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Barriers to PrEP use and adherence among adolescent girls and young women in Eastern, Southern, and Western Africa: a scoping review

Metasebia Admassu^{1*}, Christiana Nöstlinger¹ and Bernadette Hensen¹

Abstract

Background Adolescent girls and young women (AGYW) are disproportionately affected by HIV. Globally, in 2022, an estimated 4000 AGYW 15–24 were newly infected with HIV weekly, and nearly 78% of these infections occurred in sub-Saharan Africa. Oral Pre-Exposure Prophylaxis (PrEP) is a key HIV prevention option within an overall HIV combination prevention approach with an efficacy of over 90% when taken correctly. However, uptake of and adherence to PrEP remains low, particularly among AGYW. This scoping review aims to map available evidence on factors that limit PrEP use among AGYW in Eastern, Southern, and Western African countries to inform research, policy, and practice on delivery of PrEP. Our review identified factors that affect PrEP journey among AGYW along the HIV prevention cascade.

Methods Guided by Arksey and O'Malley framework and using the PRISMA extension for scoping reviews, we searched the Web of Science, Global Health, and PubMed databases. Our review focused on oral PrEP, specifically papers reporting on barriers to PrEP experienced by AGYW, and peer-reviewed English-language articles published between 2012 and 2023.

Results Of 1063 papers screened, 25 were included. Over half (60%) of the studies were qualitative; 72% were conducted in Kenya and South Africa. The barriers affecting motivation were, fear of side effects and pill burden, perceived low HIV risk, perceived stigma, PrEP use disapproval from parents and partners. PrEP access was limited by healthcare providers' stigma, isolated clinic setup, and lack of resources. Effective PrEP use was limited by a lack of parental or partner support, stigma, and lifestyle changes.

Conclusions Adolescent girls and young women face multiple and often intersecting barriers to effective PrEP use with stigma being a factor cross-cutting all steps of the prevention cascade. Similarly, lack of social support, reflected through disapproval and judgmental attitudes and low HIV risk perception, also affected two steps of the prevention cascade. Our review identified gaps in available evidence, with most studies conducted in only two countries and few quantitative studies available. Improving PrEP uptake and adherence requires interventions that address barriers across the cascade, with a particular focus on stigma and social support.

Keywords PrEP, Adolescent girls, Young women, HIV prevention, Adherence, Uptake

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Background

Despite declines in HIV incidence, HIV remains a public health concern in many African countries [1, 2]. In particular, it is well established that compared to boys and men, adolescent girls and young women (AGYW) are disproportionately affected by HIV [1, 3–11]. Every week, 4,000 AGYW aged 15–24 acquire HIV globally (UNAIDS, 2022); nearly 78% of these AGYW reside in sub-Saharan Africa [3]. In 2022 in AGYW accounted for 77% of new HIV infections among young people aged 15–24 in sub-Saharan Africa [3]. Despite the availability of antiretroviral treatment, HIV-related illnesses remain a leading cause of mortality among AGYW in Africa [12].

According to UNAIDS 2022 report, the global target of reducing new infections to fewer than 500,000 by 2020 was not met due to inequalities in HIV programmes, including, for example, uneven distribution of resources [10]. In response, the 2021–2026 Global HIV Prevention Strategy highlighted inequalities as a key driver of the HIV response and emphasized the need to ensure that marginalized communities, including AGYW, are at the center of the HIV response [10]. The targets of the Global HIV Prevention Strategy include reducing the number of new HIV infections among AGYW to less than 50,000 [10].

Increased vulnerability to HIV among AGYW is driven by a complex interplay of various factors, including increased biological vulnerability, gender inequalities leading to power imbalances, gendered cultural norms around sexuality, and structural factors, such as poverty and lack of education [1, 4, 13, 14]. Unequal power dynamics rooted in gender inequities are major drivers of HIV among AGYW [15], as these dynamics place men in positions of physical, social and economic power leading AGYW to experience fear of resource withdrawal, abandonment, or limited power to negotiate condom use [16]. For these reasons, AGYW is a priority population for HIV prevention programs [5].

Among the range of HIV prevention strategies, such as condom use, regular HIV testing as a behavioral interventions, continuous community education, stigma reduction and structural interventions, oral pre-exposure prophylaxis (PrEP) has become a crucial biomedical prevention strategy to address HIV epidemics [17]. PrEP is an efficacious HIV prevention option that involves the use of antiretrovirals among HIV-negative individuals to reduce their risk of HIV acquisition [13, 18–24]. The US Food and Drug Administration (FDA) approved the use of oral PrEP in 2012; in 2015, the World Health Organization (WHO) recommended that people at substantial risk of HIV infection (i.e., population with an HIV incidence of > 3 per 100 person-years in the absence of PrEP or individuals with

characteristics and behavior that could lead to HIV exposure), including AGYW, be offered oral PrEP as part of a package of comprehensive, combination HIV prevention services [3, 22, 25, 26].

A recent pooled review provided clear evidence that oral PrEP is effective in real-world settings among cis-gender women [27]. According to the 2022 UNAIDS Global Update, nearly 1.6 million people received oral PrEP at least once in 2021, with Eastern and Southern Africa accounting for one million individuals and Western and Central Africa nearly 200,000 people on PrEP [10].

Since the introduction of PrEP significant success have been reported in terms of HIV prevention. A recent review of intervention aimed at promoting PrEP use among AGYW in HIV endemic settings, revealed that approaches have been implemented to address barriers to PrEP use [28]. These include mHealth, drug-level feedback, adherence counseling, peer groups, and PrEP decision-supports, demand creation, integrating PrEP and reproductive health services all of which show promise in supporting PrEP uptake among AGYW [28]. However, many of these interventions have not been able to definitively assess their effectiveness [28]. Reports from FHI 360 highlight that peer-led initiatives have significantly increased uptake of PrEP among high-risk population [29]. Similarly, UNAIDS reported a declines in the number of new HIV infections among AGYW in sub-Saharan Africa between 2010 and 2022 [1]. Despite the progress and increased uptake of PrEP use since 2016, progress has been slower than desired and there is also high rate of oral PrEP discontinuation among AGYW [29]. PrEP efficacy relies on the continued use and adherence [30]. Increased uptake and continued use, requires an understanding of barriers to PrEP use among AGYW.

This scoping review aims to identify barriers to PrEP uptake and adherence in the HIV prevention cascade [31, 32]. It has three steps that correspond to motivation for, access to, and capacity to effectively use PrEP. The HIV prevention cascade has been used to assist in the planning, implementation and monitoring of HIV prevention programs by identifying gaps in the steps required for improved delivery of HIV prevention methods [31, 32].

We chose the HIV prevention cascade as a guiding framework for this review because it is a practical approach for organizing data in line with prioritizing barriers for effective interventions that potentially could improve impact; in addition can be easily adapted to any population [31, 32]. Moreover, it will provide a comprehensive summary on key barriers which we believe ultimately, inform policy and practice on the improved delivery of PrEP to AGYW [31, 32].

