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## Structural and Interpersonal Benefits and Risks of Participation in HIV Research: Perspectives of Female Sex Workers in Guatemala

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### Abstract

This study explored perceived benefits and risks of participation in HIV research among 33 female sex workers in Tecun Uman, Guatemala. Stigma associated with sex work and HIV was a critical barrier to research participation. Key benefits of participation included access to HIV/STI prevention and testing, as well as positive and trusting relationships between sex workers and research teams. Control exerted by managers had mixed influences on perceived research risks and benefits. Results underscore the critical need for HIV investigators to develop population-tailored procedures to reduce stigma, engage managers, and reinforce trusting, reciprocal relationships between sex work communities and researchers.

### Keywords

Sex workers; ethics; research participation; HIV; stigma; trust; Central America

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## Introduction

Over 20 years into the HIV epidemic, female sex workers (FSWs) remain disproportionately impacted by HIV and sexually transmitted infections (STIs) (Baral et al., 2012), and continue to face substantial structural barriers to HIV prevention, treatment, and care (Shannon & Csete, 2010; Shannon, Goldenberg, Deering, & Strathdee, 2014). Although HIV research with sex workers remains crucial to inform prevention, research with stigmatized and criminalized populations such as sex workers often raises ethical challenges, which remain poorly understood in many contexts.

Studies of research ethics conducted amongst FSWs in Asia (Reed, Khoshnood, Blankenship, & Fisher, 2014; Urada & Simmons, 2014) and people who use drugs in the U.S. (Davidson & Page, 2012; Fisher, 2011) demonstrate the importance of gathering participant perspectives to inform ethically sound HIV research. The decision to participate in HIV-related research often hinges upon perceived research benefits, which may include anticipated health benefits, financial compensation, or a desire to contribute to improved policy and scientific knowledge (Davidson & Page, 2012; Fisher, 2011; Oransky, Fisher, Mahadevan, & Singer, 2009; Reed et al., 2014). For key populations, perceived risks may include social and structural consequences (e.g., fears of stigma, legal implications of reporting illicit behaviors) and interpersonal risks, such as disrespectful treatment, confidentiality breaches, and privacy concerns (Oransky et al., 2009; Reed et al., 2014; Urada & Simmons, 2014). While this literature provides insights into ethically-relevant aspects of research with marginalized populations, few studies have addressed ethical issues pertaining to HIV-related research with sex workers outside of Asia. Moreover, prior studies of ethics in sex work research have often focused on clinical trials (Ditmore & Allman, 2011; Shagi et al., 2008) or have not been specific to HIV-related studies (Agustín, 2004; Shaver, 2005).

In Central America, a region highly impacted by high prevalence of HIV and barriers to care among key populations, including sex workers, HIV surveillance and research have increased in recent years, indicating a need for study into ethical issues related to this work (Miller, Buckingham, Sánchez-Domínguez, Morales-Miranda, & Paz-Bailey, 2013; Sabido et al., 2012; Shah et al., 2014; Tinajeros et al., 2012). In Guatemala, HIV is concentrated among key populations, including sex workers (Joint United Nations Programme on HIV/AIDS, 2013). Situated along the main entryway from Central America into Mexico, the Guatemalan community of Tecún Umán is characterized by intense population mobility and hosts a thriving sex industry in venues including bars, plazas, hotels, and truck stops. Whereas sex work is criminalized in Guatemala, it is regulated by public health regulations in certain municipalities – including Tecún Umán – which require that sex workers register and receive periodic HIV/STI testing at municipal clinics (Rocha-Jiménez, Brouwer, Morales-Miranda, Silverman, & Goldenberg, Under review). Generally speaking, sex work performed by adult women who comply with these regulations and transacted in formal establishments, such as bars or nightclubs, is tolerated. However, FSWs in informal settings (e.g., street, truck stops) often work without registration (Rocha-Jiménez et al., Under review). Sex workers in this region face immense risk of violence—Guatemala has one of the highest murder rates in the world, and violence is common along the northern border with

Mexico. In light of the immense risks experienced by FSWs in this context, there remains a critical need for epidemiological and intervention research to understand and address the HIV/STI-related vulnerabilities they face. In 2011, our team initiated a new program of collaborative research on migration, sex work, and sexual health along the Mexico-Guatemala border. The current study was conducted to gather data to inform enhanced ethical procedures for this program and future HIV research involving sex workers. In this analysis, we explore the perceived risks and benefits of participation in HIV-related research among FSWs in Tecún Umán, Guatemala.

## Methods

From June 2013–February 2014, we conducted focus groups and in-depth interviews with 33 FSWs in Tecún Umán, Guatemala. Eligible participants were females 18 years old who reported exchanging sex for money, drugs, shelter or goods in the past month, spoke Spanish, and were able to provide informed consent.

