Community perceptions about use of pre-exposure prophylaxis (PrEP) among adolescent girls and young women: A qualitative analysis

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Abstract

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Objectives: Adolescent girls and young women (AGYW) experience disproportionately higher rates of HIV acquisition compared to males of the same age, but PrEP uptake and continuation are low in this population. This study explored community perceptions around PrEP use among AGYW in Western Kenya. **Design**: Semi-structured in-depth focus group discussions (FGDs) were conducted with Community Advisory Board (CAB) members affiliated with two PrEP implementation projects targeting young women. **Methods**: FGDs were audio recorded, translated, and transcribed. Conventional content analysis and thematic networks analysis were used to identify themes relating to community perceptions of PrEP use among AGYW. **Results**: Four FGDs were conducted with 26 CAB members. Barriers to PrEP awareness among AGYW included lack of PrEP education in school HIV curriculum and failure of community leaders to sensitize and engage AGYW. Low uptake was thought to be associated with PrEP myths, and

inaccurate understanding of who could benefit from PrEP and duration of use. AGYW may believe that PrEP is only for married/pregnant women or must be taken for life. PrEP use was viewed as unacceptable for AGYW in some communities because PrEP would increase “promiscuous” behavior, leading to decreased use of condoms and contraception, and increased STI incidence and pregnancy rates. Other barriers to uptake included confusion between PrEP and HIV treatment, lack of youth-friendly services at facilities, fear of HIV testing, and ease of access to condoms compared to PrEP. CAB members recommended integrating PrEP delivery into maternal and child health and family planning services, training community health volunteers to sensitize and deliver PrEP, and involving AGYW in policymaking as ways to improve access and uptake among AGYW. **Conclusion**: PrEP scale-up among AGYW will require community sensitization of AGYW to reduce stigma and clarify misperceptions.

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Introduction

In East and Southern Africa, adolescent girls and young women (AGYW), aged 15-24 years, experience higher rates of HIV incidence than their male counterparts. AGYW account for 26% of new HIV infections while only making up 10% of the regional population[1]. In 2016, an estimated greater than 10,000 new HIV infections occurred among adolescent girls in Kenya aged 15-19 years, more than double the number of infections in adolescent males[2]. That same year, the Kenya Ministry of Health (MOH) released guidelines on the provision of pre-exposure prophylaxis (PrEP) for HIV prevention to high-risk individuals, which includes AGYW in HIV high-burden areas as a target population[3].

Ongoing programmatic rollout of PrEP in Kenya includes PrEP delivery through multiple facility delivery points, including HIV treatment clinics (known as Comprehensive Care Clinics [CCCs] in Kenya), maternal and child health (MCH) and family planning (FP) clinics[4]. PrEP has been acceptable among Kenyan AGYW offered PrEP within MCH and FP clinics in settings with high HIV prevalence[5,6]. However, only 38% of AGYW who initiated PrEP through routine MCH and FP clinics in Western Kenya continued use after one month[7]. As PrEP access expands in high-burden settings with AGYW as a target group, it is important to understand the multi-level factors influencing PrEP use in this priority population. Several studies have identified stigma, service delivery issues, and misinformation as influential barriers to PrEP use in various populations and settings[8–12]. Improved counseling, peer education, and community-level service delivery and monitoring have been identified as potential facilitators to PrEP use and adherence[9,10].

PrEP benefits depend on prevention-effective adherence among individuals with substantial risk for HIV acquisition. Few data are available to understand community-level factors influencing PrEP uptake and continuation among AGYW in high-burden settings. Community stakeholders are often included in HIV research through the use of Community Advisory Boards (CABs)[13]. CABs advise research staff by identifying public safety and other community support

systems, providing feedback on the effects of research on the community, proposing solutions to mitigate challenges, and offering suggestions for programmatic improvements. Representing diverse voices, CABs express community and stakeholder sentiments about research, as well as perspectives on knowledge and effectiveness of interventions in the communities they represent[13–15]. Additionally, CABs can help garner support among the community and foster an environment of mutual trust and increased awareness[13]. To our knowledge, no studies have examined community attitudes toward PrEP uptake and use specifically among AGYW.

