



The PrEP Care Continuum and Black Men Who Have Sex with Men: A Scoping Review of Published Data on Awareness, Uptake, Adherence, and Retention in PrEP Care

Ogochukwu Ezennia¹ · Angelica Geter² · Dawn K. Smith²

Published online: 28 August 2019

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Abstract

Pre-exposure prophylaxis (PrEP) has demonstrated high efficacy to reduce HIV infections, however, racial/ethnic HIV disparities continue among black MSM. The purpose of this review was to assess available data to inform interventions to increase PrEP awareness, uptake, and adherence among black MSM. Of the 3024 studies retrieved, 36 met final inclusion criteria and were categorized into the PrEP care continuum: (1) awareness (n = 16), (2) uptake (n = 9), and (3) adherence (n = 12). Only 26 of the studies presented analytical findings by race/ethnicity. Key barrier themes included cost, HIV-related stigma, and fear of potential side effects. A key facilitator theme identified by black MSM included gaining PrEP awareness from social and sexual networks. There are significant gaps in research on black MSM and PrEP utilization, especially regarding PrEP uptake and adherence. These data are needed to inform interventions to address current inequities in PrEP services, to help improve care outcomes for black MSM.

Keywords HIV · Men who have sex with men · Pre-exposure prophylaxis · Continuum of care · Black

Introduction

African American/black (hereafter referred to as black) gay, bisexual and other men who have sex with men (hereafter referred to as MSM) comprised 37% of new HIV diagnoses among MSM, and 26% of all persons diagnosed in 2017 [1]. Of the new HIV diagnoses among black MSM in the United States (U.S.), 63.4% occurred in the southern states as defined by the Centers for Disease Control and Prevention (CDC), in contrast to 44.9% of new HIV diagnoses among white MSM that occurred in southern states [2]. This

geographic disparity is reflected in the 2020 National HIV/AIDS Strategy, as a priority of the Strategy is to reduce disparities in the rate of new diagnoses among black MSM, in addition to people living in the southern states [3]. These disparities warrant considering black MSM, especially those residing in southern states, as a critical group to access and use daily oral antiretroviral pre-exposure prophylaxis (PrEP). PrEP, a biomedical HIV prevention method, reduces the risk of sexual acquisition by more than 90%, when taken with high adherence [4]. However, in 2015, black men comprised less than 10% of persons initiating PrEP use [5].

Data from most PrEP clinical trials, open label studies, and observational studies have included under-representative samples of black MSM. These studies included the Pre-exposure Prophylaxis Initiative (iPrEx trial) (9%, n = 214) [6], the PrEP Initiative Open Label Extension (8%, n = 125) [7], the CDC U.S. Extended PrEP Safety Trial (15%, n = 60) [8], the Demo Project (7%, n = 67) [9], the Kaiser Permanente Northern California cohort (4%, n = 41) [10], and the One Thousand Strong cohort (8%, n = 82) [11]. The few studies that included higher proportions had small numbers of black MSM, including Chan's three community study (49%, n = 109) [12], Project PrEPare-ATN 082 (53%, n = 31) [13], Project PrEPare-ATN 110 (47%, n = 93)

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s10461-019-02641-2>) contains supplementary material, which is available to authorized users.

✉ Dawn K. Smith
dks0@cdc.gov

¹ Rollins School of Public Health, Emory University, Atlanta, GA, USA

² Division of HIV/AIDS Prevention (DHAP), National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC), 1600 Clifton Rd NE MS E-45, Atlanta, GA 30333, USA

[14], and Project PrEPare-ATN 113 (29%, $n = 23$) [15]. The inclusion of large samples of black MSM in PrEP and HIV prevention research is essential for the development of effective programs, interventions, and policies that support its use in this population. It could also support progress towards national goals to increase access to PrEP services and promote PrEP knowledge, uptake, and retention in care among black MSM.

Similar disparities regarding access and use of PrEP among black MSM also occur within the scope of HIV treatment and engagement in care. Data suggests that social and structural barriers, such as poverty, stigma, homophobia, and institutionalized racism have a negative impact on engagement in HIV care among black MSM [16–19]. Black MSM are less likely to be diagnosed with HIV, be retained in care, be on antiretroviral therapy, and achieve viral suppression [20]. Factors associated with decreased engagement in HIV care among black MSM include the absence of conveniently located care facilities, services tailored to meet multiple patient needs, effective provider-patient communication, and providers who show empathy and respect for their patients [18]. It is equally as important to contextualize the availability of interventions and resources that investigate how these social and structural barriers may affect awareness, uptake, and adherence and retention of PrEP among black MSM.

Patient-focused PrEP continua of care have been proposed by several authors [11, 12, 21, 22], and some have been applied to cohorts with a significant proportion of black MSM [11, 12, 21]. PrEP continua offer concrete and measurable indicators to track the progress and utilization of HIV prevention services among people with vulnerability for HIV. For this analysis, we used three stages of a continuum

that are common to the several proposed in the literature: (1) awareness/acceptability: self-perceived HIV risk and barriers and facilitators of PrEP awareness and acceptability, (2) uptake: assess individuals at highest risk for acquisition of HIV, provide access to PrEP, linkage to care, and receipt of PrEP prescription or initiating PrEP, and (3) adherence and retention: adherence to daily PrEP medication use and retention in PrEP clinical care (Fig. 1). The following categories proposed within these continua were used to stratify results of the review: (1) PrEP knowledge and willingness (awareness), (2) prescription and initiation (uptake), and (3) adherence to PrEP prescription (adherence) and retention in care (retention). A scoping review is a type of systematic literature review that aims to synthesize knowledge in order to map key concepts, types of evidence, and research gaps in a field [23]. To better understand racial/ethnic disparities in PrEP utilization, a systematic scoping review of the literature was conducted. The review assessed the extent of available data, and identified gaps in actionable knowledge along a PrEP continuum of care, in order to inform actions to address the current inequitable awareness and use of PrEP services by black MSM.

