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## "For the safety of our health": A Qualitative Analysis of Pre-Exposure Prophylaxis (PrEP) Acceptability among Female Sex Workers in Malaysia

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#### Abstract:

Female sex workers (FSW) in Malaysia are at substantially increased risk of acquiring HIV compared to the general female population. Pre-exposure prophylaxis (PrEP) offers a novel way to prevent HIV transmission in this population. This research aims to inform culturally relevant implementation of PrEP through a qualitative exploration of the factors that determine FSW willingness to use PrEP. In-depth, semi-structured interviews (n=30) were conducted with FSW in English, Malay, or Tamil. Transcribed and translated interviews were analyzed using a grounded theory approach. FSW expressed positive interest in PrEP but preferred it as a supplement to condoms, not a replacement. Perceived challenges to PrEP use included cost, adherence, side effects, and disinterest. FSW experiences with HIV and condoms support these reactions. This research bolsters prior work on the inapplicability of behavioral disinhibition to FSW and supports PrEP implementation in combination with condom promotion.

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Keywords: PrEP • Acceptability • HIV • FSW • Malaysia

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#### **INTRODUCTION:**

PrEP and Sex Work

Female sex workers (FSW) are disproportionally affected by HIV compared to the general population (1, 2). FSW also have more partners and more frequent sex acts, putting them at higher risk of both acquiring and transmitting HIV. Unfortunately, FSW have been largely underserved in both research and practice with regards to HIV prevention, particularly with regards to non-behavioral approaches to prevention (3).

Daily oral Pre-Exposure Prophylaxis (PrEP) for HIV prevention offers the opportunity to combat the spread of HIV among FSW in a novel way. Intended for HIV-uninfected individuals at high risk, PrEP has been demonstrated to safely and effectively reduce risk of HIV infection in men who have sex with men (MSM), people who inject drugs (PWID), and serodiscordant heterosexual couples (4-7). PrEP has not, however, been evaluated among sex workers in a randomized controlled trial (8), so it is unknown whether the unique aspects of sex work would impact PrEP uptake and biological effectiveness (1).

Scale-up of PrEP among sex workers is highly promising for several reasons. First, PrEP eliminates the need for client or partner consent of condoms. Current efforts at HIV prevention focus heavily on condom use. These efforts have been largely successful, yet condom use remains suboptimal (9, 10). Among FSW, condom use may be inconsistent due to limited agency, client refusal or coercion, sexual or physical violence, higher payments by clients, and the attitude of a non-paying partner towards contraception (11-15). Furthermore, PrEP provides FSW with additional protection from HIV when there is an issue with condoms, such as breakage or slippage.

Research on acceptability of daily oral PrEP among high-risk groups, including FSW, has demonstrated that acceptability is generally high but varies depending on cost, perceived efficacy, and fear of side effects (16-18). However, these studies have predominately relied on closed-ended, survey-based methods and have therefore failed to look in-depth at the factors that may shape PrEP acceptability among FSW. In a 2012 literature review, acceptability in the context of PrEP was defined as "the product-related attributes and perceptions that potentially influence product adherence" (19). The authors of this review argue that acceptability is more nuanced than "willingness to use" alone and call for more research to assesses broader dimensions of acceptability. Research demonstrates that FSW decision-making is calculated and often involves juggling a variety of interests (20), but little is known about factors that might determine FSW willingness to use PrEP.

In order to address this gap, this study draws upon qualitative interview data in order to frame PrEP acceptability within the context of HIV-related risk perception and mitigation of HIV among FSW in Kuala Lumpur, Malaysia and to inform implementation PrEP for HIV prevention among FSW and transgender sex workers (TGSW).

Setting

This study focuses specifically on FSW in Kuala Lumpur, Malaysia. Historically, the HIV epidemic in Malaysia has been driven by male PWID. During the past two decades the epidemic has transitioned towards a generalized HIV epidemic with bridges between drug use and sexual transmission (21). New HIV diagnoses among women have increased from 1% in 2000 to 25% by 2011 (22). FSW are at much higher risk for HIV than the general population and cases are thought to be grossly underreported (21). Of the estimated 40,000 FSW in Malaysia, 4.2% are estimated to have HIV (21). In the Klang Valley, which contains the capital city of

Kuala Lumpur, the prevalence of HIV among FSW is thought to be much higher, at 10.7% (23). This rate is approximately 81.2 times that of the general Malaysian female population, which has an estimated HIV prevalence of only 0.15% (24).