Better understanding community views on uptake and access can identify important strategies for future scale-up. Such insights can inform targeted interventions and scale-up activities, and be used to foster community perspectives that influence AGYW PrEP decision-making. In this study, we explored community perceptions around PrEP use, specifically among AGYW in Western Kenya.

Methods

Study Design and Population

We recently completed a large demonstration program, the PrEP Implementation for Young Women and Adolescents (PrIYA) Program, which provided real-world programmatic delivery of PrEP via MCH and FP clinics in Kisumu County, Kenya. We are also conducting the ongoing PrEP Implementation for Mothers in Antenatal Care (PrIMA) Study, a clinical trial to evaluate PrEP delivery approaches for pregnant women in Homa Bay and Siaya Counties, Kenya (NCT03070600)[16]. Both PrIYA and PrIMA focus on PrEP uptake among AGYW and include CABs to provide guidance in program implementation.

We conducted focus group discussions (FGDs) with CAB members between October and December 2018. FGDs took place in three counties and equally spanned the PrIYA and PrIMA projects – Siaya (N=1; PrIMA), Homa Bay (N=1; PrIMA), and Kisumu (N=2; PrIYA). To achieve maximum recruitment, CAB meetings were held immediately prior to or following each FGD. CAB members included representatives from youth groups and women's groups, county government

leaders, healthcare workers (HCWs), health system administrators, and other community leaders. To leverage existing relationships and trust, participants in each FGD were sampled from the same CAB. CAB members were recruited by study coordinators and all CAB members were invited to participate.

Data Collection

FGDs were conducted using a semi-structured FGD guide with open-ended questions to explore participant beliefs and experiences related to PrEP, including: 1) knowledge about and attitude toward PrEP use among people in the participants' communities, 2) factors influencing availability and use of PrEP, 3) suggestions for improving PrEP delivery, and 4) whether they would recommend PrEP to a sister or close female friend. The FGD guide was piloted with PrIYA staff and revised to optimize language, phrasing, and ordering of questions.

Each FGD was facilitated by one of two trained Kenyan female social scientists who were not affiliated with PrIYA or PrIMA and a Kenyan note-taker affiliated with PrIYA was present during each FGD, but did not facilitate or participate in the discussion. Prior to each FGD, participants completed short surveys to collect basic demographic information. FGDs were recorded using a digital audio recorder, transcribed verbatim by the interviewer, and translated when necessary. Following each FGD, interviewers summarized the FGD in a structured debrief report[17]. FGDs lasted between 67 and 86 minutes. Reimbursement for transportation costs (1000 Kenyan Shillings – approximately 10 USD) was provided to each participant.

Ethical Approval

The study was approved by the University of Washington Institutional Review Board (IRB) and by the Kenyatta National Hospital-University of Nairobi Ethics and Research Committee (ERC). All study participants provided written informed consent.

Data Analysis

The goal of analysis was to explore themes relating to community perceptions of PrEP use among AGYW. Focus group discussions were analyzed using a combination of conventional

content analysis and thematic networks analysis[18,19]. Debrief reports were used to develop a preliminary codebook, which was refined based on review of full-length transcripts. The codebook was generated using both inductive and deductive methods through an iterative process with study staff and social scientists. Deductive codes were identified from literature reviews and content included in the FGD guide. Inductive codes were developed directly from the data, using open coding. The codebook was structured into categories based on key discussion topics (e.g. PrEP knowledge, decision making, and availability). All transcripts were imported into ATLAS.ti version 8 and coded using the final version of the codebook by two U.S.-based scientists with extensive experience conducting HIV research in Kenya. Coders independently reviewed and coded half of the transcripts, then swapped and reviewed each other's application of the coding framework. Memoing and coding occurred in parallel to ensure systematic application of codes and interpretation of concepts across all transcripts. Disagreements in code application were resolved through group discussion between the larger study team. After coding had completed, the team synthesized data to understand related concepts that comprise the network of themes underlying community perceptions of PrEP and perspectives on PrEP use, specifically among AGYW in Western Kenya.

