



Published in final edited form as:

AIDS Care. 2018 April ; 30(4): 409–416. doi:10.1080/09540121.2018.1426827.

Social and structural determinants of HIV treatment and care among black women living with HIV infection: a systematic review: 2005–2016

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Abstract

Black/African American (black) women comprised 59% of women living with HIV at the end of 2014 and 61% of HIV diagnoses among women in 2015. Black women living with HIV infection (BWLH) have poorer health outcomes compared with women of other races/ethnicities; social and structural determinants are often cited as barriers and facilitators of care. The objective of this qualitative review was to identify social and structural barriers and facilitators of HIV treatment and care among BWLH. The systematic review was conducted in six-stages using databases such as PubMed, PsycINFO, and Google Scholar: 1) searched for studies that enrolled BWLH published between January 2005 and December 2016, 2) excluded unpublished reports and commentaries, 3) limited the search to our primary keywords, 4) limited our search to studies that included participants living with HIV infection that were >60% black and 100% female, 5) extracted and summarized the data, and 6) conducted a contextual review to identify common themes. Of 534 studies retrieved, 16 were included in the final review. Studies focused on: ART medication adherence ($n = 5$), engagement/retention in care ($n = 4$), HIV care and treatment services ($n = 3$), viral suppression ($n = 1$), and addressing multiple HIV care outcomes ($n = 3$). Main barrier themes included lack of family and/or social support, poor quality HIV services, and HIV-related stigma, particularly from healthcare providers; facilitator themes included resilience, positive relationships between case management and support services, high racial consciousness, and addressing mental health. Interventions that decrease these noted barriers and strengthen facilitators may help improve care outcomes for BWLH. Also, more HIV stigma-reduction training for healthcare providers may be warranted.

Keywords

HIV-positive; African Americans; women; HIV care continuum; disparities

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Disclosure statement

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official views of their affiliated institute.

Geolocation

Data for this study were collected in the U.S.

No potential conflict of interest was reported by the authors.

Introduction

Black women comprised 59% of women living with HIV infection in 2014 and 61% of diagnoses among women in 2015 (CDC, 2016b). Reducing disparities in HIV diagnoses and improving the health of persons living with HIV infection (PLWH), including black women, aligns with national prevention goals (Office of National AIDS Policy, 2015). Early diagnoses, linkage to care, and retention in care are important steps for reducing HIV disparities and preventing HIV transmission (Skarbinski et al., 2015). Greater than 90% of new HIV infections are attributable to PLWH who are unaware of their status or not in care (Skarbinski et al., 2015).

Black women experience disparities in HIV treatment and care. Data from 61 health department jurisdictions indicated black women newly diagnosed with HIV and linked to HIV care within 90 days of diagnosis increased from 33.8% in 2012 to 50.1% in 2014 (Stein, Pierce, Hollis, & Smith, 2016). However, this was below the national target of 85%. Identifying factors associated with disparities in HIV treatment and care for black women is critical to increase the percentage who know their HIV status, are in HIV care, and are virally suppressed (Office of National AIDS Policy, 2015).

Thirty-six years after the identification of HIV infection in the United States (U.S.), there are no literature reviews focused exclusively on contextual factors that facilitate or limit access to HIV treatment and care among black women (Kennedy & Jenkins, 2011; Stampley, Mallory, & Gabrielson, 2005; Waite, Brawer, & Gipson-Jones, 2008). Such a review could identify the scant literature available regarding HIV treatment and care, support the need for more HIV research and interventions, and inform the quality of HIV treatment and care provided by healthcare professionals to black women. The purpose of this literature review is to identify possible social and structural factors related to the disparities in treatment and care among black women living with diagnosed HIV infection (BWLH).