Despite advancements in HIV treatment, antiretroviral therapy (ART) coverage among people living with HIV (PLWH) remains low. In 2013 only 47% of PLWH were currently receiving treatment (21). PLWH may not seek treatment for a variety of reasons, including lack of awareness, financial costs, time constraints, and fear of positive results (11). In Malaysia, pervasive stigma surrounding HIV compounds the problem (25). Key affected populations, like PWID and sex workers, face additional barriers to accessing HIV testing, treatment and care. For sex workers, these include criminalization, gender-based violence, and fear of status disclosure among clients (11). These barriers contribute to higher rates of late-stage diagnosis and increased risk of mortality, suggesting the need for more comprehensive prevention approaches (25).

At the time of this study, PrEP was not available in Malaysia. Current HIV prevention efforts targeting FSW in Malaysia rely on community-based organizations to distribute condoms and risk-reduction information, as well as provide referrals to HIV testing and other sexual reproductive health services. These outreach efforts have made inroads in expanding access to and use of condoms (26). Despite this, the high rates of HIV among FSW in Kuala Lumpur make it clear that there are significant gaps in HIV prevention and highlight the need for biomedical approaches like PrEP.

Additionally, global efforts to combat HIV continue to set more demanding goals. The UNAIDS "90-90-90" target for 2020 aims to have 90% of PLWH know their status, 90% of those diagnosed on ART, and viral suppression for 90% of those on ART (27). Achieving ambitious goals like this necessitates combination prevention strategies that integrate condom

promotion and community empowerment with biomedical interventions like PrEP (11). As access to and use of PrEP is expanded to places like Malaysia, it is crucial that we understand how PrEP is perceived and fits in with already existing methods of HIV prevention among high-risk populations. There is no research on PrEP acceptability among FSW in Asia. This research was intended to inform the implementation of PrEP among high-risk female sex workers in Malaysia.

#### **METHODS:**

Study Design and Sample

This study draws on qualitative semi-structured interviews and a close-ended survey. Qualitative interview questions focused on four topic areas: sex work experiences, contraception knowledge and behavior, HIV knowledge and behavior, and acceptability of PrEP for HIV prevention. This paper focuses on the latter two topics. Participants were provided with information on PrEP that emphasized its appropriateness for uninfected individuals, its high effectiveness, the importance of taking the pill daily, the need for blood tests every 3 months to check HIV status and one's kidneys, and the continued risk of STIs and pregnancy if not using condoms. The information was adapted from the U.S. Centers for Disease Control and Prevention, translated into Malay, and described both orally and in writing (28). The survey contained basic demographic questions, screens for depression and interpersonal violence, and additional questions on reproductive health. Participants were included if they were female, 18 years of age or older, reported engaging in sex work in the past 30 days, and spoke Malay, English, or Tamil. Convenience sampling with a purposive design was used to facilitate the recruitment and diversify participants along the characteristics of age and race, specifically seeking to have a range of ages and races represented in the sample.

Data Collection

Participants were recruited via three local non-governmental organizations that provide outreach and education to the sex worker community. The study purpose and procedures were explained verbally and provided in writing to all potential participants. Verbal consent was obtained from each woman who agreed to participant. Interviews were audio recorded and involved the participant, principle investigator, and a research assistant. All data collected was anonymous and used pseudonyms. Following the in-depth interview, participants completed the survey either independently or with the help of the research assistant, depending on literacy level. Participants were provided with 50 Ringgit Malaysia (approximately \$13.50 USD) and contact information for local healthcare and social service organizations. Thirty face-to-face qualitative interviews were conducted between June and August 2015. All interviews were transcribed and translated into English between August and October 2015 by an outside service. Final transcripts contained both Malay and English so that accuracy could be checked (SF). *Data Analysis* 

Analysis of transcript data was based on grounded theory methodology (29). Constant comparisons, which involves comparing pieces of datum both within and between files, was the primary form of analysis used in this study (29, 30). Open codes were used to identify key ideas (SF, JW). This analysis formed the basis for the development of a codebook (SF), which was used to code the entirety of the interviews. A selection of interviews were independently double coded by trained research staff and then compared to ensure reliability of codes. Theoretical comparisons were made to look at interactions between concepts in order to group codes into themes. During this process, codes were often regrouped in the codebook to reflect the ongoing

<sup>&</sup>lt;sup>1</sup> Conversions between the Malaysian Ringgit (RM) and US Dollar were calculated at a 3.7 RM to 1 USD, the approximate average exchange rate from May-August 2015.

emergence of themes (SF, JW, DK, SB). Coding and analysis was done using ATLAS.ti software (SF) (31). Participant characteristics were derived from survey data and generated using R Studio (SF) (32). All results are presented with participant pseudonyms.

