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“It’s very inconvenient for me”: A Mixed-Method Study Assessing Barriers and Facilitators of Adolescent Sexual Minority Males Attending PrEP Follow-Up Appointments

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Abstract

Researching PrEP retention in adolescent sexual minority men (ASMM) is critical to increasing persistence of PrEP in this priority population, yet this research is lacking. ASMM (N=1433) completed a baseline survey for an online HIV prevention program between 2018–2020. Open- and closed-ended survey items identified their beliefs about attending 3-month PrEP follow-up appointments and examined the association of Andersen’s Behavioral Model factors (predisposing, enabling, and need) and confidence to attend these appointments. Qualitative and quantitative findings show that perceived parental support is a salient factor in ASMM attending PrEP follow-up appointments. Participants did not want to have to go to the doctor and get bloodwork done trimonthly, and qualitative findings elucidated rationales for this, such as perceptions that follow-ups might be time-consuming, costly, and could out their sexuality to their parents. This study suggests that parents are gatekeepers for ASMM to initiate and sustain the PrEP care continuum.

Keywords

PrEP; retention; adolescent; sexual minority men; mixed-methods

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Introduction

In the US, adolescent sexual minority males (ASMM) account for 79% of new HIV infections among adolescents aged 13–19 years old¹. Because ASMM are disproportionately affected by HIV, the U.S. Food and Drug Administration approved pre-exposure prophylaxis (PrEP) for adolescents in May 2018². PrEP, under the brand names of Truvada® or Descovy®, is a biomedical HIV prevention method that is currently approved as a daily oral pill. PrEP is over 90% effective at preventing HIV acquisition^{2,3} and could avert up to 70% of new HIV infections among ASMM^{4–6}. PrEP is a promising strategy to address the prevention pillar of the Ending the HIV Epidemic (EHE) plan, a national initiative to end the HIV epidemic in the U.S. within the next ten years⁷.

The PrEP care continuum consists of five stages: (1) awareness, (2) willingness to use, (3) access, (4) adherence, and (5) care retention^{8–12}. The limited PrEP research that does sample ASMM^{12–20} overwhelmingly investigates the earlier care continuum stages: awareness, willingness to use, and uptake. Although this crucial research can inform the development of adolescent-tailored interventions that increase ASMM's usage of PrEP, the PrEP care continuum expands beyond the first visit where PrEP is initially prescribed. In other words, the PrEP care continuum is an iterative rather than a linear process of health care utilization. Once ASMM finish their regimen of PrEP, they must decide if they want to persist in the PrEP continuum. It is uncertain if adolescents understand the maintenance phase of PrEP. Ideally, after 3-months of receiving PrEP, ASMM will have a (1) HIV serostatus assessment, (2) side effect assessment and management, (3) medication adherence assessment and adherence counseling, and (4) HIV risk behavior assessment and harm-reduction counseling²¹. These appointments should occur every three months while individuals are on PrEP, and failure to attend these appointments could result in delay of receiving future PrEP regimens, discontinuation of PrEP, or loss to HIV prevention and care services. The care retention stage is salient because it is a gateway to HIV prevention or care continua, depending on assessment results. It is essential to understand factors associated with care retention among ASMM to ensure ASMM can continue to sustain PrEP, ultimately decreasing HIV incidence in this population.

PrEP retention of care studies are limited and none to date have explored retention in care factors among ASMM. The Andersen's Behavioral Model of Health Services could provide insight into factors that promote or hinder PrEP persistence. The Andersen Model^{22,23} is a health care utilization model that explains three overarching factors that facilitate or hinder people using health care services: *predisposing factors*, *enabling factors*, and *need factors*. *Predisposing factors* include demographic characteristics and beliefs, such as age, race/ethnicity, or attitudes about the illness or health service. Age is a prominent predisposing factor in PrEP retention, with those 18–24 years old^{24,25} and less than 30 years old²⁶ less likely to be retained in PrEP compared to those in older age groups. Similar conclusions have found PrEP discontinuation to be associated with young age, student status, and completing only and less than a high school diploma^{27–33}. Adolescents' and adults' beliefs about PrEP retention are unknown. *Enabling factors* include financial, organizational, and social characteristics that make the health service easier or harder to utilize, such as availability, cost, and family support. Adult patients without insurance are less likely to

persist in PrEP care^{24,25,34}. Although some teens may be able to initiate PrEP on their own, the additional cost and logistical factors (e.g., transportation) associated with long-term PrEP maintenance may be highly dependent on enabling factors—all of which often depend on their parents/guardians. Indeed, cost^{11,28,29,32,33,35} and parental support^{12,15,20,36–38} are factors that either facilitate or hinder PrEP use and discontinuation. *Need factors* include perceived and evaluated needs to use the health care resource, such as subjective health status (perceived need) or professional diagnosis (evaluated need). Research has described that believing one is a candidate for PrEP might be correlated with people's motivation to use PrEP^{12,15}.

It is critical to understand factors that either facilitate or hinder ASMM engaging in PrEP follow-ups to inform adolescent-tailored PrEP persistence interventions. It is also necessary to understand ASMM's beliefs about PrEP follow-up appointments and align those beliefs with Andersen's Model, ultimately informing factor-specific interventions. We conducted a mixed-method study informed by the Andersen's Behavioral Model of Health Services^{22,23} to (1) examine the association of predisposing, enabling, and need factors and the confidence to attend 3-month PrEP follow-up appointments and (2) identify ASMM's beliefs about attending 3-month PrEP follow-up appointments.