Results

Twenty-six CAB members participated in four FGDs (Table 1). Participants were a median of 37 years, primarily female (73%), with some university/college-level education (58%). Overall, CAB members were accepting of PrEP use among AGYW, but noted key barriers influencing low uptake and continuation among this population. CAB members identified three major themes relating to barriers to PrEP use among AGYW: 1) AGYW lack awareness and knowledge about PrEP, and myths about PrEP are prevalent; 2) Conflating PrEP with HIV treatment has contributed to stigma associated with using PrEP; and 3) PrEP is difficult to obtain and use, especially for AGYW. To address these barriers to PrEP scale-up for AGYW in Kenya, CAB members

recommended sensitization, alternative delivery approaches, and involving AGYW in policymaking.

AGYW lack awareness and knowledge about PrEP, and myths about PrEP are prevalent

According to CAB members, lack of PrEP awareness and knowledge, misinformation, and low risk perception have led to poor uptake of PrEP, especially among AGYW in Western Kenya. CAB members described several inaccuracies about PrEP eligibility and duration of use commonly observed among AGYW. CAB members described confusion among AGYW about how long PrEP should be used, with many believing that PrEP must be taken for life. Although not a commonly held view, multiple participants shared that they have heard some say that PrEP is a way of *"ensuring everyone is on pills"* or that the government encourages PrEP use because it does not want donated ARVs to *"expire or go to waste"*. CAB members also noted fears among AGYW that if they took PrEP and acquired HIV, currently available HIV treatments would be ineffective.

> *"Some people feel that when you are negative when you are taking it, in [the] future, in case you become positive…the ARVs may not be able to work; it may cause resistance." – Female Health System Representative, age 33 years*

Other myths identified by CAB members centered around the negative impact of PrEP on pregnancy, which especially impacts adolescents and young women interested in having children. CAB members described fears around giving birth to a "deformed child" or leading to infertility.

> *"I think there is also some myths associated with it which bring fear…that it can also interfere with unborn child and even lead to giving birth to a deformed child or something also to do with long term effect; it can also cause some diseases like cancer…" – Male County Government Representative, age 50 years*

Many participants voiced concerns that PrEP sensitization has not effectively reached the general community. This was especially true for youth. CAB members described how alternative methods, such as condoms and voluntary medical male circumcision (VMMC), are more widely known and

understood by the community due to more extensive health campaigns in the past. In addition, schools and religious groups are not supportive of PrEP use, and instead promote abstinence only.

> *"When it comes to religion and education they don't support the access of PrEP, so many times we have tried to access many school[s] just to teach about PrEP, but they give us certain topics [to avoid]...No talking about condoms, no talking about PrEP, no talking about PEP, all you do is talk about taking [ARVs]…that is it." – Female Youth Representative, age 21 years*

Also negatively influencing PrEP uptake among AGYW is the community perception that PrEP promotes "immorality" and "promiscuity".

> *"The perception of the community in general is that [PrEP] is a way of encouraging immorality among the youth because they go into the sexual scene and then they go and take [PrEP] to prevent HIV and AIDS, so it is a way of promoting [sexual activity] now." – Female Women's Group Representative, age 56 years*

Although almost all FGD participants said that they would recommend PrEP to others, one participant said that she would not consent to her unmarried daughter using PrEP, as *"that is sexual sin."* Participants shared the community's fear that PrEP use will lead to increased incidence of STIs and pregnancies among AGYW, as PrEP users will neglect to use condoms and other contraceptive methods.

> *"The few parents that I have come across are totally against it. They feel that their adolescents are being exposed… and they are being allowed to have unprotected sex as much as possible because now there is prevention of HIV and it is the HIV that they fear most and not even the pregnancies." – Female County Government Representative, age 38 years*

Conflating PrEP with HIV treatment has contributed to stigma associated with using PrEP

Participants in all four FGDs echoed the community's confusion of PrEP as both a drug for HIV prevention and an antiretroviral drug (ARV) used for HIV treatment. PrEP looks the same as ARVs in terms of size, color, and packaging. In some facilities, PrEP is also delivered through HIV care clinics (CCC), where people living with HIV receive treatment and pick up medications. CAB members noted fears from community members that if you are seen at the same clinic where people go for HIV treatment, you are assumed to be HIV-positive.

