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Applying implementation science frameworks to understand why fisherfolk continue or discontinue pre-exposure prophylaxis for HIV prevention in Uganda: a qualitative analysis

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ABSTRACT

Introduction In Uganda, fisherfolk have an HIV prevalence between 15% and 40%, significantly higher than the national average of 5.5%. Pre-exposure prophylaxis (PrEP) is effective in preventing HIV but faces challenges in uptake and continuation among fisherfolk. This study explores factors influencing PrEP continuation and discontinuation among fisherfolk in Uganda using the Consolidated Framework for Implementation Research (CFIR).

Methods Participants were recruited from two fishing communities near Entebbe, Uganda. One community received enhanced PrEP support (adherence support, educational workshops and check-in calls), while the other received standard healthcare outreach. Forty fisherfolk (20 who continued PrEP and 20 who discontinued PrEP) were interviewed 6 months after initiating PrEP. Data were analysed using directed content analysis, with high inter-rater consistency. Ethical approval and informed consent were obtained.

Results Findings highlighted several determinants of PrEP continuation and discontinuation across the CFIR domains. Intervention characteristics such as side effects and the pill burden were significant barriers, particularly for women who reported nausea and stomach issues. Individual characteristics revealed that perceived HIV risk influenced PrEP use, with women's decisions often influenced by their partners' behaviours and mobility. However, insufficient information and education, especially among women, led to misunderstandings and discontinuation. Inner-setting factors like mobility issues and the distance to healthcare clinics posed significant barriers exacerbated by the geographical isolation of fishing communities. In the outer setting, high HIV prevalence motivated PrEP initiation, but stigma, particularly the misconception that PrEP is an antiretroviral drug used by people living with HIV, led to discontinuation.

Conclusion Fisherfolk in Uganda encounter multiple barriers to PrEP continuation, with women facing more significant challenges. Enhanced support strategies are essential for improving PrEP adherence and informing future HIV prevention interventions in high-risk populations.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Pre-exposure prophylaxis (PrEP) effectively prevents HIV among high-risk populations like fisherfolk, but uptake and continuation are limited by barriers such as stigma, gender-based violence and transportation challenges.

WHAT THIS STUDY ADDS

⇒ This study, using the Consolidated Framework for Implementation Research framework, identifies key challenges specific to fisherfolk in Uganda, particularly for women, and highlights actionable strategies like mobile PrEP delivery, peer-led interventions and partner-inclusive education.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ These findings underscore the importance of community-based, gender-responsive interventions and suggest exploring long-acting PrEP options to improve adherence and retention in high-mobility populations.

INTRODUCTION

In 2022, an estimated 1.7 million new HIV infections occurred worldwide, with sub-Saharan Africa accounting for over 70% of these cases.[1] In Uganda, HIV incidence remains high, with an estimated 50 000 new infections occurring annually.[2] Among the groups most vulnerable to HIV are fisherfolk, individuals whose livelihoods depend on fishing and related activities in Uganda's lakeside and surrounding communities. This population, which includes not only people who fish but also those engaged in fish processing, trade and transport, faces heightened HIV risk due to unique lifestyle and structural challenges. Fisherfolk show HIV

prevalence rates among those aged 15–49 years ranging between 15% and 40%.[2–4] This rate is significantly higher than the national average of 5.5%.[2]

Fisherfolk communities are often geographically isolated and highly mobile, which restricts their consistent access to healthcare, particularly HIV prevention and treatment service.[5–7] Their vulnerability is further compounded by limited knowledge about HIV prevention, pervasive stigma and structural factors, including high rates of alcohol use and gender-based violence, that amplify HIV risk.[5 8 9] For example, high levels of alcohol use can impair judgement and increase risky sexual behaviours,[10 11] while gender-based violence can limit their ability to negotiate safer sexual practices and seek necessary healthcare services.[12 13] Addressing these compounding factors is essential for reducing HIV prevalence among fisherfolk and other similarly affected groups. Targeted interventions that address both individual behaviours and broader structural barriers are needed to reach these at-risk communities effectively and reduce the overall burden of HIV.