### Ethical considerations

The study was approved by IRBs at the University of California San Diego and the Ministry of Public Health and Social Assistance in Guatemala. All women provided written informed consent prior to participation. Informed consent procedures were designed to maximize women's comprehension of procedures and to ensure voluntary participation. Fluent Spanish speakers guided potential participants through the informed consent process (i.e., by highlighting key points and/or reading the informed consent form), explaining the study purpose, procedures, and risks and benefits. The principal investigator, and/or project coordinator were onsite to answer questions raised by potential participants. A Community Advisory Board (CAB) of five local organizations representing sex workers, HIV prevention organizations, the municipal clinic, and women's organizations guided the study. The CAB met prior to and following data collection to provide input on procedures, data collection instruments, interpretation of findings, and dissemination.

### Data collection procedures

Women were recruited from sex work venues such as bars, hotels, street corners, and truck stops. Guided by purposive sampling (Strauss & Corbin, 1998), we sought to recruit women representing a range of research participation experiences (e.g., research-exposed/research-naïve), work venues (e.g., indoor/outdoor), and age. Participants were recruited during outreach by trained outreach workers from an HIV prevention organization (EDUCAVIDA) which serves FSWs and other key populations. During outreach, staff unobtrusively approached women to explain the purpose of the study, ascertaining eligibility and interest in participating.

Following informed consent, women completed a brief socio-demographic survey. Focus groups and interviews were audiotaped and conducted in private offices or a location of women's choosing (i.e., settings identified as safe/private spaces where they could share their perspectives). All women received \$10 USD in in-kind goods (e.g., telephone card or

household/personal items of their choosing), condoms, HIV/STI prevention information, and referrals.

We conducted ten focus groups with FSWs who felt comfortable participating in a group session ( $n=27$ ); between 2-5 women participated in each group. Focus groups were led by a moderator who introduced topics and monitored group dynamics to facilitate representation of different perspectives (Morgan, 1988), using group interactions to generate insights (Angen, 2000). Individual, face-to-face interviews were conducted with participants who preferred to share their opinions privately ( $n=6$ ). Focus groups and interviews were based upon a loosely structured guide that was iteratively revised to explore emergent themes.

Focus groups and interviews began with defining research. These discussions emphasized examples of HIV research typically conducted with FSWs in Tecún Umán. As most prior research with FSWs in this community has been epidemiological (e.g., quantitative survey coupled with HIV/STI testing), the discussion primarily focused on epidemiological, non-intervention research. Participants were asked to share examples of HIV research they were aware of (or previously participated in); facilitators clarified and explained the differences between research and HIV/STI services (e.g., testing, educational workshops) to address challenges in operationalizing the concept of 'research.' These challenges often arose as a result of women's limited exposure to research and formal education, as well as the fact that epidemiological studies are often conducted at the municipal clinic where HIV/STI care is provided.

During focus groups and interviews, women were asked about their main reasons for participation in HIV-related research (e.g., to learn about HIV, recommended by a peer/manager), barriers to participation (e.g., confidentiality, mistrust) and related contextual influences (e.g., work environments, manager and peer roles). Discussions of recruitment tactics and confidentiality protections were based on strategies employed in recent studies locally (e.g., recruitment via outreach by HIV prevention organizations). Participants were asked to provide recommendations for future research, including recruitment locations and researcher roles; for example, we probed regarding different possible recruitment and interview scenarios (e.g., the potential for managers, peers, or medical staff to act as recruiters or interviewers).

In addition to initial focus groups and interviews, three follow-up sessions (two focus groups and one interview) were conducted with a subset of participants ( $n=7$ ). These participants were selected as they had expressed diverse and/or strong opinions during initial focus groups or interviews. Follow-up sessions provided opportunities for deeper exploration and elaboration of concepts, as well as to gather women's feedback on preliminary findings and their interpretation (i.e., "member-checking").

### Data analysis

Focus groups and interviews were transcribed and translated verbatim by bilingual staff. The transcripts were checked for accuracy by the bilingual project coordinator, and personal identifiers were removed. Transcripts were coded in NVivo 10 (QSR, Australia). Coding was based on a detailed scheme collaboratively designed by the principal investigator and project

coordinator. Using the constant comparative method (Crabtree & Miller, 1999), open coding was used to inductively generate an initial coding scheme which described the main structure and themes in the data. Codes were revised and regrouped to identify key perceived benefits and risks related to participation in HIV research. A codebook and an audit trail were maintained to track analytic decisions. Descriptive statistics were calculated to describe participant characteristics.

## Results

### Participant Characteristics

Table 1 summarizes socio-demographic characteristics of the 33 participants. The average age was 29 and 72.7% had primary school education or less. Most participants ( $n=24$ ) were of Guatemalan nationality; the remainder were from elsewhere in Central America ( $n=7$ ) or Mexico ( $n=2$ ). Two-thirds of FSWs ( $n=22$ ) engaged in sex work exclusively in entertainment venues, whereas one-third ( $n=11$ ) serviced clients in trucks, parks, and hotels/motels and identified as independent/mobile FSWs. Table 2 summarizes participants' prior research experience. Twenty FSWs had previously participated in research, with an average time of 5 month since last participating in a study.