Methods

This scoping review followed the steps proposed by Arksey and O'Malley (i.e., specifying the research question, identifying relevant literature, selecting studies, mapping the data, summarizing, synthesizing, and reporting the results) [33, 34]. We applied the preferred reporting items for systematic review and meta-analysis (PRISMA) extension for scoping reviews checklist as a framework for presenting the article selection process [35].

We used the PICO approach (population, phenomenon of interest, and context) to develop the review question [34, 36], what are key barriers to oral PrEP use (defined as uptake, continuation and adherence) among AGYW in Western, Eastern, and Southern Africa? Corresponding to step 1 of the Arksey and O'Malley framework [33]. Our population of interest was AGYW aged 15–24; the phenomenon of interest was barriers across three steps of the HIV prevention cascade, with a focus on oral PrEP (i.e., motivation to use PrEP, access to PrEP, and capacity to use PrEP effectively), while the context was the countries in Southern, Eastern, and Western Africa, where the incidence of HIV among AGYW countries is the highest globally (Table 1).

Identification of relevant studies

In step 2, we searched three databases, Web of Science, PubMed, and Global Health, to identify published literature. This search was conducted from May 2 to May 15, 2023. We used four core concepts in formulating the search strategy for each database: HIV, PrEP, AGYW, and Southern, Eastern, and Western African countries, an additional table file shows this in detail (see Additional file 1). Additional articles were identified through manual searches of the references of the studies considered eligible for inclusion.

Study selection

In step 3, we included articles based on specific inclusion and exclusion criteria (Table 1). The inclusion criteria were: studies that explored barriers to oral PrEP use, published in peer-reviewed journals and written in English, studies published from 2012 onward that included AGYW aged 15–24 years or disaggregated data for AGYW or studies that were about perceived barriers experienced by AGYW, regardless of the study population [37].

We excluded studies that were not peer-reviewed (gray literature, conference proceedings, or notes, commentaries/opinion pieces), did not include AGYW as their priority population, and focused only on AGYW from specific, distinct populations (i.e., sex workers, transgender women, pregnant women) and studies that did not specify the age of AGYW included in the study (Table 1). The selection criteria were developed, discussed, and refined within the review team. We applied these criteria during the search strategy as described above.

The search and article review was conducted by MA, with a random selection of 10% of studies reviewed by BH for consistency at the abstract review stage. At the full-text stage, CN reviewed a random selection of 10% of the articles to determine whether the articles were eligible for full-text review. Discrepancies were resolved through discussion between the reviewers based on consensus.

Charting the data, summarizing, and reporting

We used a standardized data extraction chart in Excel to extract data from the eligible studies (step 4), including the authors, publication date, aim of the study, population group, study design and data collection method, setting, and key findings (Tables 3 and 4). For quantitative results, we extracted data on factors associated with PrEP use and/or adherence that were

Table 1 Description of selection criteria

Criteria	Definition	Description
Population	AGYW aged 15–24 years	Articles with a wider age range of AGYW were included if data were provided for the 15–24 age group Articles including other study populations (i.e., health care providers, men, etc.) if the articles focused on AGYW Articles with disaggregated data for each study population, including AGYW
Phenomenon of interest	Barriers to PrEP along the three steps of the HIV prevention cascade	Articles reported any or all the steps in the HIV prevention cascade, relating to: Motivation, i.e., all articles identifying knowledge, perceived HIV risk, or other factors that might affect PrEP initiation Access, i.e., articles identifying barriers related to AGYW's inability to access PrEP despite motivation primarily barriers outside of AGYW's control Capacity to effective PrEP use, i.e., articles identifying factors related to individual capacity, and external factors contributing to discontinuation of, or stopping PrEP
Context	Southern, western, and Eastern African countries	Articles conducted in any of the three regions, regardless of the study design, and written in English from 2012 onward until the end of the search period (May 15, 2023)

considered statistically significant at the $p \leq 0.05$ level. As indicated, we used the HIV prevention cascade as a framework to synthesize and summarize the data from selected studies (step 5) [31]. It has three steps that correspond to motivation for, access to, and capacity to effectively use PrEP. The HIV prevention cascade has been used to assist in the planning, implementation and monitoring of HIV prevention programs by identifying gaps in the steps required for improved delivery of HIV prevention methods [31, 32].

PrEP uptake refers to receiving and initiating oral PrEP, the PrEP continuation phase refers to persistent participation in an oral PrEP program (i.e. continuing to obtain PrEP refills and use PrEP following initiation), while adherence refers to the consistency with which a person takes their PrEP medication as prescribed, thus ensuring the effectiveness of PrEP in HIV prevention [30, 38]. Using the HIV prevention cascade, we synthesize the evidence into motivation to initiate PrEP, factors affecting access to PrEP services, and those influencing AGYW's ability to continue with and adhere to PrEP. We opted to use the prevention cascade as a framework because it is a practical approach for organizing data in line with prioritizing barriers for effective interventions that potentially could improve impact; in addition can be easily adapted to any population [31, 32].

Results

Characteristics of the included articles

We identified 1920 studies, 1911 through database searches, and nine through the reference lists of included studies (Fig. 1). After the removal of duplicates, 1063 articles were screened, yielding 53 articles for full-text review. Of these, 28 were excluded; over half ($n=17$, 68%) were excluded because the studies did not explore barriers to PrEP use among AGYW; seven were excluded either because the study population (type and/or age) did not meet our inclusion criteria or disaggregated data for our population of interest were unavailable (Fig. 2).

Of the 25 articles included, 15 (60%) were qualitative, six (24%) were quantitative, and four were mixed-method studies (Table 2). The majority of studies ($n=18$; 72%) were published in 2022–2023 and conducted in two countries, namely Kenya ($n=5$) and South Africa ($n=13$) (Table 2).

We summarized key findings from all studies in line with three steps of the HIV prevention cascade: motivation, access, and capacity to effectively use PrEP (Tables 3 and 4; Fig. 2).

Factors affecting motivation to use PrEP services

Twelve studies (48%) described barriers that impacted AGYW motivation to consider using PrEP (Fig. 2), which included PrEP awareness, self-perceived vulnerability to

