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Social and Structural Constraints on Disclosure and Informed Consent for HIV Survey Research Involving Female Sex Workers and their Bar Managers in the Philippines

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Abstract

This qualitative study explored the ethical issues of female sex workers' (FSWs) participation in HIV prevention research. Twenty female bar/spa workers and 10 venue managers in the Philippines underwent individual semi-structured interviews; three community advisory board meetings informed the study design and interpretation of findings. Results: Informed consent was constrained by perceived government coercion and skepticism that research results would translate into community benefits. Disclosure was constrained by distrust in confidentiality and perceived intrusiveness of survey questions. FSWs and managers were frustrated by the government's inability to stop police from using condoms as evidence of prostitution. Findings suggest HIV interventions move beyond didactic prevention workshops to include FSWs in intervention design and implementation, and to reduce social and structural constraints on participation.

Keywords

female sex workers; research ethics; disclosure; consent; social; structural; interventions; HIV; substance use

In most countries, sex work is highly stigmatized and criminalized. Female sex workers are often subject to police raids, rape, violence, emotional abuse and marginalization (Platt et al., 2013; Shannon & Csete, 2010; Silverman, et al., 2011). As a result, recruitment, disclosure and participation of female sex workers in research are often compromised (Uusküla et al., 2010; Ditmore & Allman, 2011). Respect and relationality, the reciprocal 'give and take' relationship in which the researcher maintains the participant's trust (Fisher, 2011), are especially critical when conducting research with female sex workers.

In the Philippines, participation in health surveillance surveys is compulsory for female bar/spa and sex workers working in bars, nightclubs, spa/saunas, and karaoke bars in Metro Manila. Such practice may influence the way FSWs consent to other research. In previous surveys administered to sex workers and their managers conducted by the first author, missing data on substance use, condom use, manager support and venue policies regarding

condom use and availability were common (Urada, Morisky, Hernandez, & Strathdee, 2013). In that study, trained local non-government organization workers (peer educators) administered structured surveys to 498 entertainers and 48 managers in 54 venues (nightclubs, bars, spa/saunas, and karaoke bars). Findings showed that among 173 female bar/spa workers who traded sex in the past six months, inconsistent condom use (42%) was significantly associated with force/deception into their work, higher alcohol use, not following co-workers' advice to use condoms, and having less frequent contact with their managers (Urada, Morisky et al., 2013). In addition, discrepancies were found in data between workers and their managers around their venues' availability of condoms and condom use policies. Also, disclosure of substance use and sexual practices may have been underreported as reflected by low self-report of substance use (12%) and sex work (35%) than what was expected from this high risk group (Urada, Strathdee et al., 2013). The current study explored the ethical, social and structural dynamics underlying these discrepancies.

A number of studies highlight ethical challenges for research involving female sex workers. For example, barriers to recruitment or continued participation included a lack of perceived benefits to participation, inadequate compensation, research mistrust and feelings of exploitation (Metzenrath, 1998; Jeffreys, 2010). The prevalence of missing and discrepant data may arise when FSWs withhold or alter the truth about their age and other personal information in order to avoid legal action; however, researchers may reduce this by utilizing long-term participant observation methods, establishing rapport, and demonstrating respect (Agustin, 2004). Fear of privacy, confidentiality breaches, or lack of community engagement to ensure successful data collection and interpretation has led to more problems with data validity and integrity (Ditmore & Allman, 2010; Fawkes 2005; Shaver, 2005). Increased policing, arrest, and media attention have resulted from coercive recruitment practices, public exposure of sex work venues, and ill-informed policy recommendations based on incorrect or incomplete data, further leading to mistrust among FSWs (Ananda, 2009; Jeffreys, 2010). Care also needs to be taken to avoid "therapeutic misconception," – the expectation from participants to personally gain over and above what they normally would receive from participating in the research (Fisher et al., 2008). To address these concerns, investigators have cited the need to be transparent about research aims and to provide participants with education, training, and familiarity with ethical research standards (Jeffreys, 2010; Ditmore & Allman, 2011).

Guided by previous research and the UNAIDS/AVAC Good Participatory Practice Guidelines for Biomedical HIV Prevention Trials, this study examines through the lens of FSWs, their managers, and research staff, the following aims:

- Identify social and structural contextual factors that influence consent to participate in non-governmental survey interviews involving highly sensitive topics.
- Explore social and structural contextual factors that constrain participants' disclosure of sensitive topics.
- Investigate social and structural contextual factors that constrain sex workers from agreeing to participate in socio-structural HIV prevention interventions.