### Qualitative Research Findings: Overview

Fear of public disclosure related to sex work and HIV stigma was an overarching concern in women's lives, which often posed risks and barriers to research participation, particularly for mobile/independent FSWs. Key benefits of research participation included access to HIV/STI testing and prevention, as well as trusting and positive relationships with research staff. Control exerted by managers in indoor establishments was a mixed influence that could either promote or constrain research participation.

### Fear of Sex Work and HIV-related Stigma as Research Risks

Multiple and intersecting forms of sex work and HIV-related stigma and shame were described by participants as key concerns, often related to perceived risks and barriers to research engagement. This included both internalized stigma, as well as fears of community stigma related to disclosure of one's sex work involvement or HIV status.

**Internalized stigma**—Many FSWs discussed internalized stigma associated with feeling morally conflicted about their involvement in sex work. Most participants had children, and while on the one hand, they felt that their work was justified by their need to support children, they also felt ashamed for being involved in what was widely perceived as immoral work. As one participant put it,

We don't want to accept it...because quite frankly for me, I have sex in exchange for money, right? And that would be a mistake. Another error would be that my children die of hunger...so, that's the thing, and we don't accept it...yes, the women [act] very honorable...but that's not how things are.

[In-depth interview (IDI), research-exposed, age 39]

Internalized stigma and shame often translated into denial or fear of disclosing or discussing one's sex work involvement. These concerns were most strongly expressed by mobile/independent FSWs ( $n=11$ ), who often operate discreetly across informal locations (e.g., parks, vehicles, motels). Many had partners or children living in the community, from whom they attempted to conceal their sex work. As one mobile/independent sex worker explained, "It is not the same to be a closeted prostitute and one who practices openly...I have two different roles. I'm a sex worker and a housewife."

Fears regarding sex work disclosure posed important barriers to research participation, especially for mobile/independent FSWs. When asked about the reasons that sex workers might decline participation in a study, participants explained:

[Sex workers] sometimes don't accept their reality...because of shame, others because of pride, and others because they don't even understand why, because honestly, what's the first thing they say? "Oh no! I'm not a whore!" [laughs] They say that, right? But then it's obvious.

[Focus group (FG), research-exposed, age 20]

Sometimes we don't want to come because we know in what situations we're in, right? So, we think that if we come here, they can accuse us [of sex work involvement].

[FG, research-naïve, age 28]

**Community stigma**—Fear of community stigma if others became aware that they were participating in a study about sex work emerged as a key perceived social risk of research engagement. The following quote represents a common sentiment:

Q: Why do you think they [other sex workers] chose not to participate?

A: I think it must be fear or the thought "what will people say of me?"

[FG, research-exposed, age 30]

Internalized and community stigma related to sex work interacted with and were exacerbated by stigma associated with one's HIV status or disclosure of risk behaviors. Both mobile/independent and establishment-based FSWs described how stigma related to both HIV and sex work could negatively affect their capacity to participate in research and other opportunities (e.g., educational workshops, testing) they deemed important for their health:

The embarrassment is the worst enemy of women, quite frankly. Because they say, how embarrassing it is to tell other people...they fear being singled out by society...they fear that the husband may find out. They fear being HIV positive or carriers of a disease. Those are the three fears that kill women.

[IDI, research-exposed, age 39]

Nobody accepts that they are – that we are – doing this type of work...we had a case here [in which a peer didn't want to identify as a FSW]. [They feel] shame to accept themselves, that they might be infected with diseases, and about working like this...one is afraid to open up...All that must be focused on.

[FG, research-exposed, age 48]

The impact of these multiple and overlapping forms of stigma on research participation were also articulated by women who had not previously participated in research, as exemplified by the following discussion:

Q: Why do you think that some women don't want to participate?

P2: ...Some women may say, "No, I'm not going, because they're going to know what we do [sex work], they look at us in the streets and they'll know what we do" ...That's why many women don't like to come.

Q: So, would it be because of fear?

P2: Aha, because of fear...

P1: Fear that they might be sick.

P2: Because of shame.

P1: The fear that they might be sick and because they're afraid [of their HIV status] and don't want others to know.

[FG, research-naïve, ages 21 and 18]

Investigators may erroneously assume that FSWs are less sensitive than other populations to detailed questions regarding sexual behavior. However, consistent with a recent study (Urada & Simmons, 2014), women expressed concerns about being asked questions regarding more sensitive HIV risk behaviors (e.g., oral or anal sex), fearing that they might be negatively evaluated by the research team members.