Methods

Data Collection

Data were collected between July 2018 and July 2020 ($N = 1433$) as part of a baseline survey of SMART³⁹, an ongoing pragmatic trial of an online HIV prevention intervention for racially-diverse ASMM across the United States and Puerto Rico. Eligibility criteria for SMART included: (1) being 13–18 years old; (2) being assigned male at birth; (3) identifying as gay, bisexual, queer, or attracted to cisgender men; (4) having prior sexual contact with a person; (5) being able to read, write, and speak English or Spanish; (6) having consistent Internet access; and (7) self-reporting an HIV-negative or HIV-unknown status.

We followed the steps within the CAN-DO-IT Model⁴⁰ to enhance recruiting a racially/ethnically diverse sample. Social media ads featured racially/ethnically diverse youth; we regularly consulted with youth advisory councils that included racial/ethnic minority youth about recruitment strategies; and we had dedicated recruitment/retention staff who had experience recruiting youth of color for online studies. Participants were recruited via free and paid social media campaigns (e.g., Facebook, Instagram, Twitter) and participant registries maintained by the research team. Nearly all knew about the study via social media (97%, $n = 1386$). Those interested in the study clicked on a URL to an online screener. Those who met eligibility criteria were routed to an online consent form, after which they completed four capacity to consent questions that assessed their understanding of the research procedures. A brief phone call or video chat was scheduled with research staff to confirm participant eligibility, consent capacity, and complete enrollment. If participants were confirmed as eligible during this call, they were emailed a URL to the baseline survey that was hosted on REDCap^{41,42}. Data were collected using a computer-assisted self-interview, and participants were paid \$25 for their time. All procedures were approved by the Northwestern University institutional review board, with waivers of parental permission

to reduce sampling bias for youth who were not out to their parents/guardians and to reduce the risk of youth being victimized by their parents/guardians for their sexual minority status^{43,44}.

Measures

Sociodemographic characteristics.—Participants completed items assessing age, race and ethnicity, ZIP code, sexual orientation, disclosure (i.e., outness) to parents, and parental acceptance of sexual orientation. Geographic region and rurality/urbanity was derived from participants' home addresses. The Rural-Urban Commuting Area Code⁴⁵ determined rurality/urbanity. Zip codes were urban if they fell within an urbanized area (UA), and at least 30% of residents commuted to an UA. For analysis, race/ethnicity was collapsed to African American/Black, Hispanic/Latinx, White, and Multiracial/other, and sexual orientation was collapsed to gay, bisexual, and other.

Sexual history and sexual health care.—Participants completed items assessing their sexual history. Items included lifetime number of condomless anal sex (CAS) partners, lifetime number of anal sex partners, and lifetime number of HIV-positive or HIV-unknown sex partners. These items were dichotomized (no/yes). Sexual history questions determined if participants were PrEP candidates. Participants were classified as PrEP candidates if they were HIV-negative or HIV-unknown, reported at least one lifetime male anal sex partner, and met at least one of the following criteria: lifetime CAS with a male partner, lifetime STI diagnosis, or any sex with an HIV-positive male partner in the last three months. This metric is different compared to the CDC PrEP candidacy criteria²¹ because we did not ask about sexual behaviors in a six-month timeframe. Participants completed items assessing their sexual health care experiences. Items included lifetime HIV and STI testing (*no, yes, don't know*), whether they had a parent with them when they were tested for HIV and STIs (*no, sometimes, yes*), and their confidence they could get HIV and STI tested where they live (1 = *not at all confident*, 4 = *very confident*). Participants were asked if they have a regular doctor (*no/yes*) and saw a provider for sexual health issues in the last 12 months (*no/yes*).

PrEP awareness, use, and barriers.—Participants were given a brief description of PrEP: “PrEP (pre-exposure prophylaxis) is a medication that prevents people from getting HIV. PrEP involves HIV-negative guys taking a pill once a day, every day, to reduce your chances of getting HIV if you come into contact with the virus. People on PrEP go to a doctor or medical provider every 3 months for HIV/STI testing, bloodwork, and a new 3-month prescription for PrEP.” After reading this statement, participants completed items assessing their awareness, use, and barriers to using PrEP^{11,46}.

First, participants were asked if they had ever been on PrEP (*no/yes*) and if they had heard of it before this study (*no/yes*). Those who have heard of PrEP were asked where they first heard about it (e.g., a doctor, a friend). Those who were not on PrEP were asked why they were not on it (e.g., I cannot afford it, I do not want to have to go to the doctor and get bloodwork every three months). Second, participants reported if they thought PrEP was right for them (1 = *definitely yes*, 5 = *definitely no*). We refer to this as “attitudinal PrEP fit.”

Third, they reported their intention to take PrEP, if they would take PrEP if it were free, and if they would take PrEP if they could get it for free and without their parents knowing (1 = *definitely yes*, 5 = *definitely no*). Participants were asked how they thought their parents would react if they took PrEP (1 = *very unsupportive*, 4 = *very supportive*). Finally, participants rated their confidence they could get PrEP where they live (1 = *not at all confident*, 4 = *very confident*). Participants were given a brief description of the 3-month PrEP appointments: “When you start taking PrEP, most doctors require that you go to the doctor’s office every 3 months to get tested for HIV and sexually transmitted diseases and to get bloodwork done.” Participants reported their confidence they could attend these appointments (1 = *not at all confident*, 7 = *extremely confident*).