METHOD

We draw upon socio-ecological theories of HIV (and other health) risks (Rhodes, 2002, 2009), similarly to the survey research that gave rise to the current study (Urada et al., 2012; Urada, Morisky et al., 2013). Specifically, we explore social and structural contextual factors that impact consent, disclosure, and willingness to participate in research and interventions through the lens of three key research ethics principles: Respect for Persons, Beneficence and Justice (Belmont report, 1979, 1998). *Beneficence* is the practice of making efforts to help and do no harm. *Justice* dictates that selection of subjects in research must be fair and equitable. Our methodological aims were to be as transparent and participatory as possible, without causing harm to participants through heightened visibility or extensive time commitments. Further details of the collaborative methodology appear at {supplementary online document URL}.

Site Characteristics

The Philippines is one of only seven nations worldwide with a 25% or more increase in HIV incidence from 2001 to 2009 (UNAIDS, 2010). Venue- and street-based female sex workers (FSWs) are at high risk for contracting HIV; many are recruited at very young ages from impoverished provinces to work in Metro Manila.

Substance use, especially methamphetamine use, is high among adult populations in the Philippines. Shabu is the street term in the Philippines for crystal methamphetamine made from cheap medicines containing ephedrine and is the choice for 90% of substance users in the Philippines of all classes (Philippines Dangerous Drugs Board, 2008). A strong association between shabu and sex work was found among the female bar/spa workers (Urada, Strathdee et al., 2013).

Community Collaborators

Peer Ed ME PAMACQ (Peer Educators Movement for Empowerment of Pasay, Manila, Caloocan and Quezon City), is a peer-driven organization of young people. The non-governmental organization provides peer educator training and HIV awareness to youth in the Metro Manila area of the Philippines. Hosted by the Center for Environment and Sustainable Development (CESD), PAMACQ is affiliated with Pinoy Competence (a consortium of individuals and NGOs). Local health departments have hired PAMACQ members to survey female sex workers for the Integrated Health Behavioral Serologic Surveillance (IHBSS). For the current study, PAMACQ interviewers recruited and interviewed participants, and provided feedback on the research design and interpretation of the results.

Participants and Inclusion Criteria

Interviews were conducted with 20 FSWs and 10 venue managers. In addition, seven former interviewers/peer educators participated in a community advisory board (CAB) meeting to provide specific feedback about the survey research process they previously participated in as interviewers. Two other CAB meetings were held with nine participants from other non-

government organizations, government health officials, and academicians from Metro Manila.

FSWs eligible to participate in the current study were female bar/spa workers in a large suburb of Metro Manila who worked in venues that participated in a previous survey study conducted by the first author from April 2009-January 2010 (Urada et al., 2012). All had participated in a survey around HIV and sexual health practices (e.g. HIV government surveillance). Only half clearly remembered participating in the survey conducted by the first author (Urada et al., 2012). The other half could not recall due to the time lapse and because they had participated in other similar studies.

The managers were eligible to participate if they participated in the first author's previous survey (Urada et al., 2012). The managers most receptive to being interviewed were selected, as well as those from venues that were still in operation (e.g. they had not been shut down).

The female bar/spa worker participants ranged in age from 18-32 years; 5-10% was married, 30% were single moms or separated with children, up to 70% were single overall, with the rest having a live-in boyfriend (20-30%) or were married (5-10%). Managers were male and female. Community Advisory Board members from NGO, government, and academia in the Philippines included nine males, five females, and one transgender person, and ranged in age from 20-60 years old. The former survey interviewers (PAMACQ members) who participated in the CAB included two females and five males, and all were less than 30 years old.

Interviews with FSWs and Managers

Special attention was given to training the interviewers in this study on the process of gaining consent from the participants. They were advised to have the participant choose the location of the interview (e.g., restaurant, venue, clinic). They were trained to slow down the pace of obtaining consent, to have participants talk about their reactions and feelings about the consent process and their comfort level with participating in the interview. They were also taught to be open to learning from the participants during the interview, and letting the participant guide the direction of the interview whenever possible.

After the informed consent, both FSWs and their managers responded to a vignette (described below) through the use of interview guide questions. Demographic information was also collected at the end of the interviews (age, marital status, number of children). The participants were also encouraged, if they felt comfortable doing so, to talk about themselves or people they knew.

