Factors influencing adolescent girls and young women’s uptake of community-based PrEP services following home-based HIV testing in Eastern Cape, South Africa: a qualitative study

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Abstract
Home-based service delivery has been used to improve access to HIV testing and antiretroviral initiation across sub-Saharan Africa, but it has yet to be leveraged to improve pre-exposure prophylaxis (PrEP) uptake. We interviewed 37 adolescent girls and young women (AGYW) in Eastern Cape, South Africa to explore why they chose to initiate PrEP or not following home-based HIV testing and referral for PrEP, and what influenced time to PrEP initiation. Participants reported that home visits provided a source of trusted information and a way to involve family members in their PrEP initiation decisions, motivating some to start PrEP. AGYW who initiated PrEP were more likely to qualitatively perceive themselves to be at high risk for HIV compared with those who never initiated PrEP. Integrating home-based HIV testing with PrEP education and referral may be a valuable way to reduce familial barriers and boost PrEP uptake among AGYW in South Africa.

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Keywords HIV prevention · Pre-exposure prophylaxis · Home-based services · South Africa · Adolescent girls and young women

Introduction
Adolescent girls and young women (AGYW) across sub-Saharan Africa (SSA) remain one of the most-at-risk groups globally for HIV infection [1]. In South Africa specifically, AGYW aged 15–24 account for one-third of the approximate 4,500 new HIV infections that occur weekly, a rate three times that of males of the same age [2]. Oral pre-exposure prophylaxis (PrEP) has been shown to be highly effective at reducing HIV infection among AGYW if taken regularly [3]. Furthermore, modelling studies have indicated that prioritizing AGYW for PrEP services would have...
the greatest community-level impact on HIV prevention [4]. Unfortunately, as programmatic rollout of oral PrEP begins in South Africa, there remain questions regarding how best to increase AGYW’s access and uptake of PrEP, and encourage them to initiate PrEP.

A substantial number of PrEP studies enrolling AGYW reveal the complexity of recognizing one’s own vulnerability to HIV [5, 6]. Knowing one’s HIV status is vital when engaging the HIV prevention and treatment cascades. However, factors including low social support and antiretroviral-related misconceptions and stigma remain barriers to PrEP uptake and adherence [7–10]. To address these barriers, previous clinical trials and demonstration projects in SSA have proposed the development of appropriate and effective community-based strategies to promote PrEP services and uptake [10, 11].

 Provision of home-based health services has been used widely across SSA as a strategy for HIV testing [12–14], same-day antiretroviral therapy (ART) initiation following HIV testing [15], and tuberculosis testing [16]. Home-based health service delivery has been successful in improving convenience, confidentiality and eliminating structural barriers associated with accessing clinic-based health services, particularly in rural areas [16]. However, there is limited understanding of how home-based HIV testing services (HTS) may be leveraged to improve PrEP uptake among AGYW in South Africa, as AGYW continue to perceive and experience long queues, stigma and lack of confidentiality when accessing clinic-based HTS [17]. Since HIV testing is the entry point for starting PrEP, offering home-based HTS together with referral for community-based PrEP services may improve access to and uptake of PrEP among AGYW.

 In this qualitative sub-study, we explored factors influential to AGYW’s decisions to present for community-based PrEP services and initiation following home-based HTS in Eastern Cape, South Africa. We interviewed AGYW who initiated PrEP within 0–30 days of referral, as well as those who chose not to initiate PrEP, to explore differential decisions and timing around PrEP initiation.

**Methods**

**Study design**

The qualitative data used in this paper was drawn from the Community PrEP Study, a randomized controlled trial leveraging community-based platforms to improve access and adherence to PrEP for HIV-negative AGYW aged 16–25 years in Eastern Cape, South Africa [18]. This study quantitatively measured and qualitatively assessed the acceptability and feasibility of using community-based counselling and testing platforms to identify HIV-uninfected AGYW and offer PrEP. At the same time, it evaluated a behavioral intervention aimed at supporting prevention-effective adherence to PrEP. While the design of the study has been published elsewhere [18], this paper utilizes data from a proportion of the trial participants enrolled into the qualitative component using a door-to-door home-based testing approach.

**Home-based testing approach**

Trained staff visited homes to offer HTS to household members, provide PrEP information to AGYW aged 16–25 years, and refer eligible AGYW to community-based PrEP initiation sites. An adult (≥18 years and older) had to be present and give permission for testing staff to enter a home to conduct HIV testing. HTS was offered to all members of the household >11 years in a separate space. In accordance with South African guidelines, anyone age 12 or older could consent for themselves to be tested for HIV. AGYW aged 16–25 years who tested negative were separately consented to complete the baseline survey, self-administered on a tablet using ACASI (parental consent optional). Participants were then shown an informational video about PrEP [19]. If AGYW were comfortable with having their parent/guardian present during the screening process, parents/guardians were involved and were able to ask questions about PrEP. Some AGYW asked for privacy, especially around sensitive questions, or requested to come to the study site to complete the baseline survey instead. If participants showed interest in PrEP, they were assessed for study eligibility and referred to the study site to initiate PrEP. Prior sexual activity was not an eligibility criterion for this study given the structural risk factors and high HIV incidence among AGYW in South Africa.