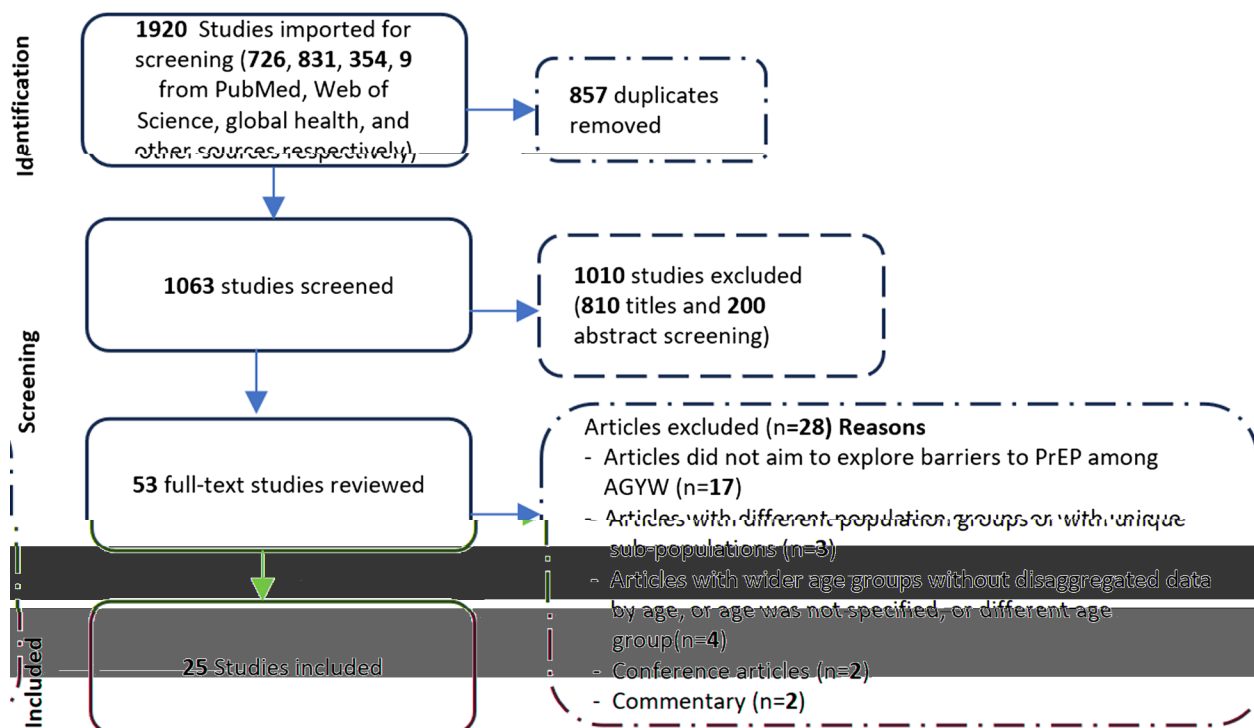


Fig. 1 PRISMA diagram illustrating the article review process

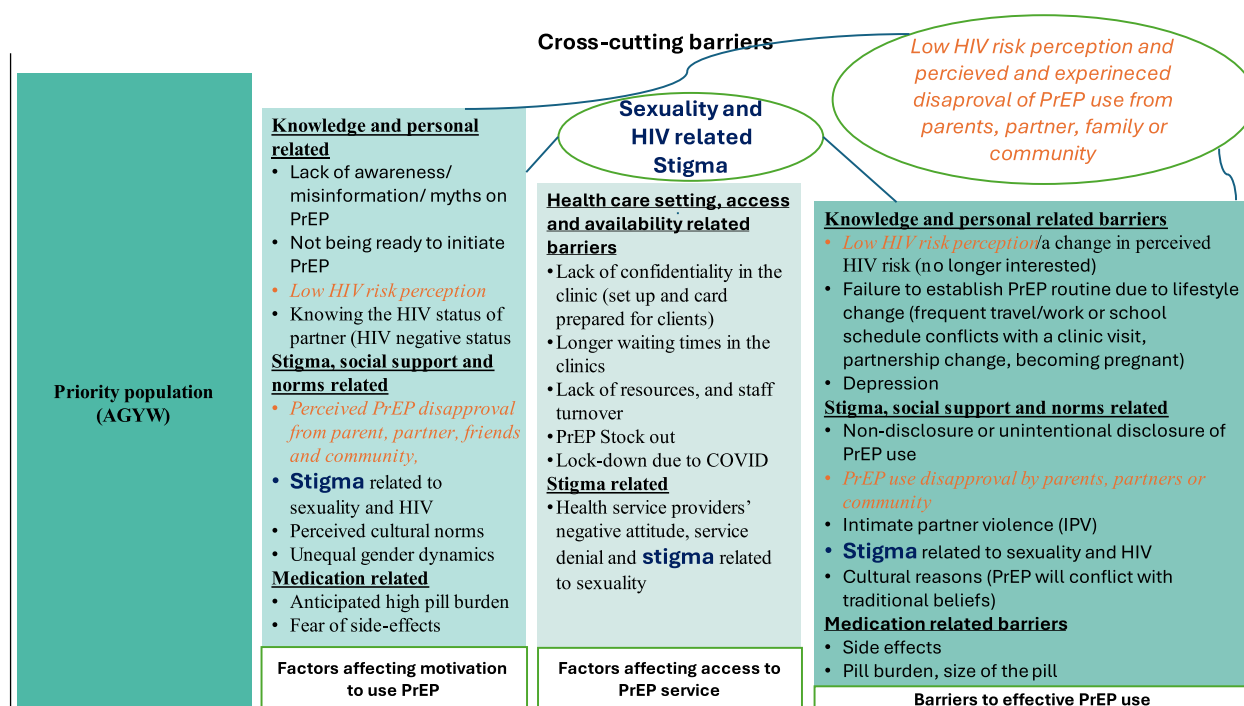


Fig. 2 Summary of key barriers affecting motivation, access, and capacity for oral PrEP effective use among AGYW

Table 2 Characteristics of studies eligible for inclusion in the scoping review ($n=25$)

Study characteristic ($N=25$)		n (%)
Year of publication	2020–2021	7 (28%)
	2022–2023	18 (72%)
Country of study	South Africa	13 (52%)
	Kenya	5 (20%)
	South Africa, and Kenya	1 (28%)
	South Africa, Kenya and Zimbabwe	1 (0.04%)
	Uganda, South Africa and Zimbabwe	1 (0.04%)
	Eswatini, Tanzania, Uganda, and Zimbabwe ^a	4 (0.16%)
	Adolescent girls and young women (AGYW)	15 (60%)
Study Population	AGYW and other populations (male, male partner, health care provider, family, friends, and community staff)	5 (20%)
	Healthcare providers mixed with (male, implementers)	3 (12%)
	General population and community advisory board	2 (0.08%)
Type of Study	Qualitative	15 (60%)
	Quantitative	6 (24%)
	Mixed methods	4 (16%)

^a One study in each country

HIV, perceived HIV and sexuality-related stigma, medication characteristics (such as side effects, pill burden, daily use), perceived disapproval or judgment of PrEP use from parents, partners, and the broader community [40, 43, 45, 46, 50, 51, 53–56, 58, 59]. Other factors affecting motivation were linked to having a preference for other

HIV prevention methods (i.e., condoms, injectable PrEP) [55, 58] (Tables 3 and 4).