Methods

The systematic review was conducted in six stages using PubMed, PsycINFO, Scopus, Embase, Global Health, OVID/Medline and Google Scholar. First, we searched for studies that enrolled BWLH published between January 2005 and December 2016. Second, we excluded abstracts, unpublished dissertations, editorials, commentaries and studies that were conducted outside of the U.S. Third, we limited the results to five areas of inquiry that address disparities in HIV treatment and care among black women: 1) biomedical (care, treatment, antiretroviral therapy (ART), medication adherence, viral suppression); 2) structural determinants of health (access to HIV care, patient-provider communication, quality of HIV care); 3) social determinants of health (stigma, discrimination, medical mistrust); 4) psychosocial context (peer support and mental health); and 5) social and sexual networks (sexual mixing, partner characteristics) (Office of National AIDS Policy, 2015; Maulsby et al., 2014). Fourth, we focused on studies that had majority representation of BWLH in the U.S., by requiring that the study population was >60% black and 100% female. Published quantitative and qualitative research studies that met the above inclusion criteria were included in the full-text review (Figure 1). Fifth, we extracted and summarized

these data in a summary table that highlighted the author names, year, location, study design, sample size, age, HIV continuum of care category, and major findings (Hall et al., 2013) (Table 1). Sixth, we reviewed the articles and utilized direct content analysis to identify common themes for barriers and facilitators for HIV care (Hsieh & Shannon, 2005) (Table 2).

Results

We screened 534 relevant titles and abstracts; 49 were selected for full review; 16 articles met inclusion criteria for final analysis (Figure 1). The 16 studies were conducted throughout the U.S. including the Northeast ($n = 5$), Southeast ($n = 6$), Midwest ($n = 4$), and West ($n = 1$) (Table 1). Barriers and facilitators of care and ART adherence emerged during the review and are summarized in Table 2.

ART medication adherence

Five individual studies and one study with multiple outcomes addressed social and structural determinants of ART adherence to HIV therapy (Brody et al., 2016; Dale et al., 2014; Dalmida et al., 2012; Edwards, 2006; Edwards et al., 2012; Vyavaharkar et al., 2010). Dalmida et al. (2012) found that black women attributed the integration of spirituality with their HIV care to improvement in their ART adherence. Diagnosing and managing depressive symptoms associated with HIV diagnosis and HIV-related stigma (Vyavaharkar et al., 2010), high levels of self-awareness (Brody et al., 2016; Dale et al., 2014) and self-efficacy (Brody et al., 2016) were also noted as facilitators to improving ART adherence. Other barriers and facilitators of ART adherence included HIV-related stigma, relationship turbulence, prioritization of caring for others over their personal care (Edwards, 2006) and social support from family members (Edwards, 2006; Edwards et al., 2012; Vyavaharkar et al., 2010).

Engagement/retention in care

Four individual studies and two studies with multiple outcomes examined barriers to engagement and/or retention in care, with HIV-related stigma being the most noted barrier to consistent access to and utilization of HIV care services (Buseh & Stevens, 2007; Fletcher et al., 2016; McDoom et al., 2015; Vyavaharkar et al., 2008; Walcott et al., 2016; Wyatt et al., 2005). These studies all demonstrated that black women have multi-level encounters with HIV-related stigma, from family, friends, religious groups, healthcare providers, employers, and prison employees. Three studies examined factors beyond the scope of treatment, and identified unmet social and structural needs as barriers to engaging in care, including transportation, housing, childcare (Vyavahar-kar et al., 2008), caring for others (Wyatt et al., 2005), poverty, poor employment opportunities, and limited access to healthcare resources (Walcott et al., 2016).

HIV care and treatment services

Three individual studies and two studies with multiple outcomes examined quality and access to HIV care (Baker, Rodgers, Davis, Gracely, & Bowleg, 2014; Halki-tis et al., 2010; Toth et al., 2013; Vyavaharkar et al., 2008; Wyatt et al., 2005). Dissatisfaction with the

quality of HIV care, and limited access, were barriers to engaging in HIV care (Baker et al., 2014; Halkitis et al., 2010; Vyavaharkar et al., 2008; Wyatt et al., 2005). Explanations for patient dissatisfaction included poor attitudes and behaviors of healthcare providers, lack of patient-provider communication, not addressing depression, and a lack of integrated services; women indicated how integrated services would increase their access to care and decrease patient burden (Toth et al., 2013; Vyavaharkar et al., 2008). Facilitators of engaging in HIV care included stable housing, childcare, transportation, and peer support (Halkitis et al., 2010; Toth et al., 2013; Vyavaharkar et al., 2008; Wyatt et al., 2005). Halkitis et al. (2010) found that women with higher utilization of support services such as transportation, primary healthcare/medical specialists, and support groups, had more encounters with their case managers and were more consistent in their HIV treatment and care.