Pre-exposure prophylaxis (PrEP) is an antiretroviral (ARV) drug that can help prevent HIV infection among HIV-negative people who are at risk of exposure.[14] Oral PrEP reduces the risk of HIV infection through sex by >90% when taken as prescribed.[15 16] Based on this evidence, Uganda's Ministry of Health (MoH) included PrEP among its HIV prevention combination interventions for key populations at substantial risk of HIV infection, including fisherfolk.[17] Despite the steady increase in PrEP use in Uganda since its adoption, only about 600 000 Ugandans were estimated to be taking oral PrEP as of July 2024. This number represents a small fraction of the approximately 27 million individuals aged 15 and older who may be eligible for PrEP.[18]

Studies in low, middle and high-income countries have found high acceptability of PrEP use but low persistence rates across settings and population groups, including among men who have sex with men, sex workers, discordant couples, adolescents and fisherfolk.[19–24] Furthermore, evidence suggests that patterns of PrEP use among diverse populations, including fisherfolk, are not continuous.[25] Some PrEP users prefer event-driven PrEP use or adjust their use as their HIV exposure and behaviour changes or shifts.[26–28] There are wide variations in PrEP initiation and discontinuation rates, ranging from 4% to 69% for initiation[29 30] and 20% to 70% for discontinuation,[31–33] depending on the population studied, length of follow-up, geographical location and age groups.

This study employed the updated Consolidated Framework for Implementation Research (CFIR) to examine the determinants of PrEP continuation and discontinuation among fisherfolk in Uganda.[34] CFIR provides a valuable lens through which to explore the complex interplay of factors at multiple levels that can impact the implementation of health intervention.[34] We aimed to identify key determining factors for PrEP continuation and discontinuation within the main CFIR domains: PrEP intervention characteristics, including drug side effects and adherence-related challenges; individual characteristics, including fisherfolks' perceived risk of self/partner, beliefs and attitudes about PrEP; inner setting, including structural characteristics of the healthcare system such as the distance/travel from clinic to where one can get PrEP; and outer setting including high HIV prevalence and stigma. By understanding these factors, tailored implementation strategies can be developed to enhance PrEP uptake and adherence among fisherfolk, who are at elevated risk for HIV.

METHODS

Study context

The present qualitative analysis drew on data from a pilot study of enhanced PrEP implementation strategies conducted in two fishing community landing sites near Entebbe in Wakiso District, Lake Victoria and Uganda.[35] Details of the intervention and its evaluation, as well as how the implementation strategies facilitated PREP uptake and persistence, are available in a prior paper.[35] One of the communities served as an intervention site (that received healthcare outreach events as well as enhanced PrEP implementation strategies), and the other served as a comparison site (that received healthcare outreach events only). Specifically, in both communities, participants (fisherfolk) were mobilised and recruited by trained healthcare workers and community leaders, and the medical implementing partner conducted outreach events where fisherfolk were mobilised by word-of-mouth using bullhorns, and community members were provided with HIV testing services, and referral for linkage to care if diagnosed with HIV. In addition, PrEP screening eligibility was conducted among those who tested HIV negative, and PrEP was offered to fisherfolk who were eligible. The Republic of Uganda MoH PrEP eligibility criteria were followed.[36]

In the intervention community only, the medical implementing partner conducted three enhanced PrEP implementation strategies (one community-wide strategy and two PrEP user-specific strategies). The community-wide strategy consisted of workshops conducted during the outreach events, which aimed to educate fisherfolk about PrEP, address misconceptions and stigma, and empower fisherfolk to advocate for PrEP in their community. The PrEP-user specific strategies were conducted by healthcare workers and consisted of (1) recommendations for PrEP users to select adherence supporters from their social network (eg, family members, coworkers, or friends) at PrEP initiation; and (2) regular check-in calls with PrEP users after initiation, including refill reminders and problem-solving about reasons for discontinuation.

Because the team was restricted to sites in which the medical implementing partner had service provision grants, there was a mismatch in healthcare access between the communities. The intervention community was further from a healthcare centre and had a

more mobile population. In contrast, fisherfolk in the comparison community had close access to a healthcare centre where PrEP prescriptions and refills were provided, as well as more consistently stable residents. In the intervention community, our prior quantitative analysis showed that a higher percentage of people-initiated PrEP and persisted on PrEP at 6 months compared with the comparison community; in contrast, PrEP users were more likely to have received at least 80% of their PrEP refills in the comparison community, potentially because of their better healthcare access.[35] In the present paper, we combined qualitative interview data collected from participants in both communities to understand reasons for PrEP continuation and discontinuation during the course of the study.

Data collection

Participants

A total of 40 fisherfolk (20 who continued PrEP, 20 who discontinued PrEP and 20 per community) participated in semistructured interviews about 6 months after they initiated PrEP. Participants were purposively sampled such that 20 had continued PrEP (10 per community) and 20 had discontinued PrEP (10 per community) in the 6-month period after initiation. Eligibility criteria included: (1) 18 or older and (2) offered PrEP at an outreach event during the study period. Participants received 20 000 Ugandan Shillings (~US$5) as compensation. The sample had a mean age of 18.0 years (SD=1.3); 52% were men and 48% were women.