#### Participant Characteristics

Characteristics of the sample are reported in Table 1. Participants ranged in age from 21 to 65 years, with an average age of 38. Most participants were of Malay (57%) or Indian (27%) ethnicity. Education levels were relatively low, with only 8 participants having completed Form 5, the equivalent to US high school. During the consent process approximately one in three women acknowledged being unable to read the form. This is most likely reflected by the 12 participants who had an education level of primary school or less. The majority of participants were in a current relationship (30%) or had previously been in one (33%). Additionally, history of arrest (77%), lifetime use of alcohol (67%) or methamphetamines (67%), positive screens for depression (67%) and exposure to physical or sexual violence in the past 12 months (43%) were frequent.

#### **RESULTS:**

Several qualitative themes emerged from the data. The first four themes illuminate contextual information on the experiences of FSW related to HIV and condoms, addressing four key areas: HIV risk perception, the ways FSW link their perceived HIV risk to clients, FSW rationales for condom use, and FSW condom use and negotiation practices. These themes aim to provide a setting for understanding the last three themes, which focus specifically on participant reactions to PrEP, including participant interest in PrEP for preserving their health, their desire to use PrEP as a supplement to condoms rather than a replacement, and potential challenges to PrEP implementation.

"Even the word can give me goose bumps": HIV Risk Perception

HIV risk perception was a salient theme in these data and participants describe high levels of perceived HIV risk. For example, when asked about her thoughts on HIV one participant named Sami [age 39] reacted by saying: "No, I am afraid of this, HIV, I cannot imagine, even the word can give me goose bumps." For many participants, this fear was derived from experiences of HIV in their community. Aditi and Sofea elaborated on their fears this way:

I personally had a friend who passed away because of HIV, but she/he was on drugs. We went for her/his funeral. No one must ever have this sickness. You can get any other sickness, but not this. [Aditi, Age 48]

They talk about this person, she/he died, but I did not see her/him. But I heard from others that some of them have already died. Why? Because they have the disease [HIV/AIDS]. Look at them, they are so slim...they cannot eat, they always get diarrhea. You cannot do anything. [Sofea, Age 35]

For both Aditih and Sofea, HIV is seen as a genuinely life-threatening disease. For them, its association with mortality makes it far more terrifying than other medical conditions or illnesses.

Misinformation about HIV transmission and treatment intensified participant fears. When asked what they know about HIV, most participants knew about the sexual transmission of HIV. Others described transmission from unclean needles. Multiple individuals made inaccurate statements about how HIV is transmitted. Quotes by Nisa and Aini highlight some of these errors:

Maybe if our friends have it, we don't know that, right? We can get infected by wounds or cuts right? [Nisa, Age 30]

They say we can get infected [by HIV] easily. I have many HIV [positive] friends at Chow Kit [a neighborhood]. Even if we didn't have sex, if we are close with our HIV friends we can also get infected by HIV. Their saliva and blood [can infect us]. [Aini, Age 34]

Another common source of confusion was related to HIV treatment. While most women were aware that there is no cure for HIV, few understood that it can be effectively treated with antiretroviral medications and managed as a chronic illness. Inaccurate information about HIV was often discussed alongside accurate information. Misinformation about HIV exacerbates fears and increases perceived susceptibility and severity of HIV. These uncertainties also expose the realities that exist for this population's access to accurate prevention information, early diagnosis, and appropriate treatment for HIV.

"I am worried if we choose the wrong customer": Linking Perceived HIV Risk to Clients

In addition to having high HIV risk perception, FSW often reported viewing clients as a potential source of HIV. Women described feeling aware of their HIV risk while providing services to clients:

I am worried if we choose the wrong customer...but I don't know because we cannot tell if the person has HIV or not...I am afraid if I get infected. [Dina, Age 38]

When we do this kind of thing [sex work], we cannot avoid...thinking about all sorts of things...like it [is] making me crazy. We mentally think about the impossible things, we can think that far (laugh)...Sometimes it crosses my mind, thing like either this guy has HIV or not. [Nadia, Age 41]

For many FSW, concerns about HIV are directly related to their experiences with clients. Coping with this constant fear often involved creative client screening methods. Some FSW attempted to screen clients based on physical or racial profiling, alcohol intoxication or drug use, appearance of the genitals, or other measures. Participants talked about screening clients this way:

I didn't just take [any] customer, I look at them first. If they look okay then I will take them. Sometimes other sex workers just want the money so they take whomever they want. But I am picky, I only take certain customers that look okay. [Nisa, Age 30]

Client-screening methods like those described above part of how FSW manage risk, suggesting that FSW are searching for a way to cope with non-disclosure of client disease status. FSW inability to truly screen clients or request disclosure is a primary challenge to HIV prevention in this population and highlights the limitations of risk perception. FSW with high-perceived risk are often unable to protect themselves in practice because they are juggling their fear and risk of HIV with other high priority issues.