Interview guides were developed to elicit experiences and perceptions about prior survey research participation, particularly surrounding risk, trust in research and interviewers, and barriers to disclosure and informed consent (for survey and intervention participation). Also, questions included perceptions of the aims of research and conditions under which they thought HIV prevention research and interventions could succeed. Interview guides for

individual interviews with bar/spa workers and managers were similar in content. Simple word changes were made depending on participant type (bar/spa worker or manager).

Vignettes were developed for use in conjunction with the interview guides, modeled after an approach used in other research on ethics with vulnerable populations (Oransky, Fisher, Mahadevan, Singer, 2009). Female sex worker participants received a case vignette of a fictitious female bar/spa worker, “Mary Ann,” to help elicit their reactions and to help them respond to a hypothetical case so that they would not have to disclose their own stories or opinions if they were not comfortable enough to do so.

Mary Ann works as an entertainer at a nightclub in Quezon City. She is 18 years old and has one child. She came to Manila because life was hard for her family in the province and someone recruited her to work in Manila. She did not know what she would be doing in her job until she got to Manila. She has as many as six men who pay her for sex in one week. She takes shabu (crystal meth) and drinks alcohol almost every day. An interviewer approaches her manager at work with a survey, asking if she could be interviewed for the study and possibly participate in an HIV prevention intervention. Her manager agrees and introduces her and her co-workers to the interviewer.

The interviewer takes her to a corner of the room and shows her this consent form [show consent form], and says “During this interview, I will ask you some questions about your life and work. Some of the questions will be very personal, but please try to answer as truthfully as you can. Your answers are entirely confidential and will be used to improve health education programs in the Philippines. Your participation in the survey is voluntary. We can omit any questions you feel uncomfortable answering or stop the interview at any time.”

The interviewer then begins to ask her questions on this survey [show survey] about whether she had ever been forced or tricked into her job as an entertainer, the number of sexual partners she has, whether she uses condoms with them, if she and her sexual partner uses drugs, and whether the manager at her workplace supports her condom use or sells condoms there.

Likewise, managers received a separate vignette of a hypothetical manager, “Mrs. Bautista,” again based on the experiences of the first author and results from manager surveys in the prior study. This vignette also includes information about a request to participate in the research to elicit reactions from the managers. The goal was to compare whether answers between the workers and managers contradicted each other or not (as had occurred in the some of the previous survey research results).

Data Analysis

A modified grounded theory approach (Charmaz, 2006; Corbin & Strauss, 2008) was used to inductively code and analyze the interview transcripts and CAB meetings. An initial set of codes was compiled to reflect the research questions, which were the same for FSWs and managers. Additional codes emerged from the data (e.g. police interactions with venues, drug treatment barriers) and were added as the analyses proceeded. The data were compared

between and across targeted participants (female bar/spa workers, managers, and staff). The first author coded and wrote memos to reflect the questions, concerns, and analytical insights emerging from the analyses. Discussions between the interviewers and the authors about the coding, memos, data collection, and analytical process were ongoing throughout the data collection and analysis period.

RESULTS

Informed Consent Process

The 20 female bar/spa workers and 10 managers who participated in previous survey research had similar understandings about the purpose of survey research and feelings about their involvement in the research process. Most FSWs thought the purpose of the research they previously participated in was to enhance their knowledge about HIV, identify targeted HIV prevention interventions, and improve clinic services. Many expected a positive outcome from research besides the incentive they received for their participation. However, one thought the purpose of survey research was “to map out the current number of HIV positives in the Philippines;” and others felt the government required them to participate in the survey research and get tested for HIV. Both of these perceptions were based on the fact that the health department regularly conducted HIV serologic and behavioral surveillance to track HIV cases. Our participants were tested frequently as part of this surveillance. A feeling of being “forced by the government” or “forced to comply with managers’ requests” to participate in survey research, was prevalent in the qualitative interviews with bar/spa workers. The health department provided a letter of endorsement of the original survey study (Urada et al., 2012) to elicit survey participation in each of the venues selected. This may have contributed to the perception among some participants that the surveys were affiliated with the government.

“Sometimes we are being forced to participate in a survey even if we do not want to because we're afraid that our manager would be angry or will fire us if we do not participate.” (*Female bar worker*)

“We were forced to join because it was the Health Department doing the interview.” (*Female bar worker*)

While the female bar/spa workers understood the concept of informed consent, they did not always trust the informed consent process. They felt that although they read and sometimes signed the forms, they had no way of knowing if the research team would actually abide by the assurances offered in the consent form. Specifically, they felt the informed consent process did not adequately protect their rights to confidentiality.

