The HIV Prison Paradox: Agency and HIV-Positive Women’s Experiences in Jail and Prison in Alabama

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Abstract
Incarcerated women face significant barriers to achieve continuous HIV care. We employed a descriptive, exploratory design using qualitative methods and the theoretical construct of agency to investigate participants’ self-reported experiences accessing HIV services in jail, in prison, and post-release in two Alabama cities. During January 2014, we conducted in-depth interviews with 25 formerly incarcerated HIV-positive women. Two researchers completed independent coding, producing preliminary codes from transcripts using content analysis. Themes were developed iteratively, verified, and refined. They encompassed (a) special rules for HIV-positive women: isolation, segregation, insults, food rationing, and forced disclosure; (b) absence of counseling following initial HIV diagnosis; and (c) HIV treatment impediments: delays, interruption, and denial. Participants deployed agentic strategies of accommodation, resistance, and care-seeking to navigate the social world of prison and HIV services. Findings illuminate the “HIV prison paradox”: the chief opportunities that remain unexploited to engage and re-engage justice-involved women in the HIV care continuum.

Keywords
agency; HIV; prison; women’s health; stigma; health care-seeking; social construction; adherence; US South; qualitative method; interpretive research

Incarcerated individuals, globally and nationally, are recognized as a key affected population with unmet needs for health and HIV care (Binswanger, Redmond, Steiner, & Hicks, 2012; UNAIDS, 2014). In U.S. prisons, HIV prevalence is an estimated 1.7% in women and 1.3% in men, compared with 0.6% in the general population (Centers for Disease Control and Prevention [CDC], 2008, 2012a, 2015a). One in seven HIV-positive Americans passes through a correctional facility each year, and 95% of inmates in jail or prison return to their communities (CDC, 2012a). This leads to an intensive interaction between correctional settings, populations, and society, which has significant implications for public health (van den Bergh, Gatherer, Fraser, & Moller, 2011).

Although women represent a relatively small proportion of offenders in U.S. jails and prisons (approximately 7%), incarceration rates among women have increased dramatically in recent decades and at a higher rate than for men: more than 700% from 1980 to 2014 (Kelly, Cheng, Spencer-Carver, & Ramaswamy, 2014; The Sentencing Project, 2015). HIV-positive women involved with the criminal justice system (“justice-involved”) are an under-researched and underserved population with distinct health profiles (Braithwaite, Treadwell, & Arriola, 2005; Meyer, Springer, & Altice, 2011).

Jails and prisons are recognized as critical sites for HIV interventions to improve the health of those justice-involved, and the communities to which they return (Spaulding, 2009; Spaulding et al., 2002). Various types of detention are referred to as “prison” in the international literature (UNAIDS, 2014; World Health Organization [WHO] Office for Europe, 2013). However, there are notable differences between jails and prisons that influence whether correctional populations in the United States and South Africa receive adequate care.
States gain access to HIV services, which may be relevant for other countries. Jails (run by local law enforcement agencies) are characterized by short-term stays for misdemeanors, making the implementation of HIV and health services more challenging, although still feasible (Dumont, Gjelsvik, Redmond, & Rich, 2013; Westergaard, Spaulding, & Flanagan, 2013). Prisons (operated by states and the Federal Bureau of Prisons) are distinguished by sentences of 1 year and longer for felonies, thus generating the greater potential and need for continuous HIV service delivery to inmates (Bureau of Justice Statistics, 2016). Moreover, prison populations are the only civilian population in the United States with a constitutional right to health care (Klein, 1978). Because U.S. prisons are venues where health care is constitutionally mandated, this generates what we term the HIV prison paradox where prisons, routinely depicted as unhealthy environments, are recognized as offering perhaps the greatest opportunity for justice-involved populations to initiate stable combination antiretroviral therapy (cART, the gold-standard pharmacologic treatment for HIV infection; de Viggiani, 2007; Spaulding, 2009; van den Bergh, Gatherer, Fraser, & Moller, 2011).

Although researchers have recognized prison as a site for HIV service linkage (Beckwith, Zaller, Fu, Montague, & Rich, 2010), due to the variability across U.S. states, there is no systematic picture of the correctional population’s engagement and retention in HIV care in correctional settings (for men or women). Rather, there is a patchwork of studies conducted in different states (e.g., Pelligrino, Zaitzow, Sothern, Scribner, & Philippi, 2015). Furthermore, most studies of the HIV care continuum (the cascade of HIV services that include testing, counseling, treatment initiation, and retention in care, for example, Mugavero, Amico, Horn, & Thompson, 2013) in correctional settings and post-release do not disaggregate results by sex/gender (Iroh, Mayo, & Nijhawan, 2015). This has led to calls by researchers for gender-based research and interventions and greater attention to women’s unique health needs in correctional settings and post-release (Bloom, Owen, & Covington, 2003; Braithwaite et al., 2005; Meyer et al., 2014). Incarceration presents an especially important opportunity for women, given co-occurring substance use and mental health disorders, coupled with lack of access to routine preventive care and health insurance, that are characteristic of this population (Bloom et al., 2003; Illangasekare, Burke, Chander, & Gielen, 2014; James & Glaze, 2006).

Women at highest risk for incarceration and HIV typically occupy the most socially excluded tiers of society (Belknap & Whalley, 2013). Black women are disproportionately affected by HIV, and by incarceration, with poor health outcomes (Carson, 2014; CDC, 2016; P. L. Fleming, Lansky, Lee, & Nakashima, 2006; E. B. Fleming, LeBlanc, & Reid, 2013). The vulnerability of women to incarceration and HIV is associated with social structures that negatively affect their health over the life course, and which interact in complex ways to drive well-documented health disparities (Binswanger, Redmond, Steiner, & Hicks, 2012; Eliason, Taylor, & Williams, 2004).

In the last decade, studies have documented the intersecting mental and physical health needs facing this population—particularly the significant role played by past trauma in the development of women’s physical and mental health problems (Harnar & Burgess, 2011; Harnar & Riley, 2013). The majority of justice-involved women meet criteria for drug or alcohol dependence (Lynch, DeHart, Belknap, & Green, 2012), have high prevalence of lifetime physical abuse—up to 70% (Browne, Miller, & Maguin, 1999), and have victimization histories (Greenfield & Snell, 1999). Up to 75% report having experienced intimate partner violence (IPV), defined as psychological, physical, or sexual violence (attempted or completed) by a current or former partner (Browne et al., 1999; WHO, 2013). IPV and HIV are correlates with significant inter-connections (CDC, 2014; Maman, Campbell, Sweat, & Gielen, 2000). Among women in prison, gonorrhea and chlamydia positivity rates have consistently been high (CDC, 2012b; Solomon, Flynn, Muck, & Vertefeuille, 2004). Such untreated sexually transmitted infections (STIs) increase HIV transmission risk and undermine HIV prevention and treatment efforts (Kalichman, Pellowski, & Turner, 2011; Ward & Rønn, 2010).