Methods

Search Strategy

The systematic literature review was conducted through a search of databases: (1) PubMed, (2) Embase, (3) Cochrane Library and (4) CINAHL. We searched for studies on PrEP published between January 1, 2010 and October 31, 2018.

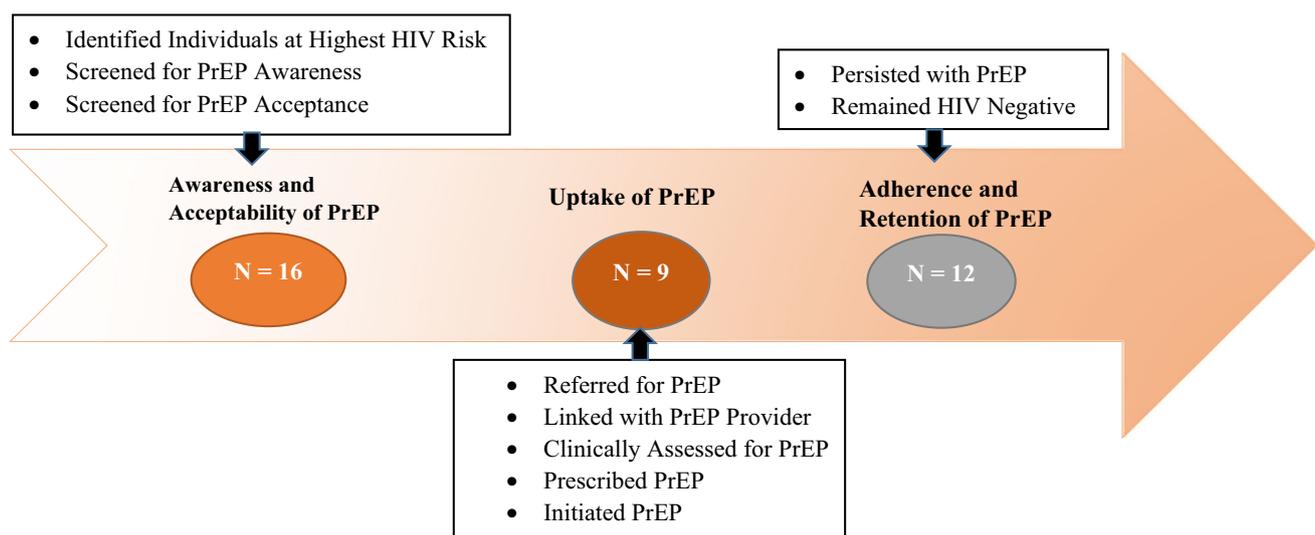


Fig. 1 PrEP Care Continuum. HIV Pre-Exposure Prophylaxis (PrEP) care continuum among black men who have sex with men, scoping literature review results, United States 2010–2018

Combinations of the following search terms were used across all databases: Pre-exposure prophylaxis, Chemoprevention, PrEP chemo-prophylaxis, Anti-HIV Agents, Anti-Retroviral Agents, HIV Infections, human immunodeficiency virus, antiretroviral, Truvada, tenofovir, and emtricitabine (see supplementary file).

Study Selection

The selection of publications included in the study analysis was conducted in six stages. First, duplicate search results were removed from the Endnote file that contained database search results, and remaining articles were compiled in a spreadsheet for the next stage of the review. Second, unpublished abstracts, dissertations, editorials, commentaries, and studies conducted outside of the U.S. were removed from the spreadsheet. Third, we limited the search results to studies focused on HIV, chemoprophylaxis, or PrEP through title and abstract review of the citations in the spreadsheet. Published quantitative and qualitative research studies that met the above inclusion criteria underwent a full-text review. Fourth, we coded for the data contained in each article into one of the following categories: (1) new clinical trial results, (2) new human observational study results, (3) new survey, focus group, or other behavioral study results, (4) new cost analysis results (e.g., program cost, cost–benefit analysis), (5) new modeling results (e.g., impact models), and (6) new laboratory human study results (e.g., drug levels, resistance), or (7) none of the above. Fifth, we limited the results of the review to studies with a substantial representation (35%) of black MSM (Fig. 2). Sixth, we categorized the data in each article within a PrEP care continuum [adapted from a continuum developed by Nunn et al. [22]].

Data Abstraction and Analysis

Two coders (O. E. and A.G.) made individual screening decisions and final decisions were made based on the above criteria. Coders abstracted information on study characteristics, participant demographics, PrEP continuum category, and major findings. The coders reconciled their results and conducted the final review of the literature. Data from each study were summarized in a table that highlighted the PrEP care continuum category, first author, year, location, study methods, sample size, and major findings (See Table 1). One of the articles was sorted into two categories within the continuum.

Results

Thirty-six studies met the inclusion criteria and were included in the final review to assess the categories of the PrEP care continuum (Fig. 2). The percentage of black MSM

within each study sample included the following proportions: 100% black MSM ($n = 10$) [24–33]; > 50% black MSM ($n = 14$) [13, 34–46]; 35–50% black MSM ($n = 10$) [12, 14, 47–54]; 100% in one modeling sample of black MSM ($n = 1$) [55] and 50% in a second modeling sample ($n = 1$) [56]. All of the included studies had a sample of at least 35% black MSM. Twenty-six out of 36 studies presented analytical findings specifically for the black MSM in their studies; the following is a summary of the results of those 26 studies [12, 14, 24–35, 40–42, 45–50, 54–56].