> *"Nobody wants to be associated with ARVs, so PrEP is [an] ARV and therefore [AGYW say] I should not be seen with a tin…carrying the drugs." – Female County Government Representative, age 38 years*

Some FGD participants expressed that AGYW, especially unmarried women, are more likely to be stigmatized for their PrEP use. Many are still living with their older relatives, who may disapprove of their PrEP use, believing it will cause promiscuity. However, participants believed that women engaging in transactional sex feel confident that PrEP will protect them from acquiring HIV when their clients refuse condom use.

> *"Some community sexual workers believe that it is the safest mode to use because the moment you start using it, you are safe, you are 100% safe, you are just sure that in the event that you get a client who doesn't want to use a condom for you…you are safe." – Female Women's Group Representative, age 36 years*

When asked about fears regarding PrEP use, several participants listed side effects they have heard community members share. Many of these side effects are perceived to be associated with ARVs, including weight gain, dizziness, nausea, and rash. Participants discussed these side effects as deterrents to PrEP use for general health reasons and for fear of being perceived to be HIV-positive.

> *"What I have heard is some say that their skin will be rough and dry. Some also say that they get big and fat and pulpy." – Female Women's Group Representative, age 36 years*

PrEP is difficult to obtain and use, especially for AGYW

Several participants said that AGYW do not seek PrEP because they are afraid to know their HIV status and they do not like the requirement to re-test due to the emotional stress and logistical barriers HIV testing entails.

> *"If you compare this age, you will find that at that age many people are afraid to know their HIV status as compared to the older pregnant women… [To use PrEP] it is a must you have to know your status. So if you compare, the younger age, they will be afraid to know their status so they won't be for the PrEP." – Female Youth Representative, age 22 years*

Additionally, facilities and HCWs providing PrEP are perceived as being over-worked and not youth-friendly. Even if an AGYW seeks out PrEP, she may not feel comfortable disclosing her risk behaviors if she feels judgment from the provider, which could also lead to poor adherence. Pregnant AGYW who may be coming to terms with their maternity status may feel even more reluctant to seek care and start to make decisions about their pregnancy, including initiating PrEP.

> *"They come to the ANC expectant, naïve, helpless… Opening up is a challenge and here the nurses have a queue to clear and… [AGYW] require ample time with adequate information to make a decision." – Female Health System Representative, age 46 years*

Participants disagreed about whether AGYW find PrEP preferable to condoms. Some participants said that condoms can be obtained more discreetly, while PrEP requires a hospital visit and screening. Others stated that AGYW prefer PrEP because it can be taken in secret, whereas condom use must be negotiated with one's partner.

> *"I know women will use PrEP more than men…because women are not really taking control in negotiation when it comes to sex, men normally make the decision on when and where to have sex so with that one it becomes very difficult sometimes to negotiate about safe sex so they prefer when they have something which they can control. So I know women will use it more."– Male County Government Representative, age 50 years*

PrEP scale-up requires alternative delivery approaches, sensitization, sustainable support, and youth involvement

CAB members identified several strategies that could improve PrEP uptake among AGYW. PrEP scale-up should consider alternative delivery points, other than the CCC, which is associated with HIV positivity and treatment. CAB members suggested expanded delivery points, including outpatient, MCH, and FP clinics. FP clinics provide an ideal delivery point for AGYW that would simultaneously provide access to PrEP and prevention education messaging around STIs and pregnancy.

CAB members noted that for any PrEP delivery system for AGYW, privacy and confidentiality must be prioritized. In addition, HCWs should be trained to offer youth-friendly services. Outside the facility, CAB members noted that PrEP delivery through community health volunteers (CHVs) could improve access and adherence. Many CAB members felt that screening and initiation should continue to be done at the hospital, but that CHVs could take refills "*to their door step,"* removing the need for repeated facility visits. However, some suggested that PrEP should only be stored at the health facilities to avoid mishandling by those who are untrained. Mobile facilities were one delivery strategy that CAB members believed could help reduce stigma.