#### Rationales for Condom Use

Given the high HIV risk perception of this population, condoms play an important role in helping FSW prevent HIV. While HIV risk motivators some to use condoms, it was not the only reason for using condoms. For some like Elly [age 39], fear encouraged caution: "Because I am afraid. I have to be careful." For Ati [age 35], condom use was linked to her development of HIV knowledge and her fear of the disease. She described it this way:

Before this I didn't care about, I didn't even know about, these diseases...Then they told me it is dangerous to not use a condom because of HIV. So I started to think about it. That is why I started to use condoms.

Ati was not the only FSW to report fear of HIV as a motivator for condom uptake or use. Some talked about how their behaviors changed after learning about HIV, its transmission, or the role of condoms. Nur [age 48] describes how her fear of HIV impacts her behavior:

Because before this I didn't have much information about this disease, about HIV. So when that [unprotected sex] happen[ed] I would feel like, ah...okay, this is safe. But now I feel [like] everything is still unsafe for me. We still have the risk, right? I just want to use a condom straight away, it is easier.

For others, condoms were not only valued for HIV prevention. Several FSW reported condoms as a way to maintain general hygiene or protect themselves from clients:

Because I feel...more comfortable...I don't have to worry about having a baby...I don't feel like I can get any infection inside...and I don't have to wash regularly. The semen

will be in the condom. It is much easier if we use a condom. It's much cleaner. [Sami, Age 39]

If he is a new customer I will feel insecure or I will feel like he is sick or he can make me sick. So I will make sure he will wear his condom. [Farah, Age 20]

These types of rationales reinforce the importance of HIV risk perception in motivating prevention, but also highlight how FSW preferences for condoms go beyond HIV prevention to incorporate how condoms function as a physical barrier between participants and their clients.

"He did not want to wear [a] condom": Condom Negotiation Practices and Challenges

Given the importance of condoms for HIV prevention among FSW, it is necessary to understand not only participant rationales for condom use but also how FSW use condoms in their daily lives. All participants had used the male condom with clients. Most described negotiating with clients about wearing condoms. These negotiations happened in two stages, with primary negotiations taking place before going "upstairs" to a private room and secondary negotiations happening once in the room with a client. Shivani [age 57], an older FSW doing sex work to meet her basic needs, describes her primary negotiations with clients this way:

[When] I go to the place where an Indian guy has booked me, I go and automatically ask him, uncle do you have a condom? Oh, it's okay if you don't have it, but you can buy it at the shop. If he does not move, I go back home. I must have a condom! If he refuses to use the condom then he cannot have it [sex].

Unfortunately, even with primary negotiations, FSW still described the physical shortcomings of condoms, as well as challenges they faced with secondary condom negotiations.

First, women reported issues with condoms breaking and slipping. Nisa talks about experiencing a condom break, "I have that experience, sometimes if I don't get arouse I will be dry. So when we have sex...it will burst...'tup'...if I heard that sound I will get up immediately." These types of breaks or leaks were concerning for FSW. Annabel [age 38]

discusses the anxiety associated with possible condom breaks: "Yes ok I always use condom, like I told you before, none of these condom are good. It can break, sometimes when we use it, it can easily break. Of course we are worried." Compensation for this fear often involved the use of two condoms for additional protection, a concerning practice that actually places FSW at higher risk for HIV.

Second, even when condom use was negotiated ahead of time, FSW encountered customers who refused to wear condoms once alone. This often led to additional negotiations. These secondary negotiations were often frustrating or angering for FSW. Most participants reported returning client money and leaving without providing services. For example, Husna reported: "I do [face issues with costumers wearing condoms] but I force them to use it. If not I don't give them my service, it's like that." Another FSW describes in more depth how client refusal of condoms once in the room violates the rules of the negotiation process that FSW have established:

When we enter the room [and] he tells me that he did not want to wear [a] condom, I will ask him to use it. If he still refuses to wear it I will give back his money. I will not jeopardize my health...But it was his fault because he did not tell me that he did not want to wear condom during our negotiation. If he goes upstairs of course he knows that we will wear [a] condom. Except if we agree to do it without [a] condom during our negotiation downstairs. If not, they cannot force us to do it. If we don't want to do it with them they cannot force us. [Dina, age 35]

While Dina is confident in her ability to decline customers that refuse condoms once in a private setting, that was not the case with all participants. Challenges to the negotiation process that resulted in unprotected sex were reported in several situations.