Awareness and Acceptability of PrEP

Seven studies identified facilitators of PrEP awareness and acceptability among black MSM [27, 31, 35, 42, 47, 50, 54]. Increased awareness of PrEP was associated with factors such as recent sexual activity, current PrEP use, disclosure of same-sex behavior to a medical provider [31], both older age [31] and younger age [42], recent condomless anal sex [31, 50], as well as having some college education and higher income [35, 42]. Moreover, black MSM who perceived a level of discrimination against persons with HIV were more likely to use PrEP to avoid this discrimination [35, 42]. Additional behavioral factors such as infrequent engagement in drug and alcohol use were also associated with increased awareness of PrEP [42]. Many black MSM saw PrEP as both an opportunity to engage in sex while using a non-condom HIV prevention method [47, 54], and as a way to allow for less anxiety when engaging in sex with an HIV-positive partner [47]. The social and sexual networks of black MSM were also identified as an influential source of information and valued perspective on PrEP utilization [27]. In the study conducted by Behler, Cornwell, and Schneider [27], findings showed a general increase in PrEP awareness among black MSM from baseline (32%) to follow-up (65%), as well as variations in reported knowledge of PrEP at follow-up: 59% of participants with black community affiliations compared to 81% in the Gay Enclave and 58% with Bridging affiliations. These findings further support the importance of social networks in developing knowledge and awareness of PrEP among black MSM.

Seven studies identified barriers to PrEP acceptability among black MSM [24, 26, 30, 34, 41, 48, 54]. These barriers included anticipated cost [24, 54], perceived effectiveness [24], medical distrust [26, 34, 41], misconceptions about who PrEP is for [41], gender-identity stigma [34], HIV-related stigma [26, 34, 48], and concerns about potential side-effects [34, 41, 54]. One study found that awareness of PrEP was low (33%) and 63% of the black MSM surveyed endorsed one or more of eight genocidal or treatment-related conspiracy beliefs presented [30]. Men who agreed with genocidal beliefs had a lower intention to adopt PrEP [adjusted odds ratio (aOR) 0.73, 95%

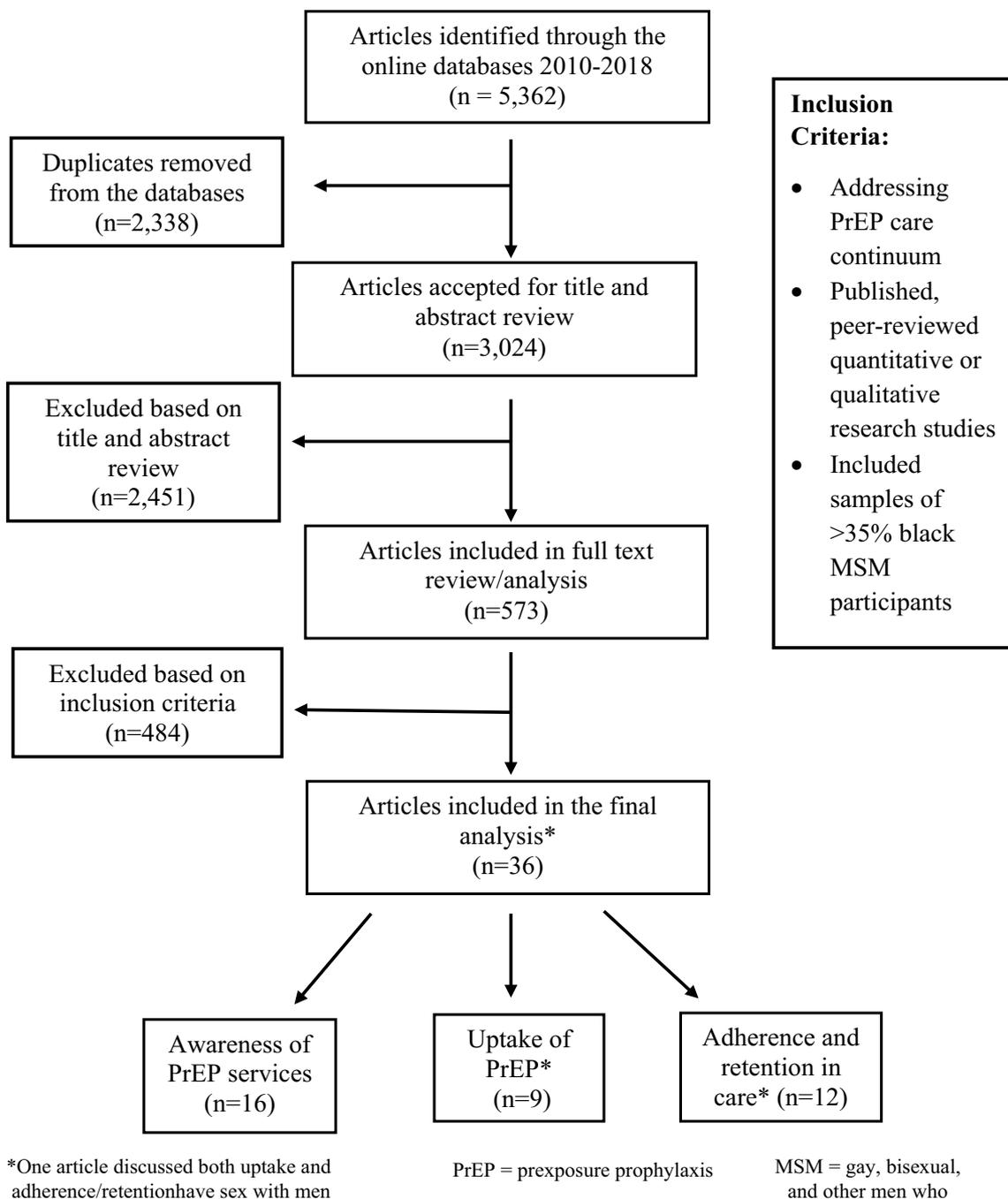


Fig. 2 Selection process for systematic review of the literature: PrEP uptake, awareness, adherence and retention among black MSM in the United States, 2010–2018

confidence interval (CI) 0.54–0.99] as did those with HIV/AIDS conspiracy beliefs (aOR 0.36, 95% CI 0.23–0.55) [30]. Many black MSM feared that PrEP would discourage men in their sexual networks from condom use and viewed PrEP as one of many options for HIV prevention [26, 41]. Cahill et al. [34] identified black MSM with inadequate knowledge of PrEP, and among those with adequate

knowledge, many of them cited limited interventions that prioritize MSM who identify specifically as heterosexual as a barrier to PrEP use. In addition to these barriers, Rolle et al. [54] identified that non-acceptability of PrEP was mostly associated with a lack of desire to take medication daily and reported condom use 100% of the time.