We aren't so open to say the truth...if you ask if I have oral sex, I feel ashamed that she'll [interviewer] know that I do that, so I don't say it. Ah, that you have had sex in...other parts [anal sex], I feel ashamed and I'll say no...there are girls, including myself, that feel ashamed to say those things, [or think] if I end up with an illness, what are they going to say?...So because of that aspect, others don't participate. I think that it's because of the shame they feel.

[FG, research-exposed, age 39]

**Concerns about research sites**—In light of concerns regarding stigma associated with community knowledge of research participation, participants suggested that research locations be selected to minimize stigma and protect privacy. Attending the municipal clinic, which offers specific hours for FSWs to receive HIV/STI testing, was perceived by mobile/independent women as a significant threat of identification as a sex worker. Many participants pointed out instances in which they had felt stigmatized or embarrassed to seek care at the municipal clinic for this reason. As one woman summarized a common barrier to clinic attendance, "We're ashamed about what people may say and how they point at us. Because there are many people that discriminate in that way." As a result of such stigma and discrimination, women suggested that research be conducted in discreet locations such as local NGO offices, where their identities and occupation could be better safeguarded.



The health center is too public...a lot of other people go there, and sometimes we may say, 'Ah, but they're going to see me'...But, if you see here [NGO office], anybody can come. The first thing to pay attention to is the paranoia and to look everywhere to see who's over there watching...I do think that at the health center you may feel a little bit embarrassed. That's the problem, because since the county here is very small, everybody knows everybody.

[IDI, research-exposed, age 39]

### **“We Have to Protect Ourselves”: HIV/STI Testing and Prevention as Research Benefits**

Participants unanimously perceived their participation in HIV research as offering key benefits for their health. Being in good health (especially knowing one's HIV status) was a top concern for all women. As one participant shared, “Our health is the most important thing and we need to be informed about everything.” Reasons for participating in research often centered around health priorities, especially the desire to protect oneself and one's family members from the threat of HIV:

Q: What are the main reasons that made you participate in a research study?

P: To know more about the diseases...we learn more and we can raise our children to [have] a better future.

[IDI, research-exposed, age 28]

Why does one participate in the studies?...Well, how am I not going to be interested...I'm a sex worker [and] it's not just the HIV; they also test for other diseases beyond the HIV...The same way I care about my health, I care about the well-being of my children.

[IDI, research-exposed, age 39]

[It's important to participate] because that way we're aware of our health and keep track of it. We're at risk in this business, because a condom can break and we don't know how those people are [in terms of their health].

[IDI, research-exposed, age 32]

**HIV testing and prevention**—Main health benefits of participation in epidemiological HIV studies were said to include free access to HIV/STI testing (including pre- and post-test counseling) and prevention (e.g., condom demonstrations and negotiation skills). Although HIV/STI testing is offered free of charge at municipal clinics, social and structural factors such as mandatory registration as a sex worker, stigma, stock-outs of supplies, personnel shortages, long waits, and limited hours posed barriers to access. For example, we learned of recent occasions in which shortages in staff and supplies had restricted access to HIV testing, and mobile/independent workers frequently discussed stigma as a barrier to accessing care. As a result of these barriers, women who had previously participated in epidemiological studies that provided HIV/STI testing perceived access to testing as a highly valued benefit of participation:

We get free counseling and we get tested...That's the benefit we receive...so I feel good about participating in all those HIV studies...for me, it's important.

[FG, research-exposed, age 26]

The [HIV/STI] tests are expensive, but in that [study] is an opportunity where they are free.

[FG, research-exposed, age 35]

**Health education**—In addition to testing, participants unanimously felt that participating in HIV research would impart key knowledge regarding their health and HIV/STI prevention information that could better equip them to protect their health:

In fact that's why I've participated so much in testing and research studies and, what are they called? Surveys. Because, honestly [it was] to have a greater security [regarding one's health], right?

[FG, research-exposed, age 39]

It [research participation]'s something good, because one is looking at her own health, how one is doing, and that orients us...for example, there are diseases that are unknown to us...in this case I've never participated in this, but that's why I'm here.

[IDI, research-naïve, age 30]

Q: Why do you think women participate in these studies about HIV?

P2: It would be because women like to know more about...what they're living in this life [sex work]. It's mostly about the diseases...because there are many men who tell you, 'look, I pay this much, so let's do it like this [without a condom].'

[FG, research-naïve, age 21]

**HIV testing: A double edged sword**—Some women's perceptions of research participation depended on the outcome of their HIV/STI test results. As one woman put it, "If a woman participates in those [studies], it's to find out if she's sick or not. So, if she's not sick, [she can] be extra careful and prevent all types of illnesses, that's why." Participant narratives pertaining to HIV/STI testing suggested that providing testing could act as both a barrier and a facilitator of research engagement (Oransky et al., 2009). Whereas getting tested was often perceived to be a benefit, this also provoked fears regarding the consequences of learning one's HIV status:

It's fear of the test results...One of the women said, 'Ah, if they tell me I'm HIV positive, I will take a pill with poison.' Another [sex worker] said, 'I'd ask my brother to shoot me.'...what they may say [about you] afterwards, that's what's worrisome. I remember many years ago, I did the HIV test and I went super nervous; my hands were sweating and my God, I was praying...Those tests never stop giving us fear.