“Being informed of consent in regards to confidentiality helps make me feel better, but does not make me completely trust you because of the possibility that you could reveal this information to others.” (*Female bar worker*)

“My suggestion is for the interviewer to discuss our rights before starting the survey so we know what to do if the interviewer fails to follow what we have discussed, especially if they are from the clinic or city hall.” (*Female bar worker*)

Managers also said establishing trust with them was important.

“It is much better if the manager knows the interviewer. The interviewer must be good, know how to get the participants attention, and how to make a conversation. Most important, the interviewer must be friendly.” (*Manager*)

“Make them more comfortable so that no one can know about the conversation. You must assure them that it will be confidential and most important, the manager must know the interviewer well.” (*Manager*)

Perceived Role of IRB

Many respondents were unaware of the definition of an Institutional Review Board (IRB). When the purpose of the IRB was explained, they were uncertain if they would call the IRB.

“Yes, it would be helpful if Mary Anne [in the vignette] was able to contact the IRB or the University. However, I don't think she'd take the time to call the IRB just to confirm the research. She'd rather take the time to earn money instead of calling only for the purpose of lessening her doubts about the research.” (*Female spa/sauna worker*)

Workers perceived the IRB, housed in the University, as a relatively foreign and distant institution bearing little perceived relevance to the everyday lives of female bar/spa workers. Given that the Metro Manila bar/spa workers have a hard time trusting the interviewers and government, why would they trust that the IRB could help them? Having this protection built in, in this case, may not be much of a protection at all.

Respect for Persons

The interview questions asked by government and non-government researchers, including local students and this project's previous survey research (Urada et al., 2012), evoked strong emotions. Questions around sexual activities, drugs, and other illicit or socially stigmatized behaviors were overwhelmingly perceived as “too personal” to the female spa/sauna workers, a feeling corroborated by their managers.

“Sometimes when we heard about the term ‘research,’ the first that comes into our minds was they are studying us and if we inform our workers [about the study] they will also hesitate to participate because they also think that they are being studied...and privacy and personal life will be uncovered.” (*Manager*)

“It's just like they gather information about us, then make an article or a book or a thesis. That is why some of my workers do not want to join any research because they said that they are just being studied. Even with the clinic research, they don't even present any results or tell us updates about what happens after they interview my workers.” (*Manager*)

Survey questions about condoms and sex evoked “*fear, shame, embarrassment and surprise.*”

“Personal questions about my profits, how many customers I had in a week/day/month, if I had sex with them or was drunk during sex or used condoms with them,

if I used drugs...These questions were hitting below the belt...But asking how much we earn, how often we drink, do we have partners or do we go out with our guests...about our emotional feelings...these are much better to talk about.” (*Female spa/sauna worker*)

The women also said they never conversed about these “personal” topics (e.g. sex, drug use, condoms), even with co-workers.

“If you would ask me about sex or what they do during bar fines, maybe I cannot say anything about that. [Note: Venues charge guests “bar fines” for taking the female workers out of the venue]. I am not comfortable talking about that even if I myself experienced bar fines during times I worked in big establishments.” (*Female bar worker*)

“I remember they asked me if I’m going out with my guest, if I have sex while I’m drunk, do I use condoms during sex, and how many partners do I have. These questions are really hard to answer truthfully. No one is comfortable answering these kinds of questions. No one will tell anybody that she was or is using drugs, especially when you are talking with the clinic staff or with someone from city hall.” (*Female bar worker*)

Confidentiality

Female bar/spa workers, especially, expressed the importance of having rapport with the interviewers and having interviewers they knew and could trust. Knowing the interviewer helped them feel “they could offer truthful answers.” The willingness to disclose sensitive information was also related to interviewer selection and the sites chosen for the interviews. The women felt more at ease and trustful about participating in research if they were interviewed in a private setting by someone with whom they had established rapport or if they trusted the research coordinator with whom the interviewer was affiliated. For example, the managers and workers knew the research staff coordinator well for her outreach as a peer educator in the past.