**Table 1** Participant categories for qualitative interviews

| Participant Category | Definition | Number of interviews | Number in entire CPS study |
|----------------------|------------|----------------------|---------------------------|
| Immediate Presenters | Presented to study site for PrEP initiation within 0–3 days of home visit | 14 | 86 |
| Delayed Presenters*  | Presented to study site for PrEP initiation within 4–30+ days of home visit | 13 | 56 |
| Never Presenters     | Never presented to study site for PrEP initiation after home visit | 10 | 176 |

*During analysis for this manuscript, we combined Early Presenters (presented within 4–14 days) and Late Presenters (presented within 15–30+ days) into a single category called “Delayed Presenters”. Of the 56 total delayed presenters in the study, 11 presented more than 30 days after the home visit.
Following a home visit, site staff monitored and enrolled participants in the following categories based on how long it took for them to present to study site for PrEP initiation after the home visit: (1) Immediate Presenters (within 0–3 days); (2) Early Presenters (within 4–14 days); (3) Late Presenters (within 15–30+ days) and (4) Never Presenters (never initiated PrEP). Participants from these categories were purposively recruited to participate in in-depth interviews. The results presented in this manuscript utilize data from a total of 37 interviews and are focused on PrEP initiation outcomes, as displayed in Table I.

**Study setting**

This study was conducted in two areas in Buffalo City Municipality in Eastern Cape, South Africa: Ndevana (rural area) and Scenery Park (urban area). These two communities are predominantly inhabited by isiXhosa-speaking people, most of whom have lived all their lives in the area. Eastern Cape province had an estimated HIV prevalence of 15.3% in 2017 [20]. The Buffalo City Municipality had an estimated HIV prevalence of 12.4% and incidence of 0.54% in 2016; among AGYW 15–24 years, the estimated HIV prevalence was 12.8% and incidence was 2.40% [21].

**Theoretical framework**

Development of our interview guides and our analysis was guided by the **Information-Motivation-Behavioral Skills model of behavior change (IMB)** [22, 23]. IMB has been used as a model to improve uptake of and adherence to medication, including adherence to ART [22–24] and daily contraceptives [25, 26], as well as initiation of care [27], and it has been applied to this study for PrEP initiation and adherence. Specifically, according to the IMB model, HIV treatment and prevention behavior change result from the joint function of three critical components: the accurate information about HIV-related health behaviors, the motivation to perform health behaviors, and the self-efficacy and behavioral skills necessary to perform the behaviors. In the case of PrEP, we examined how AGYW perceived their HIV risk and acted upon their motivations for PrEP while navigating barriers and facilitators for prevention.

**Data collection**

Participants were visited at home for PrEP eligibility screening between March – September 2019. A total of 318 women were referred to one of the four PrEP enrolment sites for PrEP initiation after a home visit. Of these, 142 (44.7%) of the referred women presented to a site and 137 initiated PrEP (one did not provide consent, and four were ineligible: one was pregnant and three were unable to have venipuncture performed for creatinine testing). Participants were randomly selected for qualitative interviews from a list containing eligible participants for that interview category. Participants were interviewed in August and September 2019 using a semi-structured interview guide. Separate interview guides were developed for each participant category listed in Table I; interview guides were developed by co-authors AMM, MA, MM, and JD. Interview topics included HIV and PrEP knowledge, reasons for (delayed) initiation or non-initiation, and PrEP disclosure. Interview questions further explored narratives about HIV risk perceptions, relationships, and previous experience with HIV as factors motivating PrEP initiation. An HIV risk scale of 1–10 (1 being at low risk and 10 high risk) was used during interviews, with follow-up questions designed to explore participants’ understanding of their own and others’ risk.

Interviews were conducted by the same female staff members that provided home-based, door-to-door HTS, fluent in both English and isiXhosa, and trained in qualitative interviewing methods and the study protocol. Prior to the interviews, a separate written informed consent was obtained from participants enrolling into the qualitative study. Interviews were conducted in a private space either at the study site or participant’s home in the participant’s preferred language (English or isiXhosa). Interviews were audio-recorded, translated and transcribed into English, and reviewed for quality control by a second staff member.

**Data analysis**

Complete transcripts were uploaded into Dedoose software (v 8.3.43). Prior to coding, a multidisciplinary, multinational team consisting of five researchers (MA, JD, LDV, LF, EKM) reviewed all transcripts and discussed emerging themes to develop the initial structured codebook, also drawing codes from research objectives and interview guides. Initially, two transcripts were independently coded by each of the five coding team members and discrepancies discussed. This process allowed for intercoder reliability to be established with weekly discussions held to resolve differences in coding applications. The codebook was iteratively refined by the team.