Table 1 Findings of systematic review of PrEP uptake, awareness, adherence, and retention among black MSM, United States, 2010–2018

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Awareness						
Arrington-Sanders et al. (2016) [31]	Multistate	Internet survey	147	147 (100%)	Yes	Black MSM had 39% PrEP awareness, 8% PrEP utilization, and 62% PrEP acceptability Awareness of PrEP was associated with older age, increased number of lifetime partners, recent sexual activity, current PrEP use, and disclosure to medical provider ($p < 0.05$) Willingness to use PrEP was associated with recent sexual activity, condom-less anal sex in the past 3 months, and higher perceived HIV risk ($p < 0.05$)
Behler et al. (2018) [27]	Chicago, IL	Individual interviews	618	618 (100%)	Yes	Increase of PrEP awareness among respondents between baseline and follow-up (32% at baseline and 65% at follow-up) Increase in PrEP awareness was greater among respondents with Gay Enclave affiliations (33% at baseline and 81% at follow-up) At follow-up, 59% of respondents with Black Community affiliations reported knowledge about PrEP, compared to 81% of respondents in the Gay Enclave cluster, 58% with Bridging affiliations, and 61% with Outsider affiliations
Brooks et al. (2012) [47]	Los Angeles, CA, Western, U.S.	Semi-structured interviews, Interviewer administered survey	25	10 (40.0%)	Yes	Black MSM disagreed with the PrEP belief—PrEP use would lead to less condom use ($M = 2.10$; $SD = 1.3$) 80% reported high acceptability of and willingness to take PrEP Facilitators of PrEP acceptability included: an opportunity to engage in sex while using a non-condom HIV prevention method, protection from HIV infection, and less anxiety when engaging in sex with an HIV-positive partner

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Brooks et al. (2018) [30]	Los Angeles, CA	Survey interview	224	224 (100%)	Yes	33% aware of PrEP 0 have taken PrEP 60% high intention to use PrEP Almost two-thirds of black MSM (63%) endorsed at least one of eight HIV/AIDS conspiracy beliefs presented In multivariable analyses, black MSM who agreed with the genocidal or treatment-related conspiracy beliefs scales had a lower intention to adopt PrEP [aOR) 0.73, 95% CI 0.54, 0.99 and AOR 0.36, 95% CI 0.23, 0.55, respectively] Black MSM had inadequate knowledge about PrEP
Cahill et al. (2017) [34]	Jackson, MS and Boston, MA	Focus groups	Group 1 = 15 Group 2 = 20	Group 1 = 2 (13.3%) Group 2 = 19 (95.0%)	Yes	Black MSM identified the following topics as barriers to PrEP utilization: potential side-effects, medical mistrust, gender identity stigma and HIV-related stigma
Crosby et al. (2014) [24]	MS, LA, AL, and GA	Internet survey	95	95 (100%)	Yes	Black MSM were willing to accept PrEP if it was 100% effective (71.0%) Black MSM were willing to accept PrEP if it cost \$100 (19.0%)
Fallon et al. (2017) [35]	Baltimore, MD	Interviewer administered survey	399	301 (75.4%)	Yes	Among men with no awareness of PrEP, 78.3% were black MSM Among men who were unwilling to take PrEP, 73.1% were black MSM Black MSM had 67% reduced odds of being aware of PrEP
Garnett et al. (2018) [42]	New York, NY, Northern U.S.	Interviewer administered questionnaire	1,673	1613 (96.5%)	Yes	Predictor of PrEP acceptance included HIV test results (OR 1.65); 95% CI (0.99–2.74) and perceived HIV-related discrimination (OR 1.60; 95% CI (1.01–2.54) 18.2% of participants reported PrEP awareness PrEP awareness was significantly associated with younger age, identifying as gay, higher education level, employment, income, stable housing, low levels of HIV stigma, less problematic drug use, and less harmful alcohol use

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Golub et al. (2017) [48]	New York, NY	Qualitative interviews; Cross-sectional survey	160	56 (35.0%)	Yes	Black MSM had a 2.88 odds of identifying HIV-related stigma as a barrier to PrEP utilization Black MSM had 81% reduced odds of identifying promiscuity or sexual stigma as a barrier to PrEP utilization No analytical findings by race/ethnicity were presented
Kubicek et al. (2015) [36]	Los Angeles, CA	Focus groups	53	30 (56.6%)	No	Findings indicate a lack of knowledge of biomedical interventions and high perceived acceptability Benefits associated with PrEP acceptability included the potential for user privacy, an ability to ensure one's safety, and benefits for serodiscordant relationships Drawbacks to PrEP acceptability included potential side effects, potential for misinterpretation of its use and cost, as well as challenges due to comorbidities
Mimiaga et al. (2016) [37]	Chicago, IL; Ft. Lauderdale, FL; Kansas City, MO	Individual interviews; focus groups	90	48 (53.3%)	No	No analytical findings by race/ethnicity were presented Most participants had no prior knowledge of PrEP Facilitators of PrEP awareness and utilization included having a perspective that PrEP was a supplement rather than a replacement for condoms, and messaging that included PrEP data Barriers of PrEP awareness and utilization, for HIV-positive men, was the belief that condom use was a more feasible form of HIV prevention than PrEP