[IDI, research-exposed, age 39]

### “There's a lot of Trust”: Relationality and Positive Researcher-Participant Relationships

The extent to which sex workers were able to access and benefit from research appeared to greatly depend on the nature of their interactions with research team members. Consistent with previous work in other countries, participants greatly valued their relationships with research staff whom they perceived as knowledgeable, trustworthy, and caring (Reed et al., 2014; Urada & Simmons, 2014). They highlighted the ways that these relationships influenced their engagement with research, which was related to the ethical concept of relationality (Fisher, 2011). For example, maintaining trusting, open relationships with research staff allowed women to share personal information and solicit advice within the context of research participation in a way that they were unable to do within their own social networks:

There is trust already... We have a lot of trust in you over anyone else. I'm not going to share these things with a friend.

[FG, research-exposed, age 30]

We can talk to you... trust is something you acquire when you open the door to others, just as you're doing with us. At least you listen; you won't judge us, that's how trust is acquired... You come smiling, greeting, that's nice. We're motivated to come.

[FG, research-naïve, age 23]

You help us a lot because we mostly don't talk to other workers... we find consolation in talking to someone [else].

[FG, research-naïve, age 23]

**Providing a safe space to talk**—Research participation was often perceived as a critical opportunity to discuss one's concerns in a safe, non-judgmental environment, which was important given the risky working conditions and limited social support most women faced. Many participants described the benefits of rapport that was cultivated when research staff expressed care for their well-being – for example, by expressing concern about their health, or by offering to accompany them to doctors' offices or hospitals. These interactions were perceived as not only promoting research engagement, but also as helping to reduce stigma and promote health. Participants in the following group shared how positive and non-judgmental interactions with staff had facilitated their research participation and encouraged them to safeguard their health:

Q: What do you think these studies are useful for?

P1: ...To start talking about our health. Another thing, because of the life we have... we don't even think that people will worry about us... ninety-five percent of people who don't have the life we do discriminate [against sex workers]. But, I found out that there was an association like this one... to see our cases, to start worrying about our lives as prostitutes... you look after our wellbeing.

P4: ...I've been invited to participate... I've thought to myself, [I should go] because it's good what they are doing... if I go out sometimes, say, to get a [HIV/STI] test

done, I might say, “ah, it takes too much time.” But if others worry about us, aren't we also going to worry about ourselves?

[FG, research-exposed, ages 30 and 39]

**Staff competence and consistency**—The expertise, familiarity, and community experience of research staff was central in determining the extent to which FSWs would feel comfortable divulging sensitive information or agreeing to participate in research. Women were much more comfortable participating in projects in which they were recruited and interviewed by individuals with deep community experience, such as staff from trusted, local organizations who were knowledgeable about the issues sex workers face.

I would like to know the persons I'm going to open up with. I want to know you're from a group like this one [EDUCAVIDA]. I wouldn't open up to just any person, I wouldn't trust just anyone...we already know you; that would make me feel better.

[FG, research-naïve, age 24]

I was invited by some people who are experts in the topic, so one feels good...if you receive the invitation from another person who isn't in this environment, I wouldn't accept.

[FG, research-exposed, age 39]

We know you and we can talk to you because you're someone who has experience.

[FG, research-naïve, age 23]

Many sex workers discussed how they would feel better assured that their information would be kept confidential by only being interviewed by trustworthy, familiar individuals:

They're afraid of the confidentiality, right? That's number one, because honestly... we're afraid that everything can spread somehow, these things. If I was interviewed by a person I didn't know, I'd be somewhat cold because I don't trust this person... And if I kind of knew her, what if this person betrayed me?

[FG, research-exposed, age 39]

Consistency and respectful treatment by research staff were particularly critical. Women with prior research experience described the establishment of longer-term relationships between research staff and sex workers as a powerful motivator for research participation. Consistent, familiar, and trusting interactions with research team members were said to mitigate fears of stigmatization or confidentiality concerns that could arise during recruitment, sharing one's personal information, or receiving HIV test results.

Just being consistent, I think, gets people enthusiastic. Because let's say that one person comes and asks, “Do you want to participate?” and you say no, and then that person leaves and they send a different one, then there's no trust, right? But if the same people are frequently coming then you get to trust them and open up... I've seen you around several times and one feels comfortable talking to you, we even take it as a friendship.

[IDI, research-exposed, age 22]

We've already participated and we feel more trust here with you because, like the first time it's like, "What are they going to ask me? What are they going to tell me? This and that. What are they going to do to me when they do the tests and see [the result]?"