Data analysis

A focused directed content analysis approach was employed to understand themes related to the continuation and discontinuation of PrEP under the CFIR domains.[37] The analysis involved four team members: an American Woman who was a PhD social psychologist, a Ugandan man Study Coordinator with an MPH and two Ugandan Study team members (one man, one woman and both with MPH degrees). They independently reviewed all notes and transcripts and then collaborated to draft a summary of preliminary themes. The Ugandan team members provided input to ensure cultural relevance and refine the themes for a shared understanding of the data. Based on these themes, the team developed a codebook that incorporated the interview guide and constructs related to PrEP continuation and discontinuation. A total of 112 passages across four transcripts were double-coded by two team members, resulting in high inter-rater consistency, evidenced by a Cohen's Kappa of 0.87.

Patient and public involvement

The research question, outcome measures and study design were directly informed by our formative qualitative research and pilot study, which elicited fisherfolk's priorities, experiences and preferences regarding PrEP.[19 35] Fisherfolk, including leadership in fishing communities, were involved in the study by helping to mobilise community members to attend healthcare outreach events. Results of the overall study were discussed with key stakeholders in meetings at the MoH and dissemination events in fisherfolk communities and healthcare facilities.

RESULTS

Themes identified under the CFIR domains

Narratives from respondents in both intervention and comparison communities revealed determinants of PrEP continuation and discontinuation across the CFIR domains. Overall, women described more determinants than men, highlighting specific gender-based challenges. In the intervention characteristics domain, women more frequently cited side effects and the pill burden as barriers to continuation. In the individual characteristics domain, women often reported perceived HIV risk for oneself or a partner, insufficient information and education about PrEP, social determinants of health such as poverty-related issues and competing needs, partner issues, gender-based violence and alcohol use as significant factors. In the inner setting domain, both men and women reported mobility issues and the distance required to obtain PrEP, but women more frequently highlighted these challenges. In the outer setting domain, women reported high HIV prevalence in the community as a motivator for PrEP initiation and continuation, while community-level HIV/PrEP stigma was a common reason for discontinuation among both genders, more frequently reported by women.

PrEP users in the intervention community described greater barriers to continuation than those in the comparison community. For example, more PrEP users in the intervention community experienced community-level PrEP stigma, poverty-related issues, alcohol use and gender-based violence. They were also highly mobile and had competing needs that hindered PrEP use.

Intervention characteristics

Side effects and pill burden: both men and women from the intervention and comparison communities reported side effects and the burden of taking a daily pill as significant barriers to PrEP continuation. However, women more frequently cited these issues as reasons for discontinuation. For example, women mentioned how side effects such as nausea and stomach issues interfered with their daily activities and responsibilities, as noted by one participant:

> I eat in time. Even when I had eaten, and I feel some dizziness…because there is when I take it and I feel dizzy. When I feel it, I eat. So, I am ready to stay on it. (Participant #51, 26-year-old, Woman, Discontinued PrEP, Intervention community)

In addition, fisherfolk who discontinued PrEP found it challenging to adhere to a daily pill regimen, especially when they were away from home for extended periods.

Some found it hard to remember to take PrEP medications daily, with one participant explaining:

> A daily pill most especially reminding yourself of it and at times you are going somewhere, and you have to have it in your pocket because you might spend the night where you are going so it was a huge challenge (Participant #56, 25+ year old, Woman, Discontinued PrEP, Intervention community).

Individual characteristics

Perceived HIV risk of self and/or partner

Both genders reported perceived HIV risk as a factor in PrEP continuation. Women often cited the behaviour of their partners, such as infidelity and mobility, which involves migration to different communities in search of fish and multiple sexual partners, as increasing their perceived risk and motivating them to continue using PrEP. One participant noted:

> I use it. I started using it like eight months ago. There are many reasons. Firstly, you have to take care of your life. I looked at my life and I hadn't made a decision. Honestly, I have many partners because am kind of distant from them, I just meet some. So, to be on a safe side. I heard about this project; instead of waiting for things to go ugly, I decided to start using PrEP (Participant #83, Man, Continued PrEP, Intervention community).