“Maybe the only way you can do it to know if they are telling you the truth is if you will live among us. I remember when she [peer educator] was still working with the NGOs; she always visited us, talked with us and taught us. She never considered the time she was at every establishment. Sometimes I saw her visiting one establishment after another, doing outreach until dawn until the establishments closed.” (*Manager*)

When the workers did not see their stories appear in the newspaper or their identities revealed, they were more trusting and agreed to be interviewed again. On the contrary, if the women were not familiar with the interviewer, they were concerned about breaches of confidentiality to family, clinic workers, and the public in general:

“My family could find out about my work.” (*Female bar worker*)

“Our conversation could be shared with a clinic.” (*Female bar worker*)

“My secrets will be exposed to the public.” (*Female bar worker*)

“I fear being blackmailed by use of a voice recorder.” (*Female spa/sauna worker*)

“The interviewer could reveal their secrets to others.” (*Female spa/sauna worker*)

In addition, some women preferred that their manager or owner be absent during the interview because some of the questions were very personal. They felt the presence of the manager would restrict their answers to “safe” answers in order to maintain a positive impression on their manager. Conducting interviews outside of the venue enabled workers to feel more comfortable and to disclose more in the interview. Managers also said their workers tended not to disclose information to them, but that they would like to build a closer relationship with them.

“Maybe if we will know about the results of this research, it might help us understand the situation or if ever our workers have problems, maybe we can know from this research. Because we also would like that our workers are “open” with us, that they would not hesitate to tell anything to us.” (*Manager*)

“If you were to ask me I will be glad if you will visit us once a week to talk and to share especially with my workers because some of them might have problems that they cannot disclose to us or maybe they are longing for someone to talk with.” (*Manager*)

Risks and Benefits of Participation - Interactions with Police

For both the female bar/spa workers and their managers, the risks and benefits to participating in research seemed off balance. To them, risks to participating in research were high (breaches to confidentiality leading to police arrest, job loss, or family learning of their work) and they were disappointed when their participation in research did not lead to positive changes in their situations. Under these circumstances, non-disclosure of sensitive information was an important survival strategy.

“We have been explained our rights in past surveys, but it is still difficult to offer 100% of the truth because of the risk of police raids or being identified by our families or friends. We don't want to have our lives publicized about this kind of work. Therefore, it's important to understand and not blame our level of anxiety in answering with 100% truthful responses. I need to protect myself and my work.” (*Female spa/sauna worker*)

The spa/bar workers and their managers were especially concerned about their interactions with police.

“Police raid establishments so that they have incomes... they use their authority to have money. They use us and our bars to profit from, especially during Christmas. Some plant condoms on us so that they might use it as evidence when they file charges on us. They say that it is evidence of prostitution inside our workplace. We do not have the capacity or power to do anything against the police.” (*Female bar worker*)

“We avoid having condoms here in the videoke because police use it as evidence for prostitution. And that is why as a member of the managers association I am

very disappointed why the health department cannot help us or protect us from police raids. They are the ones who organized managers in an association and every time the health department asks us to mobilize and participate we are always there to support them, but they cannot provide us what we need.” (*Manager*)

“Police raid our business even when we are not doing anything. That is also the reason why we do not want to have condoms in our place because they use it as evidence against us. They bring our workers to the police station and look for their working permits. Sometimes when our workers are new, they don't have permits, so we have to pay the penalty fees for them. Sometimes police tell us we must give them, for example, 2,000 pesos [US \$45] per day. It is a bribe so that policemen do not raid the establishment. I attended a meeting in the City Health Department to discuss how to resolve this issue. Other than the City Health officers, police heads (with high ranks) were there, a city administrator was present, and members of the manager association and members of the AIDS Council. City Health requested the Mayor's administrator send a letter to all police precincts to stop raids, but police said the reason establishments were being raided is because they let entertainers dance naked and that is illegal. Also, they said that raids are done by policemen coming from other cities and they cannot monitor it or control it. So the forum did not help us stop the raids.” (*Manager*)

Fear of Arrest for Drug Use

The minimum sentence for possession of 0.17 ounces of illegal drugs in the Philippines is 12 years of imprisonment (Philippines Dangerous Drugs Republic Act No. 9165, 2002). Venues prohibited drug use where the women worked so that they did not disclose their drug use even to their coworkers. The women were more comfortable with questions about drinking than answering questions about other substances, especially illicit substances. For example, one woman knew someone who used drugs, but asked to change the topic when the interviewer asked her more specific questions about the kind of drugs used, where it can be obtained, and how much it costs. She was willing to state the following, however, indicating the prevalence of dependency and addiction and the recognized use of illicit drugs to help the women manage their roles as sex workers.