Code reports, which aggregate transcript excerpts of similarly coded text, where compiled for key codes relevant to PrEP uptake, such as ‘perceived risk’, ‘introduced to PrEP’, ‘motivations for PrEP (initiation, delayed uptake, and non-initiation)’, and ‘PrEP disclosure’. Code reports were stratified by participant category. The analysis team wrote summary memos on code reports, and created data display matrices to compare themes across participant categories. Weekly calls were held to discuss themes from summary.
memos and identify areas for additional analysis. In addition, we approached the data with a view that components of the IMB model would generally organize emerging themes; hence, we created a matrix to visualize differences in information and motivation for starting PrEP across participant categories. During analysis for this manuscript, we agreed to merge the Early Presenters and Late Presenters into one category called “Delayed Presenters”. Further in-depth analysis of the Never Presenters was completed by creating a matrix comparing factors that may have influenced PrEP non-initiation across participants. In the final processes of analysis, a workshop was held consisting of a multi-disciplinary team of researchers and the main protocol team members. Workshop attendees reviewed the themes and ensured that the example quotes were meaningful and accurately represented.

Quantitative data pertaining to participant socio-demographic characteristics including age, family structure, and education, as well as behavioral characteristics including sexual behaviors, HIV prevention, and knowledge of HIV risk were captured during the baseline survey administered during the initial home visit. Survey data was entered into a REDCap database and descriptive statistics tabulated using STATA.

**Ethics approval**

The protocol, informed consent documents, and tools were approved by the ethical review committee at the University of Cape Town (HREC 289/2018). Approval to conduct the research in Eastern Cape Province was provided by the Eastern Cape Provincial Department of Health.

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**Fig. 1** Spectrum of PrEP initiation pathways following a home visit. The various factors that influenced PrEP initiation are shown in the top half. Circles in the bottom half represent participant categories for differing PrEP initiation outcomes, with bullet points summarizing the factors influencing their PrEP initiation decisions and timing.
Results

By exploring participant’s home visit experiences and reasons for PrEP initiation, we identified the following themes: levels of perceived risk and HIV fears determine whether AGYW start PrEP or not; additionally, the ability to confirm PrEP information and social network response outcomes influence the timing of initiation. These themes are described below for each participant category and summarized in Fig. 1.

Participant characteristics

Participant characteristics for the subset who completed qualitative interviews are shown in Table II. The median age of participants was 22 years (IQR: 19–24), with 38% in school. Just over half of participants indicated ever having sexual intercourse. The median number of days to present to site for PrEP initiation was 0 (IQR: 0–1). The median household size was 5 (IQR: 3–6). The median social support was 5.4 (IQR: 4.8–5.8) and knowledge of HIV risk was 2 (IQR: 1–5). The median number of friends who had discussed HIV prevention was 4 (IQR: 2–6).

Table II  Participant characteristics for subset who completed qualitative interviews

| Characteristics (n / %) | Immediate Presenters (n = 14) | Delayed Presenters (n = 13) | Never Presenters (n = 10) | TOTAL Sample (N = 37) |
|------------------------|------------------------------|-----------------------------|--------------------------|---------------------|
| Age (median, IQR)      | 21 (20–24)                  | 21 (18–22)                  | 22 (21–23)               | 22 (19–24)          |
| Site                   |                             |                             |                          |                     |
| Urban                  | 2 (14.3)                    | 3 (23.1)                    | 2 (20.0)                 | 7 (18.9)            |
| Rural                  | 12 (85.7)                   | 10 (76.9)                   | 8 (80.0)                 | 30 (81.1)           |
| In school              |                             |                             |                          |                     |
| 5 (35.7)               | 5 (38.5)                    | 4 (40.0)                    |                          | 14 (37.8)           |
| Days to present to site for PrEP initiation (median, IQR) | 0 (0–1) | 7 (4–23) | N/A | 4 (0–9) |
| Household size (median, IQR) | 5 (3–6) | 6 (5–8) | 7 (4–9) | 5 (4–8) |
| Relation to household  |                             |                             |                          |                     |
| Head of Household      | 1 (7.1)                     | 0 (0.0)                     | 0 (0.0)                  | 1 (2.7)             |
| Family member          | 12 (85.7)                   | 12 (92.3)                   | 7 (70.0)                 | 31 (83.8)           |
| Adopted/foster/step child | 1 (7.1) | 0 (0.0) | 1 (10.0) | 2 (5.4) |
| Partner / Wife         | 0 (0.0)                     | 1 (7.7)                     | 1 (10.0)                 | 2 (5.4)             |
| Refused                | 0 (0.0)                     | 0 (0.0)                     | 1 (10.0)                 | 1 (2.7)             |
| Ever had sexual intercourse | 7 (50.0) | 10 (76.9) | 4 (40.0) | 21 (56.8) |
| *Frequency of condom use (last 6 months) |                             |                             |                          |                     |
| All the time           | 3 (21.4)                    | 6 (46.2)                    | 1 (10.0)                 | 10 (27.0)           |
| Some of the time       | 3 (21.4)                    | 3 (23.1)                    | 2 (20.0)                 | 8 (21.6)            |
| Never                  | 1 (7.1)                     | 1 (7.7)                     | 1 (10.0)                 | 3 (8.1)             |
| 14 (100.0)             | 13 (100.0)                  | 10 (100.0)                  |                          | 37                  |
| Ever tested for HIV    | 6 (46.2)                    | 1 (10.0)                    |                          | 14 (37.8)           |
| Ever heard of PrEP before | 5.5 (4.8–5.8) | 5.1 (4.2–5.9) | 5.7 | 5.4 |
| **Social support (Range: 0–7) (median, IQR) |                         |                             |                          |                     |
| Ever discussed HIV prevention with anyone |                     |                             |                          |                     |
| Yes                    | 13 (92.9)                   | 13 (100.0)                  | 9 (90.0)                 | 35 (94.6)           |
| No                     | 1 (7.1)                     | 0 (0.0)                     | 0 (0.0)                  | 1 (2.7)             |
| Refused                | 0 (0.0)                     | 0 (0.0)                     | 1 (10.0)                 | 1 (2.7)             |
| **Knowledge of HIV risk (Range: 0–7) (median, IQR) | 2 (1–5) | 2 (1–4) | 4 (3–5) | 3 (1–5) |