Qualitative inquiry has shed some light on women’s experiences receiving HIV care in correctional facilities. Several studies found a lack of privacy (in HIV testing and treatment), poor provider–patient relationships, lack of trust, poor social support, and being refused access to medication as major barriers to effective HIV care for women (Fasula et al., 2013; Fearn & Parker, 2005; Hatton & Fisher, 2011). Studies have found that HIV peer educators and counselors, social support, positive provider–patient relationships, and directly observed therapy were associated with more positive perceptions of HIV treatment (Altice, Mostashari, & Friedland, 2001; Boudin et al., 1999; Mostashari, Riley, Selwyn, & Altice, 1998; Roberson, White, & Fogel, 2009). Incarceration was viewed as having negative mental health effects due to lack of treatment access, negative interactions with correctional staff, a loss of dignity, and being cut off from social support (Altice et al., 2001; Green, Miranda, Daroowalla, & Siddique, 2005). Conversely, some data suggest women view jail and prison as key venues for initiating treatment for HIV, substance use, or mental health problems (Alves, Maia, & Teixeira, 2016; Fasula et al., 2013; Fearn & Parker, 2005; Hatton & Fisher, 2011; Roberson et al., 2009). In some of these studies, stigma appears to be an underlying dominant theme, yet there is...
little qualitative research documenting specific experiences with HIV stigma for women living with the virus in jail and prison settings, and its impact on HIV treatment.

Post-release, it is unclear whether the potential benefits of HIV and other treatments accessed in correctional institutions lead to sustained improvements in health outcomes for women, as few follow CDC (2012a) guidelines for discharge planning. Recent studies have reported that women are less likely to be connected to care, remain engaged in treatment, and achieve optimal HIV health outcomes, compared with men, which suggests HIV care lapses and dropout, post-release (Meyer et al., 2014).

How women in jail, in prison, and post-release seek, rather than receive, HIV care, as agents, is understudied (Iroh et al., 2015; Williams et al., 2013). Women living with HIV who have been incarcerated move between correctional and community settings and between correctional settings (mainly from jail to prison). How they continually negotiate “multiple health care transitions” unique to this population to obtain HIV and related care is not well established (Binswanger, Redmond, Steiner, & Hicks, 2012, p. 99; CDC, 2012a; Mitty, Holmes, Spaulding, Flanigan, & Page, 1998; van den Bergh, Gatherer, Fraser, & Moller, 2011; Zaitzow, 1999).

Given the multiple, complex health needs of women living with HIV in jail and prison, and the limited data to inform interventions (Fasula et al., 2013; Fearn & Parker, 2005; Hatton & Fisher, 2011; Mitty et al., 1998; Roberson et al., 2009), we undertook a qualitative study with justice-involved women in two cities in Alabama.

**Study Objectives and Conceptual Approach**

We used qualitative methods to explore “agency” for HIV-positive women incarcerated in jail or prison in Alabama (Denzin & Lincoln, 2011; Sewell, 1992). Although theories of agency are rich and varied, some sociologists have viewed agency (individual action) and structure (social relations) as dynamic social constructs that are co-created and shift according to time and geographic place (Giddens, 1979). Traditionally, an assumption of, or proxy for, agency (and its use in the literature) has been individual action vis-à-vis society (Logie & Daniel, 2016). In gender studies, women’s choice and actions to leave abusive relationships were emphasized as a focal point of agency studies. Nevertheless, this conceptualization was seen to fail to reflect women in the most constrained settings and in non-Western societies, a critique led by Madhok, Phillips, and Wilson (2013).

The critique of this conception of agency as a social theory to describe and explain marginalized women’s experiences emphasized that it neglected structural problems of poverty, inequalities, intersectionalities of race, gender, class, stigma, and discrimination, and the ways these forces shape women’s health risks, particularly their risk of IPV (Campbell & Mannell, 2014; Parpart, 2010). As a rejoinder, agency has been reconceptualized in recent years to better reflect the multiple constraints of marginalized women in social context, including their use of silence, secrecy, and invisibility as agentic strategies (Parpart, 2010; Sprague et al., 2016). Those studies have offered powerful insight into women’s textured experiences (Campbell & Mannell, 2016). Such reconceptualized notions of agency may be similarly suited to enhancing understanding of marginalized justice-involved women’s real-world perceptions and experiences of HIV care, particularly in correctional settings in the Southern United States.

We used agency as a theoretical construct to position HIV-positive women, not solely their actions or choices, but their perceptions and experiences, within the social world of jail and prison in the Southern state of Alabama. Research questions were twofold:

**Research Question 1:** How do justice-involved HIV-positive women describe their lived experiences, with particular attention to accessing the HIV care continuum in correctional settings?

**Research Question 2:** How is agency expressed and/or constrained for HIV-positive women seeking to access HIV care in these settings and post-release, particularly in the U.S. South where HIV incidence is increasing among women?

**Ethical Approval**

The study was approved by the University of Massachusetts Boston Institutional Review Board, protocol number 2013210. We obtained informed written consent from each participant prior to interviews. All participants also provided written consent to recording and transcription of their interviews.

**Method**

**Study Setting**

Women in the Southern U.S. region (comprising 17 states) are more likely to acquire HIV (CDC, 2015b, 2016). Eight of 10 states with the highest rates of new HIV diagnoses, and 44% of persons with HIV, are located in the South (CDC, 2015b; P. L. Fleming et al., 2006). In addition, women living with HIV in the Southern states are more likely to be incarcerated, compared with women living with HIV in other regions (Carson, 2014; Pelligrino et al., 2015). They may also be more likely to rely on correctional institutions for HIV diagnosis and treatment (Beckwith et al., 2010; Pelligrino et al., 2015).
This study focuses on formerly incarcerated women living with HIV in Alabama, which has the fourth highest rate of incarceration for women in the United States (Carson, 2014). The state has low levels of public health information about HIV, fewer HIV providers per capita, a low tax base for health care, and significant health disparities among those with HIV (P. L. Fleming et al., 2006; Shachar, Greenwald, & Rosenberg, 2009; Whetten & Reif, 2006). Studies of women’s access to HIV services in correctional settings and post-release in Alabama are few (Hammett & Drachman-Jones, 2006; Lichtenstein, & Malow, 2010; Pelligrino et al., 2015). In addition, for over two decades, Alabama (together with Mississippi and South Carolina) segregated inmates in prisons on the basis of their HIV status. In 2012, the state lost a federal lawsuit brought by the American Civil Liberties Union (ACLU; 2011, 2012; Human Rights Watch [HRW], 2010). Regardless of the type or severity of the offense, all HIV-positive women were sent to the only women’s prison in the state, Julia Tutwiler (situated in Central Alabama), to serve their sentences. Although the segregation of female (and male) inmates living with HIV was outlawed in 2012, reports indicate that the women’s prison had begun to end segregation in 2010 (ACLU, 2011, 2012).