Perspectives on 3-month PrEP follow-ups.—After the brief description of the 3-month PrEP appointments, participants answered their beliefs about going to 3-month PrEP appointments with the open-ended question: “What do you think might be some of the good and bad things about going to these doctor appointments every 3 months?”

Quantitative Analysis

Descriptive analyses of sociodemographic characteristics, sexual history and health care characteristics, and PrEP characteristics were performed. We noted when sample sizes varied due to missing data. Multivariable linear regression was conducted to examine the association between Andersen Model factors and confidence to attend 3-month PrEP appointments. The outcome variable was a 7-point item assessing “How confident are you that you would be able to attend these doctor appointments every 3 months?” (1 = *not at all confident*, 7 = *extremely confident*). Variables included in the regression model were informed by the Andersen Model^{22,23,47} and prior PrEP retention studies.^{24–26,34,48} *Predisposing factors* were age (14 or younger as a reference group), race/ethnicity (White as a reference group), sexual orientation (gay as the reference group), and attitudes about going to the doctor and getting bloodwork every three months. *Enabling factors* were confidence to get HIV tested where they live, attitude about PrEP’s affordability, parental support of taking PrEP, and rurality (urban reference group). *Need factors* were if participants saw a provider in the last 12 months for sexual health, attitudinal PrEP fit, and PrEP candidacy.

Qualitative Data Analysis

The qualitative analyses illustrated teens’ perceptions of the advantages and disadvantages of attending trimonthly PrEP appointments that expanded on quantitative findings. An inductive content analysis⁴⁹ was used to identify prevalent beliefs of what “good/bad things” might happen if participants went to trimonthly PrEP appointments. Two coders were involved in the qualitative analysis. A total of 1433 participants responded to the open-ended question. The first coder translated responses from Spanish to English ($n = 74$). The two coders independently read responses to gain familiarity with the data. The coders discussed open-codes, combined open-codes with similar content to form categories of beliefs, and developed a codebook based on these categories. The codebook included a definition of the belief, inclusion and exclusion criteria, and example excerpts. The coders independently coded the first 20% of responses ($n = 287$) with the codebook. The second coder conducted an interrater reliability test in SPSS⁵⁰, with a kappa reliability threshold

being 0.80⁵¹. Interrater reliability results revealed a strong agreement with code usage ($\kappa = 0.95\text{--}0.99$). Coders discussed any disagreements and reached a consensus on how to code responses that were disagreed upon. Given the high interrater reliability, coders equally split the remaining cases ($n = 1146$) and independently coded their respective halves ($n = 573$). Responses that did not elaborate on advantageous or disadvantageous beliefs (e.g., “It would be good”; “It would be a hassle”) were removed from the analytic sample ($n = 152$, 10.6%). This led to a final set of 1281 cases (89.4% of total sample) that were retained in the analytic sample. We then conducted mixed-method analyses. Chi-square analyses examined whether theme frequency differed by social demographic and attitudinal factors that were significant predictors in the regression model. Thematic analyses also explored whether meaning or context differed by these factors.

Results

Sociodemographic Characteristics

Table 1 presents the sociodemographic characteristics of the sample. Regarding sociodemographic characteristics, teens ranged in age from 13 to 18 years old, with an average age of 16.8 ($SD = 1.3$ years). The sample was racially/ethnically diverse, with 36.4% reporting to be White, 35.7% reporting to be Hispanic/Latinx, 11.7% reporting to be Black/African American, and 10.7% reporting to be another race. The sample was relatively geographically diverse, with 39.0% living in the South, and 16.5% living in rural areas. The majority either self-identified as gay (66.8%) or bisexual (25.1%). Most were out to their mother (66.1%) and father (53.2%). However, not all youth perceived their parents to be accepting of their sexual orientation. One-third of teens reported their mother (34.4%) and father (34.4%) were not accepting or somewhat not accepting of their sexual orientation.

Regarding healthcare engagement, most participants indicated they have a regular doctor ($n = 958$, 66.9%), with 21.4% reported they saw a provider in the last 12 months about sexual health issues like HIV testing, STI testing, and PrEP. One-third of participants were tested for HIV (33.1%) or an STI (30.1%). Most of those who were HIV or STI tested did not have their parents with them when obtaining these tests (75.7% and 70.1%, respectively). One-third of youth were very confident they could get an HIV or an STI test where they live (35.7% and 36.2%, respectively). Regarding sexual behavior, seventy percent (71.1%) had anal sex. Over half of teens had condomless anal sex (55.4%), with the average number of lifetime condomless anal sex partners being 2.16 ($SD = 5.20$). A small number of participants ($n = 9$, 0.6%) reported having had sex with an HIV-positive or HIV-unknown partner. A little over half of teens (55.8%) were eligible for PrEP.

PrEP Characteristics

Table 2 shows the PrEP-related characteristics of the sample. Although most teens heard of PrEP (73.0%), few had ever been on it ($n = 62$, 5.9%). The sample learned about PrEP through various sources, with 32.1% reporting they learned about it via looking it up online. Most participants were unsure if PrEP was right for them (45.3%), with similar proportions noting they were unsure if they intended to take PrEP (50.4%). There were various reasons for youth not currently using PrEP, with the top three endorsed reasons being concern

that their parents might find out they use it (51.5%), they need more information about it (40.0%), and they do not want to go to the doctor and get bloodwork trimonthly (28.6%). About a quarter noted they are very confident that they could get PrEP where they live (23.1%) and are extremely confident they could attend the 3-month follow up appointments (24.2%). Half (53.9%) perceived their parents would be very or somewhat unsupportive of them taking PrEP. Most would probably or definitely take PrEP if it was free (73.7%) or free and without their parents' knowledge (83.4%).