Misinformation about PrEP, lack of understanding about the difference between PrEP and HIV treatment, and myths surrounding PrEP were mentioned by four studies as affecting PrEP initiation [40, 50, 51, 56]. Myths

Table 3 Findings from qualitative ($n = 15$) and mixed method studies ($n = 4$) on PrEP use ($n = 19$)

Author, period of data collection and year of publication	Population/Study design/Sample size	Country/ies	Aim/Phenomenon of interest	Findings
Joseph Daniels et al. [39] Mar. and July 2020, 2023	AGYW (16–24), (ID) ^a , $n = 42$	South Africa	Understand the relationship between PrEP use, social support, and adherence	Barriers to effective PrEP use: PrEP use disapproval by parents
Zoe Duby et al. [40] Nov. 2020 and March 2021–2023	Program implementers (managers, project coordinators), HSP ^b /nurses, social workers/counselors, peer group trainers, and outreach workers, (interview), $n = 38$	South Africa	Explore the experience of implementing a PrEP program/investigation of PrEP acceptability/ence	Barriers to motivation to PrEP use: Misinformation/a lack of understanding about PrEP, daily pill taking and PrEP stigma, disapproval and resistance from the community, Barriers to PrEP access: for younger adolescents the need to request consent from parents to initiate PrEP, COVID-19 control regulations, and shortage of supply, Barriers to effective PrEP use include unsupportive parents and communities, adverse side effects, or hearing about bad experiences from peers.
Tali Cassidy et al. [41] 2017–2020	YW ^c , friends, and family) YW(18–25), MM ^d (survey and interview) $n = (164, 23)$	South Africa	Describe PrEP user's experiences and engagement with PrEP and adherence	Barriers to effective PrEP use: Difficulty disclosure of PrEP use, discouragement from family and friends, forgetting to take daily pills, dealing with side effects, clinic visit schedules and procedures
Marie C.D. Stoner et al. [42] March 2017 and 2018–2022	AGYW (16–25), MM (survey and IDI), $n = (200, 22)$	South Africa	When and why declines in PrEP adherence occur to inform the development of adherence support interventions	Barriers to effective PrEP use: Lack of support from family, and partner, failure to establish routine (due to experiencing traumatic events, changing in partnership, change in frequency of clinic visit) Disclosing PrEP enrollment plan to family showed statistically significant among AGYW in the higher declining group($n = 106, 52\%$) Vs low declining group($n = 94, 49\%$) $p = 0.025$

Table 3 (continued)

Author, period of data collection and year of publication	Population/Study design/Sample size	Country/ies	Aim/Phenomenon of interest	Findings
S.Bergam et al. [43] 2022		South Africa AGYW (18–25), FGD and IDI, n = 46	Examine young women's expectations and understanding of PrEP	Barriers to motivation to PrEP use: the lack of knowledge on PrEP, fear of HIV stigma, judgment, and disapproval Barriers to PrEP access: lack of confidentiality in clinics (set up, the card they carry) Concerns associated with Access: Stigma from health care providers, clinic setup (prone to stigma and perceived lack of confidentiality) 25.8% (n = 449) of AGYW reported experiencing 1 of 7 manifestations of stigma in the last three months (i.e., Clinical staff being harsh because AGYW asked for birth control, and HIV testing, treated badly because of the age, gossip, felt judged or shamed, looked down)
Laura Nyblade et al. [44] 2018–2020 2022		South Africa AGYW(18–24 and 16–24) ^e , clinical and non-clinical, MM (FormativeFGD), and (randomized trial), n = (85, 449)	Explore stigma toward AGYW seeking SRH, in particular PrEP from the perspective of clinical and non-clinical staff and AGYW who seek SRH services at the clinic	Barriers to motivation to PrEP use: Unequal gender dynamics
Abigail Harrison et al. [45] 2019 2022		South Africa, AGYW (18–25), (FGD and IDI), n = 46	Young women's description of opportunities and challenges for using PrEP	Barriers to motivation to PrEP use: anticipated sexual stigma and judgment engrained in gender inequality, limited women's autonomy to initiate PrEP, economic dependency on a partner, Barriers to PrEP access: indirect setup within the clinic, perceived healthcare provider judgment, and indiscretions
Morten Skovdal et al. [46] March and June 2019 2022		Zimbabwe AGYW (18–24), (FGD and IDI) n = 26	Explore the role of gender norms in shaping AGYW's hypothetical engagement with PrEP	Barriers to effective PrEP use: family mistrust driven by community rumors and misinformation
Millicent Atujuna et al. [47] June to Nov. 2016, 2022		South Africa AGYW and male (18–24), (IDI), n = 50	Explore the role of family in AGYW PrEP use	

Table 3 (continued)

Author, period of data collection and year of publication	Population/Study design/Sample size	Country/ies	Aim/Phenomenon of interest	Findings
Danielle Giovenco et al. [48] 2017–18 2021		South Africa AGYW(16–25), (IDI), n = 22	Examine the impact of disclosure of PrEP use to various social groups and its impact on adherence	Barriers to effective PrEP use: partner disapproval following disclosure, lack of support, stigmatization from mothers and friends
Shannon O'Rourke et al. [49] 2017–18 2021		South Africa AGYW(16–25), (longitudinal interview), n = 22	How motivation, risk perception, social and environmental influences, and other life factors informed AGYW's decision to try PrEP and exploration of 12 months of AGYW's PrEP journey	Barriers to effective PrEP use: lack of social support including partner disapproval of PrEP use, size of the pill (form), Side effects, travel to other areas (forgetfulness), cultural reasons (PrEP would conflict with the traditions), change in relationship status (death of parent or partner), and becoming pregnant
Michele Lanham et al. [50] Oct 2017, 2021		Kenya, South Africa, and Zimbabwe fHSP (IDI), n = 113	Explore HSP attitudes toward and experiences delivering PrEP to AGYW	Barriers to motivation to PrEP use: lack of PrEP awareness, fear of stigma (related to HIV and sexuality), Barriers to PrEP access: Providers' negative attitude toward AGYW being sexually active Barriers to effective PrEP use: Side effects, lack of PrEP use disclosure to partners and parents, stigma

Table 3 (continued)

Author, period of data collection and year of publication	Population/Study design/Sample size	Country/ies	Aim/Phenomenon of interest	Findings
Elzette Rousseau et. [51] 2017–2020 2021		AGYW (18–25 and 1625 ⁹), (IDI and FGD), n = 137 Kenya, and South Africa	Explore AGYW's PrEP-user journey from awareness and initiation of PrEP to early use and persistence. Highlights individual and relational enablers and disablers of PrEP engagement	Barriers to motivation to PrEP use: Low awareness of PrEP (efficacy, use), stigma and PrEP misconception in the community (PrEP seen as ART), perceived partner or family disapproval of PrEP use, Barriers to effective PrEP use: Side effects, Pill-taking burden, HIV-related stigma, relationship preservation taking precedence over HIV prevention, perception of protection against HIV despite frequently missing doses, travel or school work schedule conflicts with clinic visits, or social activities disrupting pill-taking routine, nondisclosure of PrEP use, or unintentional disclosure Barriers to PrEP access: limited financial and human resource
Maya Jackson-Gibson et al. [52] 2021		AGYW(16–24), HSP community-based staff, and community leaders, (FGD and IDI), n = 55 Kenya	Explore known facilitators and barriers to PrEP implementation, uptake, and persistence among AGYW	Barriers to effective PrEP use: side-effects, community stigma, frequent relocation of AGYW from the project area
Nrupa Jani et al. [53] March to June 2017, 2021		AGYW (15–24), and male partner (≥ 18), (IDI), n = 28 Tanzania	Assess key relationship and contextual factors influencing uptake and adherence to PrEP	Barriers to PrEP use (motivation) and Adherence: Anticipated HIV stigma from parents, partners, and peers