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Mustanski et al. (2013) [50]	Chicago, IL	ACASI	171	81 (47.4%)	Yes	No significant difference in PrEP interest by race/ethnicity were identified (F(3166)=0.84, p=0.47) PrEP interest was negatively correlated with number of unprotected anal sex acts On average, YMSM were above “somewhat likely” to be interested in using PrEP Level of education was associated with PrEP interest: those with high school education or GED had less interest in PrEP than those with more education No analytical findings by race/ethnicity were presented 66% of participants had heard of PrEP or PEP 39% of participants knew someone who had used or is using PrEP or PEP Barriers to PrEP awareness and uptake: beliefs about PrEP conspiracy theories, HIV-related stigma Facilitators of PrEP awareness and utilization: prevention education programs, youth groups, health care providers, friends, or Internet
Mutchler et al. (2015) [38]	Los Angeles, CA	Demographic survey; qualitative interviews	48	42 (87.5%)	No	
Philbin et al. (2016) [26]	New York, NY	Qualitative interviews	31	31 (100%)	Yes	PrEP attitudes and beliefs among black MSM were analyzed across four ecological levels Individual level- participants had issues with potential side effects and giving medication to healthy people Interpersonal level- PrEP would discourage condom use and should be used as part of HIV prevention and not only method Community level- Lack of trust in pharmaceutical industry; PrEP was not meant for them Structural level-The need to overcome HIV and sexuality related stigmas first, before tackling PrEP

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Rolle et al. (2017) [28]	Atlanta, GA	Cross-sectional survey	482	219 (45.4%)	Yes	44.7% of black MSM would be willing to use PrEP Among black MSM, PrEP willingness was mostly associated with unprotected sex in the past and interest in additional ways to protect against HIV Other more closely associated reasons for PrEP willingness included unknown HIV status of sex partner, doctor recommendation, and counselor or healthcare worker recommendation Among black MSM, PrEP unwillingness was mostly associated with use of condoms 100% of the time, inability to afford medicine, and no desire to take medication every day Additional reasons that were closely associated with unwillingness to use PrEP included dislike of taking medication, preference to use other ways to prevent HIV, side effects, and other reasons
Thomann et al. (2018) [41]	New York, NY	Focus groups	24	16 (66.7%)	Yes	Various themes emerged among black MSM participants with regards to PrEP awareness and acceptability: misconceptions about who should take PrEP, mistrust of medical professionals and pharmaceutical companies, com-munication of HIV prevention, side effects, sexual and provider stigma, and need for tailored interventions and messaging around PrEP

Uptake

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Biello et al. (2018) [43]	Boston, MA; Chicago, IL; Los Angeles, CA	Focus groups	36	25 (69%)	No	No analytical findings by race/ethnicity were presented Among this sample of high-risk YMSM, while knowledge of and interest in PrEP was high, stigma, marginalization, and access to information presented as substantial barriers to broader uptake and adherence in the community Stigma related to perceived HIV status, marginalization due to same-sex sexual behaviors, and lack of adequate access to information regarding PrEP were suggested barriers to uptake of PrEP
Desrosiers et al. (2019) [32]	Washington, DC	RCT Randomized to either a PrEP or control counseling group Then encouraged to obtain PrEP from a PrEP provider	50	50 (100%)	Yes	At the end of the 3-month study, six participants in the intervention group, compared with none in the control group, had initiated PrEP (p = 0.02)
Downing et al. (2018) [44]	National	Online survey	652	332 (51%)	No	No analytical findings by race/ethnicity were presented PrEP aware 79.8% Ever used PrEP 12.1% Believe that PrEP users don't need to use condoms (14.6%)
Kuhns et al. (2017) [49]	Chicago, IL; Houston, TX	Computer-assisted personal interviewing	394	193 (49.0%)	Yes	Black MSM had an 84% reduced odds of PrEP uptake compared to white MSM
Pines et al. (2014) [51]	Baltimore, MD; Chicago, IL; Los Angeles, CA; Pittsburgh, PA	ACASI	419	177 (42.2%)	No	No analytical findings by race/ethnicity were presented Three sexual risk trajectory groups were identified: low risk (N = 264; 63.0%), moderate risk (N = 96; 22.9%; mean duration of consecutive high-risk intervals ~ 1 year), and high risk (N = 59; 14.1%; mean duration of consecutive high-risk intervals ~ 2 years)

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Rolle et al. (2017) [54]	Atlanta, GA	Prospective cohort	184	184 (100%)	Yes	53% of participants had heard of PrEP prior to EleMeNT PrEP program The most common reason for interest in PrEP uptake was the possibility of having sex without condoms in the future The most common reason for disinterest in PrEP uptake was consistent condom use Those who did not initiate PrEP uptake cited daily adherence as a reason for disinterest
Smith et al. (2012) [29]	Atlanta, GA	Focus groups	77	Groups 1 and 2 = 19 (100%)	Yes	Black MSM identified convenience of locations that dispense PrEP, and possible mail order prescription of PrEP as facilitators to PrEP uptake Black MSM identified potential side effects, cost, low perceived susceptibility, and specific fear of risk compensation as barriers to PrEP uptake
Taylor et al. (2014) [52]	Boston, MA	Focus groups	39	Group 1 = 5 (25.0%) Group 2 = 12 (63.2%)	No	No analytical findings by race/ethnicity were presented Barriers: Mental health concerns and substance use/abuse Facilitators: Daily rituals; anticipatory changes in schedules; external reminders (text messages); perceived freedom from condom use; perceived safety within serodiscordant relationships
Adherence and retention Arrington-Sanders et al. (2018) [31]	Multistate	Open-label study	262	144 (55%)	Yes	Black males were less likely to have sub-protective levels than non-Black males at 4, 8, 12 weeks Self-reported displacement due to sexual orientation was associated with sub-protective levels while older age was associated with protective levels
Chan et al. (2016) [12]	Providence, RI; Jackson, MS; St. Louis, MO	Medical record review of patients prescribed PrEP; Longitudinal approach was used to measure adherence and retention	267	Site 1 = 8 (6.8%) Site 2 = 63 (71.6%) Site 3 = 38 (61.3%)	Yes	Black MSM had 1.32 odds of starting PrEP Black MSM had 87% reduced odds of retention in PrEP care after 3 months Black MSM had 26% reduced odds of retention in PrEP care after 6 months