[FG, research-exposed, age 30]

**Lack of rapport**—The implications of a lack of rapport between researchers and sex workers were also frequently discussed. These implications included a lack of respect and fears of negative consequences, including breaches of confidentiality (e.g., unauthorized public disclosure of personal information) (Urada & Simmons, 2014).

I imagine that the fears [are a barrier]...I came [to a study] with another one [peer] and asked her why she didn't go. She said she was really angry for being asked uncomfortable questions. "They will mock us," she said. "They have mistaken ideas of what we'll do." It's between fear and mistrust because they say, "And even worse, if I'm going to be recorded. What will I do if they show it on TV or upload it on the Internet?" So, they have a wrong idea of what's going to happen here.

[FG, research-exposed, age 26]

### **Manager Influences: Heterogeneous Implications for Research Participation**

The role of third parties such as managers affected attitudes toward research participation in multiple, sometimes conflicting ways. In this setting, bar managers and owners generally act as 'gatekeepers' who determine how their employees spend their time. As the following participant explained the implications of this for bar-based FSWs' access to research:

If they invite me...first, I do need permission from my manager, the owner. If she says yes, ok, then I will go. If she says no, well, even if I want to go, I can't...you should talk to the owner so that when you come to invite us, they're already informed...On the one hand, there is fear [that FSWs will report abusive practices] and on the other hand, they [managers] have to know the purpose of the study so they can easily let us attend and say yes, as opposed to no. That's how it is.

[FG, research-exposed, age 28]

Accounts of manager influences ranged from instances in which managers had encouraged sex workers to participate in research, to circumstances in which they could constrain research access by prohibiting employees from leaving the venue or not allowing outreach workers to enter the establishment. Participants described varied experiences in this regard:

P3: They don't give permission [to participate] in some places, but in others they do. For instance, our lady boss gives us permission. It's wrong to not grant permission, because it's for our own good.

P2: Maybe it doesn't happen in other places because there are bosses who don't even let them out...they want to keep you inside.

[FG, research-exposed, ages 30 and 28]

It happens in many businesses where the owners say “no, no, no,” and what are you going to do? You choose not to participate to keep the boss happy, that's what most of us girls do. It happens.

[FG, research-naïve, age 23]

There are managers who are mean and say, “no, the girls are working right now and they don't have time,” even though we're not working... At the current place I'm at, the lady is nice. Because I asked her yesterday if she was going to give us permission to come and she said it was fine to come here. The other one was different.

[IDI, research-exposed, age 32]

We heard of numerous circumstances in which manager roles could potentially result in unsafe or unethical research experiences. For example, some participants discussed instances in which managers had asked them to recount what the researchers had asked about and how they had responded to the researchers' questions after returning from an interview. Both research-exposed and research-naïve women operating out of bars also cited concerns of being ‘fined’ by their managers for leaving work to participate in research:

I think that the bar owners shouldn't oppose any of that, because it's true that we work at their businesses, but it shouldn't be as if we were imprisoned or anything like that. If we can attend any kind of orientation or something [research], there shouldn't be any obstacles...we shouldn't be charged with a fine. However, there are many bosses like this. I worked with a lady who didn't even let us go to the restroom because she gave you a fine. If you needed to go to the doctor she gave you 15 minutes...she always gave you fines.

[FG, research-naïve, age 23]

There are managers who think badly, they think maybe we'll go do bad things [upon leaving the bar]...like getting drunk in the street, or seeing a guy...They think badly and sometimes they'll charge us a fine for lying, sometimes even 150-200Q [approximately \$20-\$25 USD].

[IDI, research-exposed, age 22]

Bar-based FSWs discussed the importance of ensuring the buy-in and cooperation of managers for enhancing their ability to safely and comfortably participate in research. Better engagement of managers in research (e.g., through trainings or as research participants themselves) and efforts to increase their awareness of the purpose and benefits of HIV-related research were suggested:

P2: She [the manager] wouldn't allow us to attend... They [the managers] need the training to understand the reasons we need to go... They aren't the ones who are going to get involved with a bunch of men, it's us... They need to be talked to as well, so that when there are talks here, they will say, “go.”

P1: Some of the managers don't let us come to the surveys...like my friend said here, it's good that they also go to the talks, because in that case they'll be informed about the risks we might face here.

[FG, research-exposed, ages 30 and 23]

Q: Do you think it would be important for bar owners to get involved in some type of research study?

A: Maybe in some bars, because there are workplaces where bosses don't care for their workers. We're taken care of at the business we work for.

[IDI, research-exposed, age 32]

## Discussion

In this study, we analyzed the perceived risks and benefits of participation in HIV-related research among female sex workers in Guatemala. Access to HIV-related care and relationality (i.e., positive researcher-participant relationships) were key structural and interpersonal benefits of research participation for FSWs. Participant narratives contextualized these themes as linked to broader inequities related to stigma, poor access to care, limited social and psychological support, the clandestine nature of sex work, and human rights violations. These issues interfaced with concerns regarding confidentiality, trusting and respectful practices of research staff, and control exerted by managers.