First, a minority of women described asking for substantially higher payments from customers in exchange for not using condoms. Sabrina describes this, saying: "Normally if I

want to get extra money from them I allow it...I test the customer, okay, if you want to pay RM 300 or you pay me more than RM 150 I allow you to ejaculate inside me."

Second, FSW reported being more likely to agree to sex without a condom when financially strained:

If it is an emergency, I don't have any money at all, because I have problems getting customers now. It is challenging for us to get even one customer, so I have no choice and take it. I am aware of the risk but I can only hope for the best. [Sofea, Age 35]

Third, secondary negotiations regularly take place in private spaces that diminished FSW control and can contribute to violence. Nadia [age 41] talks about an experience of sexual violence due to a custom refusing to wear a condom:

I think I went through that once...not once but it does occur a few time. This type of people who refuse to wear condom, get mad and do all this. Sometimes I feel scared to go to their place especially if the place is deserted. So I cry if I feel unsafe and I will reject the customers offer. If they still want it and force me until at some point I be terrified, I will do it with him but that will be the first and last time...I will not take him again, I recognize the guy. I will not accept his offer again because he scares me.

The challenges with condoms discussed in this section, specifically breaks or leaks and ineffective condom negotiations due to financial incentive, financial constraint, or violence, highlight the large issues FSW face when trying to protect themselves from HIV. PrEP has the potential to enable FSW to protect themselves when other efforts fail, and FSW reactions to PrEP are most likely informed by their awareness of the shortcomings of condoms, their sole HIV prevention tool. The next three sections elaborate on FSW responses to PrEP, starting with their positive reactions and interest, followed by the barriers they perceive to using PrEP.

"For the safety of our health": PrEP for Preserving Health

Of the 30 women interviewed, none had previously heard of PrEP. Reactions were positive on the whole. The majority of participants (90%) responded that they would be willing

to take PrEP if it were offered to them as a daily pill. This high interest rate was also reflected in participant statements during interviews. Most participants reported viewing PrEP positively because it provides a way to proactively prevent HIV:

If you ask my opinion, I don't mind to take the [PrEP] medicine because it is used to prevent the disease. If people want to say anything I can tell them that this is for prevention, I don't want to wait until I get the disease, then it will be too late. [Nisa, Age 30]

Participants expressed willingness to spend their own money on PrEP because of the perceived preventative benefit. Dinny [age 19] states: "This is for prevention, and I am worried [about HIV], so I will try to buy it." Aditih [age 48] describes how much she would pay for PrEP, saying:

If you have to buy the medicine for the safety of our health, then we do not have any choice but to buy it. No two ways about it at all. Rather than we spend so much of money for HIV, RM 300 [a participant generated cost equivalent to \$81 USD] is nothing. I will buy [it] for myself and take the medications.

Others expressed interest in PrEP because it served as a way to protect FSW when they forgot condoms while high:

I think those injection drug addicts should take this PrEP medication because they are high risk to get the [HIV] disease. Those sex workers who didn't use condom are in high-risk group as well but most of us know about this. So we use condom when we have protected sex. But sometimes if we are high with drug we will forget to wear condom right? [Nur, Age 48]

Positive reactions to PrEP were not limited to preserving the health of participants themselves. Participants also expressed willingness to share information about PrEP to others, particularly friends or partners who were high-risk of contracting HIV. Husna [age 26] describes her willingness to share PrEP for the good of others, saying: "Of course I will recommend it [PrEP] to my friends because it will bring goodness to them." This desire to share knowledge of

PrEP with others is not all encompassing, but specifically related to individuals that FSW trust. Sabrina explains how she would determine who to tell about PrEP:

If like my friend come to my room, my friend that know about my [sex] work, so it is ok with me [to share information about PrEP]. But let say if my family or my children they didn't know about this and suddenly they find a box with HIV on it, they will think differently right? [Sabrina, Age41]

"I will still use a condom": PrEP as a Supplement to Condoms rather than a Replacement

While participants expressed enthusiasm about PrEP, their narratives also revealed that they viewed it as a supplement to, rather than a replacement of, condoms. In several interviews women rejected PrEP initially if they thought it required them to give up condoms. Researchers framed PrEP as something that should be used with condoms, but these types of reactions happened anyway. In the survey, 83% of participants reported still being willing to take PrEP even if they had to continue using condoms.

