. ; 2007.
37. Smith JA. Validity and Qualitative Psychology. In: *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage Publications; 2003:232–235.
38. Dedoose. Version 7.0.23. Los Angeles, CA: SocioCultural Research Consultants, LLC 2016 www.dedoose.com.
39. Institute of Behavioral Research. TCU Drug Screen V. <http://www.odmhsas.org/picis/TraningInfo/Texas>. Christian Univ Drug Screen 5 Scoring and Interpretation Guide 4-1-15.pdf Published 2014.
40. Bush K, Kivlahan DR, McDonell MB, Fihn SD, Bradley KA. The AUDIT Alcohol Consumption Questions (AUDIT-C): An Effective Brief Screening Test for Problem Drinking. *Arch Intern Med*. 1998; 158(16):1789. [PubMed: 9738608]
41. Shuper PA, Joharchi N, Irving H, Rehm J. Alcohol as a Correlate of Unprotected Sexual Behavior Among People Living with HIV/AIDS: Review and Meta-Analysis. *AIDS Behav*. 2009;13(6): 1021–1036. [PubMed: 19618261]
42. LaVeist TA, Isaac LA, & Williams KP. Mistrust of health care organizations is associated with underutilization of health services. *Health services research*. 2009;44(6):2093–105 [PubMed: 19732170]
43. Begier Elizabeth M., et al. Undiagnosed HIV infection among New York City jail entrants, 2006: results of a blinded serosurvey. *JAIDS: J Acquir Immune Defic Syndr*. 2010;54(1):93–101 [PubMed: 20042868]
44. Machtinger EL, Wilson TC, Haberer JE, Weiss DS. Psychological trauma and PTSD in HIV-positive women: A meta-analysis. *AIDS Behav*. 2012.
45. Nightingale VR, Sher TG, Hansen NB. The impact of receiving an HIV diagnosis and cognitive processing on psychological distress and posttraumatic growth. *J Trauma Stress*. 2010.
46. Sherr L, Nagra N, Kulubya G, Catalan J, Clucas C, Harding R. HIV infection associated post-traumatic stress disorder and post-traumatic growth – A systematic review. *Psychol Health Med* 2011.
47. Stevens PE, Doerr BT. Trauma of discovery: Women's narratives of being informed they are HIV-infected. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV*. 1997.
48. Turan B, Budhwani H, Fazeli PL, et al. How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. *AIDS Behav*. 2017.
49. Fletcher F, Ingram LA, Kerr J, Buchberg M, Bogdan-Lovis L, Philpott-Jones S. "She Told Them, Oh That Bitch Got AIDS": Experiences of Multilevel HIV/AIDS-Related Stigma Among African American Women Living with HIV/AIDS in the South. *AIDS Patient Care STDs*. 2016.
50. Quinlivan EB, Messer LC, Roytburd K, Blickman A. Unmet core needs for self-determination in HIV-infected women of color in medical care. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV*. 2017.
51. Wakeman SE, Rich JD. HIV treatment in US prisons. *HIV Ther*. 2010;4(4):505–510. [PubMed: 20953349]

Legend:

* Identified based
on quantitative data** Identified based
on qualitative data

Figure 1:
Overview of the sampling frame

Table 1:

Socio-demographic characteristics (N = 28)

	% (n) or M(SD)
Female	39.2% (11)
Male	60.8% (17)
Age in years	47 (7.12)
Black, Not Hispanic	78.6% (22)
Latino/Hispanic	21.4% (6)
Married or in long-term relationship	92.9% (26)
Has children	96.4% (27)
Unemployed	92.9% (26)
Currently on Medicaid	89.3% (25)
Unable to pay for basic necessities in past year	75.0% (21)
Ever homeless	71.4% (20)
Currently homeless	7.1% (2)
Lifetime number of times incarcerated (>24 hours)	8.19 (6.64)
Incarcerated in the past year for > 24 hours	17.9% (5)
Diagnosed with HIV while incarcerated	60.7% (17)
Lifetime history of problematic drug use or alcohol use (TCU & AUDIT criterion)	96.4% (27)
Current problematic drug or alcohol use (TCU & AUDIT criterion)	28.6% (8)

Table 2:

Medical Mistrust Index (N = 28)

<i>Items</i>	<i>Strongly Disagree % (n)</i>	<i>Disagree % (n)</i>	<i>Neutral % (n)</i>	<i>Agree % (n)</i>	<i>Strongly Agree % (n)</i>
You'd better be cautious when dealing with healthcare organizations	21.4 (6)	7.1 (2)	25 (7)	28.6 (8)	17.9 (5)
Patients have often been deceived or misled by healthcare organizations	10.7 (3)	21.4 (6)	21.4 (6)	25 (7)	21.4 (6)
When healthcare organizations make mistakes, they usually cover it up	14.3 (4)	14.3 (4)	21.4 (6)	35.7 (10)	14.3 (4)
Healthcare organizations sometimes do harmful experiments on patients without their knowledge	14.3 (4)	25 (7)	28.6 (8)	25 (7)	7.1 (2)
*Healthcare organizations keep your information private	7.1 (2)	14.3 (4)	35.7 (10)	32.1 (9)	10.7 (3)
Sometimes I wonder if healthcare organizations really know what they are doing	0 (0)	25 (7)	39.3 (11)	25 (7)	10.7 (3)
Mistakes are very common in healthcare organizations	10.7 (3)	21.4 (6)	32.1 (9)	14.3 (4)	21.4 (6)

* Item is reverse-coded

Table 3:

HIV Health Characteristics (N = 28)

HIV Health Characteristics	% (n) or M(SD)
Years since HIV Diagnosis	14.14 (8.01)
Ever been prescribed ART	82.1% (23)
Currently on ART	67.8% (19)
CD4 cells/mm ³	482.57 (341.83) range= 1-1249
Virally Suppressed	39.3% (11)