Quantitative Results

The quantitative analyses examined which Andersen Model factors were associated with confidence to attend PrEP follow-up appointments. Table 3 presents the association of predisposing, enabling, and need factors and confidence to attend 3-month PrEP follow-up appointments. Regarding *predisposing factors*, compared to those 14 years old or younger, participants 17 and 18 years old were more confident they could attend 3-month PrEP appointments ($\beta = .390$; $p = .04$ and $\beta = .547$; $p = .003$, respectively). African American and Latinx teens were less confident they would be able to attend PrEP follow-ups every three months compared to White participants ($\beta = -.385$; $p = .005$ and $\beta = -.222$; $p = .029$, respectively). Participants who self-reported as queer, pansexual, questioning, and other sexual orientations tended to be less confident that they could attend PrEP follow-up appointments than gay-identified participants ($\beta = -.316$; $p = .043$). Participants who selected they are not on PrEP because they do not want to have to go to the doctor and get bloodwork done trimonthly were less confident they would be able to attend trimonthly PrEP appointments ($\beta = -.732$; $p = .001$).

Regarding *enabling factors*, ASMM who had more confidence they could get tested for HIV where they live were more confident they could attend trimonthly appointments ($\beta = .469$; $p = .001$). Participants who perceived greater parental support of their PrEP-taking had more confidence they could attend PrEP follow-ups than participants who perceived lower parental support of taking PrEP ($\beta = .260$; $p = .001$). Finally, regarding *need factors*, the more youth thought PrEP was right for them, the higher their confidence to attend PrEP follow-up appointments every three months ($\beta = -.324$; $p = .001$).

Qualitative Results

We now turn to an in-depth look at teens' perceptions of the advantages and disadvantages of attending PrEP follow-ups that align with the Andersen's Model. Table 4 lists the nine beliefs that emerged from the inductive content analysis of advantageous or disadvantageous aspects that might happen if participants attend 3-month PrEP follow-up appointments. Overall, the qualitative findings elaborate on why perceived parental support is a key enabling factor, as well as why participants might want and not want to attend the trimonthly PrEP appointments.

There were three advantageous beliefs about attending trimonthly PrEP appointments. The most commonly mentioned advantageous belief was that participants could be *aware of their HIV/STI status via regular HIV/STI testing* (40.1%). This frequent testing could detect early HIV/STI infections. Second, teens denoted that if they tested positive for HIV/STIs or

experienced PrEP adverse effects, they could *promptly obtain treatment to address HIV/STIs or PrEP adverse effects* (9.4%). A youth wrote, “If you do have any STDs, you will know right away and get treatment early on.” One-third of adolescents (34.2%) noted that going to the doctor every three months might mean they are *generally staying healthy*. These advantageous beliefs align with predisposing factors, where participants expected attending PrEP follow-ups to result in positive outcomes: awareness of HIV status, obtaining HIV/STI and PrEP treatment, and staying healthy overall.

There were six disadvantageous beliefs about attending PrEP follow-up visits. Four beliefs reflected the perception that parents were enabling factors to PrEP care retention. First, ASMM (9.8%) mentioned that they would have *to disclose their sexuality, sexual behaviors, and PrEP-taking to their parents*, and there could be consequences for outing themselves, such as punishment or shame. A teen iterated, “My parents finding out that I am sexually active and would punish me.” Second, and because participants would rather not disclose their sexuality or PrEP-taking to their parents, 11.6% of teens expressed they would have to *lie to their parents about their reasons for attending recurring medical appointments*. Teens noted they might have to lie because they perceived their parents would be suspicious of them utilizing health care every three months. Because youth commonly noted they would have to keep their PrEP follow-ups a secret, it would be challenging, if not impossible, to navigate the logistics of attending and paying for PrEP care. Third, participants (10.6%) referenced they *cannot afford the out-of-pocket expenses without being on their parents’ insurance plans or without their parents paying for these expenses* (e.g., HIV/STI testing costs, copays, prescription costs). A teen elaborated, “Testing is expensive. HIV alone is around \$80, and the standard bundle of HIV/STI testing is around \$130. Put that into a year, and it would cost about half a grand.” Fourth, and the last parental enabling factor, 10.1% of youth illustrated it might be challenging to *find reliable transportation to get to a health care facility without their parents’ driving assistance*. Overall, ASMM may be less eager and less confident in their ability to attend PrEP follow-up appointments because they are concerned about (1) parents becoming aware of and being unsupportive of their PrEP-taking and sexual behaviors, (2) accessing PrEP and testing services without financial assistance from parents, and (3) getting to PrEP and testing services where they live, without driving assistance from parents.

Youth described two disadvantageous beliefs that aligned with the predisposing factor of attitude toward the health care service. First, one-fifth of ASMM (26.6%) voiced that these trimonthly appointments could be *time-consuming and cause schedule interferences* with their schooling, extra-curricular activities, or work. Finally, 13.8% of youth reflected that attending PrEP appointments would result in frequent bloodwork, and they disclosed they were *apprehensive about needles*. A teen noted, “I dread giving blood every year, so I definitely would not be happy going every three months.” Teens may have not wanted to attend trimonthly appointments because attending follow-up appointments might cause scheduling interferences, be time-consuming, and mean more bloodwork.