“Regarding drugs, some know how to get help but some don't, and even if they know someone could help them, they still keep doing it because it gives them confidence.” (*Female bar worker*)

The interviews also revealed that some bar/spa workers refuse to take an HIV test because it might detect their drug use. One female bar worker said she thought almost half of the bar workers where she worked were using drugs. In addition, fear of retribution also makes female bar workers reluctant to reveal their drug use to managers and interviewers.

“Here in our industry we cannot blame people using drugs because this can help them to boost their guts in this kind of work.” (*Female bar worker*)

“I have a co-worker in the past that used shabu. According to her, she used it to help her be more comfortable in what she was doing because she was a dancer and she needed to dance naked. Before they go into the establishment they already took

drugs outside or maybe at home. Maybe managers notice it, but because it did not happen at the workplace, they just ignore it.” (*Female bar worker*)

“There are many programs implemented by government about drugs, but of course they will be afraid to ask for help.” (*Female bar worker*)

“Sometimes our managers don't allow us to use drugs and this will affect our work, we can be kicked out of our work once our manager knows about drug usage...also we are afraid that you will report us to the police.” (*Female bar worker*)

The managers also corroborated what their workers said about drug use.

“We have a policy...we do not allow our workers to use drugs, but because we do not have any control over our workers when they are not working, we cannot stop those who use drugs. We cannot remove them because we do not have evidence that they are really doing it. So all we do is remind them about the rules and regulations and about the punishment.” (*Manager*)

Participation in Interventions

Participants do not regard “interventions” as benefitting them.

“The interviewers kept saying research is for the betterment of governments programs but for me, I don't think so... because since I started to work in this kind of industry and participated in many different research studies, I don't feel and see the appropriate programs for us... because I'm still here! I don't see any programs that are for us only; only services from the government, and we need to pay for these services in order to work. They said check-ups are free, but before we can get working permits and health cards we still need to pay and sometimes give donations.” (*Female bar worker*)

However, most bar/spa worker participants thought they could benefit from research if they could be involved in a worthwhile intervention or see their concerns addressed. These concerns included a change in the government's clinic hours to better accommodate their schedules, reducing or eliminating fees associated with clinic attendance and registration/health cards, helping them find alternative employment and training, and stopping unwanted police raids and abuse/bribes from police. Other changes included obtaining free yellow health cards, having more accessible clinics (e.g. open 24 hours or free STI exams before work instead of having their salaries deducted to pay for special services and check-ups). They also wanted on-site medical care and training so they would not have to use their resting periods to travel to the clinic or to city hall. Finally, they wanted to be consulted about what changes they wanted both in terms of life goals and potential research interventions.

“I haven't had a chance to go to college due to the lack of finances...it is really hard here in our country to look for a job...sometimes they wanted a degree holder or one who finished college to give high salaries...we need help for some of us to go back to school, improve how to speak English so that we can apply to a call center, or have trainings about cooking, dressmaking or other livelihoods that would help us gain opportunity to work in another country.” (*Female bar worker*)

“To gain knowledge not only about HIV but our rights, our skills or talents ... or maybe some of us could go back to school and finish our studies so that we can get better work... instead of forcing us to do things just to earn money, having to drink or have bad customers that force us, hold or kiss us...I hope this could be real... we always experience that they do so much research but we do not experience any results and sometimes they ask us to take an HIV test after...so we feel we are just being studied.” (*Female spa/sauna worker*)

“And if they will ask me they also need to have an idea on how to help us to get out of this kind of job not only helping us preventing HIV, because if we have something else to learn how to earn money that would be the easiest way for us to prevent having HIV.” (*Female bar worker*)

“Also, we need to be involved in the program not only to attend seminars “sitting in a classroom type” like students, but asking us about what we want just like you are doing right now.” (*Female bar worker*)

Managers were also receptive to participating in an intervention with their workers, despite the fact that the workers did not always want them to be present. The managers were supportive of the wishes of their staff but also felt that they did not get enough support from the government to stop police raids or the police's use of condoms as evidence of prostitution, despite joining a managers' association. They hoped that discussing these issues with the researcher might lead to changes in the government and in getting their needs addressed.