**Sampling and Recruitment**

We purposively selected participants who met eligibility criteria: adult females above age 18, HIV-positive, indicated for cART whether or not it was actively prescribed, and with one or more experiences of incarceration in jail and/or prison in Alabama in the previous 4 years. Two community-based organization (CBO) partners involved in study conceptualization and design identified and screened potential participants based on inclusion criteria. Both CBOs are service providers. AIDS Alabama provides HIV services to men and women in Birmingham (North Central Alabama), the largest city in Alabama (population approximately 1.1 million in the region as of 2013; U.S. Census Bureau, 2013a) and home to the University of Alabama Birmingham (UAB) and its 1917 Clinic. The 1917 Clinic has provided comprehensive medical and social services to HIV-positive adults since 1988 (UAB School of Medicine, 2016). The CBO in Montgomery, Aid to Inmate Mothers (AIM), is situated in the state capital (South Central Alabama, population approximately 200,000; U.S. Census Bureau, 2013b). Montgomery is less resourced compared with Birmingham. AIM provides selected social (non-medical) services to former female inmates in a setting in which few services for this population are available. Both cities are key catchment areas of HIV and social services for women leaving jail and prison. However, the satellite sites from which participants were recruited and interviewed offered only non-medical services (housing, social support, and substance rehabilitation).

**Data Collection**

We used a five-part semi-structured question guide to probe women’s life histories from childhood to present: (1) socio-demographics; (2) early life experiences in childhood and adolescence including trauma (probing women’s pathways into the justice system); (3) experiences accessing HIV and health care services in jail, in prison, and after release; (4) experiences related to substance use; and (5) mental health, psychosocial support, and related interventions. The findings reported here are primarily derived from Parts 1 and 3.

In-depth one-on-one interviews (IDIs) were conducted with 28 participants (range = 34–134 minutes, M = 74 minutes) during January 2014 on-site at the two CBOs. Participants were given US$25 stipends for their transportation and time. Interviews ceased when we reached a point of data saturation (Denzin & Lincoln, 2011). Of 28 initial interviews, we excluded three conducted with participants who demonstrated severe uncontrolled thought disorders, rendering those narratives confused and the interviews unreliable (Morse, 2015). Results are reported from the final sample of 25 participants. All participant interviews were conducted by the two co-principal investigators—D.W.P. (White male clinical psychologist with expertise in HIV, mental health, IPV, and substance use), C.S. (White female social health scientist with expertise in HIV in Black women and IPV)—and a doctoral student (White female post-master’s student with expertise in HIV, IPV, and mental health). All three have expertise in qualitative research methods (Tong, Sainsbury, & Craig, 2007).

From March 2013 to May 2015, we conducted an additional 16 in-depth interviews with key informants who are service providers in Birmingham and Montgomery, and who work directly with the study population in a variety of roles and settings. The purpose of the second type of interviews was threefold: (a) to inform the study design and methods; (b) to further understand the social context for HIV-positive women in Alabama and HIV services available to them in jail, in prison, and upon release; and (c) to cross-check reports emerging from participant interviews, which served as a form of validation of qualitative data (Denzin & Lincoln, 2011). Validation with key informants took place over the period January 2013 to June 2014—preceding, during, and after participant interviews.

We used digital audio recorders to capture 40 of the 41 total interviews, along with field notes. The research team debriefed daily on patterns emerging following IDIs (Tong et al., 2007).
Data Analysis

One researcher conducted initial coding of raw transcripts (M.S.). We pre-set categories to collect initial data on HIV services in jails and prison, which we coded. To develop analytical categories from the codes, and establish patterns and relative importance, two researchers (M.S. and C.S.) conducted independent coding, producing preliminary codes from transcripts using content analysis. This included demonstrations of agency, which researchers identified by reviewing reported acts, intentions, self-reflections, obstacles, enablers, and responses to experiences in jail or prison and post-release into the analysis. One researcher (C.S.) cross-checked the emerging categories against the raw transcripts, making adjustments based on the frequency and consistency of the reports. Primary themes were identified and refined through an iterative process of developing, discussing, verifying, and agreeing on final themes among all members of the research team (M.L.S., B.R., D.W.P., and C.S.).

Results

Participant Socio-Demographic Characteristics

Among the 25 participants, the mean age was 49.5 (range = 32–62) and most participants self-identified as Black (76%) or White (20%). The mean age of HIV diagnosis was 35 (Table 1). All women were accessing cART at the time of the interview. Most had been living with and managing HIV for a number of years (range = 4–28). The majority of participants had an incarceration history of jail only (64%) versus jail and prison (36%), and multiple incarcerations were frequent (roughly half of participants had four or fewer incarcerations; the other half had five or more). Almost half of respondents were on disability (44%) and few reported working full time (16%). Women had consistent, frequent exposure to and experience of sexual violence beginning early in the life course, with recurring victimization as adults, encompassing multiple rape experiences (48%), IPV (36%), and other revictimizations. Participants reported histories of significant mental health problems, including depression (40%), anxiety (12%), schizophrenia (12%), and bipolar disorder (8%). Almost all women had engaged in cyclical substance use of crack cocaine (96%). Incarceration and substance use were interlinked, often occurring over decades.

We present women’s self-reported experiences in jail and prison in Alabama. From the data, two prominent themes emerged related to those experiences. The first theme reflects the encounters of the majority of respondents with correctional staff, and women’s socialization into jail and prison as HIV-positive inmates. This theme captures the “special rules” that were applied to participants on the basis of their HIV-positive serostatus. A second dominant theme captures women’s perceptions and experiences accessing HIV and related health care in jail, in prison, and post-release, as well as their interactions with medical staff and correctional authorities when seeking to navigate the HIV care continuum. Selected quotes are representative of not just these participants but the majority.

Theme 1: The Social World of Prison—Special Rules for HIV-Positive Inmates

Among the participant narratives, the application of a different set of rules governing what HIV-positive female inmates could do (e.g., occupations and privileges), and their movement within correctional facilities, emerged independently across the women’s accounts (Figure 1). These were evident in jail but more pronounced in prison, likely related to the longer duration of incarceration. This reflects correctional settings in which a social reality, encompassing a dominant set of norms and behaviors, was established and then reinforced by corrections’ staff. De Viggiani (2007) notes, “offenders sent to prison enter a complex social world of values, rules, and rituals designed to observe, control, disempower and render them subservient to the system” (p. 115). HIV-positive women were inducted into the social world of jail or prison by being placed into solitary confinement. Women were left to make sense of this reality in ways that affected their agency in relation to being HIV-positive. We found two main agentic strategies were used by women to cope with the restrictions placed on them as HIV-positive inmates: agentic accommodation and agentic rejection. Accommodation was demonstrated by participants as finding the agentic space to enable their health and freedom within the established rules. Rejection was reflected in respondents’ statements and actions, including active questioning and resistance of practices and strictures women described as being used to bind and label them as HIV-positive. A third phenomenon was also visible: agentic diminishment. This was evident when women described their agency as contracting due to direct actions (generally negative) taken by corrections’ staff.