Participants described comfort with condom use and the routines that integrated condom negotiations within the process of price and service negotiation that was already in place. When relating condom negotiation practices to PrEP, Farah [age 20] reports how use of PrEP would provide her with extra protection but would not change her existing condom negotiation routine:

If I take this medicine I will still use a condom. I will not use a condom only with the regular customer because I already make a deal with them by saying that it is alright for them to not wear it. But if I can wear it, I will use it even if I take this medicine so it can give me double protection.

Others describe how using PrEP would serve as a backup for preventing HIV when customers refuse to wear condoms:

But it is better if I take this medicine...and my customers still wear it [condom]...Its not like if I take this medicine and I have 10 customers, all 10 of them will not wear condom...If I have 10 customers, [and] 1 or 2 refuse to wear [a condom], then I am not that worried...because I have this medicine. [Dina, Age 35]

The idea of not using condoms while taking PrEP was viewed as concerning or unsafe. Sabrina expresses her hesitation to take PrEP this way: "But I am not comfortable, not confident [with PrEP]...I have more confidence in using a condom." Sabrina confidence in condoms but not PrEP might be related to the physical barrier it provides. Others reiterated this fear of not being protected by PrEP alone, stating:

If I don't wear it [a condom] I will feel like I still can get infected, even if I am on that medication [PrEP]...I am worried so I have to wear it. Even if I take the medicine. No I still need to use it. [Nadia, Age 41]

If I wear condom and took this medicine as well it will give me double protection. I have to take care of both. If you just take this medicine but you did not wear condom, everything can come in, I feel insecure. If I took both, condom and the medicine I feel safer. [Dina, Age 35]

I don't know but if we don't wear it what if he has syphilis? We don't know that. So we have to wear it, whatever happens, we have to wear it. [Angel, Age 35]

A minority of those interested in PrEP were interested in the opportunity to forgo condoms with customers. Aditih talks about her perspective on condoms and PrEP:

I [will] feel secure because I am taking the [PrEP] medication. Moreover my customers will be happy they don't need to use condoms. So the sex workers will be happy to take this medication as their customers do not need any condoms. In whatever way you see women being protected, that is the main thing.

#### Challenges to PrEP Implementation

Several important challenges emerged around PrEP implementation: cost, adherence, fear of side effects, and disinterest. Many participants expressed concern about how much PrEP would cost and how they would pay for it. Sania [age 48] put these concerns perfectly saying: "I listen about this but [I think] it is so expensive. If the sex workers can afford this, they can take it. If the sex worker cannot afford they cannot take it." The majority of participants asked the researchers for the price. An FSW named Hur [age 33] describes how important the cost would be to her decision to take the drug saying:

I have to see the price first and compare it. If I can afford it I will buy. But if I cannot afford it if the price is more than RM500 [approximately \$135 USD], how can I purchase the medicine [if it costs that much]?

Since PrEP was not available in Malaysia at the time of interviews, we were unable to provide participants with a cost. When asked how much they could afford most FSW cited not being able to pay very much:

I can afford it if it is about RM10, if it is more that that I don't want it (laugh). I cannot afford it. People like me cannot afford to buy this kind of thing. It's expensive, if the price is RM50, I consider it to be expensive. [Nadia, Age 41]

In US dollars, 10RM is equivalent to only \$2.70. The average income of participants in this study was equivalent to \$430 per month, but ranged from a low of \$74 to a high of \$2200. Other FSW reported being able to afford a bit more than Nadia, but those willing to pay more also reported higher incomes from sex work.

Issues related to adherence also emerged. Some FSW compared adherence to PrEP to taking other medications. Shelly [age 37] put it this way: "I need to take my medicine for my blood pressure. So if I can take the medication for high blood pressure, why can't I take this?" Husna [age 26] compares it to her regularity of having a cigarette: "If we can remember to take our cigarette of course we can remember to take this medicine." And yet, she also discusses the challenge of establishing routines within the context of her lifestyle, reflecting:

So that means I take it at the same time every day, like that? To remember that I should take it every day is quite challenging. I can take it every day but I am worried that I forget to take it. Because we don't have a fixed schedule, right? I sleep at anytime.

Other participants also shared Husna's concern about the impact of her irregular routine on taking PrEP. Establishing a routine to take medications was something Nur [age 48] reported struggling with previously:

I am worried that I cannot take it on time. Because I have problems taking my medicine on time. I take it after lunch, or at early in the morning. I didn't take it on time. So to be disciplined in taking the medicine on time is a problem for me.