“[I will support] anything that will help my establishment and my workers. More trainings not only about HIV but maybe something that could help us give the workers livelihood assistance so that they may have additional earnings. If you will have an intervention you must consider the time involved so that business will not be affected. It should be well coordinated with the manager. It is also best if you work with the government for endorsement, especially if the intervention could help us managers suppress police raids. Also, how can our workers access services from the Health Department and clinics during their most convenient time? It will be great to be involved in planning because we can suggest what we want and it might be a way for us to help you convince other establishments.” (*Manager*)

“It is much better if we [workers and managers] both participate because both of us could learn. I think for managers you will have a hard time convincing them especially when they think that they would not benefit from it, especially the owners, but maybe they can send their managers to be their representatives. For the workers I think it will be hard to convince them; they are always thinking of their incomes for a day. If you could replace their income maybe you can convince them easier.” (*Manager*)

“I suggest ... something that could help us, especially our workers, would be teaching them to earn extra money, and to have a scholarship program for them so they can go back to school. If they finish their studies, they'd have a chance to leave this kind of work.” (*Manager*)

Managers also discussed interventions that would help workers pay for medicines and other health services, as well as money for acquiring permits, so management wouldn't have to pay penalties for new workers. Managers also suggested having seminars that would help workers learn to save money, flexibility in health service appointment times, and schooling, other training, or small business loans to help workers leave their establishments. But they also warned about loss of income and other impediments to participation in an intervention.

“The clinic gave them free medicines just in case they were infected, but when they get fever or colds they spend their own money, or sometimes we lend them money and deduct it from their salary. But there are times when even the establishment does not have money, especially on a weekday. We allow them to work without permits or licenses until they have earned enough money to get the permits. But when there is an inspection from the health department or a police raid, we are closed down temporarily and we pay penalties. Maybe they need a lending company so they can have a small business in addition to their incomes as dancers. Maybe there could be a seminar on how workers could save money in the bank for their future or for an emergency.” (*Manager*)

“The workers need free services that fit their schedules. For example, instead of workers going to the health department and city hall to complete their requirements, why not have somebody from their staff come to our establishment? Or they could give the person a meal and transportation allowance? Why not have a 24/7 clinic so that our workers can go, even at night, for free.” (*Manager*)

“Some of my workers are bored by the seminar conducted by the health department, others say that speakers are not friendly or they feel that they do not belong, and others think of the money that they will earn for that day. Just like the workers, we are also concerned with our income and our time. If you could give them something to replace their income, that would be great. You don't need to give their whole income. If they are earning 3000 pesos/day, maybe you can give 1500-2000/day. In the past, some of my workers and I were paid to be peer educators for 500/month inside our establishment and at an establishment near us. You need to be sensitive in setting schedules. Do not schedule on pay days.” (*Manager*)

“How about making a partnership with a lending company so that they can borrow money to begin a business and give them a seminar on how to manage a small business? Not only seminars about their health but also on how to be a good person. Workers here in these kinds of industry have different stories about why they chose to work here. It would be great if someone could help them. For example, a woman works here but she really wants to finish college. If someone will offer her scholarship, she can go back to school and fulfill her dreams. That's what the government needs to do, assess their needs and concerns before designing a program for them. How can they know if someone who works in a bar needs a seminar about HIV? They are doing more initiatives with health issues but they are not giving the women other opportunities. If you want to have an intervention, ask the women what their concerns are and from what they say, you can make a

program. The most important thing for them is to earn money. Get their trust and their interest. One strategy is to coordinate with the manager so she can be the one to convince the workers. That would be exciting because I think it would be the very first time we would be involved in making plans about what is being given to us.” (*Manager*)

DISCUSSION

We explored the experiences of female bar/spa workers and managers participating in behavioral HIV prevention research. Experiences included their process of consent to research, their knowledge of the role of the IRB (and their likelihood of acting on this knowledge), barriers to disclosure of sensitive topics, and the necessary conditions for their involvement in HIV research prevention interventions. Common themes across both female bar/spa workers and managers were issues with trust (e.g. research in general, project interviewers), intrusiveness of survey questions, sense of being forced to comply with research, and the belief that nothing would happen as a result of the research. Findings showed that female sex workers, in both the prior survey and in this study, found it difficult to disclose sensitive topics such as substance use and sex work due to social and structural issues.

The female bar/spa workers in this study clearly believed that the benefits to participating in research did not always outweigh the costs (breaches to confidentiality leading to police arrest, job loss, or family learning of their work). Some bar/spa workers even refused to take an HIV test (often required in HIV surveillance data collection) for fear that it would detect drug use, and could result in arrest or getting kicked out of their job. Others felt they were simply being researched without feeling any benefits afterwards or changes as a result of the research.