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Daughtridge et al. (2015) [39]	Philadelphia, PA	Prospective cohort	23	13 (57.0%)	No	No analytical findings by race/ethnicity were presented 4 weeks—73% adhered to PrEP prescription 16 weeks—69% adhered to PrEP prescription 24 weeks—69% adhered to PrEP prescription 28 weeks—88% adhered to PrEP prescription
Garcia et al. (2016) [25]	New York, NY	Qualitative interviews	31	31 (100%)	Yes	Barriers to PrEP acceptance included HIV-related stigma as well as gender-identity stigma from social and sexual networks Barriers to PrEP adherence included a perceived lack of self-efficacy to accurately and consistently use PrEP, perceived lack of self-control, and personal agency
Hamilton et al. (2018) [56]	Atlanta, GA	Stochastic, dynamic, network model	10,000	5,000 (50%)	Yes	At modeled coverage and adherence, PrEP could avert 3% to 20% of infections among black adolescent MSM PrEP was efficient among Black MSM, with the number needed to treat (NNT) to avert an infection of 25–32

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Havens, et al. (2017) [40]	Multistate	Open-label study	101	52 (51.5%)	Yes	<p>Significant differences by race/ethnicity based on baseline drug exposure ($p=0.009$)</p> <p>Compared with low drug exposure, high-exposure participants showed increase from baseline in parathyroid hormone levels and decline in fibroblast growth factor 23 by study week 4, with no differences in creatinine, phosphate, or transient receptor potential channels</p> <p>At 48 weeks, the median (interquartile range) percent decline in total hip bone mineral density was greater in those with high- compared to low- exposure [-1.59 (2.77) vs $+1.54$ (3.34) %, respectively; $p=0.001$]</p> <p>In high-exposure participants, this correlated with week 4 TFV-DP (inversely; $r=-0.60$, $p=0.002$) and fibroblast growth factor 23 (directly; $r=0.42$; $p=0.039$) but no other variables</p>
Havens et al. (2018) [46]	Multistate	Open-label study	69	37 (54%)	Yes	<p>In multivariable models, compared to other races, black race ($p=0.021$) was significantly associated with bone toxicity after 48 weeks of TDF/FTC PrEP in YMSM. OR 5.0 (CI 1.3–23.6) $p=0.021$</p>
Hosek et al. (2017) [15]	Multistate	Open-label study	200	93 (46.5%)	Yes	<p>At week 4, 56% of participants had TFV-DP levels consistent with ≥ 4 pills per week. By week 48, 34% of participants had TFV-DP levels consistent with ≥ 4 pills per week, with a noticeable drop-off occurring at week 24</p> <p>Four HIV seroconversions occurred on study (3.29/100 person-years)</p> <p>Condomless sex was reported by 81% of participants and condomless anal sex with last partner was associated with higher TFV-DP levels</p> <p>Median levels of TFV-DP among black MSM were below protective threshold of ≥ 4 pills per week across all time points</p>

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Koester et al. (2015) [53]	Boston, MA Chicago, IL; San Francisco, CA	In-depth interviews	59	26 (44.1%)	No	No analytical findings by race/ethnicity were presented Facilitators to PrEP adherence included receiving detectable drug lab results Barriers to PrEP adherence included stigma associated with not-detected (non-adherence) results 57% of patients did not show up at an initiation visit
Serota et al. (2018) [33]	Atlanta, GA	Observational cohort	178	178 (100%)	Yes	4 seroconversions, 1 after PrEP initiation with high adherence, 1 with low adherence, and 2 after they discontinued PrEP
Smith et al. (2015) [55]	National	Deterministic modeling	10,000	10,000 (100%)	Yes	Black MSM who never use PrEP: an estimated 323 annual HIV infections would occur among those who always use condoms, 1007 among sometimes condom users, and 1094 among never condom users Black MSM who never (or inconsistently) use condoms: 295 (272) infections would occur among those who report at least 90% PrEP adherence and 744 (684) infection occur with less than 50% adherence Black MSM who are consistently (or sometimes) taking PrEP: the highest protection is seen with consistent condom use, 87 (220) HIV infections Estimated HIV prevention effectiveness of consistent PrEP and condom use is 92%, exceeding prevention effectiveness rate of consistent PrEP use alone (73%) and consistent condom use alone (70.5%)

Multiple PrEP categories

Table 1 (continued)

First author, year	Location of study population	Methodology	N	N (%) Black MSM	Major findings by race and ethnicity	Major findings
Hosek et al. (2013) [13]	Chicago, IL	Randomized 3-Arm clinical trial TDF/FTC; placebo; or no pill All received Many Men, Many Voices	58	31 (53.5%)	No	<p>Uptake: No significant differences by race/ethnicity were identified</p> <p>Unwillingness to take PrEP if it had to be taken more than once a day ranged from 0 to 38% ($p=0.003$)</p> <p>Willingness to take PrEP if partner was HIV+ ranged from 17 to 62% ($p=0.02$)</p> <p>Adherence and retention: No analytical findings by race/ethnicity were presented</p> <p>Rates of detectable tenofovir in participants in the FTC/TDF arm was 63.3% at week 4 and 20% at week 24</p> <p>Self-reported medication adherence averaged 62% (range 43–83%)</p> <p>No statistically significant difference in self-reported adherence between two study pill arms (placebo vs TDF/FTC)</p> <p>In the FTC/TDF arm, the median number of doses missed (out of possible 30) was 10, with a range from 5 missed doses (weeks 16 and 20) to 17 missed doses (week 24). Similar fluctuations occurred in the placebo arm with a range from 6 missed doses (week 24) to 19 missed doses (week 16)</p>

PrEP preexposure prophylaxis, N number, MSM gay, bisexual and other men who have sex with men, US United States, OR odds ratio, CI confidence interval, GED general education diploma, YMSM young MSM, PrEP post-exposure prophylaxis, ACASI audio computer-assisted interview, TDF tenofovir disoproxil fumarate, TFV-DP tenofovir diphosphate, FTC emtricitabine, M mean, SD standard deviation, FF statistic, RCT randomized clinical trial, r correlation coefficient