Viral suppression

One individual study and one study with multiple outcomes examined social and structural determinants of viral suppression (Dale et al., 2014; Kelso et al., 2014). Black women who perceived high racial discrimination and reported high critical consciousness (cultural self-awareness) were significantly less likely to have a detectable viral load and more likely to have CD4 cell counts above 350 cells/mm³ (Kelso et al., 2014). Dale et al. (2014) examined resilience and viral load; black women with high levels of resilience had lower viral loads than their counterparts.

Discussion

Our review suggests that social and structural factors, including suboptimal patient-provider communication, HIV-related stigma, lack of social support, and unmet needs (e.g., transportation, financial stability, and childcare) all contribute to challenges in HIV treatment and care for black women. Available studies (Table 1) suggest that social and structural factors (Table 2) need to be considered by providers, and underscore the importance of relationships and communication between patients, providers, and the support networks of BWLH.

The finding of healthcare provider stigma as a barrier for HIV care and treatment is of concern and is aligned with a study which reported negative clinical encounters by black compared with white HIV-infected women (Beach et al., 2011). Training physicians to more effectively engage patients in non-stigmatizing dialogue and empowering black women to address specific topics with their providers may be important strategies for improving communication and satisfaction with HIV care services (Beach et al., 2011).

These studies suggest important roles for interventions through healthcare providers (Gaston, Gutierrez, & Nisanci, 2015). Culturally tailored communication strategies, developed with affected communities of black women, is also an additional tool for improving care for BWLH (Arya, Behforouz, & Viswanath, 2009). It is vital that we improve trust, increase culturally appropriate care, and actively follow-up on missed visits, to strengthen engagement and retention in care for BWLH (Aziz & Smith, 2011; El-Bassel, Caldeira, Ruglass, & Gilbert, 2009). Moreover, addressing depression, unmet needs (i.e.,

childcare, unemployment, and housing), and increasing peer-support may be well-received if these factors are considered as part of care for BLWH (Rao et al., 2012; Toth et al., 2013).

This review has limitations. First, nine of 16 (60%) studies included small sample sizes, larger samples of black women will be needed for future studies, to provide for more robust analyses and be generalizable to larger groups of women. Second, factors such as geographic location may play unique role for black women, especially in the southern U.S., an area which has a historical context of institutional racism (i.e., limited or no resources available due to a lack of insurance coverage) which may create additional HIV prevention and care challenges for people of color (Adimora, Ramirez, Schoenbach, & Cohen, 2014). Third, many of the studies were qualitative and included face-to-face interviews; social desirability biases may have played a role in some responses. Using computer-assisted quantitative surveys may offer additional privacy and decrease this type of bias.

Conclusion

Given the disproportionate burden of HIV infection among black women in the U.S., (CDC, 2016b) the development of social and structural interventions that increase accessibility and acceptability to services are vital. Moreover, of 84 Centers for Disease Control and Prevention evidence-based HIV interventions (CDC, 2016a), none were developed exclusively for BWLH. In order to reach national HIV prevention goals for women of color, future studies, with larger samples of BWLH, are needed to increase the number of culturally appropriate interventions and evidence-based practices for addressing social and structural factors that impede treatment and care for BWLH. Findings discussed in this manuscript support the need to address the ongoing disparities in HIV treatment and care among black women.

Acknowledgements

The authors equally contributed to the conception, data collection, data analysis, data interpretation, writing, and final development of this manuscript. The authors have no funding sources and financial conflicts to report.