We examined differences in qualitative themes by factors that were significant in the regression model: age, race, sexual orientation, perceived parental support, confidence to get HIV tested where they live, and attitudinal PrEP fit. These factors were dichotomized for

mixed-methods analyses: Age (under 18 years old vs. 18 years and older); race (white vs. teens of color); sexual orientation (gay vs. other sexual minority orientation); perceived parental support (somewhat to very unsupportive vs. somewhat to very supportive); confidence to get HIV tested (not at all to somewhat confident vs. confident and very confident); and attitudinal PrEP fit (yes definitely and yes probably vs. definitely not and probably not).

ASMM who were 18 years old were more likely to note cost and insurance difficulties compared to ASMM under 18 years old (13.4% and 8.8%; $\chi^2 = 6.910$; $p = .009$). Those who were 18 years old described more bloodwork apprehension than those under 18 years old (16.4% and 12.1%; $\chi^2 = 4.594$; $p = .032$). Teens who overall had unsupportive parents listed more occurrences of transportation difficulties than teens who had overall supportive parents (12.3% and 7.7%; $\chi^2 = 7.623$; $p = .006$). Youth who were overall not confident they could get HIV testing where they live were more likely to list cost and insurance difficulties compared to those who were overall confident they could get HIV testing (12.9% and 9.3%; $\chi^2 = 4.022$; $p = .045$). ASMM who were overall confident they could get HIV testing where they reside described more consistently that they might have to keep their follow-up visits a secret from parents relative to ASMM who were overall not confident they could get HIV tested (13.1% and 8.8%; $\chi^2 = 5.349$; $p = .021$).

Discussion

Our mixed-method study results are the first to quantitatively examine factors associated with ASMM's confidence to attend these PrEP follow-up appointments and qualitatively identify ASMM beliefs about attending these visits. Regarding PrEP awareness, 73% of our teens were aware of PrEP, which is higher compared to national, non-intervention studies that range from 16% to 55%^{17,20,52}. ASMM from large urban or metropolitan cities do report higher percentages of PrEP awareness compared to national samples, ranging from 68% to 82%^{13,18}. Our awareness proportions are at or surpass the proportions of ASMM from these large urban or metropolitan samples. ASMM at-large may be more aware of PrEP due to PrEP dissemination in the past three years, from Truvada® commercials to social marketing campaigns⁵³. Although three-quarters of teens in our study were aware of PrEP, fewer than 6% of them ever used it. Regarding PrEP uptake, national studies show that 1% to 4% of ASMM use PrEP^{12,15,17,20,54}. ASMM residing in urban areas show higher percentages of lifetime usage, ranging from 3% to 39%^{13,18,19,53}. Similarly to PrEP awareness, it is possible that more teens have access to PrEP due to PrEP dissemination, health care provider education, and PrEP navigation initiatives on a local, state, and national level. Regarding PrEP uptake barriers, the most commonly cited reason for not being on PrEP was because participants were worried their parents would find out about their PrEP-taking. This is consistent with prior studies reporting parental support as a key barrier to ASMM using PrEP^{15,17,20}. Although awareness and uptake of PrEP are essential strategies in the EHE plan⁷, their effectiveness will be reduced if ASMM cannot engage in the entire PrEP care continuum. The sustainment of daily oral PrEP relies heavily on attending trimonthly medical visits.

Our findings align with prior studies investigating PrEP retention factors with adults and provide new insights into predisposing, enabling, and need factors among adolescents. Regarding predisposing factors, our quantitative results indicated that age, race, and sexual orientation were predisposing factors associated with confidence to attend PrEP follow-up appointments. Our findings show that participants 13 and 14 years old were less confident they could attend 3-month PrEP follow-ups compared to participants 17 and 18 years old. Similar studies have shown that younger ages in adult samples (e.g., 19–24 years old) are the least likely to be retained in care^{24–26}. Our findings report that African American and Latinx ASMM, compared to White ASMM, were less confident they could attend trimonthly PrEP visits. There are racial/ethnic disparities in PrEP continuum outcomes, including discontinuation and care retention, where African American and Latinx adults were either more likely to discontinue PrEP or less likely to be retained in care compared to White adults^{25,28,30,33,48}. Teens in our study who self-identified their sexual orientation other than gay or bisexual (e.g., queer, pansexual, questioning) were less confident that they could attend retention visits than gay-identified teens. A prior study²⁵ has shown that adults with a sexual orientation other than gay and bisexual were more likely to discontinue PrEP than gay adults. PrEP interventions that are tailored to different communities could address racial and sexual orientation disparities. HIV/STI testing campaigns adapted for Black and Latinx adolescent and young adult sexual minority men are successful in increasing testing⁵⁵. We can infer that PrEP retention interventions that are tailored to communities might be successful in ensuring persistence in PrEP.

Our qualitative results on predisposing factors illustrate youth perceive attending PrEP follow-up appointments might cause advantageous outcomes, such as HIV status awareness, HIV/STI and PrEP treatment, and overall wellness. However, teens also revealed that attending appointments could result in disadvantageous outcomes such as schedule interference and bloodwork. Our results demonstrate that ASMM 18 years old were more likely to list bloodwork apprehension and cost/insurance difficulties compared to ASMM under 18 years old. It is possible that as ASMM get older and the possibility of using PrEP becomes more of a reality, bloodwork and cost associated with PrEP care could be more salient concerns. PrEP retention interventions need to take into account the developmental context of adolescents and young adults, such as needle phobia that is common among these age groups that could be mitigated by patient-nurse communication⁵⁶.