Uptake of PrEP

One small, pilot randomized trial of 50 black MSM, evaluated the impact of the C4 PrEP counseling intervention (from HPTN 073) against a control on initiating PrEP [32]. Most men in both arms did not successfully initiate PrEP use, however, six in the PrEP counseling arm, compared to zero in the control group, initiated PrEP ($p=0.02$) [32]. Only four in the PrEP counseling arm were still taking PrEP at 3 months [32]. Two of the studies that were reviewed discussed facilitators and barriers for PrEP uptake among black MSM [28, 29]. Of the black MSM who participated in the optional PrEP program supplement of the EleMEnt study, 53% had heard of PrEP prior to the program [28]. The most common facilitator of PrEP uptake among black MSM was the possibility of having sex without condoms in the future [28]. The most common barrier to PrEP uptake among black MSM was consistent condom use [28]. Those who did not initiate PrEP uptake (10%, $n=18$), cited daily adherence as a reason for disinterest in initiating PrEP [28]. In addition to these results, in the study conducted by Smith et al. [29], black MSM reported convenience of locations that dispense PrEP, and possible mail order prescription of PrEP as facilitators to uptake of PrEP. However, cost, potential side effects, low perceived susceptibility for HIV infection, and fears of risk compensation among peers were identified as major barriers to PrEP uptake among black MSM participants [29]. Uptake of PrEP among black MSM was also consistently low when compared to other races [49]. Black MSM had an 84% reduced odds of PrEP uptake when compared to white MSM study participants ($p=0.001$), with no evidence suggesting any increase in PrEP use over the course of the study period [49]. Again, the social and sexual networks of black MSM were identified as an influential source of information and valued perspective on PrEP uptake [49].

PrEP Medication Adherence and Retention in PrEP Care

Five studies examined PrEP medication adherence and retention in PrEP care [12, 25, 33, 55, 56]. Chan et al. [12] found high levels of self-reported PrEP medication adherence, with adherence rates ranging from 72 to 81% over a 6-month period, providing usual clinical care without a specific adherence intervention. A decrease in retention in PrEP care among MSM also occurred, ranging from 73 to 60% over a 6-month period [12]. Another study identified facilitators and barriers of adherence to PrEP medication and retention in PrEP care [25]. Negative support from social networks affected self-worth and was identified as a barrier to retention in PrEP care, which many of the men believed was crucial for men to engage with HIV prevention methods

such as PrEP [25]. An open label study with black MSM in Atlanta, found difficulty with completing PrEP initiation visits and with low persistence in PrEP care [33]. Incident infections were observed in non-adherent and non-persistent patients [33]. One modeling study estimated the number of HIV infections that would be prevented among 10,000 black MSM based on series of combinations in PrEP adherence and condom use over 1 year [55]. Smith et al. [55] estimated that among black MSM who never used PrEP: 323 infections would occur among those who always use condoms, 1007 among those with intermediate condom use, and 1094 among those who never use condoms. On the other hand, among black MSM who never use condoms, with 90% PrEP adherence, 295 infections would occur, and 744 infections would occur with less than 50% PrEP adherence [55]. Among black MSM who consistently used condoms with 100% PrEP medication adherence, only 87 new HIV infections were estimated to occur [55]. A second modeling study estimated the number of HIV infections averted among black adolescent MSM across 26 scenarios of coverage in the modeled population with varied levels of medication adherence [56]. The model found that 2–20% of infections could be averted with a median number needed to treat of 26.9 to 32.3 [56].

Four studies examined adherence to PrEP through measured drug levels in participants over time [14, 40, 45, 46]. ATN 110 provided PrEP to MSM ages 18–22, of whom 93 (46.5%) were black MSM [14]. In ATN 110, there were no differences by race for biologic variables (side effects, renal health) or sexual behaviors, but medication adherence was significantly lower for black MSM than MSM of other race/ethnicities [14]. Median PrEP drug levels were below the protective threshold level of ≥ 4 pills/week for black MSM participants [14]. The authors suggested additional studies are needed of potential racial differences in the pharmacokinetics of drug levels assessed by dried blood spots. ATN 117- a sub study of ATN 110 and ATN 113-evaluated metabolic factors and bone density response to PrEP use and included 51.5% black MSM ($n=52$) [40]. Fewer black MSM had high drug exposure, due to lower adherence, and high drug exposure was associated with declines in bone mineral density from baseline to week 48 at the hip [40]. Of the two clinical trials for which ATN 117 [40] was a sub study, only ATN 110 [14] published statistical data by race; ATN 113 [15] did not. An open-label observational study of adolescent and young adult MSM taking PrEP accompanied by a counseling intervention, found that black MSM had blood drug levels indicating lower levels of protective medication adherence (at least 4 doses per week) than for youth of other race/ethnicities [45]. At 12 weeks, sub-protective levels were found in 55.6% of black youth and 31.5% of non-black youth ($p=0.001$) [45]. Among black youth only, at 12 weeks, those who reported having been kicked out of their housing were

86.8% less likely to have protective levels of adherence than those reporting being stably housed [45]. In multivariable analysis, black race, compared to non-black race/ethnicities, was significantly associated with bone toxicity at 48 weeks, OR 5/0 (95% CI 1.3–23.6) [46].

Discussion

In this scoping review we identified a limited number of published studies ($n=36$) that assessed PrEP use among black MSM along an adapted PrEP continuum of care: awareness and acceptability of PrEP ($n=16$), uptake of PrEP ($n=9$), and adherence and retention to PrEP care ($n=12$), including one study that contributed to two categories. Of these studies, 26 presented findings by race/ethnicity specifically for black MSM. To our knowledge, this is the first systematic scoping review that assesses the extent and content of literature specifically regarding PrEP for black MSM, as stratified along a PrEP care continuum.