Another participant illustrated how she was influenced to continue using PrEP due to the perceived risk of her partner and the nature of his work:

> My husband may go and spend like 4 months away from home, and then come back. Now, when he comes back, it is there and then that I start using PrEP. The other reason is that the behavior of fishermen is that they move so much and they can't pass-by women. Today, he can be with this one, tomorrow he is with the other one. So, that also makes me use the drug so much, that I can't forget to use it (Participant #85, Woman, Continued PrEP, Comparison community).

Conversely, some fisherfolk who discontinued PrEP perceived themselves as not being at risk for HIV, especially if they only had one sexual partner, were abstaining from sex, or used condoms. One participant explained:

> I had spent some months without having sex with my partner because he was away so I saw no reason of taking these drugs every day (Participant #52, Woman, Discontinued PrEP, Intervention community).

A man who discontinued PrEP use explained how changes in his personal beliefs and lifestyle reduced their perceived risk of HIV, making PrEP less necessary:

> You know, as you grow up, there are some things that you change as a person. Let me tell you, before, I was a Catholic but now I am a born again. I no longer go to the places which I used to go to. What does that mean, that the places where I used to find women, where we used to have alcohol from, sleeping around with women. I can no longer do that. All I need is to have one woman whom I am going to have as a wife. Currently, that is what has protected me, the fact that I am no longer engaged in sexual activities. I will not say that it is PrEP which has brought about my loss of interest in women but it is my Faith which is stopping me (Participant #60, Man, Discontinued PrEP, Intervention community).

Insufficient information/education and lack of awareness about PrEP

Women more frequently reported insufficient information and education about PrEP regarding its benefits and usage as barriers to continuation. They highlighted a lack of community education and insufficient information from healthcare providers on how PrEP can protect against HIV infection or where to access it was associated with poor adherence and/or discontinuation. One participant noted:

> When you sensitized us, you told us that it protects against HIV infection. Also, there are men who don't want to test. Now, I was told that if you take PrEP…you never know, you may have sex with someone and the condom breaks, but you will still not contract HIV. So, it really made me decide to continue with it (Participant #51, Woman, Discontinued PrEP, Intervention community).

Participants who discontinued PrEP often lacked sufficient correct information regarding its usage. One participant expressed confusion about the correct usage of PrEP, asking whether it should be taken daily or only when planning to have sex, and voiced concerns about potential challenges and side effects from missing doses:

> I once asked if I am supposed to take PrEP only when I'm going to have sex and I was told that I have to take it every day. Then I inquired that what if I don't take it because it is not there; won't I experience challenges trying to take it again? I also wanted to know that because I called the provider when I still had 5 pills left. But I have not taken some days without taking it. So, I want to ask you that because it is you to tell me. Doesn't it affect me in any way? (Participant #54, Man, Discontinued PrEP, Intervention community).

Another participant was unclear about the duration and necessity of continuous PrEP use, stating:

> They told me that every day I take one pill for six months. But after taking it for 6 months, you re-test. So, I don't know if I should continue doing so (Participant #66, Man, Discontinued PrEP, Intervention community).

Misinformation about PrEP and its side effects was a significant factor in PrEP discontinuation. Fisherfolk often stopped using PrEP due to rumours and incorrect information about its potential harm. One participant illustrated this issue:

> I was somewhere, and they were testing me for HIV. The doctor said that we shouldn't use the medication because it damages the liver, which made me afraid and worried. That's one of the reasons I decided to take a break from

using PrEP (Participant #56, Woman, Discontinued PrEP, Intervention community).

Social determinants of health (includes poverty-related issues and competing needs)

Both men and women mentioned poverty-related issues and competing needs, but women more often discussed these factors. Women talked about economic challenges, food insecurity and the impact of these issues on their ability to adhere to and continue using PrEP. Fisherfolks were reluctant to continue taking PrEP on an empty stomach, while others discussed a lack of funds for transport to get refills. One participant shared:

> Maybe if I don't get what to eat because this pill needs good feeding and enough fluids. So, those would have been the barriers, though I still try and make sure that I take it (Participant #68, Man, Discontinued PrEP, Intervention community).

Another participant highlighted:

> I am a Muslim, and I don't take alcohol. This was not a challenge, but the issue of lacking what to eat before taking the drugs was big to me because you may not want to take drugs which are strong on an empty stomach (Participant #52, Woman, Discontinued PrEP, Intervention community).

Additionally, one participant noted:

> Personally, I earn less from my work. So, you may not be able to take it. Sometimes, you may not get what to eat in time and yet you're supposed to take it. So, those are some of the challenges that come along (Participant #78, Man, Discontinued PrEP, Comparison community).