Adherence and uptake were also linked for some participants. After being told about PrEP, Sami expressed her concern about forgetting to take the pill daily by comparing it to her past issues with taking drugs during pregnancy:

Oh no, I am going to die. It's quite hard for me to take medicine. I am sensitive about medicine. When I was pregnant I don't take any medicine. They gave me a lot of medicine during my pregnancy but I didn't take any of them. [Sami, Age 39]

The third primary concern for FSW was side effects of the drug. Dina put her concerns this way: "If it has any side effects I will think first before I take it. What kind of side effects, right?" Many participants did not independently report this type of concern and when asked directly about side effects, many answered yes but struggled to elaborate why.

Lastly, in a few interviews, participants made it clear that they were not interested in taking PrEP for a variety of reasons, including a desire to exit sex work, reduced risk perception, or fear of medicine. Participants described their unwillingness to take PrEP this way:

I want to quite my job. I don't want to eat this, I don't. People who work everyday might be interested. If they work everyday they can eat this. [Shivani, age 57]

Old people like us...we don't want to take any medicine. So we have to pass [information] to the younger girls. [Sarah, age 55]

No, I don't want to [take PrEP], I'm scared of seeing these medicines. [Seema, age 65] These quotations highlight how lowered risk perception or juggling of risk perception with other considerations, may impact acceptability of PrEP, particularly among older FSW.

#### **DISCUSSION:**

If we wish to effectively address the generalizing HIV epidemic and high HIV prevalence among FSW in Malaysia, it is essential that we understand the potential barriers and facilitators

to PrEP (21, 23). This research frames FSW acceptability of PrEP within the context of participant perceptions of HIV risk and experiences with condoms. This research adds several things to the literature. It is the first qualitative study utilizing individual in-depth interviews to explore PrEP acceptability among FSW, providing a richer perspective on PrEP acceptability than previous research. It is also the first research on PrEP acceptability in Asia.

Unanticipated findings included the importance of condoms in current negotiation practices of FSW, as well as FSW preference for PrEP as a supplement to condoms, not a replacement. These reactions can be linked to FSW experiences with HIV and condoms to illuminate the underlying drivers of FSW interest in PrEP (Figure 1). Notions of PrEP for preserving health reflect the high-risk perception FSW have of acquiring HIV. FSW view HIV as a life-threatening disease that constantly looms over their interactions with clients. Uncertainty about HIV transmission and treatment reinforces and intensifies these fears. These perceptions reflect the reality of late diagnosis and inadequate HIV treatment coverage in Malaysia. PrEP for preserving health is also driven by FSW awareness of the shortcomings of condoms.

Additionally, FSW desire for condom use in combination with PrEP is related to the established HIV prevention routines and practices of this population. Condoms serve as instrument for FSW to assert themselves with clients during the transaction process preceding services. These activities have become ingrained in how FSW deal with clients. FSW also perceived condoms as clean, physical barriers between themselves and clients. FSW reactions to PrEP are mediated by these factors, and the potential value of PrEP does not, for most women, negate the values and necessity of condoms. These findings highlight the complexity that informs acceptability of PrEP in this population.

This study also has limitations. First, all but two participants were recruited via local NGOs. This type of recruitment may have resulted in participants with increased awareness of HIV, access to condoms, and HIV testing due to their interactions with these NGOs, making them different from the general FSW population in Malaysia. Second, as HIV status was not asked for we unsure whether participants would have been eligible to take PrEP.

#### Conclusions and Recommendations

While PrEP is now legal in Malaysia, there are currently no subsidies for the cost. Participants voiced willingness to pay something for PrEP, but PrEP would still need to be subsidized by the Malaysian government in order to be affordable for FSW.

Adherence is a primary concern with PrEP, as low adherence impacts effectiveness (5). This data demonstrates that this population has prior experience taking drugs and is able to draw parallels between their experiences with other drugs and PrEP. Regardless, this population is prone to housing and financial instability and coaching on adherence needs to assistant individuals with developing and maintaining routines despite irregularities in their daily activities.

Behavioral disinhibition, or the discontinued use of condoms following the introduction of PrEP, is often raised as a concern (5). The results of this study support other PrEP acceptability research suggesting that this may be less applicable among FSW (16, 17). There is ongoing support for integrating PrEP with behavioral prevention methods(1, 11). These findings strengthens those suggestions by demonstrating that FSW prefer PrEP in combination with condoms. Therefore, a successful PrEP intervention must build upon the condom promotion activities already in place in the country.

High participant buy-in and willingness to share information about PrEP with others, particularly with other high-risk individuals or follow sex workers, suggests the importance of a peer-driven model. Implementation of PrEP should build upon FSW trust in their social network by mobilizing and training local NGO outreach staff and peer on PrEP and routine building.