Social constraints to participating in research faced by the female bar/spa workers in this study included fear of disclosure of personal information that could lead to stigmatization, embarrassment, shame, or other consequences if family or others within their community found out about their sex work or drug use. The bar/spa workers and managers clearly expressed the need to know and trust the researcher or research coordinator. Other studies have raised similar issues about the researcher's role and maintaining trustworthiness for female sex workers (Sanders, 2006; Cwikel & Hoban, 2005).

Structural constraints included dissatisfaction with government support by both the female bar/spa workers and their managers over their inability to stop police raids and bribes, and frustrations regarding clinic practices. Police have allegedly taken advantage of anti-sex trafficking legislation (Philippines Congress, 2003), especially around the protection of minors, as a rationale to raid venues in the Philippines and elsewhere. Police have used condoms as evidence of prostitution, thereby increasing HIV risk among female bar/spa workers by forcing condoms to be unavailable in the workplace. Also, journalists' investigations of underage girls working in nightclubs/bars have led to arrests of bar owners under international anti-trafficking law and have resulted in widespread media coverage (Tubeza, 2013). Such incidences may cause female bar/spa workers to fear and distrust

interviewers because they fear their identities would be revealed to the public and their families. Therefore, having a proven track record is necessary to establish trust and reduce perceived and actual risks to participants.

Despite concerns regarding disclosure and confidentiality, bar/spa workers and managers were interested in participating in an intervention following the research, although their interest in HIV 101 activities were limited; Women noted gaining public speaking skills in peer mobilization activities and wanting job skills training that would help them earn more money. They were particularly interested if it would enable them to prepare for legal work outside of the bar/spa industry and reduce the exploitation and risks that workers assume in this industry. In addition, participants expressed interest in planning and participating in intervention research. Sex workers have provided input for STI management guidelines and clinical trials in other studies (Campbell & Cornish, 2012; van der Meulen, 2011).

BEST PRACTICES

- Explain the role of the IRB to subjects and provide clear instructions on how to report unethical practices to the IRB.
- Employ community-based research assistants the subjects trust.
- Do not collect identifying information on participants in cases where confidentiality assurances are not enough.
- Engage participants in the research process.
- Consider designing and evaluating holistic interventions that provide training beyond HIV prevention.

RESEARCH AGENDA

Research could further examine other social and structural constraints on disclosure and informed consent, such as gender inequity and violence issues which female sex workers face across the globe. Research is needed on how global, national, and local policies and practices, including more specific policing and trafficking (force/coercion and underage prostitution) practices, may affect female sex workers' ability to participate in and consent to intervention research. In many international settings, the lack of certificates of confidentiality assurances and protections comparable to those given by the U.S. government also needs further exploration.

EDUCATIONAL IMPLICATIONS

Ethics committee members, researchers, and staff need to be educated about the lack of familiarity that vulnerable populations have with terms such as "IRB" and "intervention" or their recourse to the IRB with information about unethical research practices. Housed in the University, the IRB may be viewed as a relatively foreign and distant institution bearing little relevance to the everyday lives of female sex workers. Therefore, research participants need to be educated about Institutional Review Boards. For example, they need to know their rights to respect and confidentiality. Where participants feel obligated to engage in

research due to structural factors and power imbalances, researchers and ethics review committees need to better address these issues of voluntariness.

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Biography

Lianne A. Urada is an Assistant Professor in the Division of Global Public Health, Department of Medicine, at the University of California, San Diego. She is an HIV/AIDS social welfare intervention researcher who has published about female sex workers in the Philippines, Russia, Peru, and Mexico. For her dissertation, she collected survey data from 498 female bar/spa workers and their managers from 54 venues in the Philippines, and published on the social and structural risks associated with the female sex workers' HIV risk behaviors. She designed and conducted the current ethics study in the Philippines, including all staff trainings and CAB meetings. She coded all transcripts and led the data collection, analysis, and interpretation of data as well as the writing of the manuscript.

Janie Simmons is an ethnographer and Principal Investigator at the National Development and Research Institutes (NDRI) and faculty and mentor at the Fordham University Research Ethics Training Institute (RETI). Her research focuses on HIV risk linked to structural barriers, poverty, substance use disorders, gender dynamics, intimate partner violence and trauma, and has contributed to the research ethics field. She assisted with the study conceptualization and design, construction of the interview guides and coding categories, as well as the interpretation of findings and writing of the manuscript.

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