Solitary confinement. All women, including the participants, were routinely offered HIV testing in Alabama on entry to jail and prison (Alabama Department of Health, State of Alabama, 2012). Participants reported the practice of being held “in isolation” while their HIV serostatus was confirmed or reconfirmed. A participant described how she tried to make sense of her HIV diagnosis during confinement:
[T]hey put you in isolation till your Western Blot comes back, even if you tell 'em you're [HIV-]positive. And I was in isolation Christmas Eve and Christmas with nothing but a bible. It was cold. No hot water. It was miserable. But, anyway, it made me reflect on my life, you know? So I decided then to get as much knowledge as I could [about HIV].

The quote above is an illustration of the accommodation strategy. She referenced the deprivations of being confined, linking the rationale for her isolation to her HIV-positive status. Rather than recounting anger, she recalled converting an experience—meant to socialize inmates into prison by stripping away material comforts—into an opportunity to expand her agency, to learn about HIV.

One participant was HIV-negative and later seroconverted. She shared her observations of the first time she witnessed how an HIV-positive inmate was treated:

They had one of them locked in, 'cause she was HIV . . . And they put her food through the little hole . . . They ain’t let her out, 'cause she was HIV . . . Yeah, [they treat her] like she was poison, and she couldn’t be around us or nothing like that.

Although she was HIV-negative at the time, this respondent did not condone this discriminatory treatment. Rather, her agentic response was to question this practice, demonstrating agentic rejection. This harm to an HIV-positive inmate would likely influence HIV-negative women’s understandings of what it means to be HIV-positive, and how they could expect to be treated in correctional institutions. This also illustrates how stigma was established as a norm in these correctional settings (Goffman, 1963; Parker & Aggleton, 2003).

A respondent described her perception of isolation as a “medical procedure” and indicated that she successfully received cART:

When we first go in, how they do it is they put you in a room to yourself until they make sure that you’re completely healthy, before they put you in a cell in the dorm. For a month, you stay by yourself, and they take you back and forth and do tests and stuff . . . [A]nd, if you need medications, you got your medications. It was hard being by yourself . . . [but] I had no problem.

In this interpretation, she describes the socialization of those HIV-positive as normal. Her rationalization of this as routine medical practice (likely how it was viewed and/or portrayed by corrections authorities) fits with agentic accommodation. Paradoxically, this strategy may have expanded her agency concerning her own health. In normalizing this procedure as a necessary one, with a focus on testing to produce results that would be used to inform her health care, she seemed to avoid the stigma others recounted, and successfully initiated cART—a critical step in HIV management (Link & Phelan, 2001; Mugavero et al., 2013).

Segregated housing on the basis of HIV serostatus included restricted meal times, food consumption, and

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Table 1. Participant Characteristics.

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<thead>
<tr>
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<th>Range</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
<td>32–62</td>
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<tr>
<td><strong>Number of children (dependants)</strong></td>
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</tr>
<tr>
<td><strong>Years living with HIV</strong></td>
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<tr>
<td><strong>Highest level of education</strong></td>
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<tr>
<td><strong>Number of incarcerations</strong></td>
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<tr>
<td><strong>Age of first incarceration</strong></td>
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<td><strong>Race</strong></td>
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<td>Black</td>
<td>18 72</td>
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<td>1 4</td>
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<tr>
<td>Black/West Indian</td>
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<tr>
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<tr>
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<td>2 8</td>
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<tr>
<td>Volunteer</td>
<td>1 4</td>
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<td><strong>Sexual orientation</strong></td>
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<tr>
<td>Heterosexual</td>
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<tr>
<td>Bisexual</td>
<td>1 4</td>
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<td><strong>Mental health</strong></td>
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<td>Bipolar disorder</td>
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<td><strong>Type of violence experienced</strong></td>
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<td>Childhood verbal/physical abuse</td>
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<tr>
<td>Adolescent sexual abuse</td>
<td>4 16</td>
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<tr>
<td>Adolescent verbal/physical abuse</td>
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<tr>
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<tr>
<td>Rape or attempted rape (in adulthood)</td>
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<tr>
<td>IPV</td>
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<td>IPV and rape</td>
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<td>8 32</td>
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<tr>
<td>Death of family member</td>
<td>12 48</td>
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<tr>
<td>Other trauma</td>
<td>19 76</td>
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Note. IPV = intimate partner violence.
forced HIV disclosure. Inmates with HIV were housed apart from the “general population” (meaning HIV-negative inmates) for the duration of their stay—a long-standing practice confirmed in published reports (ACLU, 2011; HRW, 2010), though this was changing during the time when some participants were incarcerated (discussed below). A participant described the next phase, following isolation, for HIV-positive inmates who were inducted into the prison environment:

After the 14 days of solitary, [she was] put in the HIV and AIDS dorm . . . there was 22 of us . . . [they put her there] ‘Cause I was HIV[-positive] . . . They just told [the inmates] we were HIV[-positive] [so they would be kept apart from others] . . . They did separation in just one dorm . . . where everybody else [HIV-positive] would be, you know, populated. We weren’t allowed to [go elsewhere].

Basic needs, such as food, as well as exercise and movement, were viewed as privileges that were afforded or revoked by correctional staff. Participants depicted wardens and staff as applying constraints on women’s agency that appeared to be harsher and more severe because of participants’ HIV-positive serostatus. The duration of meal times was reported as tightly controlled, with separate meal times for those living with HIV. Sometimes meals were missed entirely. One participant recalled,

I know there were mornings that . . . the guards felt that we shouldn’t be around the other inmates, and sometimes we didn’t even get to go eat breakfast or dinner . . . they [prison guards] never said “HIV.” They always told [us] we had AIDS . . . “Y’all got AIDS.”

She continued, highlighting the “rushed” meal times and the shame she felt due to the stigmatizing remarks of the guard:

Some guards would make us go into the cafeteria and give us like 10 minutes to eat, and they’d get us out and bring the other ones, people, in like we were . . . [The guards acted like we were] gonna give them HIV . . . basically . . . [the guard said]: “You got AIDS . . . you . . . you dyin’ anyways. You got AIDS. You don’t need to eat.” I’ll never forget that. When she [the female guard] said it to me, I cried so hard, and took off back to the dorm. I was so embarrassed.

This participant reported her sense of self-efficacy and agency were reduced by the labeling of the guard. This was another clear example of how stigma processes were enabled and reinforced by corrections staff, also illustrating women’s agentic diminishment. Significantly, shame and reduced agency might also negatively affect women’s willingness to link to HIV care during incarceration or post-release, while adversely affecting HIV risk behaviors, treatment adherence, and health outcomes (Boarts, Sledjeski, Bogart, & Delahanty, 2006; Scheyett et al., 2010).
their privileges, including visitors and phone calls. One participant recalled, “They wouldn’t [let] me [have visitors] . . . They put a hold on everything . . . I don’t know [why] . . . They wouldn’t even let me call.”