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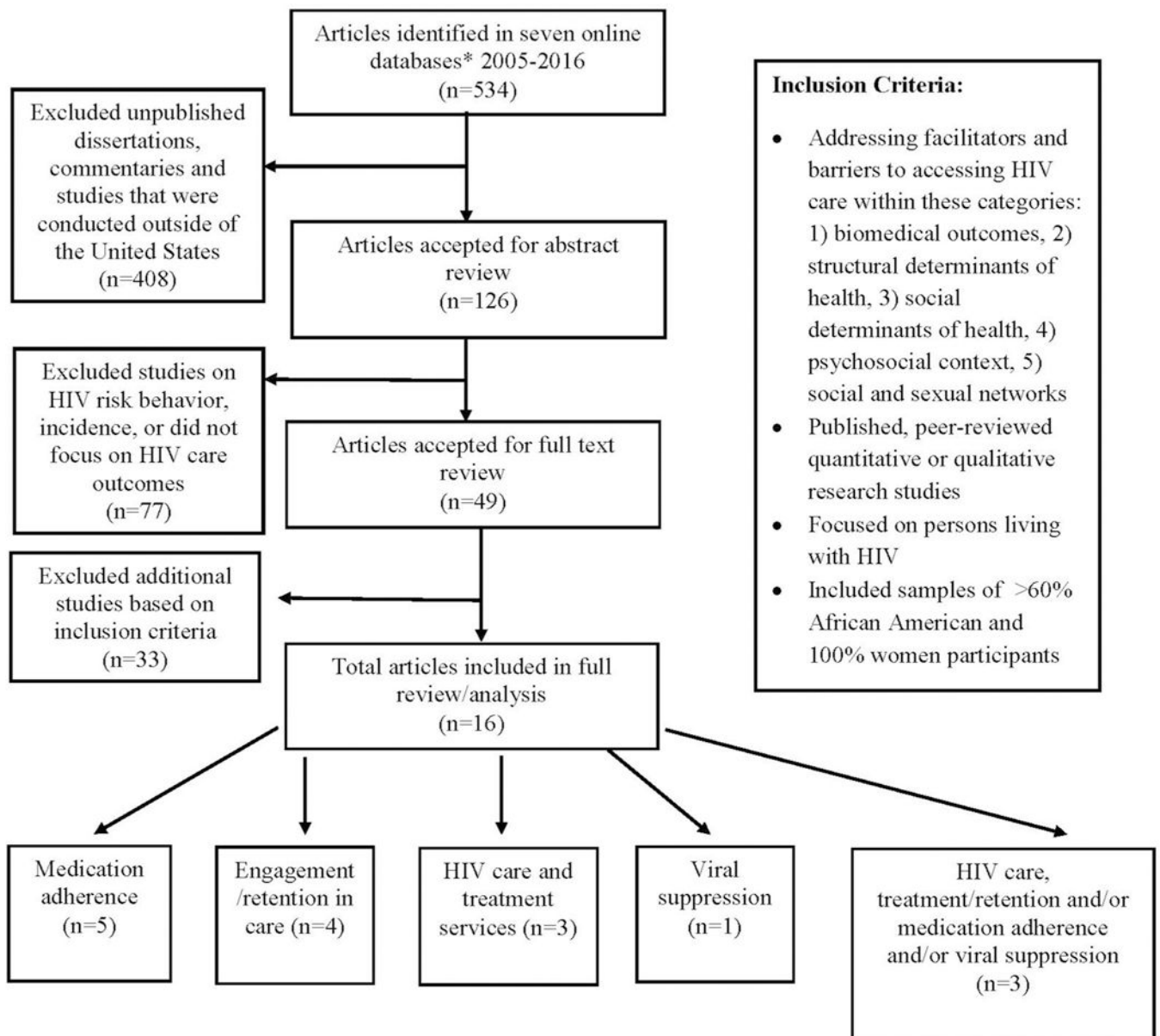


Figure 1. Selection process for systematic review of the literature, HIV care outcomes among HIV-Positive black women, 2005–2016. *The literature search included the following databases: PubMed, PsycINFO, Scopus, Embase, Global Health, OVID/Medline and Google Scholar.

Literature review findings of social and structural barriers and facilitators contributing to HIV treatment and care disparities among black women.

Table 1.