Table 3 (continued)

Author, period of data collection and year of publication	Population/Study design/Sample size	Country/ies	Aim/Phenomenon of interest	Findings
Pia Juul Bjertrup et al. [54] 2017	AGYW (16–25) PBW ^h (> 16), and Health care workers, (IDI), n = 35	Eswatini	Explore structural and social factors that influence the experience of PrEP use and continuation among AGYW and PBW	Barriers to motivation: AGYW without a child fear stigma related with sexuality Challenges related to effective PrEP use: Pill fatigue, family member resistance or judgment to AGYW PrEP use
R. Muhumuza et al. [55], 2018/19	AYP ⁱ (13–24), (FGD and IDI), n = 84	Uganda, South Africa, and Zimbabwe	Explore barriers and facilitators of PrEP uptake among AYP to help formulate and inform PrEP implementation activities	Barriers to motivation: fear of stigma related to HIV (daily pill taking linked with ARV drugs), parental influence, doubting PrEP efficacy, PrEP taking schedule and timing, perceived side effects, myths, and misconceptions, absence of a sexual partner or faithfulness, preference of other PrEP methods Barriers associated with access: health workers attitude, cost of PrEP, long waiting time at the clinic, Barriers associated with the effective PrEP use: pill burden,
Jaclyn N. Escudero et al. [56] Sep. 2018 and Feb. 2019	Community Advisory Boards (CAB), (FGD), n = 26	Kenya	Explore community perceptions around PrEP use among AGYW?	Barriers to motivation to PrEP use: lack of PrEP awareness and knowledge, misinformation, fear of side effects, negative community norms toward AGYW sexuality, fear of retesting for HIV status Barriers to PrEP access: providers are perceived as overworked and not youth-friendly Barriers to effective PrEP use: HIV and sexuality-related stigma, family disapproval

Table 3 (continued)

Author, period of data collection and year of publication	Population/Study design/Sample size	Country/ies	Aim/Phenomenon of interest	Findings
Sarah E Nakasone et al. [57] May to Nov. 2017		South Africa	Explore attitudes toward AGYW accessing PrEP (in theory) and identify facilitators and barriers to PrEP access among AGYW	Barriers to access PrEP: health care providers' negative attitude toward AGYW PrEP use, longer waiting times, clinic/service setup, limited resources, and staff turnover

^a In-depth interview
^b Health service provider/s
^c Young women
^d Mixed method
^e The formative Survey was conducted among the age group 16–24
^f Health service providers experienced in providing PrEP and non-experience
^g Age 16–25 was recruited from South Africa Johannesburg
^h Pregnant and breast feeding women
ⁱ Adolescents and young people
^j Antiretroviral drugs

Table 4 Findings from quantitative studies that reported factors affecting PrEP use (n=6)

Author, year of publication	Population/study design/ sample size	Country (ies)context	Key outcome(s)	Aim	Findings
Mayanja, Y et al. [58] Jan. 2019 to Dec. 2020), 2022	AGYW (14–24), prospective cohort, n=265	Uganda	PrEP initiation	Identify factors associated with PrEP initiation	PrEP initiation = 30.6% (n=81). Had 2–9 sex partners in past 3 months Vs 1 sexual partner (aRR ^k = 2.36, 95% CI: 1.20–4.63) and ≥10 partners (aRR 4.70, 95% CI 2.41–9.17), preferred oral PrEP Vs not (aRR 1.53, 95% CI 1.08–2.19), separated/divorced vs single (aRR 1.55, 95% CI 1.04–2.33, p=0.002), aged 20–24 at enrollment vs 14–19 (aRR 1.07, 95% CI 0.74, 1.54) Primary reason for declining PrEP (n=184/265), 33.7% low HIV risk perception, 27.2% dislike for daily pills, 21.7% not ready, 12.5% preference for other methods (e.g. Condom), 2.7% side effects, and 2.2% stigma
Giovenco, D et al. [60] Oct. 2016 to 18, 2022	AGYW (16–25) randomized open-label PrEP trial, n=409	South Africa and Zimbabwe	PrEP use at 3 and 6 months	Effect of self-reported IPV in the year before PrEP initiation on adherence over the 1 st 6 months on PrEP	<21 years: Evidence of PrEP use at 3 months no IPV= 26.1% vs experienced any IPV = 11.5% (aRR=0.43 95%CI 0.22, 0.86; p=0.016) >21 years: Evidence of PrEP use at 3 months no IPV = 16% vs experienced IPV 33.9% (aRR=2.21, 95%CI 1.34,3.66; p=0.002)

Table 4 (continued)

Author, year of publication	Population/study design/ sample size	Country (ies)context	Key outcome(s)	Aim	Findings
de Dieu Tapsoba, J et al. [61] Oct. 2018 and April 2019, 2022	AGYW (18–24) Cohort study; $n = 336^m$	Kenya	PrEP discontinuation between June 2019 and January 2020	Factors associated with discontinuing PrEP	Factors associated with persisters but nonadherent vs. discontinued PrEP ($n=144$): older age ≥ 22 years (aOR 2.13, 95%CI, 1.01,4.49], $p=0.048$), more likely to be active in DREAMS program(aOR ⁿ 3.85[95%CI 1.07 to 13.82], $p=0.039$), think they would be at moderate-to-high risk of HIV if not taking PrEP (aOR10.17, [95%CI 5.14 to 20.13], $p<0.001$) and more likely to use injectable contraceptives (aOR 3.28, [95% CI 1.4 to 7.67], $p=0.006$) The primary reason for PrEP discontinuation ($n=105$): lifestyle demand (returning to school, being away from home)(30.5%), stockouts (24.8%), side effects, pill burden, pill packaging (24.7%), low HIV risk perception(18.1%)
Ohiomoba, R et al. [62] 2021, 2022	AGYW (15–24) Retrospective cohort; $n=549$	Kenya	PrEP discontinuation Mar 2017 and Dec 2019	Factors associated with PrEP stopping and persistence.	Common reason for stopping PrEP age >18, change in perceived HIV risk (22.3%) and relocation (20.5%) for AGYW age <18, a change in perceived HIV risk (56.6%), family refusal (11.3%)
Vellozo, J et al. [63] 2016 to 2018, 2021	AGYW(16–25) a randomized open-label trial, $n=423^o$	South Africa and Zimbabwe	PrEP use at Weeks 13, 26, and 52 post-initiation.	Time-varying depressive symptoms on effective PrEP use	55.2% of visits had detectable levels of PrEP among AGYW with elevated depressive symptoms vs 59.4% with no/mild depressive symptoms (aRR = 0.73; 95% CI: 0.53, 0.99; $p=0.04$) ^p

Table 4 (continued)