By invoking these restrictions, officers’ actions were portrayed by respondents as reducing their agency and basic freedoms, including movement. Moreover, due to the practice of separate housing, HIV-positive inmates’ status became known to all corrections authorities and inmates. Privacy and confidentiality were breached, thus limiting participants’ agency and freedom to disclose their HIV status voluntarily, also rendering them vulnerable to HIV stigma and discrimination, reported elsewhere (e.g., HRW, 2010). Prison staff appeared to disclose inmates’ HIV serostatus to family members without their consent. One respondent shared her experience of forced disclosure, recounting her loss of privacy as a loss of dignity and agency:

The social worker brought my children to visit me for Christmas . . . My children are always happy to come see mom [referring to herself] . . . I noticed this particular visit I go to the visiting room, which was an isolated place. And my children devastated, crying. I’m like, “What’s wrong?” and the first thing they say to me, “Why didn’t you tell me?” [She asked] “Tell you what?” [her children said] “Are you going to die? The warden just told us that you were HIV-positive.” Girl, I couldn’t talk.

A respondent describes her experience in jail, demonstrating the application of the first strategy—agentic accommodation:

Some people knew [she was living with HIV]. Some people treated me different. I had to block that out of my head . . . I got to work as a trustee. One jail I went into they . . . automatically made me trustee. I done laundry. I wasn’t allowed to do nothing with the food, canteens, or nothing like that.

This participant described exerting psychological control to overcome what she perceives as HIV stigma to find herself an occupation in jail within the strictures established for those living with HIV in correctional institutions.

Other participants pursued agentic rejection, spurning stigmatizing practices as punitive. One woman (who seroconverted later) recollected her first prison visit, when she saw how HIV-positive inmates were treated:

It’s like they were being punished because they had HIV . . . They got to come out for 1 hour a day. And during that time is when they got their shower. They had to eat in their cells, and they were all in a cell separated from each other . . . they were close enough they could talk . . . but I just thought that was mean . . . Because that was all that was wrong with them, is they were positive, and they kept them separated.

One respondent expresses her strong view that these actions were unnecessary and designed to be degrading. In questioning these actions, the participant uses her agentic freedom to critique the unjust practices that were socially constructed and reified within the prison system. Similarly, a different participant recalled the guards’ unwillingness to break up a fight between HIV-positive inmates, likely due to fear of HIV exposure:

They [two female inmates] go outside and beat each other down, [trying to] kill each other. He’s not comin’ in [no guard arrives] . . . there was bloodshed and . . . the officer wouldn’t break them up ‘cause they were bleeding [long pause] . . . it was horrifying to me. You know? And then the girl was hurt and just laying on the floor . . . Which, honestly . . . it’s scary. I comprehend that, but, damn! [emphatic].

She continues, acknowledging the guards’ fear response as human, expressing her disbelief and unwillingness to validate their actions:

They finally called the doc . . . and got the blood up, and then they finally locked . . . handcuffed them and took them out. They probably would’ve killed their selves. I really believe that . . . I can understand being scared . . . I really can. I was scared . . . myself, but, those were some horrible things they did to them girls in there.

This participant was also applying the strategy of agentic resistance. She was rejecting “othering” on the basis of HIV status (e.g., Goffman, 1963). By appealing to the moral sensibility of the interviewer, she refused to accept the perpetuation of stigma that appeared to be commonplace in these settings.

**Theme 2: The HIV Care Continuum in Prison—Discontinuous Yet Stable**

The second set of themes centered on women’s perceptions and experiences with HIV service provision. This encompassed HIV testing, treatment for HIV, STIs, and other health conditions, as well as engagement with nurses, HIV-trained physicians, and corrections staff in jail, in prison, and post-release (e.g., Iroh et al., 2015). Participants’ agentic actions in this domain could largely be characterized as agentic care-seeking.

**HIV testing but absence of counseling.** Respondents communicated that HIV testing was consistently available but pre- or post-test counseling was conspicuously absent in jail, in prison, and, generally, post-release. One participant
tested positive but never received HIV medications during her time in jail. Women were alerted to test results from jail following release through routine partner notification by the public health department, as HIV is a notifiable health condition in the state (Alabama Department of Health, State of Alabama, 2012). Previous partners would be contacted and told to report to the public health department. When there, women might be informed that they were HIV-exposed and should seek HIV testing, or they might be told that they had tested seropositive, based on blood tests sent to laboratories during incarceration. A respondent elaborated,

I had to go to the health department . . . when I went there they told me, “You is HIV-positive.” I said, “What? What is HIV?” They says, “A thing like you have sex with a man and you catch HIV.”

Although she received no counseling on-site, she was told to attend education classes, which she did repeatedly, recalling the sessions as positive, enabling encounters:

They told me I had to go to this place . . . It was in there, in the facility of UAB . . . [she went for] [HIV education] class . . . I liked the classes. They talk to you real good about it [HIV] . . . [and] I learned.

Like the participant just cited, a different respondent was tested in jail but learned her results after discharge. She described the officious way she learned she was HIV-positive:

They called me up and [she went] to the health department and he [public health officer] sat me in a room that wasn’t even his office, and he sat down. He said: “Well, I’ve got some bad news for you. You’re HIV-positive.” . . . [long pause] I was speechless. And, about that time, some guy comes in and says, “Oh, you’re in my office.” So this guy says: “Oh, we’re done.” And that’s it [she slams the table for emphasis]. That’s all he said. That was all he said. So yeah, that was pretty, pretty mind-blowing.

This participant appeared to have distanced herself from any psychological distress that she experienced at the time. However, in this account, she is expressing her agentic power by holding the public health officer accountable for his lack of professionalism, empathy, and for not providing basic, necessary information like the availability of medications, and how to connect to medical care.

HIV treatment: Infrequent, delayed, interrupted, and sometimes poor. On the whole, the narratives highlighted late cART initiation, infrequent and sometimes poor HIV treatment in prison, incorrect medication provided (described as leading to harmful drug interactions), the use of outdated medication regimens, and treatment interruption. However, HIV providers were generally characterized as competent, once women were able to secure an appointment, which was reported as challenging and infrequent. The following accounts revealed respondents’ perceptions about and actions to seek care, also illustrating how they chose to navigate those obstacles.

A participant was tested in jail but received the results several months later from the public health department. She described a pattern of treatment delay, her dissatisfaction with the outcome, and her belief that if she had started treatment earlier, it would have improved her health because she was already quite ill by the time she initiated cART:

I went to jail . . . around April . . . I think the health department contacted me, told me that they sent a letter . . . in June . . . 3 months later . . . The health department looked at it like, “that could have made all the difference” . . . in my treatment . . . Because [it was] 7 months later before I started on meds [indicating late treatment initiation].