> *"When we have mobile clinics, it will be like a normal thing, stigma will be reduced and the people will be taking it as a normal thing and therefore it is not harmful to have PrEP drugs with you, you can walk in any time and out and pick your PrEP whenever you want as opposed to having it in a fixed place like in a hospital." – Female Health System Representative, age 46 years*

Participants made suggestions about possible sensitization strategies. CHVs, midwives, or peer educators could be trained to sensitize the community about PrEP. Several participants recommended that the Ministry of Health and Ministry of Education work together to integrate health education and PrEP information into the school curriculum in secondary schools and in colleges. Youth could also be reached in youth forums, where they would be more comfortable

sharing their views and asking questions. Importantly, participants acknowledged the need to first sensitize policy makers and community leaders.

> *"Even the leaders themselves, we have not reached them with enough information…so as much as we are saying that we have not sensitized the adolescents, even the leaders themselves we have not done much to reach them with this information about PrEP and they still live with those myths and misconceptions." – Male County Government Representative, age 50 years*

All FGDs discussed PrEP availability, stating that PrEP is available in all government health facilities: *"PrEP is available…everywhere…it's like oxygen."* Participants perceived that the government and its non-governmental partners have provided PrEP to meet the current demand, but *"if we increase demand, then there will be need to increase funding for it."* People engaging in risky sexual behaviors generate demand, and further demand creation might influence availability, especially if there is rapid expansion in uptake. There is also concern about the sustainability of PrEP, given the current mechanisms supporting access.

> *"PrEP has been spearheaded by most of the partners…but these projects are short lived… I think on the government side we have not really allocated finances to continue with these programs without the partners. So we are seeing a gap especially in terms of sustainability…So I know this discussion will also be used as resource [for] mobilization so that we can continue with the programs at the end of the programs which the partners are running and eventually it can be taken over fully by the government." – FGD1, Male County Government Representative, age 50 years*

Effective and sustainable implementation will require the consultation of key opinion leaders. Notably, participants emphasized the importance of involving adolescents in policymaking.

> *"I would tell them to involve the adolescents in making that policy like when they are in that board meeting the adolescents should be there because this is about them, it is not about you guys, you are making policies according to you and according to your own*

perception and the kind of funding that you are having not caring about us like what we are going through…where we are." – Female Youth Representative, age 21 years

Discussion

This qualitative study was conducted among community stakeholders within a setting where programmatic PrEP delivery for AGYW is ongoing. Our analysis revealed multiple factors perceived as barriers to PrEP use among AGYW. Myths and misconceptions about PrEP among AGYW are thought to persist within the community due to poor sensitization, limited delivery approaches that are currently only facility-based, and persistent disease- and behavior-related stigma. Our participants also identified potential solutions for addressing these challenges, including focusing community-level PrEP messaging to dispel misinformation, expanding PrEP access points for AGYW, and working directly with AGYW and community leaders to increase PrEP demand. To meet PrEP targets and prevent new HIV infections among AGYW most at-risk, it will be increasingly important for PrEP programs to consider community perspectives as PrEP scale-up continues.

Recent studies have explored topics related to the general use of PrEP in several sub-Saharan African countries, through qualitative interviews, focus groups, and consultations[8–12,20]. Consistent with our findings, community members in these studies identified misinformation and misconceptions as significant barriers to PrEP uptake[8–12,20]. Our data suggest that even in communities where PrEP is widely available and large-scale sensitization programs are ongoing[21], additional strategies are needed to dispel myths and address misconceptions held by community members that impede PrEP use among AGYW. A 2017 systematic review of PrEP use values and preferences in different populations identified acceptance of PrEP, once presented with more information, although safety, side effects, and effectiveness were barriers to use[22].