In our findings, we have identified a fundamental issue within research conducted among various racial/ethnic populations. Data are often presented with very general and overarching conclusions, without presenting findings specific to racial/ethnic populations included in a multiracial sample. Being explicit and interpreting results in a way that represents the demographic characteristics of participants can be important in providing critical race-specific context about the experiences of the participants that may be associated with the outcomes. Although black MSM are currently facing the highest burden and not experiencing declines in new diagnoses of HIV infection in the U.S. [1], there is overall significant lack of data reported for black MSM as participants in biomedical HIV research studies, as evidenced through this review. In addition, while there is geographic variability in the published studies, to date, nearly all studies are urban and not reflective of the geography of the HIV epidemic among black MSM.

Moreover, we must acknowledge the scarcity of research publications that met our inclusion/exclusion criteria of having $\geq 35\%$ study population who self-identify as black. Many of the studies that include black MSM do not include a sample size that is generalizable to the broader population of black MSM. The onus falls upon public health researchers and practitioners to make the concerted effort to be strategic when conducting biomedical HIV prevention research that focuses on minority populations. Intentional inclusion of greater numbers of black MSM in PrEP studies is essential for the results generated from such research to be applicable to those who will benefit most from expanded and sustained access to and utilization of PrEP. Presenting key data and findings by race/ethnicity increases the availability of information needed to develop race/ethnicity informed

interventions and programs to address HIV prevention among populations most at risk, including black MSM.

The findings of our review suggest that some studies reported that social and structural determinants of inadequate health, including limited patient-provider communication, HIV-related stigma by health professionals and social networks, cost, and medical distrust, contributed significantly to the challenges of delivering PrEP to black MSM at the levels indicated by the rate of HIV acquisition among them. Studies from our review also suggest social and structural factors such as quality and continuity of care, access to care, perceived HIV vulnerability, and influence of social and sexual networks should be considered to promote PrEP awareness, uptake, as well as medication adherence and retention in care.

A gap also exists in conducting research that addresses PrEP along each point of the PrEP care continuum. Most of the studies identified through this scoping review focused on awareness of PrEP, with little attention paid to the importance of uptake of PrEP and maintaining adherence to PrEP. Further research to understand each point along the adapted PrEP care continuum is critical to developing effective PrEP interventions and to measure progress in PrEP implementation [21, 22].

Although awareness of PrEP was the most frequently researched category of our review, data are still limited with regards to generalizability of findings to black MSM. Similarities in findings among these studies showed that social networks and support are important to increasing awareness to PrEP [26, 27, 41], as well as increasing uptake and adherence [25, 49]. Yet, few studies were found that present data demonstrating how social networks can be utilized to fill in the gaps related to uptake and adherence. These findings point to a need for more targeted research using existing social networks and/or building more social networks for the purpose of moving black MSM through the PrEP care continuum for optimal HIV prevention results.

The process of PrEP uptake, as measured along the PrEP care continuum, includes being referred for PrEP, linking with a PrEP provider, being clinically assessed for PrEP, being prescribed PrEP, and initiating PrEP. During this process, providers are able to assess possible disengagement from care among patients who may not fill their PrEP prescriptions or return for refill appointments [22]. Studies included in this scoping review discussed possible barriers to PrEP uptake, however, the number of studies was small, with only four presenting findings that were specific to black MSM [28, 29, 32, 49]. Without sufficient data regarding PrEP uptake among black MSM, it will be difficult to develop effective PrEP interventions targeted to increasing and measuring their uptake of PrEP.

Studies of medication adherence and retention in clinical PrEP care were also fewer than those that assessed PrEP

awareness. It has been established that HIV prevention effectiveness of PrEP is dependent on near daily medication adherence [21]. As adherence increases, the potential for HIV infection decreases [55], which is the primary goal of PrEP use. However, as established in studies in our review, black MSM are not achieving adherence levels and protective thresholds for PrEP medication shown to be most effective in preventing HIV infection [14, 40]. Adherence and retention interventions are important to ensure that PrEP is taken daily and for as long as needed. More data are needed to address the low adherence levels and rates of retention in PrEP care among black MSM, taking into account possible barriers and facilitators to improve adherence and retention.

Limitations

This study had several limitations. Peer-reviewed articles that would be deemed eligible for inclusion based on our criteria may have been missed due to our cutoff date of October 31, 2018. Additional studies that may have been relevant and eligible could have been published after this date. Also, although all final selected articles met inclusion criteria, ten of those studies did not produce results specifically stratified by race/ethnicity. This reduced the number of studies with race-specific findings. Finally, there were issues with fluidity with regards to the content of selected articles and which category within the adapted PrEP care continuum into which they could be classified. One of the articles was sorted into two categories within the continuum, while others were more appropriately categorized in only one.

Conclusions

Our findings from this scoping review demonstrate the scarcity of available data to inform critical understanding of PrEP awareness, uptake, and adherence and retention among black MSM along the PrEP continuum of care. The relatively small body of research does not provide adequate insight into the perspective and experiences of black MSM. Among the estimated 1.1 million American adults with indications for PrEP use, 309,000 (38%) are black MSM [57]. Jenness et al. [58], have very recently estimated that for HIV incidence in black MSM to decline to the same level as for white MSM in Atlanta, it would require that black MSM have more than twice the awareness, use, and adherence to PrEP as currently observed for white MSM. Given the disproportional rates of HIV infection among black MSM in the U.S., it is imperative that we understand the multiple reasons why PrEP uptake by black MSM has not occurred at the pace that it has among other populations. These data are essential to build more effective PrEP messages, programs,

and interventions for this population. Researchers and practitioners must be intentional about using the most appropriate recruitment and analytical methods to assess and report data that are specific to the experiences of black MSM. This approach to improve PrEP use and retention in care is vital, especially in the Southern U.S. where HIV incidence, prevalence, and mortality rates, as well as racism, discrimination, stigma, and other social barriers to care disproportionately effects the lives of black MSM. Moreover, the PrEP care continuum is crucial in understanding stages where evidence-based interventions are most needed. Recently, a federal plan to end HIV in the U.S. over the next 10 years has been proposed; a key component of which is rapidly expanding PrEP providers and utilization [59]. To address the current disparities in PrEP use, more focus should be placed on developing research that considers all processes across the continuum for black MSM.

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