### Perceived Research Benefits

These findings resonate with key principles in ethical guidelines for human subjects research, including principles of beneficence and justice (National Institutes of Health, 1979), contextualized within the unique social and structural circumstances of sex workers in Guatemala. Perceived research benefits encompassed notions of beneficence that included access to HIV/STI testing, prevention, and counseling; social support; and broader efforts of research staff to ensure their well-being. Caring and educative practices of research staff emerged as crucial to address participants' immense needs for health and social supports. This raises questions regarding where research ends and service provision begins, especially when conducting research in resource-poor settings where access to care may be minimal. Similar concerns have been raised regarding structural disparities in access to care and the role of research staff in non-therapeutic as well as clinical trials involving drug use and sexual health, particularly related to the ethical obligations of clinical trials conducted in lower-income countries (Padian, McLoy, Balkus, & Wasserheit, 2010; Joint United Nations Programme on HIV/AIDS (UNAIDS), 2012). These findings echo previous concerns regarding gaps in access to care for sex workers in Guatemala (Porrás et al., 2008; Rocha-Jiménez et al., Under review) and suggest the urgent need for efforts to scale-up access to voluntary, respectful, and free health and social support services.

FSWs emphasized access to trusting and meaningful relationships with researchers as key research benefits, reflecting the principle of relationality – that is, that research may be most beneficial and accurate when it appreciates and acknowledges the relationships between participants and investigators (DuBois, 2008; Fisher, 2011). In this study, participants

highlighted expectations regarding the professional roles of front-line research staff, and extended past these to include more meaningful interpersonal relationships (Fisher, 2011). The blurred (and sometimes conflicting) responsibilities resulting from the roles of research staff as both researchers as well as “concerned citizens” may cause burnout and stress (Fisher, 2011; Fisher, True, Alexander, & Fried, 2013), particularly when working with marginalized populations. Increased appreciation and support for the wider roles played by (and expected of) front-line research team members are needed to reduce stress and ensure responsiveness to community needs and expectations. These guidelines can be informed by future studies that explore the perspectives and concerns of front-line research staff engaged in HIV research with sex workers and other key populations.

### Perceived Research Risks

Participants identified structural factors such as stigma associated with both sex work and HIV, as well as manager control, as barriers to research engagement, which relate to the broader context of discrimination and human rights violations experienced by sex workers in Central America (Goldenberg, Strathdee, Perez-Rosales, & Sued, 2012; Infante, Aggleton, & Pridmore, 2009; Rocha- Jiménez et al., Under review) and other settings (Lazarus et al., 2012; Scambler & Paoli, 2008; Shannon et al., 2014; Brown, Davtyan, & Fisher, This issue).

Internalized and community stigma were critical barriers to participation which could also undermine the validity of data collected. Studies with sex workers in Peru (Brown et al., This issue), India (Reed et al., 2014) and the Philippines (Urada & Simmons, 2014) have identified stigma and a lack of respect for persons as concerns associated with HIV and sexual health research. This evidence indicates the need for researchers to enhance efforts to reduce stigma and its impacts on research, for example, by hiring staff from community-based organizations that adopt a non-judgmental approach; training team members to demonstrate respect and reciprocity; hiring current or former FSWs to lead, conduct and/or assist with research; and to support broader efforts of sex workers to organize and advocate for respectful treatment and de-stigmatization of their work.

The roles of managers in constraining or facilitating research participation also posed concerns, especially related to researcher obligations to protect confidentiality. The organization of sex work in many contexts may render it nearly impossible to recruit or enroll FSWs in a study without their manager's knowledge. Although some research has included managers (Anderson et al., Under review; Morisky et al., 2010), most studies do not, or may only engage managers during formative stages of research, such as when introducing the study or requesting permission to conduct outreach in their establishments. These practices may be insufficient to address ethical concerns related to manager control, particularly when researching more delicate topics or gathering data that could portray third parties in a negative light (e.g., trafficking, abuse in the workplace). Seeking advice from sex workers and a CAB that is knowledgeable about these issues (and potential inclusion of managers on CABs) can help identify appropriate strategies to involve managers in a given setting. Where appropriate, enhanced engagement of managers in research (e.g., as participants in HIV prevention interventions) is recommended to enhance their buy-in, reduce safety risks, and increase sex workers' capacity to participate.