Regarding enabling factors, our findings position parents as a critical group that could either facilitate or hinder enabling factors of PrEP retention. Cost and logistical factors (e.g., transportation) influencing PrEP persistence could depend on parental support and engagement in PrEP retention^{33,38}. The intersection of parental support and logistic factors can be seen where teens who reported having unsupportive parents were more likely to describe transportation difficulties than teens who had overall supportive parents. Likewise, participants in our study who perceived greater parental support for taking PrEP had more confidence they could attend the trimonthly appointments than participants who perceived lower parental support of PrEP-taking. Other studies indicate parental support of PrEP and acceptance of sexual minority identity is associated with PrEP uptake^{15,20,36–38}. Although age might be a predisposing factor in PrEP care retention, age is a complicated variable. Age might reflect an enabling factor as barriers to PrEP retention may decrease with

age. For example, older adolescents may be more likely to have disclosed their sexual orientation to their parents, have more capacity to transport themselves to appointments, control their schedules without parental assistance, and have more financial autonomy to pay for expenses. There might be a mediating factor between age and other enabling factors like living situation, as older participants may not live with their parents and therefore have more autonomy and financial resources to utilize sexual health care services.

Similar to the clinical purview debate of who should be prescribing PrEP⁵⁷, there is an ongoing debate if parents should or should not be aware of and be involved in their child's PrEP usage^{44,58}. On one end of the spectrum, our results show parental support and engagement might ameliorate teens' concerns over enabling factors of PrEP follow-ups, such as navigating schedules, driving to health care facilities, and paying for health care. After all, parents are expected to be involved in the health care of their children living with a chronic health condition (e.g., asthma, diabetes, HIV)⁵⁹⁻⁶². On the other end of the spectrum, our results show there might be harmful consequences if parents were aware of their child taking PrEP. These two claims situate two intervention targets: parent-targeted interventions or built environment-targeted interventions.

Parent-targeted interventions attempt to improve parents' positive attitudes about PrEP and sexuality. There is a critical need to examine parents' perspectives about their role in their child's PrEP care. Indeed, Huebner and Mustanski⁵⁸ noted that PrEP research and social marketing campaigns are severely lacking in exploring parents' PrEP knowledge, attitudes, and behaviors. Research is needed to move beyond examining parents' perspectives about their child participating in PrEP trials or research^{36,63,64}, and instead focus on factors and attitudes of parents themselves being involved in their child's PrEP care. After all, ASMM view parental permission and support as a facilitator to participating in HIV prevention trials/research^{54,65,66} and PrEP uptake^{15,20,36-38}, and therefore parental-sampled research is necessary.

Parental support for PrEP starts with parental acceptance of their youth's sexual orientation. Parental acceptance of their child's sexual minority identity has influenced positive health outcomes in children, while parental rejection has triggered adverse health outcomes^{67,68}. Parent-targeted sexual minority stigma-reduction research and interventions are critical in moving parents closer to PrEP support. Although critically needed, there are only a couple of sexual minority stigma-reduction interventions for parents^{68,69}. Family-based PrEP and sexual minority stigma-reduction research and interventions have untapped potential for improving PrEP care continuum outcomes among ASMM.

Environmental-targeted interventions integrate PrEP care into youth's ecology. First, at-home, school-based, and mobile van HIV testing and PrEP delivery might resolve time, transportation, and suspicion concerns youth cited in this and other studies^{28,35}. These options could provide youth with various ways to get tested and sustain PrEP care, especially since ASMM in our study who had more confidence they could get tested for HIV where they live were more confident they could attend trimonthly appointments. Second, PrEP providers and PrEP staff should be trained in youth development and provide services that address youth's unique financial and developmental context, such as providing

out-of-pocket financial assistance, offering transportation vouchers, and adapting insurance statements that provide confidentiality for teens who utilize sexual health care services⁷⁰. Third, advocacy work is essential to increase the number of states with laws that explicitly allow minors to access HIV preventative services and HIV testing without parental consent. Thirty-nine states have explicit language that allows minors to access HIV testing without parental permission, while only 16 states have explicit language that allows minors to access HIV preventative services like PrEP without parental consent⁷¹.

There is a middle ground between these two binaries of either incorporating parents throughout the PrEP care continuum or none at all. The third intervention target is teens involving their parents when teens are ready to loop parents into parts of their care that they want them (or need them) to be involved in. Research might assess how to improve teens' self-efficacy for child-parent communication about PrEP. Such research might inform technology-based interventions to improve teens' self-efficacy to ask their parents for assistance in the PrEP care continuum. In addition, technology-based interventions might also improve ASMM's self-efficacy to disclose their sexuality to their parents⁷². Future studies and interventions should explore health care providers in facilitating these child-parent-provider communication surrounding sexuality disclosure, PrEP interest, and parental PrEP involvement⁷³.