One respondent reported HIV care as infrequent, indicating that she begged to see the HIV specialist:

I didn’t see a doctor for 5 months . . . For 5 months! And I begged them folks, ’cause the AIDS Doctor come in to the prison, and everybody was seeing him in the dorm but me. And I kept telling [the] guards and . . . they wouldn’t let me see him . . . They kept saying, “I wasn’t on the list, I wasn’t on the list.”

She then received the wrong medication:

They had me on four [medications], which caused my CD4 count to drop. I was down under 400 [CD4 cell count] when I come out of prison . . . They gave me the wrong medicine. Mixed the medicines up.

She continued, reflecting on a different doctor and subsequent jail visit. This time her HIV medication appeared to be withheld:

Now [I had] seen Dr [omitted] 2 or 3 times . . . I was already on meds when I got there [to jail], but they wouldn’t give my meds. And then they put another prescription with it, which messed me up . . . the HIV meds [interacted] with it.

This same participant described her delayed treatment for HIV and for syphilis, which prompted her to act. She filed a grievance:

And then . . . when I first got to prison, I found out I had syphilis. Now, I had syphilis and they . . . told me [that she would receive] three shots. They gave me one shot when I
first got there, then, when I tried to go back to the infirmary to get the other one the following week, they wouldn’t let me in . . . I had to wait . . . 3.5 months [without the rest of the needed treatment] and, finally, I wrote a grievance.

She continued,

I was trying to find out what was going on ’cause I started getting rashes on my hands and my feet . . . And they told me . . . [she could not] . . . go back there [to see the doc] and they had to restart all the shots over again . . . So they finally got me cured. Doc finally got me . . . the shots . . . three shots [over] 3 weeks, I think . . . Yeah, as far as I know [I was cured of syphilis]. Yeah though [she chuckles] . . . It took them about 3.5 months to get the syphilis cured!

Her saga is filled with irritation yet humor, and she largely describes a diligent approach to seeking care. A different participant indicated insufficient action was taken to initiate her on treatment. She expressed her dissatisfaction, also describing how she disclosed her status to her cellmate out of a sense of obligation, which highlights that the participant may be engaging in self-stigmatization or anticipated stigma (Earnshaw & Chaudoir, 2009):

They didn’t do enough [to get me into treatment], nope . . . Nothing. None of it [such as blood tests]. They expected me to, I guess, to fill out a sick call [a form used in prison requesting to see a doctor]. But I was not, I’m not a sickly person, so that would have been unusual for the other inmates to see that. And, I did tell my cellmate [she was HIV-positive] because I felt like it was only the right thing to do, you know?

One respondent indicated that, after cART initiation, she was seen routinely. She described a procedure for initiating a doctor visit and a long wait but depicted the HIV specialist as very knowledgeable:

You would have to fill out a sick call . . . You would have to sit there probably 6 hours before you could see the doctor . . . The whole day, sitting there waiting . . . So, needless to say . . . I wouldn’t do that anyway. But . . . the HIV specialist comes in once a month, and he tells you your CD4 count and your viral load and that’s it . . . This man was not very talkative [she laughs]. He was . . . very, very quiet. Very . . . very intelligent, almost to the extent where you felt intimidated, you know?

A different respondent cited treatment interruptions as problematic. She also refers to the HIV medication issued as sub-standard and describes her activist-based approach to educate her cellmates about treatment adherence:

They [HIV-positive women inmates] were missing days at a time . . . So, I started having to advocate [for treatment and instructed her cellmates to do so, too. She said]: “Listen, you can’t just take your medicine any kind of way you want. You have to take your medicine every day and you have to be on a regimen!” Then they were given monotherapy [an ineffective, outdated medication regimen] and there was no such thing as monotherapy anymore, and I was like, how do you give these people monotherapy?!

She and others described behaviors to seek treatment and overcome the reported delays, drug interactions, and initial treatment denial. They appeared to use whatever means were available within these restricted settings—for example, follow-up, inquiring, begging, problem solving, waiting, or filing a sick call or grievance—with the majority of respondents demonstrating a steadfast approach to seeking care.

Discussion

In participants’ accounts, expanded and disabled agency were visible in the same settings, highlighting multi-level factors affecting women’s agency. Theme 1 painted a portrait of an environment that established and reinforced social norms fostering HIV stigma and discrimination. The practice of isolation and forced separation (e.g., in housing, eating, prison occupation, use of toilets) on the basis of HIV serostatus had no medical rationale, and was used, ostensibly, to break the spirit or will of inmates, and to constrain women’s agency and freedoms. The goal seemed to be to bring them into conformity with the collective norm of the jail or prison. In this case, the social world of jail and prison was one in which “othering” based on HIV status was meant to reduce women to a single label, “having AIDS” (Goffman, 1963). This was, perhaps, most powerfully depicted by the participant’s recollection of the guards’ consistent remark, using the vernacular of the South: “Y’all got AIDS.”

The social process of blaming and discrediting HIV-positive women in correctional institutions accorded with the deliberate process of stigmatization and discrimination as Link and Phelan (2001) describe it:

Stigmatization is entirely contingent on access to social, economic, and political power . . . Thus, we apply the term stigma when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold. (pp. 366–367)

Research has shown that when applied to oneself as self-stigma or anticipated stigma, the “spoiled identity” coined by Goffman (1963) can lead to reduced self-esteem and efficacy, with significant negative psychosocial and health implications (Parker & Aggleton, 2003). How much of this was replicated outside the prison walls was
unclear. As de Viggiani (2007) observes, “prison communities exhibit and share the cultural norms and values of their host societies” (p. 119). Such practices can compound existing barriers for justice-involved women by generating stigma and actual or perceived discrimination that may contribute to delayed HIV care linkage and lapses, alongside other negative health effects, including depression (Helms et al., 2016; Schulz et al., 2006). Studies have found that depressed inmates (women and men) had low scores for coping and self-efficacy (Scheyett et al., 2010). Depression and incarceration have independently been associated with disease progression and higher risk behaviors among HIV-positive individuals, including increased risk of onward HIV transmission to sex partners and poor medication adherence (Boarts et al., 2006; Helms et al., 2016; Stephenson et al., 2006).

In terms of enablers of women’s health, respondents reported instances in which corrections’ staff were worried about inmates’ health. These were infrequent overall but appeared to have a high impact when they did occur. Other HIV-positive inmates routinely served as supports for participants, offering them strength through words of comfort, which appeared to generate a type of solidarity among HIV-positive inmates who faced the same constraints. Despite the highly restricted and controlled nature of these settings, most participants found ways to enhance their agency—using isolation as a pivotal experience to inform themselves about HIV, to normalize the experience, or to find an acceptable occupation in prison. In their narratives, women found ways to cope, to supersede the category of stereotyping associated with being HIV-positive, and to convert their experiences into a point of learning or moment of truth that occurred on a longer trajectory of their health and well-being.