It is important to acknowledge the importance of social status, power, control, and education in the demand for PrEP. The challenges FSW face in their condom negotiations reflects the local context. When compared to FSW in Britain, who are not criminalized, health issues are perceived as less important and FSW face less challenges with safe work spaces, violence, and control over interactions with clients (20). PrEP fills a gap in Malaysia's HIV prevention efforts, especially for women. Combination HIV prevention efforts should incorporate FSW empowerment as a component of harm reduction (3, 11, 33).

Lastly, while this research has added to our understanding of PrEP acceptability, any scale of PrEP should endeavor to assess whether this acceptability is linked to product adherence by embedding an acceptability study into a PrEP clinical trial (19).

Overall, this research has demonstrated that PrEP acceptability in this population is driven by circumstantial need for additional methods of protection for HIV. PrEP should be implemented in combination with condom promotion efforts among FSW in Malaysia.

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### **TABLES AND FIGURES:**

Table I. Description of the Sample (n=30)

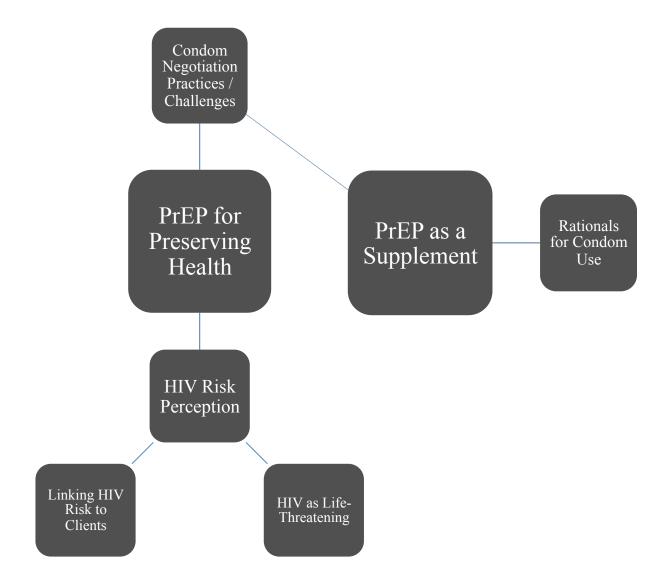
Characteristic			
	N (%)		
Age (years), mean ± SD	$37.8 \pm 11.2$		
Education Completed	11 (25)		
Primary or less	11 (37)		
Form 1-4	11 (37)		
Form 5 / Holding SMP	8 (27)		
Holding STPM or above	0		
Ever Arrested	23 (77)		
Depression <sup>+</sup>	20 (67)		
Physical or Sexual Violence in the past 12 mo.	13 (43)		
Ever Use of Select Drugs°			
Alcohol	20 (67)		
Heroin	3 (10)		
Methamphetamine	20 (67)		
Race/ethnicity			
Malay	17 (57)		
Chinese	1(3)		
Indian	8 (27)		
Other	4(13)		
Sex Work Employment	( - /		
Full-time	15 (50)		
Part-time	13 (43)		
Periodic	2 (7)		
Type of Sex Work°	_ (.)		
Street Based	18 (60)		
Internet	2 (7)		
Phone/Phone Aps	18 (60)		
Pimp/Mamasan	5 (17)		
Average Monthly Income (MYR), mean $\pm$ SD <sup>†</sup>	$1665.00 \pm 1754.66$		
Relationship status	1002.00 = 172 1.00		
Single	11 (37)		
Married/Partner	9 (30)		
Separated/Divorced/Widowed	10 (33)		
Preferences for Seeking Health Care°	10 (33)		
Government Clinic	19 (79)		
Private Clinic	15 (63)		
	* *		
Government Hospital	21 (88)		
Private Hospital NGO	16 (67)		
	16 (67)		
Pharmacy  Physical Even in part 12 ma	16 (67)		
Physical Exam in past 12 mo.	12 (40)		

<sup>\*</sup>CES-D 10 Screen
\*Will not total to 100% because multiple response

Table II. PrEP Acceptability (n=30)

Characteristic	YES N (%)	NO N (%)	MAYBE N (%)
If PrEP were made available as one pill a day to prevent you from becoming infected with HIV, would you take it?	27 (90)	2 (7)	1 (3)
Would you take PrEP even if you have to use condoms?	24 (83)	2 (7)	3 (10)
Would you take PrEP if you needed to be tested once every 6 months for HIV?	28 (97)	1 (3)	0
Would you want your sexual partner(s) to know if you were taking PrEP?	23 (79)	3 (10)	3 (10)

Figure 1.



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