Individuals may have other priorities or healthcare needs that take precedence over taking PrEP. Fisherfolk reported multiple competing needs, such as being busy trying to secure livelihoods and managing irregular schedules (eg, work, daily chores), including time pressures that lead to forgoing healthcare or forgetting to take medication while on trips. These competing needs diverted their attention and resources away from PrEP use and led to discontinuation. As one participant stated:

> A fisherfolk travels to islands and at times the lake might become unstable and he ends up staying there for a long period of time yet he left his medication at home (#81, Man, Discontinued PrEP, Comparison community).

Additionally, lack of stable housing situations coupled with these competing priorities often resulted in nonadherence and discontinuation of PrEP. One participant highlighted the impracticality of taking PrEP pills for fisherfolk with transient lifestyles, suggesting that injectable PrEP, which is a long-acting rather than a daily medication, would be more suitable due to their irregular schedules and lack of stable living conditions. A participant stated:

> That is right, now look at that one, [he points at another fisherfolk] He is holding a torch implying that he was on water throughout the night. That one fishes silver fish, he goes on water at about 6:00 PM and he returns early in the morning at 6:00 am, he then goes to the bar and takes his booze. In case he kept his medicine with someone somewhere there in the village, he will not have the time to go and take it. Having PrEP through pills can only be handled well by people like me who has a home; it is only such people who can take the pills. But this cannot work well with the fisher folks; it is the injection which can work well for them (Participant #60, Man, Discontinued PrEP, Comparison community)

Partner issues

Supportive partners played a positive role in encouraging and facilitating PrEP adherence. For example, one woman mentioned:

> My husband cannot fail to support me. In fact, if we are together, I make sure that he takes his and I also take mine. I encourage him (Participant #53, Woman, Continued PrEP, Intervention Community).

Another man shared:

> Yes, they told me and I selected my wife because we were both taking it together. She was the first and she kept reminding me and when I also got it, I reminded her (Participant #65, Man, Continued PrEP, Intervention community).

On the other hand, fisherfolk encountered significant obstacles due to gender-based violence and the fear of violence from their partners, which greatly affected their ability to start or continue taking PrEP. One participant shared her difficulties, saying:

> Yes, that was also a problem, because when my husband toughened up, I had no way of explaining it to him and making him understand it well. I didn't have enough information to tell him that the medicine was for such and such purposes. Even when he accused me of not trusting him, I didn't have the facts to answer him. The truth is, he also can't account for his movements, or that he has other women. There was no way I could educate him, and the same was true for my friends. He kept on insisting that I was lying. He asked me why everyone wasn't taking it and how I was the only one who had gone to get it. Since I lacked enough information, my words were few, and I could only reply with what little I knew about PrEP (Participant #90, Woman, Discontinued PrEP, Comparison community).

The fear of disclosing PrEP use was also a major concern for both men and women. One participant said:

> Yes, the fear is always there and it's a lot. That is why most of the time, I hide it and take it at 6am because I have not yet got a single partner. I have not yet opened up to one single relationship (Participant #80, Woman, Continued PrEP, Intervention community).

Another participant explained the difficulties of explaining PrEP use to a partner:

> There is a problem with that [disclosing to partner that you are on PrEP] because it is hard to explain to her that this

> one I swallow prevents against the virus. There are so many questions there. You are always on tension and smuggling it. Maybe what I see there, maybe when you've come with your spouse, and they explain to the both of you clearly. You then agree to take or leave it. I came for it by myself, I have a wife but I came for it as me (Participant #86, Man, Continued PrEP, Comparison community).

Alcohol use

Both genders noted alcohol use as a barrier, but women more frequently linked alcohol consumption to risky sexual behaviours and non-adherence to PrEP. They shared that excessive alcohol consumption contributed to increased risky sexual behaviours that led to HIV infection and potentially hindered PrEP adherence. One participant highlighted the impact of alcohol on PrEP adherence, stating:

> Protection was the first thing I thought of but of course sometimes lacking what to eat was a challenge. For those who take alcohol, they have to stop taking when they are taking PrEP but good enough for me I don't take alcohol. Many people refuse to start PrEP because they cannot leave alcohol. Others fail to start because they don't know where they will get the next meal (Participant #93, Woman, Discontinued PrEP, Comparison community).

Fisherfolk discontinued PrEP because they found it challenging to avoid alcohol while taking the medication. One participant explained:

> The other challenge I saw with PrEP is that you take it and don't drink alcohol, yet I used to take it. So, I found a challenge with that (Participant #95, Man, Discontinued PrEP, Comparison community).