The participants who described seeing inmates treated poorly refused to be a party to discrediting others. By refusing to condone behavior they saw as morally objectionable, participants effectively deconstructed these practices—which may have served in subtle yet important ways to mediate them. Sewell (1992) indicates that this is the beginning of transforming the social structure:

> Agents are empowered by structures, both by the knowledge of cultural schemas that enables them to mobilize resources and by the access to resources that enables them to enact schemas. . . resourceful agency that sustains the reproduction of structures also makes possible their transformation—by means of transpositions of schemas and remobilizations of resources that make the new structures recognizable as transformations of the old. (p. 27)

If we view corrections staff as individuals given power to debase HIV-positive inmates, we can see some of the study respondents, similarly, as resourceful agents that seek to effect a transformation through individual actions whether fully intentional or not. Although their strategies differed, we found those that applied agentic resistance were seeking to deconstruct, and thus alter the existing stigmatized prison structure.

In accessing the HIV care continuum (Theme 2), we found participants’ behaviors to be active and health seeking. Counseling was characterized as wholly absent and treatment as delayed, infrequent, interrupted, and of poor quality. The long wait times reported might dissuade women from pursuing actions to promote their health and access cART. Success would, in part, be determined by women’s ability to overcome the delays, frustrations, and interruptions of existing care and treatment. Women’s narratives illuminated the range of agency they displayed in these situations. Their reports indicate that they persisted; although participants documented various protracted struggles in their lives, particularly substance use, we looked for alternative interpretations but had no accounts related to HIV services in jail and prison in which women said something akin to “I gave up” or “it was too much.”

The Paradox

We found what we term “the HIV prison paradox” in correctional settings. These environments have been depicted as unhealthy (Belknap & Whalley, 2013; Binswanger et al., 2012; CDC, 2012a; de Viggiani, 2007; Eliason et al., 2004; van den Bergh, Gatherer, Fraser, & Moller, 2011), yet they offer justice-involved populations critical opportunities to secure HIV services both to engage and re-engage in HIV care. This is a reality that has been recognized by other researchers and international agencies (Beckwith et al., 2010; Binswanger et al., 2012; Hammett & Drachman-Jones, 2006; Iroh et al., 2015; Spaulding et al., 2002; UNAIDS, 2014). Notably, jail and prison stays interrupt the cycles of substance dependence that participants reported as critical barriers to achieving stability in their lives, while facilitating medication adherence (e.g., National Institute on Drug Abuse, 2015). One respondent underscored this contradiction:

> I thought [sometime post-release]: “Oh my god! I can’t wait to get back to Tutwiler to find out about my [CD4 cell] counts.” And then, at the same time, once you get there, you don’t see the HIV doctor but every 3 months.

In relation to Theme 2, this quote is illustrative. Barriers to HIV care for justice-involved women may be higher outside correctional settings than inside them. She seems to be indicating that although far from ideal, HIV services may be more routine and accessible in correctional, compared with community, settings—especially
when incarceration is cyclical, as it was for nearly all (24/25) of the participants. This finding has implications for viewing the full HIV care continuum and linkage between points of care. The participants consistently recounted recurrent return to substance use following release, often for decades. This could disrupt continuous HIV care and thwart medication adherence, which might result in lapses or dropout in care and, potentially, a return to care in prison, once substance use ceased during incarceration (Iroh et al., 2015).

This is supported by a recent systematic review of 92 studies, which mapped the HIV care continuum among justice-involved individuals before, during, and after incarceration. The review found that HIV outcomes were significantly worse before and after incarceration, compared with the general population, but were better during incarceration (e.g., rates of viral suppression averaged 40% in correctional settings vs. 28% nationally; Iroh et al., 2015). In addition, homelessness and sex work were reported in this population, and women recounted those periods in their lives as transient, while encouraging high HIV risk behaviors that have the potential to undermine optimal HIV outcomes.

In IDIs, all three interviewers (shared in routine debriefs) found that respondents typically described themselves as terrified after each received their HIV-positive diagnosis. Women reported little prior knowledge about HIV and its management. Despite this major health problem, engagement in HIV treatment was not viewed as these participants’ greatest priority—a point confirmed by key informants during interviews. Rather, it was challenges for women to overcome substance dependence and the desire to restore relations with their family members (particularly their children) that occupied them most during interviews. This suggests that HIV care may be a secondary concern and could lead to drop out of care and poor medication adherence (Williams et al., 2013). We also found an important link between the need for trauma treatment, to potentially enhance HIV treatment uptake, and support adherence (Harner & Burgess, 2011; Harner & Riley, 2013).

These findings did not surprise key informants who were knowledgeable about the HIV context in Alabama. They emphasized the low levels of public health information about HIV, and the high levels of stigma and discrimination typically faced by HIV-positive individuals, in the state.

Given the large published literature on the presence of HIV stigma in HIV-positive women’s lives, globally (Loutfy et al., 2015; Mahajan et al., 2008), what might be distinctive about HIV stigma for women in prison in Alabama? First, although HIV stigma has been documented among incarcerated women, there is not yet an exhaustive profile of the magnitude of HIV stigma among this population of women, internationally, or in the United States (UN Office on Drugs and Crime [UNODOC], 2008). Neither is there a comprehensive understanding of the extent of HIV stigma experienced by HIV-positive persons in the United States more generally, and differences by region, that might be associated with education, awareness, and other factors. This gap in the evidence base has been highlighted by UNAIDS (2008):

Much of what we know about the stigma attached to HIV and the resulting discrimination towards people living with the virus is anecdotal or fragmented. Existing surveys show that while much is known about the influence of stigma there is no clear picture of the actual magnitude of it.

In response, UNAIDS (2008) and international partners developed The People Living With HIV (PLHIV) Stigma Index. The Index was launched as a pilot in the United States in 2013, but a national survey has not yet been conducted (PLHIV Stigma Index North America, 2016). The Stigma Index coordinator for North America, Laurel Sprague, noted that new questions were being added to the pilot to fill gaps in the research evidence, including specific questions “about stigma and discrimination in detention facilities (prisons, jail, immigration centers)—settings that differ substantially from other social settings (Davids, 2014, p. 1). In addition, stigma experts noted that the intersection of HIV stigma with race and gender has not been sufficiently studied in the U.S. context, and further investigation was recommended (Davids, 2014).

**Study limitations and future research.** As a descriptive exploratory study, this research was limited to capturing the types of agency Alabama women enacted, and how women navigated the HIV care continuum in jail and prison in geographic and social context. Given the study design/methods, we were not able to predict or explain elements of women’s behaviors or related factors that might have determined or influenced linkage and retention in HIV care or dropout. Additional research could investigate the health transition to the community setting, care lapses or delays that have been reported in other studies, and the reasons for this. Research could also explore differences by sex/gender, as the systematic review referenced above did not disaggregate those factors (Iroh et al., 2015; Meyer, Springer, & Altice, 2011). In addition to the transition from incarceration to community settings, women in this study did not identify difficulties with transitions from jail to prison. However, this may be yet another health transition that presents significant challenges to accessing and maintaining HIV treatment for women and should be explored.