Previous research on ethics in sex work research has identified problematic experiences, including feelings of exploitation, a lack of respect, and disappointment when the research did not improve policies or programs (Reed et al., 2014; Urada & Simmons, 2014). Although our study did not identify these as major concerns, this may be related to the lower exposure of sex workers to research in this setting, compared with other locations. Sex worker empowerment and peer-based HIV prevention research aimed at strengthening FSWs' capacity to advocate for improved health, working conditions, and human rights has been effective in reducing sexual risk in other settings, notably India and the Dominican Republic (Blanchard et al., 2013; Erausquin, Biradavolu, Reed, Burroway, & Blankenship, 2012; Kerrigan et al., 2006; Reza-Paul et al., 2008; Shahmanesh et al., 2009). Such research designs address inequities in power and privilege, offering important means of addressing ethical concerns that can arise when sex workers are not meaningfully engaged in research. The feasibility and ethics of these research and intervention models should be further explored in Central American and Mexican border settings, where frequent mobility and migration can pose barriers to the development of social networks and solidarity (Goldenberg et al., 2012).

### Strengths and Limitations

Although findings of this study may not be generalizable to all contexts, such as countries where strong sex workers' rights movements have shaped research (e.g., India), the lessons learned remain relevant to these and other settings, especially those where sex work research is in its earlier stages. While we initially faced challenges defining the concept of 'research' (versus service provision) with participants, we worked closely with our community partners to provide additional training and revise our data collection instruments to ensure that the project yielded relevant and meaningful data within the local context. This was a critical learning opportunity, as it demonstrated the need for subsequent capacity-building to improve 'research literacy' to strengthen sex workers' capacity to assess the risks, benefits, and complexities of research participation.

This study builds on the small but growing body of empirical data that can serve as an evidence base for ethically relevant procedures and guidelines pertaining to HIV research with key populations such as sex workers. For example, these findings can inform 'codes of conduct' for researchers based in sex workers' priorities and experiences, which can inform and complement traditional ethical guidelines. This is important given the different ways in which FSWs, IRBs, academics, and policymakers may view research ethics (Fisher, 1999, 2004, This issue). Finally, our results support calls for increased recognition of the contextual and situational nature of research ethics, especially as they relate to key populations (Beyrer & Kass, 2002; Fisher, 2011; Urada & Simmons, 2014). As sex workers remain criminalized and marginalized in many settings globally, ethical considerations in HIV research ultimately depend on local structural forces including stigma and discrimination, human rights abuses, and safety and autonomy in the workplace.

## Conclusions

In this study, key perceived benefits of research included access to HIV/STI prevention and testing and positive researcher-participant relationships. Perceived risks of research engagement included stigma related to sex work and HIV, as well as control exerted by managers in some indoor establishments. To the best of our knowledge, this is the first study to explicitly address ethical issues arising in HIV research with sex workers in Central America. Given the importance of trust between research teams and sex workers, longitudinal studies conducted in close and meaningful partnership with sex work communities (e.g., via close involvement of a CAB, ongoing follow-up visits) are recommended to foster ethical and appropriate HIV research. Continued efforts to reduce stigma, engage managers, and build and reinforce reciprocal relationships between sex work communities and researchers remain essential.

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**Table 1**

Socio-demographic characteristics of female sex workers (N=33), Tecun Uman, Guatemala, 2013-2014

| Variable   | n (%)*       |
|--|--------------|
| Age, in years (mean, range)  | 29.5 (20-48) |
| Education  |              |
| None   | 4 (12.1%)    |
| Some primary school/Completed primary school                           | 20 (60.6%)   |
| Some middle school/Completed middle school                             | 4 (12.1%)    |
| Some high school/Completed high school                                 | 5 (15.2%)    |
| Marital status   |              |
| Single or Divorced   | 27 (81.8%)   |
| Married  | 4 (12.1%)    |
| Widowed  | 2 (6.1%)     |
| Nationality  |              |
| Guatemala  | 24 (72.7%)   |
| Other Central American country   | 7 (21.2%)    |
| Mexico   | 2 (6.1%)     |
| Work environment   |              |
| Entertainment establishment only (e.g., bar, cantina, or casa cerrada) | 22 (66.7%)   |
| Independent/mobile (e.g., truck stop, hotel, park)                     | 11 (33.3%)   |
| Registered sex worker  | 23 (70.0%)   |

All variables represent n (%) of participants unless otherwise stated.

**Table 2**  
**Participant experiences with HIV-related research studies, among female sex workers**  
**(N=33), Tecun Uman, Guatemala, 2013-2014**

| Variable  | n (%)            |
|---|------------------|
| Ever participated in a research study                         | 20 (61.0%)       |
| Time since research participation, in months (mean, range) ** | 5.0 (0.1 - 12.0) |
| Types of previous research participation **                   |                  |
| Biological testing for HIV/STIs                               | 19 (95.0%)       |
| Survey or questionnaire                                       | 10 (50.0%)       |
| In-depth interview  | 14 (70.0%)       |
| Focus group   | 5 (25.0%)        |

All variables represent n (%) of participants unless otherwise stated.

\*\* Among research-exposed women only (i.e., those who had previously participated in a research study) (n=20)

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