First author, year	Source of the data, location	Study population	N, % African American, % female, age mean years (SD) or (range)	Methodology	HIV care continuum category	Major findings
Baker et al. (2014)	Secondary data analysis, Northeast U.S.	Patients of an HIV Care Clinic	N = 157; 100% African American in the analysis; 100% female; 39.85 (SD = 8.72)	Randomized, controlled, intervention; ACASI questionnaire implemented at baseline and follow-up; baseline data used for analysis	HIV care and treatment services	<ul style="list-style-type: none"> • Satisfaction with medical services (88%, $n = 140$) • Communication with healthcare providers, detectable viral load, education, income, self-reported health status, and sexual orientation were significantly associated with satisfaction with healthcare ($p < .05$ for all outcomes)
Brody et al. (2016)	Primary data collection, Midwest, U.S.	Participants of the Interagency HIV Study (WIHS)	N = 22; 98% African American in the analysis; 100% female; 46.51 (SD = 13.05)	Qualitative narrative, autobiographical and interview design	Medication adherence	<ul style="list-style-type: none"> • Mutuality-fostering relationships involving reciprocal care and empathy • Self-awareness-recognition of personal strengths and weaknesses and multiple factors contributing to life choices and trajectories • Self-efficacy-active coping, self-advocacy, and utilizing resources
Buseh, Kelber, Stevens, and Park (2008)	Primary data collection, Midwest, U.S.	Community-based purposive recruitment	N = 29; 100% African American in the analysis; 100% female; 40.0 (range: 25–54) ^a	Qualitative narrative interview design, data collections – 2000–2003; 10 face-to-face interviews lasting 2–3 h	Retention in care	<ul style="list-style-type: none"> • Multi-level encounters with HIV-related stigma including family, friends, and healthcare providers
Dale et al. (2014)	Primary data collection, Midwest, U.S.	Ruth M. Rothstein CORE Center/ Cook County Health and WIHS	N = 138; 87% African American; 100% female;	Cross-sectional questionnaire of a longitudinal study	Medication adherence ^a Viral suppression	<ul style="list-style-type: none"> • High resilience and increased HAART adherence (OR = 1.08, 95% CI 1.00–1.15)

First author, year	Source of the data, location	Study population	N, % African American, % female, age mean years (SD) or (range)	Methodology	HIV care continuum category	Major findings
Dalmeida, Holstad, DiIorio, and Laderman (2012)	Primary data collection, Southeast, U.S.	Patients from a large infectious disease center	N = 20; 100% African Americans in the analysis; 100% female; 46.8 (SD = 6.5)	Two group sessions using focus group methodology; Six individual interviews using a focus group guide, a semi structured interview script, and a phenomenological approach	Medication adherence	<ul style="list-style-type: none"> • High resilience and decreased detectable viral load (OR = 0.94, 0.89–0.99) • Spirituality, when integrated with HIV care and treatment services, improved patients' medication adherence
Edwards (2006)	Primary data collection, Northeast U.S.	Patients from Johns Hopkins Medical Institution - Moore Clinic	N = 20; 100% African Americans in the analysis; 100% female; (range: 20–49) ^a	Journal entries and semi-structured interviews	Medication adherence	<ul style="list-style-type: none"> • HIV-related stigma, relationship turbulence, and prioritization of caring for others over their personal care as barriers to medication adherence. • Social support from family members was facilitator to medication adherence
Edwards, Irving, Amutah, and Sydnor (2012)	Secondary data analysis, Northeast, U.S.	Patients from Johns Hopkins Medical Institution - Moore Clinic	N = 20; 100% African Americans in the analysis; 100% female; (range: 20–49) ^a	Journal entries and semi-structured interviews	Medication adherence	<ul style="list-style-type: none"> • Social support was a facilitator of medication adherence
Fletcher et al. (2016)	Secondary data analysis, Southeast, U.S.	Patients of five South Carolina clinics or AIDS organizations	N = 42; 100% African Americans in the analysis, 100% female; 37.7 (SD = 9.2)	In-depth face-to-face interviews	Retention in care	<ul style="list-style-type: none"> • Multilevel HIV-related stigma • Stigma subsequently complicated disclosure decisions, resulting in limited support in social, professional and medical settings
Halkitis, Kupprat, and Mukherjee (2010)	Retrospective data analysis, Northeast, U.S.	Analysis of case management records, support services records, and medical charts	N = 46; 63.0% African Americans in the analysis; 100% female; 46.58 (SD = 5.98)	Examined descriptive and relational data	HIV care and treatment services	<ul style="list-style-type: none"> • Positive relationships between case management and supportive services increased HIV care and treatment services