Limitations

While the current study is the first to provide insight into PrEP care retention factors and attitudes among ASMM, there are limitations. The teens in this study were enrolled in an intervention research trial³⁹. ASMM who participated in the trial may have different experiences and attitudes than those ASMM were ineligible or who are not participating in the trial, thus limiting the generalizability of findings. One example of this is that 73% of this sample heard about PrEP and 6% reported lifetime use, which may not represent ASMM on a national-level who do not self-select into intervention trials^{20,52}. Moreover, since only 62 participants were ever on PrEP, our qualitative findings may represent adolescents' perceptions of hypothetical PrEP retention rather than their actual PrEP care retention experiences. We expected teens to complete the survey and write their open-ended responses via their smartphone. Completing the survey through their phones might have affected the quality and length of open-ended responses, although research shows that online qualitative surveys have the capacity to offer rich data depending on survey and wording design⁷⁴. In addition, the open-ended question that elicited teens' perspectives was double-barreled. Splitting the question into two discrete questions of good things and bad things may provide more nuanced data. As most teens in our sample had never been on PrEP, future studies should examine experiences of the entire PrEP care continuum among PrEP-using ASMM via cross-sectional and longitudinal designs.

Conclusions

With oral PrEP recently approved for ASMM and new PrEP modalities in development⁷⁵⁻⁷⁸, research has recently explored the PrEP care continuum among ASMM¹². Although PrEP research among ASMM is just beginning, there is a clear acknowledgment that there must

be attention on how to retain PrEP-using ASMM. This is the first published study to examine ASMM's factors and perspectives about attending PrEP follow-up appointments—a key concern when implementing PrEP programs for this population. Interventions should consider adolescents' developmental and family context if they want to be effective. Our results suggest that parents are key gatekeepers for ASMM to engage and sustain PrEP care services. Studies should investigate parents' attitudes and intention to engage in the PrEP care continuum with their children, with results from these studies informing family-based interventions. Future research is necessary to determine different environmental-targeted interventions that youth find acceptable, such as providing HIV testing and PrEP delivery in at-home, school-based, and other community-based settings.

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Table 1.Sociodemographic Characteristics (*N* = 1433)

	N	%	M	SD
Age			16.8	1.3
13 years old	14	1.0		
14 years old	76	5.3		
15 years old	160	11.2		
16 years old	278	19.4		
17 years old	329	23.0		
18 years old	576	40.2		
Race/Ethnicity				
Asian	79	5.5		
Black/African American	167	11.7		
Hispanic/Latinx	512	35.7		
White	522	36.4		
Native American/Alaskan Native	12	0.8		
Native Hawaiian/Pacific Islander	4	0.3		
Multiracial or another race	137	9.6		
Geographic Region (n = 1353)				
Northeast	225	16.6		
Midwest	251	18.6		
South	528	39.0		
West	349	25.8		
Rurality/Urbanity (n = 1385)				
Rural	229	16.5		
Urban	1156	83.5		
Sexual Orientation (n = 1431)				
Gay	956	66.8		
Bisexual	359	25.1		
Pansexual	64	4.5		
Queer	17	1.2		
Unsure/Questioning	27	1.9		
Another sexual orientation	8	0.6		
Outness to Parents				
Out to mother (n = 1396)	923	66.1		
Out to father (n = 1264)	673	53.2		
Acceptance of Outness, Mother (n = 923)				
Not accepting	67	14.3		
Somewhat not accepting	135	20.1		
Somewhat accepting	243	28.2		
Accepting	478	51.8		
Acceptance of Outness, Father (n = 673)				

	N	%	M	SD
Not accepting	96	14.3		
Somewhat not accepting	135	20.1		
Somewhat accepting	190	28.2		
Accepting	252	37.4		
Have a Regular Doctor				
No	475	33.2		
Yes	958	66.9		
Seen a Provider for Sexual Health Issues Last 12 Months Doctor				
No	1127	78.7		
Yes	306	21.4		
Lifetime HIV Testing				
No	888	62.0		
Yes	474	33.1		
Don't Know	71	5.0		
Parent with You when Tested for HIV (n = 474)				
No	359	75.7		
Sometimes	18	3.8		
Yes	97	20.5		
Confidence Can Get HIV Test Where You Live				
Not at all confident	123	8.6		
Somewhat confident	394	27.6		
Confident	405	28.3		
Very confident	511	35.7		
Lifetime STI Testing				
No	911	63.6		
Yes	431	30.1		
Don't know	91	6.4		
Parent with You when Tested for STI (n = 431)				
No	302	70.1		
Yes	109	25.3		
I don't know	20	4.6		
Confidence Can Get STI Test Where You Live				
Not at all confident	120	8.4		
Somewhat confident	378	26.4		
Confident	417	29.1		
Very confident	518	36.2		
Lifetime Anal Sex				
No	414	28.9		
Yes	1019	71.1		
Lifetime Male Condomless Anal Sex Partners			2.16	5.20
Lifetime Condomless Anal Sex				
No	639	44.6		

	N	%	M	SD
Yes	794	55.4		
HIV-Positive/Unknown Sex Partner				
No	1424	99.4		
Yes	9	0.6		
PrEP candidacy				
Not a PrEP candidate	634	44.2		
PrEP candidate	799	55.8		

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Table 2.PrEP Characteristics (*N* = 1433)