Second, increasing numbers of women living with or at risk of acquiring HIV are Black and located in the South (CDC, 2015b, 2016). Indeed, 76% of participants...
were Black women who are at highest risk for contracting HIV, for incarceration, and for health disparities. Due to our study design and methods, we were unable to tease out differences of HIV stigma and discrimination in jail versus prison, or HIV care barriers that were associated with race or ethnicity. Future research should use frameworks such as intersectionality to disaggregate those differences. There is also need for research to address how the social marginalization and devaluation of particular groups of women is socially constructed and reified through institutional structures, including social (families and communities) and prison settings. Particular attention needs to be paid by researchers to factors that reinforce overlapping processes of racism, sexism, together with the stigma associated with having been incarcerated (e.g., committing unlawful offenses) and with HIV (whether anticipated, experienced, and/or self-stigma), as well as interventions best placed to mediate these (Haley et al., 2014; Moore, Stuewig, & Tangney, 2016).

Notably, for these Alabaman women, participants stressed that their experiences of HIV stigma and discrimination in jail and prison did not have the same indelible mark as their debasing experiences of sexual violence, repeated rapes, and victimizations as girls, adolescents, and adults, which resulted in significant traumas for participants. This amplifies the need, noted by other researchers, for trauma-informed approaches to addressing women’s health needs, and supplementary substance rehabilitation and mental health services for justice-involved women, with earlier HIV prevention, treatment, care, and support interventions (Bloom et al., 2003; Braithwaite et al., 2005; Harner & Burgess, 2011).

Third, even as this study was being conducted, jails, and particularly prisons, were changing in Alabama with desegregation continuing apace. Already the social world of prison was labile (e.g., ACLU, 2012). Research on how reform of correctional settings may reduce HIV stigma and potentially improve HIV services in these locations is recommended. Our research was not able to detect major differences between HIV experiences in jail and prison. We were able to corroborate previous literature indicating that opportunities for cART are greater in prison because of the U.S. constitutional mandate for HIV treatment to be provided and due to longer prison sentences (Klein, 1978; Spaulding, 2009). Future research should investigate differences in provision of HIV services in these settings more systematically.

Fourth, qualitative studies such as this one must recognize social desirability as a potential limitation (Denzin & Lincoln, 2011). This study population was older, and interviews were long and wide-ranging, covering childhood to adulthood with data reported here comprising one part. We were vigilant about watching for this and found in our routine debriefings that participants used interviews as a rare opportunity to reflect on and share their life histories, rather than seek approval from researchers.

Fifth, in our initial design, we had planned to secure interviews with correctional staff and authorities in these facilities. How staff perceive their agency vis-a-vis HIV services, and how they might mediate (expand or disable) care for HIV-positive inmates, would have added an additional rich dimension. Our research request was denied without explanation, however. The ACLU had won a lawsuit against the Alabama Department of Corrections in 2012, and in 2014, when interviews commenced, we learned that a published U.S. Department of Justice (DOJ) investigation of the prison highlighted ongoing sexual abuse perpetrated by correctional staff, concluding, “the State of Alabama violates the Eighth Amendment of the United States Constitution by failing to protect women prisoners at Tutwiler Prison from harm due to sexual abuse and harassment from correctional staff” (DOJ, 2014, p. 1). ACLU and DOJ findings would most likely have influenced the willingness of prison authorities to allow researchers access to the prison.

Despite these important limitations, the strength of this study was its ability to capture Alabaman women’s experiences of being HIV-positive and navigating health and HIV services in jail and prison, which has been underresearched to date—particularly in the United States. The South is where high levels of incarceration and increasing HIV incidence are evident (Carson, 2014; CDC, 2015a, 2015b, 2016; P. L. Fleming et al., 2006). Women’s thick and rich narrative histories afforded insight into the socially constructed and highly ritualized world of jail and prison in Alabama, and how women developed agentic strategies to adapt, cope, and obtain HIV services in ways that were health-promoting within highly constrained environments. Agency, used as a theoretical approach to powerfully explore IPV for marginalized women (Campbell & Mannell, 2016), was marshaled to position participants within the social structure of jail and prison. This approach allowed us to locate women—the central unit of analysis—as agents within correctional institutions, to uncover their lived experiences of being HIV-positive, and to capture HIV care-seeking behaviors and barriers they face in ways we have not seen in published research. Findings offered both new descriptive accounts of a hard-to-reach marginalized group and interpretive insights into their distinctive perceptions and experiences as justice-involved Southern women living with HIV.

Conclusion

Study findings revealed the HIV prison paradox in which HIV services in these correctional settings in Alabama offered great promise for women to receive HIV testing and counseling, and to initiate cART. Indeed, many
participants deployed agentic care-seeking to successfully initiate treatment (Beckwith et al., 2010). Yet the HIV care continuum for justice-involved women was fragmented and interrupted. Our findings support strategic opportunities, some identified by others, that could be exploited to maximize HIV care and support in jail and prison, and may also be relevant to other settings (Westergaard et al., 2013). These include (a) on entry: providing counseling, together with HIV testing. This is a key moment to inform women about the critical importance of prevention, the benefits of HIV treatment, and how to access cART (Mugavero et al., 2013); (b) during incarceration: rapid and consistent treatment initiation to facilitate their timely linkage to HIV care; (c) discharge planning: to identify community-based HIV services, encompassing: substance rehabilitation, safe housing, and mental health services to address women’s unmet health needs: creating an opportunity for the health transitions between correctional and community settings to be bridged, in keeping with CDC guidelines (CDC, 2012a; 2013); (b) during incarceration: rapid and consistent treatment initiation to facilitate their timely linkage to HIV care; (c) discharge planning: to identify community-based HIV services, encompassing: substance rehabilitation, safe housing, and mental health services to address women’s unmet health needs: creating an opportunity for the health transitions between correctional and community settings to be bridged, in keeping with CDC guidelines (CDC, 2012a; 2013); and (d) post-release: linking women to clinics and social services through partnerships between corrections departments and local CBOs (trusted by justice-involved women) to ensure a transition and facilitate engagement and adherence in long-term HIV care (Rich et al., 2013; Sprague & Simon, 2014).

Finally, our results emphasize the need to transform socio-structural environments within which HIV treatment is accessed, and in which stigmatizing and discriminatory practices toward women with HIV appear to be perpetuated. Sensitization training on HIV and human rights for correctional officers, as well as other inmates, is necessary. Robust, effective monitoring and enforcement mechanisms are crucial to safeguard inmates and their right to health care and to ensure that correctional settings protect the dignity, health, and human rights of all persons—regardless of HIV status, race, ethnicity, gender, or sexual orientation (Coyle, 2003; WHO Office for Europe, 2013).

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References


AIDS and Behavior. Advance online publication (Feb 10). doi:10.1007/s10461.


Corrections facilities as partners in reducing HIV disparities. *Journal of Acquired Immune Deficiency Syndromes*, 63(Suppl. 1), S49–S53.


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78–89.

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