*Not applicable to n = 16 who reported never having sex or not having sex in the past 6 months
**Not applicable or incomplete responses for n = 3. The multi-dimensional social support scale includes an average of ratings for 12 items such as friends, family, and significant others (0 = low support and 7 = high support)
***Knowledge of HIV risk represents total score (0 = low knowledge and 7 = high knowledge) calculated from participants’ responses to statements of risk factors for HIV

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had sexual intercourse (57%), with 27% reporting always using condoms in the past six months. Only 38% of participants had heard of PrEP prior to the home visit, and the median number of days to present to the site for PrEP initiation across this sample was 4 days (IQR: 0–9).

Self-risk perception influence on PrEP initiation

AGYW’s perceptions of their own HIV risk influenced their decisions whether to initiate PrEP. Most Immediate Presenters and Delayed Presenters viewed themselves at moderate or high risk before starting PrEP, whereas most Never Presenters viewed themselves at low risk.

Nearly all participants described other AGYW in their communities as being at high risk of getting HIV. They described their peers as having frequent unprotected sex, being pressured by unequal relationship power dynamics, and not thinking through decisions before acting (“enjoy being caught up in the moment”, Immediate Presenter, age 21). Participants consistently described others’ use of drugs/alcohol when “going out” and a high risk of rape as putting them at increased risk for HIV. However, participants differed in terms of how they viewed their own risk of becoming infected with HIV.

Immediate and delayed presenters

The majority of Immediate and Delayed Presenters described their own HIV risk before starting PrEP as moderate or high, saying they were “scared” of getting HIV. Most described risk in an externalized way, citing high rates of HIV among their peers, fear of getting raped, concern that “the condom can burst”, or that condom use was out of their control, such as these AGYW:

“I was doing it for my future, trying to protect my future. You see how the youth is? HIV is everywhere. I didn’t want to grow up, get married and transmit HIV to my child.” (Delayed Presenter, age 20)

“As a girl, we never know what is waiting for us when we leave the house. Rape is very prominent and someone can get AIDS by being raped. I told myself that I must take PrEP as someone who likes to go out. Even if I get raped and the guy wants to give me HIV, I’ll be protected.” (Delayed Presenter, age 22)

“In our time chances of getting HIV are very high especially in our area and we as the youth are at risk because of rape and our boyfriends forcing us to not use condoms.” (Immediate Presenter, age 19)

Some who initiated PrEP further shared how they felt that PrEP added an extra level of protection beyond condoms, so they relied on using both methods concurrently to provide protection: “I take PrEP and I condomise. […] I feel protected with PrEP and I’m not only relying on condoms” (Delayed Presenter, age 18).

Another way that AGYW externalized risk was through attributing it to uncertainty about their partner(s)’ sexual behavior, explaining “our boyfriend are not truthful to us” (Immediate Presenter, age 25), “since I am sleeping with one partner does not mean my partner is also sleeping with me alone” (Immediate Presenter, age 20), and “I’m in a long distance relationship so I don’t know what he is up to” (Delayed Presenter, age 18). Several participants also described how personally knowing family members living with HIV contributed to their perception of being at risk for HIV.

A minority of PrEP initiators (primarily Immediate Presenters) described risk as internalized: having multiple partners or casual relationships themselves. This Immediate Presenter described recognizing her risk and changing her behavior after starting PrEP: “I have decided to focus on one partner because I used to have two partners” (Immediate Presenter, age 19).

Regardless of whether they internalized or externalized their risk, Immediate and Delayed Presenters connected their high risk to fear of getting HIV. They commonly cited their primary motivation for starting PrEP as wanting to be “protected”. They also consistently described a shift in risk perception to feeling at lower risk for getting HIV once starting PrEP, resulting in being “not afraid” and having peace of mind.