In our study, community stakeholders reported that their community members perceived PrEP use among AGYW as either a result or a cause of risky behaviors. All participants felt that

negative attitudes about PrEP were more common among those less familiar with PrEP. Importantly, participants recognized these attitudes as stigmatizing and felt that community-level stigma surrounding PrEP use was the primary reason that AGYW are reluctant to inquire about PrEP at health facilities and initiate use. This finding is consistent with other studies in which widespread stigma toward PrEP users was a prevailing concern among participants[8–12,20]. Community stakeholders in our study felt that the community was generally supportive of PrEP use among HIV serodiscordant couples and female sex workers (e.g. traditional high-risk groups), but that AGYW accessing PrEP are seen as misbehaving or "promiscuous". Unpairing PrEP from traditional high-risk groups and marketing PrEP as a health promotion intervention with benefits for AGYW could reduce behavior-related stigma and improve uptake.

Community stakeholders described how confusion around PrEP as an HIV prevention strategy versus ARVs for HIV treatment further fuels PrEP stigma. To move beyond this confusion, participants in our study supported PrEP access points outside of HIV treatment clinics, either integrating PrEP within routine outpatient, MCH or FP clinics, or moving delivery to the community. These PrEP delivery approaches could reduce HIV disease-related stigma and reach a broader population of AGYW. Community-based delivery strategies that promote universal access, rather than only targeting at-risk, often highly stigmatized groups, have been shown to be acceptable in other populations and could increase PrEP uptake among AGYW[23]. Similarly, emphasizing that PrEP is an HIV prevention method and not a repurposed ARV used for HIV treatment could increase clarity around the community's understanding of PrEP. Additionally, securing the support of key opinion leaders could play a significant role in raising community awareness about PrEP and normalizing its use. Incorporating PrEP into school-based campaigns and ongoing HIV and reproductive health curricula could also normalize PrEP and reduce fears about HIV testing among AGYW. Involving AGYW in the design and implementation of PrEP programs will also ensure programs are tailored to address issues unique to AGYW's experience navigating PrEP.

Participants also felt that judgment from HCWs experienced by AGYW was a key deterrent to PrEP use and should be systematically addressed by healthcare leadership. Previously, health system administrators in Kenya recognized the potential for HCWs to label PrEP clients as "promiscuous" and that HCWs' negative attitudes toward high-risk groups indicate a need for targeted training of providers[10].

Our study has limitations. We sampled from a finite pool of potential participants, reducing the generalizability of our results. However, we were able to gather rich information regarding community experiences, beliefs, and perceptions across several counties where programmatic PrEP delivery is ongoing. In addition, FGDs served as a platform for participants to voice the views of the populations with whom they regularly interact and CAB members were selected to serve on CABs due to their knowledge of community beliefs and status within their respective communities. Each FGD was comprised of participants from the same CAB; they had previously attended several CAB meetings and had developed a rapport with one another. PrIYA and PrIMA research coordinators did not perceive any potential power dynamics influencing FGD dialogue.

Future PrEP scale-up for AGYW should be implemented with a comprehensive understanding of implications at the community and health system levels. PrEP demand creation will require addressing misconceptions and reducing disease- and behavior-related stigma through extensive sensitization of target populations and the community in general. Meanwhile, alternative delivery approaches in health facilities and in the community can increase PrEP accessibility and acceptability. As AGYW continue to be at high risk for HIV acquisition, their involvement in policymaking, along with key opinion leaders, will be critical for developing effective implementation strategies and understanding of PrEP awareness and acceptability among AGYW.

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Table 1. Demographic Characteristics of FGD Participants

Characteristic	***n (%) or Median (IQR) N=26***
Age (years)	37 (28–46)
Sex	
Female	19 (73%)
Highest level of education started	
Primary	1 (4%)
Secondary	9 (35%)
Polytechnic	1 (4%)
University/College	15 (58%)
Years of education completed	15 (12–17)
Role in CAB	
Youth representative	6 (23%)
Healthcare worker	6 (23%)
Women's group representative	5 (19%)
Healthcare planner	3 (12%)
County government leader	3 (12%)
Education sector representative	2 (8%)
Religious group representative	1 (4%)