Author, year of publication	Population/study design/ sample size	Country (ies)context	Key outcome(s)	Aim	Findings
Sila, J et al. [59] Jun. 2017 to Oct. 2018 2020	AGYW (15–24) Survey, n=470	Kenya	PrEP initiation	Identify factors associated with PrEP initiation	Characteristics associated with PrEP initiation (n=20/470) Vs decline: had a partner of unknown/positive HIV status (PR=6.05, 95%CI 1.83,20.01; p=0.003) condomless sex (last 6 months) (PR= 1.21 95%CI 1.02, 1.44; p=0.033), alcohol use (past 30 days) (PR=2.17, 95% CI 1.43,3.33; p<0.001), unmarried/not living with a partner (PR=0.55,95%CI, 0.31,0.98; P=0.041), experienced IPV (PR=4.85, 95% CI 1.03,22.73; p=0.045), ^l high self-perceived HIV risk (PR= 1.65 95%CI, 1.41,1.99; p<0.001), ^h those with partner age difference ≥ 10 years (PR=6.57 95%CI, 2.35,18.370; P<0.001), had a partner who has other sexual partners (PR=2.31, 95% CI 1.83-2.92, p<0.001), high behavioral HIV risk (PR= 1.75, 95%CI 1.24,2.46; P=0.001), high self-efficacy to take daily medication (PR=0.74,95%CI, 0.09,6.43; P=0.003), low social support (PR=2.01, 95%CI, 1.63,2.48; P<0.001), depressive symptoms (PR=5.36, 95%CI2.62,10.95; P<0.001)

^k Adjusted relative risk

^l Intimate partner violence

^m 359 were enrolled in the PrEP program, but 336 were the focus of this analysis.

ⁿ Adjusted odds ratio

^o Multivariable models adjusted for study site at baseline and time-varying data on the number of sexual partners, condom use during vaginal sex, any transactional sex, any IPV and posttraumatic stress disorder symptoms

^p Number of participants for the overall trial was 427, but 423 were included in the analysis for which results are presented

^q Prevalence ratio

^r N=388

^s N=358

included the belief that using PrEP would lead to birth defects and infertility and that PrEP was a strategy used by governments to prevent expired antiretrovirals from being wasted [56, 57]. Medication attributes, such as pill burden and side effects, were reported in four studies as limiting motivation to use PrEP [40, 56, 58, 59]. A quantitative survey conducted in 2020 in Kenya among AGYW attending family planning (FP) clinics revealed that among AGYW who had high HIV risk (111/359=24%), pill burden (51%) was a key reason why AGYW declined an offer of PrEP [59]. Similarly, a study conducted between November 2020 and March 2021 in South Africa among PrEP programme implementers reported that providers perceived daily pill taking and fear of side effects as discouraging AGYW from initiating PrEP [40].

Two of the quantitative studies reported that self-perceived HIV risk also affected motivation to use PrEP service [58, 59]. A quantitative study conducted among 470 AGYW in Kenya in 2020 reported that AGYW with high self-perceived risk of HIV acquisition were more likely to initiate PrEP than AGYW with low perceived risk (PR:1.65, 95% CI, 1.41, 1.99, $p < 0.001$) [59]. Similarly, a cohort study conducted between January 2019 and December 2020 in Uganda, among AGYW accessing a clinic providing sexual and reproductive health, including HIV, services to women vulnerable to HIV found that 33.7% of AGYW declined PrEP offer due to low self-perceived [58].

Nine studies reported that anticipated stigma related to sexuality and HIV also affected motivation to use PrEP, as did fear of judgment or disapproval of PrEP use due to gender norms related to the sexuality of AGYW [40, 43, 50, 51, 53–55, 58, 64]. A qualitative study conducted in 2017 in Eswatini found that AGYW who did not have a child feared the stigma of starting and continuing PrEP [54]. In South Africa, a qualitative study conducted between November 2020 and March 2021, which aimed to explore the experience of delivering PrEP to AGYW, found that providers reported stigma, disapproval, and resistance from family and community as delaying the PrEP uptake or leading AGYW to decline an offer of PrEP [40]. Similar findings were reported in a quantitative study conducted between January 2019 to and December 2020 in Uganda where 2.2% of AGYW declined an offer of PrEP due to fear of stigma.

Three studies reported that norms related to sexuality of AGYW limited PrEP use [43, 46, 56]. In a study on community perceptions of AGYW starting PrEP conducted between September 2018 and February 2019 in Kenya, the community generally approved PrEP use for specific populations, including sero-discordant couples and sex workers [56]. However, they were less approving of AGYW's use of PrEP, with PrEP

use perceived as promoting promiscuity [56]. A qualitative study conducted in 2019 in urban South Africa reported that negative community perceptions such as judgment and disapproval influenced the decision of AGYW to use PrEP [43]. In a 2019 qualitative study among randomly selected AGYW residing in rural and urban settings characterized by high levels of poverty and HIV in Zimbabwe [46], participants raised concerns about how PrEP was associated with sex work and thus feared being labeled “loose women” if they sought PrEP services [46].

Factors affecting access to PrEP services

Nine (36%) studies [40, 43, 44, 46, 50, 52, 55–57] (Tables 3 and 4) reported barriers related to access to PrEP services as affecting use, which included health service providers' negative attitudes toward AGYW's sexuality; PrEP and other supply stockouts; human resource shortages; clinic setup (isolated HIV clinics); and long waiting times in the clinic [40, 43, 44, 46, 50, 52, 55–57].

Three studies reported health care providers' negative attitudes (perceived as overworked or not youth-friendly) as affecting access to PrEP services [46, 50, 56]. In a mixed-method study conducted between 2018 and 2020 in South Africa 40.5% ($n = 182/449$) of AGYW experienced stigma from clinical staff, and 75% ($n = 98/130$) of clinical and nonclinical staff believed that providing PrEP would lead to sexual risk-taking among AGYW [44]. A study conducted in October 2017 in Kenya, South Africa, and Zimbabwe identified negative attitudes toward AGYW sexuality as preventing providers from offering PrEP, particularly to girls aged < 19 years, as reported by a nurse: “They are too young for sex” and “Sex could wait” [50]. Similarly, in a study conducted in South Africa in 2017, an employee of the Department of Health explained that “...[giving adolescents PrEP] will mean setting them free to engage in unprotected sexual intercourse...” [57].

Other access-related barriers included a shortage of staff and supply stockouts [40, 52, 57]. In six qualitative studies clinic schedules (visit hours) and screening procedures to initiate PrEP, perceived lack of confidentiality in clinics, and long waiting times were reported as limiting access to PrEP [43, 44, 46, 51, 56, 57]. A study conducted between September 2018 and February 2019 in Uganda, South Africa, and Zimbabwe identified the cost of PrEP as a reason for limited access [55]. In a study conducted between November 2020 and March 2021 in South Africa among programme implementers on PrEP, the need to request parents' or guardians' approval (consent) for adolescents to be able to initiate PrEP acted as a barrier to accessing PrEP services [40].