First author, year	Source of the data, location	Study population	N, % African American, % female, age mean years (SD) or range	Methodology	HIV care continuum category	Major findings
Kelso et al. (2014)	Primary data collection, Midwest, U.S.	Recruited through the CORE Center Site of the Chicago Women's Interagency HIV Study	N = 67; 100% African Americans in the analysis; 100% female; 44.9 (SD = 8.93)	Detailed, structured interview; brief physical and gynecologic examinations; semi-annual specimens; Self-report data	Viral suppression	<ul style="list-style-type: none"> Black women who perceived high racial discrimination, yet reported high critical consciousness were Less likely to have a detectable viral load ($B = -0.79, p = 0.03$, odds ratio = 0.45) More likely to have CD4 cell counts above 350 ($B = 1.00, p = 0.06$, odds ratio = 2.72)
McDoom, Bokhour, Sullivan, and Drainoni (2015)	Primary data collection, Northeast, U.S.	Patients from a primary care clinic in Metropolitan Boston Area	N = 20; 100% African Americans in the analysis; 100% female; 56 (range 50–63) ^a	Semi-structured interviews	Retention in care	<ul style="list-style-type: none"> Social support was a facilitator for consistent HIV care retention HIV-related stigma, particularly from healthcare providers, was a barrier to continuity of care
Toth, Messer, and Quimlivan (2013)	Primary data collection, Southern, U.S.	Patients from a primary care clinic	N = 140; 85% African American in the analysis; 100% female; 46.1 (SD 10.43)	Cross-sectional survey	HIV care and treatment	<ul style="list-style-type: none"> Depression, illness severity, and psychological abuse were associated with >5 barriers to HIV care and services
Vyavaharkar, Moneyham, and Corwin (2008)	Primary data collection, Southeast, U.S.	Recruited through community based organizations and university based research study of rural women with HIV disease	N = 22; 100% African American in the analysis; 100% female; 44 (SD 9.24)	Focus groups	HIV care and treatment services and retention in care ^a	<ul style="list-style-type: none"> Lack of transportation, stigma, lack of support, housing and childcare, dissatisfaction with quality of care services, limited availability of services were barriers to continuity of HIV care
Vyavaharkar et al. (2010)	Secondary data collection, Southeast, U.S.	Recruited from community-based consortiums that provide HIV prevention and care	N = 340; 100% African Americans in the analysis; 100% female; 41.25 (9.47)	Self-reported data, cross-sectional questionnaire	Medication adherence	<ul style="list-style-type: none"> Addressing depressive symptoms through social support facilitated patients engagement in long-term HIV care

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First author, year	Source of the data, location	Study population	N, % African American, % female, age mean years (SD) or (range)	Methodology	HIV care continuum category	Major findings
Walcott, Kempf, Merlin, and Turan (2016)	Primary data collection, Southeast, U.S.	Recruitment through HIV care clinics and a residential facility for HIV-positive persons; Included service providers (n = 14) and women living with HIV (n = 46)	N = 60; 89% African American; 100% female; 44.6 (SD = 9.6)	In-depth interviews (service providers); focus groups (HIV-positive women)	Engagement/retention in care	<ul style="list-style-type: none"> Structural community factors, such as poverty, poor employment opportunities, limited access to healthcare resources, stigma, transportation challenges and access to illicit substances, were barriers to engaging in HIV care
Wyatt, Carmona, Loebl, and Williams (2005)	Primary data collection, West, U.S.	Patients of community-based clinics, county hospitals, ethnicity- and AIDS specific organizations and drug rehabilitation centers	N = 75; 100% African Americans in the analysis; 100% female; 40 (SD = N/A)	Structured interview assessment	Engagement/Retention in care HIV Care and Treatment Services	<ul style="list-style-type: none"> Substance use, confidentiality issues, limited financial resources, difficulty in getting an appointment, excessive waiting for healthcare provider, caring for others (family and friends) were barriers to continuity of HIV care

Table 2.

Emergent themes for barriers and facilitators for HIV care and treatment among black women, 2005–2016.

Barriers to care	Facilitators for care
<ul style="list-style-type: none"> • HIV-related stigma among family and friends • HIV-related stigma among healthcare providers • Poor quality of HIV care services, including confidentiality concerns, difficulty in getting an appointment, excessive waiting for healthcare provider • Inadequate social support • Unmet needs beyond HIV treatment and care including, limited financial resources, lack of childcare, housing, and reliable transportation • Relationship turbulence, and prioritization of caring for others over their personal care • Substance use 	<ul style="list-style-type: none"> • High resilience • Comprehensive and integrated services - including Spirituality components for enhancement of care • Positive relationships between case management and supportive services • Social support from family and friends • High racial consciousness in the context of perceived racism • Addressing symptoms of depression

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