“When I was not taking PrEP [before initiating PrEP], I had this feeling that I can contract HIV at any time but now I have that mindset that I can never have it while I am taking PrEP.” (Immediate Presenter, age 21)

Never presenters

In contrast, most Never Presenters saw themselves at low risk for acquiring HIV, primarily since they were already using condoms and protected themselves consistently (“I protect myself all the time”, Never Presenter, age 22), or because they felt they were in a low-risk relationship (e.g., “trust my partner,” Never Presenter, age 25). Never Presenters often connected their low self-risk perception to why they chose not to initiate PrEP: they felt “protected” already. This Never Presenter described why she rated herself at low risk for getting HIV:
“Because we’ve been together for more than 10 years now so I will put myself at 1 [risk rating 1/10] […] I’ve been trying all the ways not to get HIV because I think having one partner will be helpful and that helps me not to get HIV or if we both have it, will we be interested in treating it as a couple, you see?” (Never Presenter, age 23)

Never Presenters also consistently described how they previously viewed HIV as something that was feared and that “killed”, but with the availability of HIV treatment today, becoming HIV positive was not as frightening. Several described “dying with HIV” as an untrue rumor, sharing their belief that people living with HIV can continue living if they test regularly and/or take treatment consistently, as these Never Presenters explained:

“They said that it [HIV] was a disease that was wrong but now it’s no longer the same. We were scared, there were books that were given to us at school to read and they had bad pictures, wrong pictures of people. They were so scary. […] But now it’s not the same because there are ARVs and you take only one pill at a time maybe around 8. An individual chooses and its different.” (Never Presenter, age 25)

“Actually there is no dying because people wait until they get sick with HIV but what you have to do is to test every 3 months or maybe every 6 months so that you can know where you stand with HIV in time before you get sick, and most people don’t do that, they don’t [thinking]… I mean I don’t know what they think, they wait until they die.” (Never Presenter, age 23)

Importance of adequate, trustworthy information before initiating PrEP

AGYW’s ability to confirm PrEP information received during the home visit influenced the timing of PrEP initiation in this study. We found that AGYW who had already heard about PrEP were catalyzed to action by the home visit, presenting quickly for PrEP, while women who were first introduced to PrEP at the home visit took longer to initiate PrEP.

Overall, participants across all categories reported positive door-to-door study staff interactions and being provided with reliable information during home-based HTS. During home-based HTS, AGYW consistently described how they were informed of PrEP as a prevention method for young women at risk to further curb HIV. This young woman expanded on how she viewed the study staff who came to her home as a trustworthy source of information:

“I saw this [a poster at a shop] and got interested and I got discouraged by my peers, but since the door-door people came and introduced Prep I got interested very much. They showed me the video which contained a lot of information and they just introduced what I was interested in and they made everything very easy.” (Immediate Presenter, age 19)

Like this participant, many other participants described a primary reason for initiating PrEP was that they felt like they had enough information.

Delayed Presenters

While many participants were first introduced to PrEP by the door-to-door team, the Immediate Presenters were an exception, as most were already aware of PrEP prior to the delivery of home-based HTS. They gave examples of other informative introductions to PrEP including community outreach activities, hearing about PrEP from others, peer recruitment, and clinic education and media, as these Immediate Presenters described:

I heard other girls at school talking about PrEP, but I didn’t pay attention and I also saw at the TV (Immediate Presenter, age 19)

We were educated about PrEP before we started taking it. We were told at the clinic that the government is now issuing pills to the youth to assist curb[ing] the spread of HIV, as most people are already infected with the virus. As young women we often go out for drinks and then get raped… I heard at the clinic from the nurses. By the time the ladies came, I had heard about it before hand. (Immediate Presenter, age 24)

For Immediate Presenters, home-based HTS provided AGYW with the opportunity to confirm sources of information and alleviate doubt sometimes instigated by others, ultimately sparking action to initiate PrEP.

I heard other girls at school talking about PrEP, but I didn’t pay attention and I also saw at the TV (Immediate Presenter, age 19)

We were educated about PrEP before we started taking it. We were told at the clinic that the government is now issuing pills to the youth to assist curb[ing] the spread of HIV, as most people are already infected with the virus. As young women we often go out for drinks and then get raped… I heard at the clinic from the nurses. By the time the ladies came, I had heard about it before hand. (Immediate Presenter, age 24)
also able to make personal decisions on why they would or wouldn’t initiate PrEP. These included, for example, having enough knowledge about HIV transmission, HIV treatment, and low risk perception(s).

Influence of social support on PrEP initiation

AGYW enrolled into the study following referral after home-based HTS described social support from their mothers, aunts, brothers, cousins, friends and/or partners as an important part of their decision pathway towards initiating PrEP. Social support varied across our participant categories: Immediate Presenters reported receiving positive support from family members and/or friends to start PrEP, while Delayed and Never Presenters encountered or anticipated more discouragement and mistrust from their social networks.

Participants (both Immediate and Delayed Presenters) reported how other family members were present during the home visit and actively involved in their decisions to initiate PrEP. Several AGYW described how they appreciated the home visit because it allowed them to involve their family in the decision-making process, commenting “it was a lot comfortable at home because the environment, that I was with my parents” (Immediate Presenter, age 25), and “when they came they found me with my family and explained the whole thing to us all. So I went to the site with my whole family knowing about PrEP already” (Delayed Presenter, age 22).