Barriers to effective PrEP use

Eighteen (72%, $n=18$) studies described barriers relevant to the third step of the HIV prevention cascade, effective PrEP use [39–42, 47–56, 60–63] (Tables 3 and 4). Ten of the studies reported a lack of family, partner, and social support as a barrier to PrEP continuation and adherence [39, 41, 46–49, 56, 62, 65]. In a qualitative study conducted between 2017 and 2018 among AGYW recruited through a youth-friendly clinic in a peri-urban settlement in South Africa, negative consequences after the disclosure of PrEP use, including violence or being told to stop using oral PrEP, affected continued PrEP use [48]. Similarly, in a qualitative study conducted in 2020 in South Africa, lack of social support and fear of stigma were reported as challenging adherence to PrEP for some AGYW [39].

Six studies reported stigma related to sexuality and HIV as an important barrier to effective PrEP use [39, 42, 51, 52, 56, 58]. Similarly, a qualitative study conducted between 2017 and 2018 in South Africa reported that AGYWs stopped taking PrEP, as taking PrEP conflicts with traditional beliefs [49].

Similar to motivating PrEP use, five studies described medication attributes (i.e. side effects, pill burden, size of the pill, forgetting to take pills daily) as affecting effective PrEP use [41, 42, 49, 55, 66]. A quantitative study conducted in Kenya and two mixed-method studies in South Africa reported that stock-outs and PrEP follow-up care procedures, including the required frequency of clinic visits, retesting for HIV, and adherence monitoring, affected the capacity of AGYW to effectively use PrEP [41, 42, 61].

Lifestyle changes, including travel for work or school, marriage, and changes in the social support system, were reported in five of the studies as limiting effective PrEP use [49, 51, 61, 62, 65]. Similar to motivation to use PrEP, two studies identified low HIV risk perception as a challenge to PrEP continuation and adherence, which was usually linked to a change in partnership and learning of a partner's HIV-negative status [61, 62].

Two studies reported that age was also associated with the capacity of AGYW to effectively use PrEP, with adolescents less likely to continue to use PrEP [61, 62]. A retrospective cohort conducted between 2016 and 2018 in Kenya among AGYW recruited through the DREAMS programme reported that PrEP discontinuation was higher among girls aged < 18 years relative to young women [62]. Similarly, a cohort of AGYW in Kenya reported that women aged > 22 years were more likely to continue to use PrEP 3 to 4 months post-enrollment than were those aged < 22 years (OR 2.7 [95% CI, 1.43, 5.11], $p=0.002$) [61].

In a randomized controlled trial in South Africa and Zimbabwe that aimed to assess the effect of time-varying depressive-symptoms on PrEP adherence, highlighted that AGYW with persistent elevated depressive symptoms were less likely to have detectable tenofovir-diphosphate levels (TFV-DP) in dried blood spots (a marker of PrEP adherence) after 52 weeks compared to those with no/mild depressive symptoms [63]. A quantitative study conducted between October 2016 and 2018 in South Africa explored the association between intimate partner violence (IPV) and PrEP adherence among AGYW at three and six months post-initiation [60]. The study found that, at month three after the initiation of PrEP, the relationship between IPV and PrEP adherence depends on age. Under aged 21 years, 12% who had experienced IPV persisted with PrEP until three months post-initiation, compared to 26% of AGYW who reported no IPV. Conversely, among young women aged > 21 years, PrEP continuation at three months post-initiation was 34% among those experiencing IPV compared to 16% among those not experiencing IPV [60].

Discussion

This scoping review mapped the available evidence on barriers to oral PrEP use among AGYW to the HIV prevention cascade. Our review found barriers from individual- through structural-level and factors that cross-cut AGYW's motivation to initiate PrEP, ability to access PrEP and capacity to continue with and adhere to PrEP, particularly stigma and gendered norms related to sexuality. For motivation to use PrEP, the most commonly reported barriers included lack of awareness and misinformation about PrEP, fear of pill burden and side effects, perceived PrEP use disapproval from parents, sexual partners or community, low HIV risk perception and perceived stigma related to sexuality and HIV. Access-related barriers included healthcare providers' stigma and negative attitudes toward AGYW's use of PrEP, staff shortages, PrEP stockouts, and lack of confidentiality in the clinic and/or isolated clinic set-up. The capacity to effectively use PrEP was affected by a lack of partners, parental, family and community support, low HIV risk perception, pill attributes (i.e. side effects, pill burden, and size), stigma, and lifestyle changes.

We used the HIV prevention cascade as a framework to guide our review of the literature to systematically assess and group the identified barriers [31]. However, some barriers affected multiple steps in the cascade. Stigma, including anticipated stigma, cut across all three pillars, affecting motivation (i.e., sexuality and HIV-related stigma), access (i.e., discrete/isolated clinic setup, fear of being judged by service providers i.e., a belief that PrEP use could cause immoral sexual behavior through risk

disinhibition), and effective use (i.e., fear of being seen as HIV positive when taking pills) [67].

HIV-related stigma has been commonly cited as limiting motivation and effective use of PrEP among other populations; in a scoping review of North American studies exploring HIV-related stigma and its effects on PrEP use among men who have sex with men and transgender women [13, 49, 68]. Similarly, gendered cultural norms related to sexuality in AGYW limited motivation and access to and continued use of PrEP, with AGYW anticipating being considered a “loose woman” and healthcare providers refusing to offer PrEP to AGYW. This particularly affected adolescent girls, who saw themselves being denied PrEP due to cultural norms related to sexuality despite being sexually active [51, 69, 70]. This finding highlights the intersectionality of age and stigma, where cultural and gendered expectations intersect to disproportionately affect AGYW motivation, access and effective use of PrEP. Similarly, a more recent qualitative study (2023) in South Africa among individuals with AGYW also reported how anticipated stigma contributed to non-adherence and missing doses [9].

In addition to stigma, health service providers' common belief that providing PrEP would encourage riskier and more frequent sex among AGYW limited access to PrEP; this belief has been reported to impact the provision of other sexual and reproductive health services, such as FP services [53, 57, 67, 71]. Thus, a policy focus on, service providers' training would facilitate unbiased adolescent-provider dialogues. In addition, it would provide an opportunity for strengthening the provision of adolescent- and youth-friendly services [72]. Within such approach, a South African study stressed that reinforcing positive message to health workers would help them provide PrEP service to AGYW [53]. In this study, the health workers were said to be eager to support the introduction of PrEP if they were informed that it was a way of protecting the ‘future’ of the county [53]. It was also believed that reinforcing positive messages to health workers would help them to provide PrEP for AGYW [53]. As these studies have shown, strategies are needed to create an environment in which the sexual and reproductive health of AGYW can be improved, creating positive social and sexual norms to promote safer sexual behaviors and access to services [69]. Specifically, promoting PrEP as a health promotion tool for both partners rather than a risk reduction tool has been a key recommendation [40, 56, 73]. As demonstrated in the field of FP regarding contraceptive choices, it will be crucial to offer AGYW different PrEP choices in a non judgmental environment. This approach can reduce the frequency of clinic visits and enhance discretion, particularly if

long-term PrEP options are made available, and if such interventions are to be effective [72].