Inner setting

Mobility issues/distance/travel from clinic to where one can get PrEP

Both men and women reported mobility issues and the distance to healthcare clinics as significant barriers to accessing PrEP. However, women more frequently highlighted the challenges of travelling to distant clinics for PrEP refills, particularly due to their daily responsibilities and the nature of their work. The fishing communities, especially those in the intervention areas, are located in hard-to-reach regions on the shores of Lake Victoria. This geographical isolation makes it difficult for individuals to travel to healthcare facilities where PrEP services are available. The distance and travel logistics, including the time required and the means of transportation, were significant barriers to PrEP access and continuation. One participant emphasised this difficulty, stating:

> You should not need to be far away from those people. You know, as humans we are very lazy. You will tell them to come and find you at Grade A or Grade B and they…[PrEP users…] will find it difficult getting 2,000 to board to and from to pick their refills. They will find it to be expensive and not go. But if people are closer to us, say, every week providers go to [intervention or comparison site], then it will help a lot (Participant #54, Man, Discontinued PrEP, Intervention community).

Other participants pointed out the challenge of mobility due to the nature of their work that impacted their ability to continue with PrEP. One participant explained:

> I can tell you that our fisherfolk here on the lakeshores… someone may go from here to Kigungu and spend a week there. Now, when they spend a week there, they may continue to Kasenyi, which will pose a challenge that they will not have their pill bottle close to them (Participant #54, Man, Discontinued PrEP, Intervention community).

To mitigate this challenge, participants suggested that more frequent visits from health workers to the fishing communities could help address these barriers:

> My program would be that if we were to start that medication and we want to help our colleagues to stay on the medication, I think we would have to be given time and we know that medication or the tin they have given us can last us a month or two months. Then, our health workers start regularly visiting the fishing communities so that the people can easily access the medication because the truth is that people really need that medication but where to get it from is the issue, especially when they have not seen the health workers (Participant #65, Man, Discontinued PrEP, Comparison community).

Outer setting

High HIV prevalence in the fishing community

Fisherfolk were motivated to start and continue using PrEP to protect themselves, their families and their communities from HIV infection, recognising the potential for HIV transmission within close-knit fishing communities with high HIV prevalence. One participant explained:

> After being sensitized about it and what it prevents, especially for us the fisherfolk who are highly mobile, but also, sometimes we fail to let go, specifically regarding sex. But again, most of the time, HIV spreads much more through we the fisherfolk. So, when I tested negative, I saw it as an opportunity to protect myself from acquiring HIV, and so, I started (Participant #68, Man, Continued PrEP, Intervention community).

Sexual behaviours such as multiple partners, condomless sex and sex work among fisherfolk were highlighted as a motivating factor for starting and continuing PrEP use. The need for self-protection was emphasised by one participant:

> Just because the community in which we stay is very difficult. There is too much promiscuity. So, when you get a chance, you have to protect yourself (Participant #74, Woman, Continued PrEP, Intervention community)

Our intervention played a key role in creating awareness about PrEP in communities that did not have healthcare facilities. One woman shared her decision to start PrEP after learning about its benefits during a community sensitisation event at the intervention site:

> I never had plans of starting taking PrEP because I even did not know about it but when I was in the market going after my daily work, I heard people saying they are giving out drugs for vaccinating HIV. I went where they were and I listened to what they were teaching. I heard of the benefits of PrEP like protecting myself from getting infected in case I had sex without a condom. Our men at these landing sites are after women, they have so many women and yet most of the women here are prostitutes, prostitutes have HIV and when our men are drunk they don't even use condoms. So I decided to start using PrEP (Participant #52, Woman, Continued PrEP, Intervention community).

Similarly, another participant recognised the unpredictable and high-risk environment of the fishing community as a reason to start and continue with PrEP use:

> I decided to take PrEP because of the community in which we stay. It is a fishing community, and you don't know the situation. Even when you say that you're going to protect yourself, you will still face challenges. But if it finds that you have been taking PrEP, then you may have higher chances of not getting infected (Participant #78, Man, Continued PrEP, Comparison community)

Community-level HIV/PrEP stigma

Stigma related to HIV and PrEP within close-knit communities was noted as one of the reasons why fisherfolk discontinued PrEP use. Fisherfolk feared being stigmatised if they were seen accessing HIV prevention services like PrEP. One participant explained:

> I attended [outreach events] twice, but because of the community in which we stay, whereby they think that whoever goes there is an HIV positive person. So sometimes it becomes a challenge… the people in the market, the drunkards, the people who sell timber would all know that, that teacher is positive (Participant #52, Woman, Discontinued PrEP, Comparison community).