Immediate Presenters

Many Immediate Presenters reported receiving positive support from family members and/or friends to start PrEP. This young woman demonstrated this when she reported that:

“When they tested me at home, they told me more about it and I also discussed it with my mother. She says, if I want to take it, I should take it, if I don’t then its fine. She supports me.” (Immediate Presenter, age 20)

One Immediate Presenter described how the home visit gave the opportunity for her mother to ask questions directly to the research staff, ultimately resulting in her mother’s support:

“P: They asked a lot of questions to the person who was introducing PrEP to me. I: so your mother asked a lot of questions from the Counsellors? P: yes

Never presenters

Never Presenters mainly reported hearing of PrEP through home-based HTS and community outreach activities. Although a few reported a lack of knowledge, the majority of Never Presenters were able to describe PrEP accurately:

“What I know about PrEP is that PrEP is a pill that you take but before you take that pill you must be educated about it and be given a progress about it... PrEP can be helpful with our youth because there are still young girls who are free from HIV and who can still be safe... I don’t see anything wrong with PrEP because you protecting yourself from HIV, not other people. I am not jealous of PrEP and it needs to protect everyone.” (Never Presenter, age 23)

This suggests that Never Presenters might not have been primarily dissuaded by a lack of information, but that they were
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I: so what did the Counsellors tell your mother?
P: The counsellor told my mother that PrEP is safe to use and a lot of people are using it, it was not the first time she heard about PrEP.
I: so it was not difficult to convince her? [Laughing] P: yes [Laughing]” (Immediate Presenter, age 25)

Other Immediate Presenters described how their friends who were taking PrEP motivated them to also want to begin PrEP:

“I just heard from my friends since they went to the study site, they told me that there’s a pill called Prep which protects you from contracting HIV and those ladies who are doing door-door came and I was interested” (Immediate Presenter, age 20)

“I heard from a friend who was coming back from the study site. […] She told me that there is a pill that is very helpful that you get from Baptist church and then those people [home visit study staff] came and I told them that I am interested.” (Immediate Presenter, age 24)

Delayed Presenters

In contrast to the positive support described by Immediate Presenters, Delayed Presenters described a spectrum of responses from their social networks. Those who took 4–14 days to present to PrEP initiation sites described more positive or neutral responses from family and friends, while those who took 14–30+ days to initiate described actively discouraging or negative responses. For some Delayed Presenters who described initial PrEP hesitancy, encouragement from a friend or family member was the tipping point in their decision to initiate PrEP, such as this young woman who took 4 days to initiate PrEP:

“I had to think about it first before, but my family encouraged me to take PrEP because it’s only us youth who is always getting infected with HIV most of time.” (Delayed Presenter, age 22)

While this participant was able to make informed decisions about PrEP, her perceptions of youth risk and familial encouragement prompted her to initiate PrEP. For some participants, support was only accorded to them following a process of negotiation with family members (i.e. aunts or mothers). This Delayed Presenter took 4 days to present for PrEP after her mother “agreed”:

“I spoke to my mother. We agreed that now I can come. I didn’t have any problem and she also had no problem. She was there when your people came to my home to explain about PrEP then she said she does not see it as a wrong thing she sees it as a right thing….that a person stays protected.” (Delayed Presenter, age 25)

The perceived need for family approval might explain some AGYW’s late presentation to PrEP initiation sites. For example, this Delayed Presented explained why it took her 32 days to initiate PrEP after the home visit, as she first needed to negotiate support with her mother and aunt:

“P: Yhooo what can I say, even now I don’t live here at Ndevana I stay with my mother at [mentions the name of the place] so now I asked for permission from her to come here since I missed it last time, I spoke to her because she thought I was lying the last time, they called me and I spoke to her, that is why I managed to come..
I: okay so your mother knows?
P: Yes, but she also does not want me to take these pills, she says I’m bringing bad luck to myself, it’s my maternal aunt who approves.” (Delayed Presenter, age 19)

Never presenters

Some AGYW, particularly Never Presenters, discussed how they anticipated disruptions in their relationships as a result of taking PrEP. They also expressed fears relating to anticipated stigma, and shaming by partners and community members. For example, this Never Presenter expressed how taking PrEP could create mistrust in her relationship:

“Yes, I would have went there [study site], but on the other hand, I would say, ‘No, I would not go.’ Because being with a guy for a long time who you trust, and you have that thing [PrEP] saying what if he sees you going to the clinic, or maybe heard by someone that was at the clinic, who saw you taking that pill, how is he going to feel after so many years together, trusting each other, you see?” (Never Presenter, age 23).