Low self-perceived risk of HIV acquisition is a barrier for motivation to initiate PrEP and, for those who accessed PrEP, to effective use. This finding is not surprising, given that studies have consistently shown that AGYW risk perception does not always align with their sexual behaviors [74]. AGYW might engage in high-risk behavior such as transactional sex or having multiple partner, still perceive themselves as having a low risk of HIV infection [74]. One of the factors that influence AGYW to engage in a risky behavior are economic hardship, leading them to engage in transactional sex, where sex is exchange for money or gifts [66, 74]. This increase their exposure to HIV, as many of the sexual partners are older and more sexually experienced and the gender and power imbalance often limits AGYW ability to negotiate condom use [74]. However, PrEP offers a female-controlled HIV prevention method that can address intersecting barriers such as the age-gendered power imbalances, by providing AGYW the opportunity to decide on its use without the need for prior negotiation with sexual partner [75]. Making sure AGYW and their communities are aware of their risk through education and campaigns and increasing awareness on PrEP benefits are recommended [66, 76]. PrEP access was also affected by stock-outs and staff shortages, hence support for drug supply and the allocation of enough manpower should be incorporated to sustain PrEP provision [72].

Our findings highlight that a lack of social support, including support from partners and parents, and disapproval of PrEP use, whether perceived or experienced, lead to nondisclosure of PrEP use. This reduced effective use. In African countries, communicating with children about sexual matters is taboo, making it difficult for AGYW HIV-related issues with, and thus disclosing, PrEP use to, their parents' guardians [77]. A study conducted in Eswatini and included in our review showed how AGYW struggled with whether they needed to involve their partner or parents in their decision to use PrEP [54]. One South African study that explored the dimensions of PrEP use stigma among AGYW reported that disclosing PrEP decreased the stigma associated with PrEP use [78]. Another South African study included in our review suggested that PrEP awareness among parents was low and that strategies to disseminate information, e.g., through brochures, TV, and radio, were needed to explain the purpose of PrEP to parents, which in turn could help them support their daughters to use PrEP [48]. Thus, intergenerational HIV prevention interventions should aim at improving good communication between children and parents, while at the dyadic level,

fostering positive and healthy relationships with partners to support AGYW in PrEP decision-making [40, 79].

It is important to emphasize that AGYW are not a homogeneous group, and given the age span included in our review, are at different stages of physical, social, and cognitive development; hence, they experience unique barriers to PrEP use as their capacity evolves dynamically with time and social context. For example, our review revealed that the effect of experienced IPV differed by age and that for young women, lifestyle changes such as travel and marriage affected effective PrEP use [51, 61]. Similar to delivering PrEP in different settings, young women need access to different HIV prevention methods, including alternative PrEP formulations [55, 58]. Preference for injectable PrEP has been reported by female sex workers in Kenya, as a single injection provides protection for a prolonged period, and this formulation does not require one to remember to take pills daily [80]. Given the heterogeneity of AGYW and the variety of barriers, a one-size-fits-all approach will not be effective in achieving global-level PrEP coverage goals among AGYW. Some studies have investigated promising and innovative means of PrEP promotion and delivery. Peer-led and community-based delivery of sexual and reproductive health services is an innovative approach to reducing barriers and meeting AGYW where they are [81]. In South Africa providing same-day community-based PrEP initiation and refill services was found to be highly acceptable [82]. Community-based delivery using comprehensive, adolescent- and youth-friendly approaches, is highly needed for AGYW living in communities with a high HIV burden [83]. Integrating PrEP into existing Sexual and Reproductive Health (SRH) services would create opportunities to go beyond HIV prevention and improve uptake of other SRH services such as averting unplanned pregnancies, identifying and managing STIs, increasing HIV testing and promoting dual protection and condom use [72].

Although this review focused on oral PrEP, future research should explore the acceptability, effectiveness, barriers and access related to alternative PrEP formulations, such as long-acting injectables of the Dapivirine vaginal ring, among AGYW in different cultural settings. Such studies could help address the barriers identified in this review that are associated with daily oral PrEP, such as pill burden, anticipated side effects and adherence challenges, potential offering AGYW more suitable options that align with their lifestyles. Additionally, research on digital health interventions (e.g., mobile apps, SMS reminder, telehealth support) could provide insight into how and for whom digital tools might help overcome barriers to PrEP adherence by offering discrete reminders, education, and connection

to support networks. These interventions may prove especially valuable for AGYW who experience stigma or lack a supportive environment.

Our review has several strengths: we reviewed a large number of articles, and three reviewers were involved in the screening and data charting process. However, we included only studies written in the English language, which might have led to the omission of evidence from West African countries in particular. We acknowledge that excluding non-English studies may result in an underrepresentation of region-specific barriers to PrEP uptake and adherence. Additionally, the review focused on oral PrEP only, including other HIV prevention methods, i.e., injectable PrEP, would have provided a more comprehensive understanding of gaps in the HIV prevention cascade for PrEP, regardless of the formulation. However, as the majority of studies were published in 2022 or 2023, we anticipate that we would have identified few studies on the dapivirine vaginal ring or injectable PrEP. Furthermore, many of the identified barriers are not limited to the formulation of PrEP but rather are reflective of the context in which AGYW attempt to meet their HIV prevention needs. Nevertheless, focusing only on oral PrEP may limit the generalizability of our findings to other forms of PrEP, potentially introducing biases that should be considered when interpreting the results.

Conclusion

This scoping review identified barriers to PrEP use among AGYW along the HIV prevention cascade. Our findings illustrate that AGYW face multiple barriers to effective PrEP use, with HIV and sexuality related stigma as an important cross-cutting issue that affected all steps of the HIV prevention cascade. Although our review focused on oral PrEP, some of these barriers, such as stigma, social norms, side effects, and availability might also affect the use of future PrEP formulations. Notably, the majority of studies included in our review were conducted in only two countries, and few quantitative studies were available. More research in other settings involving larger numbers of AGYW are needed for context-specific evidence. Despite this gap, our review highlights recommendations that can enhance social support, reduce stigma, and increase community-level awareness of how PrEP can promote a healthy lifestyle. Health systems must also be equipped with sufficient resources, particularly if PrEP demand increases. Furthermore, service providers should understand the personal and social challenges that AGYW experiences and provide a supportive environment in which to offer PrEP services.

Supplementary Information

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Additional file 1: Table 1. Construction of database, string, and results.pdf.

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Authors' contributions

BH and MA conceptualized the review, and BA supervised the review process. MA extracted all the data from the database, and all the authors participated in the review process. The first draft of the manuscript was written by MA, BH, and CN, who were involved in continuous review and editing of the manuscript. All authors reviewed and approved the final version of the manuscript.

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Data availability

All data generated or analyzed in the scoping review is included in the published article and on additional file.

Declarations

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Not applicable.

Consent for publication

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Competing interests

The authors declare no competing interests.

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