	N	%
Heard of PrEP		
No	387	27.0
Yes	1046	73.0
Where did you first learn about PrEP? (n = 1046)		
Looked it up online	336	32.1
Friends	99	9.5
Someone I was dating or having sex with	73	7.0
An HIV testing counselor or outreach worker	57	5.4
A doctor or medical provider	54	5.2
Research staff	37	3.5
A family member	19	1.8
Another method	371	35.5
Lifetime PrEP Usage (n = 1046)	62	5.9
PrEP fit attitude		
No, definitely	24	1.7
No, I don't think	116	8.1
I'm not sure	649	45.3
Yes, I think	417	29.1
Yes, definitely	227	15.8
Intent to Take PrEP (n = 1400)		
No, definitely	41	2.9
No, probably	265	18.9
I'm not sure	706	50.4
Yes, probably	262	18.7
Yes, definitely	126	9.0
Why Not Use PrEP? (Check all that apply)		
I am worried my parents would find out I was taking PrEP	507	51.5
I don't know enough about it	394	40.0
I do not want to have to go to the doctor and get bloodwork every three months	281	28.6
I think I am at no or low risk for HIV	273	27.7
I am not sexually active	237	24.1
I cannot afford it and/or I do not have insurance	226	23.0
I do not want to have to take a pill every day	141	14.3
I think condoms are a better choice than PrEP	92	9.4
I am in a serious relationship	60	6.1
People who use PrEP are perceived negatively by others	52	5.3
Other reason	100	10.2
Confidence Can Get PrEP Where You Live		
Not at all confident	250	17.5

	N	%
Somewhat confident	504	35.2
Confident	348	24.3
Very confident	331	23.1
Confidence Can Attend 3-month PrEP Follow-Up Appointments		
1, Not at all confident	107	7.5
2	78	5.4
3	133	9.3
4	252	17.6
5	322	22.5
6	195	13.6
7, Extremely confident	346	24.2
How Parents React if Taking PrEP		
Very unsupportive	399	27.8
Somewhat unsupportive	374	26.1
Somewhat supportive	477	33.3
Very supportive	183	12.8
Would Take PrEP if Free (n = 1400)		
Definitely wouldn't	17	1.2
Probably wouldn't	85	6.1
Might	266	19.0
Probably would	388	27.7
Definitely would	644	46.0
Would Take PrEP if Free and Without Parents Knowing (n = 1400)		
Definitely wouldn't	21	1.5
Probably wouldn't	55	3.9
Might	157	11.2
Probably would	274	19.6
Definitely would	893	63.8

Table 3. Multivariate Regression of Confidence to Attend 3-Month PrEP Appointments (*N* = 1433)

Factor	Variable	β	SE	P-Value
	Age (Ref, 14 or younger)			
	15 years old	-.177	.209	.397
	16 years old	-.042	.192	.826
	17 years old	.390	.189	.04
	18 years old	.547	.185	.003
	Race/Ethnicity (Ref, White)			
Predisposing	African American/Black	-.385	.136	.005
	Hispanic/Latinx	-.222	.101	.029
	Other/Multiracial	-.180	.133	.176
	Sexual Orientation (Ref, Gay)			
	Bisexual	-.082	.100	.414
	Another sexual orientation	-.316	.156	.043
	I do not want to have to go to the doctor and get bloodwork every 3 months	-.732	.106	.001
Enabling	Confidence I can get tested for HIV where I live	.469	.046	.001
	I cannot afford PrEP and/or I do not have insurance	.077	.118	.515
	Parental support	.260	.044	.001
	Rurality/Urbanity (Ref, Urban)			
	Rural	.097	.115	.399
Need	Seen provider for issues related to sexual health last 12 months	.088	.109	.42
	Attitudinal PrEP fit	-.324	.048	.001
	PrEP candidacy	.143	.090	.114

Table 4.

Beliefs of Attending 3-Month PrEP Follow-Up Appointments (N = 1281)

Factor	Belief	N (%)	κ	Examples
Predisposing	Regular HIV/STI testing and status awareness (+)	514 (40.1)	.976	"I would know on a regular basis whether or not I have an STD/STI." "I would personally want to make sure I am staying HIV- and STI-free to stay on PrEP."
	Staying healthy (+)	438 (34.2)	.972	"Would keep me healthy." "Good because I would be monitoring my health."
	Time-consuming and schedule interference (-)	341 (26.6)	.989	"Lose time in school and band." "The only bad thing would be my work/class schedule conflicting with when appointments are available."
	Bloodwork apprehension (-)	177 (13.8)	.945	"Bad: I hate needles." "The needles to get tested would hurt."
Enabling	PREP effectiveness and HIV/STI treatment (+)	120 (9.4)	.955	"Making sure organs are not being affected and medications are working as intended." "Getting tested every 3 months ensures that if one does contract HIV, that person will be able to begin treatment as early as possible."
	Secrecy or suspicion (-)	148 (11.6)	.953	"I would have to continually make excuses to conceal why I'm leaving the house." "My parents would be suspicious of why I'm always at the doctors."
	Cost or insurance difficulties (-)	136 (10.6)	.978	"The costs can be high for me to go to the doctor without my parents knowing as I am on their insurance." "I won't be able to go because doctor fees are way beyond my budget."
	Transportation difficulties (-)	130 (10.1)	.972	"I don't know how I would get there—I don't have a car." "Transportation would be kind of a nuisance since I don't have a license." "Bad thing is parents might find out I'm gay." "My parents would know that I'm having sexual relations."
Outing themselves (-)	126 (9.8)	.970		

Notes. Beliefs denoted by a "+," are perceived to be advantageous aspects about attending 3-month PrEP follow-up appointments. Beliefs denoted by a "-," are perceived to be disadvantageous aspects about attending 3-month PrEP follow-up appointments. Percentages do not add to 100% as participants could list more than one belief.