AGYW valued their relationships and assessed how introducing PrEP would impact these relationships, particularly those with their partners. For some, like this young woman, she thought that PrEP would compromise that trust after so many years being with her partner, and so she chose not to initiate PrEP.
Some AGYW highlighted anticipated stigma by community members as a reason for not initiating PrEP:

“I got all the information yes it was clear, maybe I am just careless but I want it, or maybe it’s being ashamed, I am ashamed of being seen by the people in [name of community center] taking PrEP.” (Never Presenter, age 25)

Of note, while some AGYW expressed concern about how they may be perceived if others knew they were taking PrEP, they were not deterred, as expressed by these Immediate Presenters:

“We [participant and cousin] kept on postponing [to go to the site to start PrEP], but I realized that my decision is depending on my friends but as soon as those people went to my home I was interested. You must make your own decision and not depend on others that’s what I realized.” (Immediate Presenter, age 19)

“She [study staff] told us not to be scared of taking PrEP, and we must not be shy to tell other people that we are taking PrEP because we are doing it for ourselves.” (Immediate Presenter, age 20)

### Accessibility barriers to PrEP initiation

Besides low risk perception and negotiating social support, Delayed Presenters and Never Presenters also described how other life priorities and scheduling conflicts impacted their PrEP initiation timelines. Delayed presenters frequently cited school and work scheduling conflicts as reasons for late presentation to the study site. One participant explained why it took her 13 days to present for PrEP initiation after home-based HTS: “I was busy with schoolwork. I get home from school at 4pm.” (Delayed Presenter, age 20).

Several Never Presenters commented that the study site was far away and that the site operating hours conflicted with their schedules, such as this woman who explained why she did not present for PrEP at the research site: “I got lazy to come here [to research site]. It’s too far […] 30 minutes to come and go back home” (Never Presenter, age 19).

### Discussion

While delivery of HIV program services (i.e., HTS and ART initiation) via home visits has been used in SSA [14, 15], home-based services have not been widely studied or leveraged for the delivery of or referrals to PrEP services. Towards this, our study qualitatively examined AGYW experiences associated with home-based HTS, with direct referral and linkage to community-based PrEP services in Eastern Cape, South Africa. We found that home visits that combined HTS with PrEP information provided AGYW a source of trusted, reliable information, and a way to include their family members in PrEP initiation decision making. This motivated some AGYW to present to community-based PrEP initiation services. AGYW who had previously heard about PrEP tended to initiate PrEP faster than those whose first introduction to PrEP occurred during a home visit. Among those that had not previously heard about PrEP, confirmation of information against multiple sources further facilitated PrEP initiation. Among AGYW in our study, those that initiated PrEP were more likely to qualitatively perceive themselves to be at high risk for HIV compared to AGYW that never presented for or initiated PrEP.

Our finding that risk perception correlates with PrEP initiation behavior parallels those from a study in Malawi focusing on PrEP interest among AGYW [28] and a study in Eswatini among men who have sex with women [29]: those who showed interest in PrEP perceived themselves at high risk and were afraid of getting HIV, whereas those who were not interested in PrEP perceived themselves at low risk. Although potentially affected by social desirability bias, 60% of Never Presenters reported never having sex, which may have contributed to their low self-perceived HIV risk. Besides low risk perception, Never Presenters in our study also described HIV as something no longer to be feared given widespread availability of ART. This suggests that taking PrEP to prevent HIV was not a priority since HIV could now be easily treated. Similar perspectives that HIV is no longer feared and that pregnancy is the biggest concern were shared by young women and men in a PrEP study conducted in rural Kenya and Uganda [11]. Overall, findings from our study and others [5, 28] continue to suggest that scale-up of PrEP programs include risk awareness counselling and messaging to improve uptake.

Studies across global contexts have reported that adolescent sexual activity is often stigmatized and that parents and caregivers find it difficult to discuss sex and HIV with adolescents [30–34]. This extends to PrEP initiation, as parents may perceive that PrEP will encourage their children to be sexually active [35, 36]. Similar to other studies in SSA, AGYW in our study described external HIV risk factors, such as partner infidelity, not fully trusting condoms, and fear of rape, as the main sources of risk in their lives [5, 28, 37]. This externalizing or “othering” of risk may be a mechanism to minimize stigma associated with some of their own behaviors, including perceptions of sexual promiscuity [5]. This externalizing of HIV risk may be particularity
important in the context of home visits where parents and/or other family members are present during the introduction of PrEP. Consequently, framing PrEP as a tool of agency and empowerment, with HIV risk stemming from age and geography, rather than a tool of protection from stigmatized individual behaviors [36], may allow for more openness to PrEP during family discussions.

Similar to reports from the open-label HPTN067/ADAPT PrEP study in Cape Town, South Africa [7], some AGYW in our study wanted “proof” that PrEP worked and that it was not harmful, while others encountered mistrust or doubts from their social networks about PrEP. Towards this, we found that access to and availability of multiple sources of information about PrEP facilitated its initiation. Specifically, for some AGYW in our study, home visits that integrated HTS and PrEP information served to “legitimize” PrEP in front of other household members [8]. This gave these AGYW the opportunity to ask questions to overcome doubts. For others, seeing or knowing other AGYW who were taking PrEP alleviated these concerns. This was similar to youth in a population-level PrEP study in rural Kenya and Uganda [11]. Together, these scenarios highlight the importance of multi-level community PrEP education targeting individuals, their families, schools, and communities, to generate support for PrEP and alleviate initial suspicions or doubts.