PrEP resembles the drugs taken by people living with HIV (ARVs). Most community members do not differentiate PrEP from the drugs taken by HIV clients, which is a source of stigma and causes fisherfolk to discontinue PrEP. One participant explained:

> I went to an island and when someone saw me pull out my bottle to take my pill as I was going to sleep, he thought I was on ART. I taught him. I heard him talking about me and I taught him. I told him that what he was talking about is actually the best thing, and that they have spent a long time in the islands but don't know what to do. So, people think that way, but we gradually sensitize them (Participant #68, Man, Discontinued PrEP, Intervention community).

Another fisherfolk described the challenge of being mistaken for an HIV-positive person because PrEP looks similar to ARVs:

> Another challenge was that I faced a lot of stigma from people who said that maybe I was taking ARVs. They said I may be positive and that I may be lying to them because PrEP looks exactly the same as ARVs. So, I felt that people would think of me as a positive person. So, that also scared me (Participant #81, Woman, Discontinued PrEP, Comparison community).

As such, the fear of gossip, discrimination and judgement from peers was a concern. One participant shared:

> When I stopped taking PrEP is because of the people that we stay with. Now, my friends used to come home to my room and could find it there, and when you meet up later with them, you hear them talking about you. So, I decided to first put a halt to it. When they are finally able to understand what it does, then I will take it again (Participant #78, Man, Discontinued PrEP, Comparison community).

DISCUSSION

PrEP users in the intervention community reported facing more significant barriers to continuation compared with those in the comparison community. Key obstacles included heightened community-level PrEP stigma, poverty-related issues, alcohol use, gender-based violence, high mobility and competing needs. Notably, women experienced more barriers than men, particularly in the domains of individual characteristics, intervention characteristics, and outer settings.

Fisherfolk described a range of barriers that influenced PrEP continuation and discontinuation in resource-limited and underserved fishing communities around Lake Victoria in Uganda. Issues such as gender-based violence and fear of violence, coupled with structural and social barriers, significantly impacted PrEP continuation. As shown in our prior mixed-method analysis comparing the intervention and comparison sites, implementation strategies such as adherence reminders, educational workshops, and community health worker support played a crucial role in overcoming these challenges, leading to increased PrEP uptake and persistence.[35]

Our study corroborates previous research on the impact of gender-based violence and partner support on PrEP adherence. Fear of partner violence and controlling behaviour posed significant barriers to PrEP use among women, reflecting findings that gender-based violence is a critical barrier to healthcare access.[38–40] Conversely, supportive partners facilitated PrEP continuation and adherence, highlighting the importance of inclusive strategies that involve partners in PrEP education, utilisation and support.[41] Supportive partners can support in PrEP enrolment, continuation and adherence. Literature indicates that high levels of gender-based violence in fishing communities can severely impact women's health behaviours and their ability to seek and adhere to preventive health measures.[42] Our findings align with this, as women with supportive partners were more likely to continue using PrEP, whereas those fearing violence or lacking partner support often discontinued its use. Addressing these gender-specific barriers is essential for improving PrEP adherence and continuation among fisherfolk.

Our findings also highlight that structural issues, including poverty and limited healthcare infrastructure,

compound these barriers. Fisherfolk, particularly women, cited financial constraints, food insecurity and competing needs as major obstacles to regular PrEP use. These socioeconomic challenges align with prior research indicating that poverty can drastically limit access to preventive healthcare services, as individuals prioritise immediate needs over long-term preventive health measures.[41] Addressing these issues requires a multifaceted approach, including the provision of financial or food support programmes alongside PrEP services, to alleviate some of the socioeconomic burdens that undermine adherence.

The geographical isolation and mobility of fisherfolk add a significant layer of complexity to PrEP adherence, as many must travel long distances or rely on inconsistent transportation to access healthcare services, limiting their ability to maintain a steady regimen. Previous studies highlight how mobility challenges and limited transportation in remote areas hinder healthcare access, especially for preventive services requiring regular refills and check-ups.[25 42] Participants suggested that injectable forms of PrEP could alleviate some adherence challenges associated with daily pill regimens, particularly for those with transient lifestyles. Implementing mobile PrEP delivery services or increasing the frequency of healthcare provider visits to fishing communities could help bridge these access gaps, while involving local organisations in PrEP distribution might make services more accessible to fisherfolk with limited mobility. Future research could explore the feasibility and acceptance of long-acting injectable PrEP in these high-mobility communities to determine if this approach could improve adherence.