In this study, social support from peers and family members (especially females) provided AGYW with the encouragement needed to initiate PrEP. Alternatively, AGYW described anticipated or experienced negative reactions from their social networks as barriers to PrEP initiation. In HPTN 082, an open-label study of PrEP in Zimbabwe and South Africa, participants who declined or delayed their PrEP use discussed anticipated stigma and fear of embarrassment more often than those who accepted PrEP at enrollment [36]. HPTN 082 further showed that empowering women to disclose PrEP use to their social networks reduced stigma and improved PrEP adherence [36]. Other PrEP studies among AGYW in SSA have similarly reported more anticipated stigma among those who delayed or refused PrEP, including not being trusted by partners [11, 28] or negative reactions from family members [10]. While previous studies have examined the effects of stigma and disclosure after AGYW have initiated PrEP [36], few studies have examined the influence of discussing PrEP with family members before or alongside initiation as was done in this study. In our study, some AGYW described wanting to get permission or approval from a key family member such as a mother or aunt before initiating PrEP. Our results echo recommendations to sensitize families and communities to PrEP to reduce anticipated stigma [9, 10] and improve parent-adolescent communication around HIV prevention [30, 38, 39].

Some AGYW in our study discussed distance to a PrEP services site and scheduling conflicts as reasons for delaying or never initiating PrEP. Some Never Presenters said that they wanted to start PrEP but did not have the chance due to work or schedule conflicts. In a study of home-based tuberculosis testing in the Eastern Cape, South Africa [16], home-based testing helped participants overcome apathy and “laziness” toward TB testing by making it more convenient, with some reluctant participants ultimately being encouraged by their family to be tested. Some Delayed Presenters in our study shared a similar experience of the home visit, specifically that encouragement and support from family served as the tipping point to motivate them to initiate PrEP. Likewise, most Immediate Presenters had previously heard about PrEP, but this visit gave them that extra push needed to confirm prior information and motivate them to show up at the study site to start PrEP. Future research and PrEP scale-up programs should explore the acceptability and feasibility of home-based PrEP initiation to overcome these barriers to PrEP initiation among AGYW. Furthermore, additional supply-side approaches to delivering and improving uptake of PrEP must be explored.

Our study is one of the first to explore a home visit approach to PrEP introduction, and the first to report on PrEP initiation in Eastern Cape, South Africa. This study has several limitations. First, since permission was required from an adult household member for study staff to enter the home for HTS, our sample may not be representative of all adolescent girls in the study communities, such as those who stay alone or whose head of household refused entry to the study team. Second, the dynamics of having parents and family at home during the screening process was not included as a topic on the IDI guide, and was only discussed if the participant brought it up themselves, limiting our depth of analysis in this area. Third, participants’ responses about their introduction to PrEP may have been influenced by recall bias (mean time to interview from home visit was 101 days, range 45 to 188 days), though most seemed to be able to recall PrEP information presented to them at the home visit accurately. Social desirability bias likely affected self-reported sexual activity responses, resulting in an artificially low number of AGYW who reported never having sex. Finally, most of the interviewers were the same staff members that conducted home-based HTS, potentially leading to response bias. However, themes across participant responses seemed consistent despite whether it was a new interviewer or not.
Conclusions

Maximizing the impact of PrEP requires improving access to and uptake of PrEP by those in need of HIV prevention services. Consequently, integrating home-based HTS with PrEP education and referral to PrEP services may be a low-hanging, but critical approach to decreasing potential familial barriers. First, introducing PrEP to AGYW and their families may eliminate or minimize the need for AGYW to have difficult conversations with their family post-PrEP initiation. Second, because AGYW who started PrEP had a higher perceived risk for HIV compared to those that did not start PrEP, integrated home-based HTS-PrEP education can present AGYW’s HIV risk in a less stigmatized way that is not centered on individual sexual behavior, but rather on externalized risk based on age and geography. Third, broader campaigns to increase awareness of PrEP in communities could further boost PrEP uptake following home-based HTS, as AGYW who had previously heard about PrEP presented for initiation more quickly. While home-based testing and PrEP education are not the panacea, they are a valuable part of a tool kit that can be effective at introducing it to those who have never heard of PrEP and bringing in those may have initially been hesitant.

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Authors’ contributions

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Availability of data and material

De-identified data presented in this manuscript will be shared upon reasonable request and receipt of a completed data request form.

Code Availability

Not applicable.

Declarations

Conflict of interest

The authors have no competing interests to declare that are relevant to the content of this article.

Ethics approval

The protocol, informed consent documents, and tools were approved by the ethical review committee at the University of Cape Town (HREC 289/2018). Approval to conduct the research in Eastern Cape Province was provided by the Eastern Cape Provincial Department of Health. This study was performed in accordance with the ethical standards of the 1964 Declaration of Helsinki and its later amendments.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent to publish

Not applicable.

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