Stigma related to HIV and PrEP within close-knit communities presents a significant barrier to effective HIV prevention. Many community members did not differentiate PrEP from ARVs drugs used by people living with HIV, leading to stigma and discontinuation of PrEP. This confusion arises from limited awareness about PrEP among the general population, particularly among fisherfolk. Although the government has adopted PrEP as an HIV prevention intervention, awareness among fishing communities remains low.[25] This limited awareness perpetuates the misconception that people using PrEP are HIV positive, causing fisherfolk to avoid accessing HIV prevention services for fear of being labelled as such. Therefore, expanding PrEP awareness campaigns specifically tailored to fisherfolk communities is essential to reduce stigma and increase knowledge about PrEP. These campaigns should involve community leaders and use local media channels to ensure wide reach.

Strength and limitations

This study is not without limitations. It focuses on specific fishing communities in Uganda, which may not represent the full diversity of fisherfolk experiences in other regions. The reliance on self-reported data introduces potential biases.[43] Additionally, the perspectives of healthcare providers were not included, which could have provided a more comprehensive understanding of the factors that influence PrEP use. Lastly, age-specific challenges were not examined, and seasonal variations in fishing activity affecting PrEP adherence were not considered.

This study has several notable strengths. First, it provides a comprehensive analysis of the determinants of PrEP continuation and discontinuation using the CFIR, allowing for a structured and multifaceted understanding of the factors influencing PrEP use among fisherfolk. Second, including narratives from both intervention and comparison communities provides a balanced perspective and enhances the validity of the findings. The qualitative approach allowed for in-depth insights into the lived experiences of PrEP users, capturing the nuanced and context-specific challenges they face. Lastly, the study's emphasis on key populations in a high-prevalence setting like Uganda contributes valuable knowledge to the field of HIV prevention and informs future programmatic and policy efforts.

CONCLUSION

In summary, our study highlights the significant factors impacting PrEP continuation and discontinuation among fisherfolk in Uganda, with women facing a broader range of challenges than men. Key facilitators for PrEP continuation included supportive social networks, perceived HIV risk and targeted education on PrEP benefits, underscoring the importance of community involvement and accessible health information. However, substantial barriers, such as transportation and mobility constraints, community-level stigma and intimate partner violence, contributed to high rates of PrEP discontinuation, particularly for women. These findings underscore the importance of developing and implementing tailored interventions that address these unique obstacles, including improving education on PrEP, supporting women facing intimate partner violence developing stigma reduction campaigns, and exploring alternative PrEP delivery models, such as injectable options. Future research should focus on testing these targeted strategies in diverse and hard-to-reach settings, such as island communities, to enhance the effectiveness and sustainability of PrEP programmes. Engaging entire communities in these efforts will be critical for achieving optimal outcomes in the fight against HIV in high-prevalence areas.

Research in context summary panel

Evidence before this study

PrEP has been shown to be an effective HIV prevention strategy in multiple high-risk populations, including fisherfolk. However, uptake remains challenging, particularly in resource-limited settings where individuals face complex social, economic and geographical barriers. Previous research highlights factors such as community stigma, gender-based violence and lack of awareness as

major obstacles to PrEP continuation. Additionally, logistical issues like transportation difficulties and the daily pill burden further hinder PrEP continuity, especially in communities with limited healthcare access. Although interventions have been proposed, the effectiveness of targeted support in overcoming these unique barriers remains underexplored, particularly among fisherfolk.

Added value of this study

This study offers a detailed examination continuation and discontinuation among fisherfolk in Uganda. By applying the CFIR, the study identifies a comprehensive range of barriers and facilitators across individual, community and systemic domains. Key findings indicate that women in particular face a diverse set of challenges, including intimate partner violence, and that fisherfolk in general experience community PrEP and HIV stigma, which is exacerbated by mobility and transportation barriers. The study provides actionable insights, suggesting that tailored interventions—such as peer-led, mobile PrEP delivery, community sensitisation, and partner-inclusive education—may improve PrEP continuation and retention.

Implications of all the available evidence

The findings underscore the need for targeted, community-based interventions to support PrEP continuation in high-risk and mobile populations. Addressing gender-specific barriers, such as partner violence and stigma, while providing flexible PrEP delivery models could substantially enhance PrEP retention. These insights highlight the importance of multilevel approaches that engage community leaders, local organisations and healthcare systems to create a more supportive environment for PrEP use. Future research should assess the feasibility of long-acting PrEP options, like injectables, in these high-mobility contexts and evaluate the effectiveness of interventions that incorporate transportation support and stigma-reduction strategies.

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