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HIV PREVENTION RESEARCH ETHICS TRAINING INSTITUTE
 Director, Oella B. Fisher, PhD

Social and Structural Constraints on Disclosure and Informed Consent with Female Sex Workers and their Managers in the Philippines

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Accepted for publication in the Journal of Empirical Research on Human Research Ethics
Funded by: Fordham University RETI (NIDA R25DA031608-02), NIDA T32 DA023356, R01DA028692-04S1
 APHA 2013

Specific Aims

To identify social and structural contextual factors that:

- 1) influence female sex workers' consent to participate in survey research involving highly sensitive topics.
- 2) constrain disclosure of sensitive topics.
- 3) constrain decision to participate in HIV prevention interventions.

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Background/Rationale

In most countries, sex work is highly stigmatized & illegal.

Female sex workers are often subject to police raids, rape, violence, emotional abuse and marginalization (Metzenrath, 1998).

This has affected recruitment, disclosure & participation of female sex workers in research (Uusküla et al 2010; Ditmore & Allman 2011).

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Background of Survey Research: Philippines



Participation in government health HIV surveillance surveys is compulsory which may influence how FSWs consent to non-governmental research.

In previous surveys, missing data on substance use, condom use, manager support and condom venue policies were common among FSWs & managers (Urada et al 2012; 2013)

Discrepancies in responses were found between workers & managers.

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Anticipated Themes

Perceived benefits/motivations for research participation and disclosure are affected by:

- **Respect:** How much participants feel respected by the interviewer/ research and how much deference influences participation.
- **Trust:** Perception of interviewer and concerns about confidentiality breaches influences disclosure.
- **Risks:** Perceptions that disclosure of sensitive topics may result in arrest, penalties, punishment, or job loss.

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Study Population

- 3 CABs (12 individuals from NGOs, government, university, peer organization) and 7 focus group participants (former interviewers- peer educators, including former FSW)
- 20 venue-based FSW who previously participated in a survey (e.g. recent HIV government surveillance and/or my previous survey of 500 FSWs) around sexual health practices
- 10 venue managers selected from 47 managers (54 night club/bars, spa/saunas, karaoke bars) who previously participated in my survey research

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Community Advisory Boards



Community Consultations

CAB meetings/consultations with peer educators, health department and university officials, Non-government organization personnel.

Consultation/debriefing throughout research process and to ensure relevancy of the results prior to dissemination

CAB critiqued interview questions/vignette, consent process, recruitment and methods.

Interviewers from peer-driven organization affiliated with this project

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Research Design

- Face-to-face, 1-on-1 semi-structured to unstructured interviews with 20 female entertainers, 10 managers (30 min.-1 hour).
- Showed former survey & consent form to participants to elicit feedback about the consent process & surveys.
- Scripted narrative probes kept interviews hypothetical (vignettes).

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Procedures

- IRB approval obtained; Verbal informed consent allowed.
- Former interviewers helped identify participants.
- Recruitment across different types of venues.
- Special attention by interviewer to process of gaining consent: place of interview chosen (restaurant, venue, clinic), pace, openness to learning from participants.
- Reimbursement for time, food, transportation
- Most declined to be tape recorded; interviews recorded by hand instead.

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Vignette- "Mary Ann"

Mary Ann works as an entertainer at a night club 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 6 men who pay her for sex in one week. She takes shabu (crystal meth) and drinks alcohol almost everyday. 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.

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Vignette - Manager

Mrs. Bautista is a manager at a spa/sauna or night club in Quezon City. An interviewer approaches her at the venue with a letter from the City Health Department supporting a study being conducted by a student at an American university and professors from the University of the Philippines. The interviewer asks her if she would like to participate in a survey and also maybe in an intervention that may help lower the risk of HIV among her workers. She agrees to participate in the survey that lasts about 1 hour. They go and sit down.

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Sample Interview Questions

- What are risks involved in this type of research?
- Why might she not feel comfortable answering certain survey questions?
- Are there certain conditions under which she might consider answering these questions more truthfully?
- How much did the woman understand the consent form?
- How much do you think Mary Ann trusts the research?
- What do you think managers may understand, want from research?
- What do you think Mary Ann and other entertainers may understand about HIV prevention interventions and the goals of the project?
- What are the necessary conditions for Mary Ann and other entertainers to participate in an intervention (safe, open)?

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Data Analysis

- Initial set of codes compiled to reflect questions.
- Additional codes emerging from data added as analysis proceeds.
- Data compared between and across targeted participants-- interviewers, sex workers, & managers.
- Memos written to reflect questions, concerns, analytical insights emerging from analyses.
- Ongoing discussions between Drs. Urada and Simmons & with interviewers about coding, memoing, data collection & analytical process.

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Interview Results: Themes & Exemplars

RESPECT:

Survey questions were repetitive & some "offensive"

Surveys evoked "fear, shame, embarrassment, surprise... Personal questions about my profits, how many customers I had, if I had sex with them, was drunk during sex, or used condoms with them, if I used drugs...These questions 'hit below the belt'..."

-Female sex worker

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Instead, asking how much we earned, how often we drink, do we have partners or do we go out with our guest.. about our workplace policy about condoms and about our emotional feelings are much better to talk about..."

- Female sex worker

TRUST

FSWs fear their personal information will appear in the newspaper, families will find out about their job.

Trusting the interviewer matters; previous contact helps.

"Sometimes when we heard the term 'research,' the first that comes into our minds was they are studying us...workers think their privacy and personal life will be uncovered..." -Manager

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BARRIERS TO INFORMED CONSENT

Interviewer: You mentioned about being scared. Does the consent form that we read a while ago help or not help you or others be more comfortable that this interview will be confidential? Why?

FSW: Yes, it helps, but not very much. Because..we just read it and during the consent process/form, we do not know if you will follow the consent.

Interviewer: Is there any suggestions that you can give us so that women like you who work in a bar, spa or ktv would be comfortable?

FSW: I think before starting the interview they should or you should discuss our rights with us and what to do if the interview did not follow what was agreed upon.

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"We are unaware of the IRB."

"We are forced to join because it was the Health Department doing the interview."

"Sometimes we are being forced to participate in a survey even if we do not want to because of being afraid that our manager would be angry or kick us off our job when we do not participate with them."

- Female sex workers

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BARRIERS TO DISCLOSURE ABOUT DRUGS

"We are afraid you will report us to the police...Here in our industry we cannot blame people using drugs because this can help them boost their guts in this kind of work. There are many programs implemented by government about drugs...but of course they will be afraid to ask for help."

-Female sex worker

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"Almost half at my work use drugs. Some are afraid to ask for help for drug use...afraid of getting kicked out of the job...Others refuse to take an HIV test which might detect their drug use."

-Female sex worker

BARRIERS TO DISCLOSURE- POLICE



"Government cannot help stop police raids, even for Managers' Association members"

- Bar Manager

"Police raid establishments so that they can profit from us, especially during Christmas...Some plant condoms to use as evidence to file charges on us. We do not have the capacity or power to do anything against the police."

- Female sex worker

RISKS

Benefits don't outweigh risks:

"No changes" seen after research (e.g. clinic services) "maraming nagrerresearch dito pero wala naman natutulong saamin"

"We always experience so many research but we do not experience any results and sometimes they ask us to take an HIV test after...so we feel sometimes we are just being studied."

-Female sex worker

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INTERVENTIONS "Our time is Gold"

- **"Intervention" term unfamiliar to FSWs**
- **Consider participants' schedules, time (need to make money)... "Our time is gold" - FSW**
- **FSWs want to participate in planning, delivery of intervention (practice public speaking)**

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“Gain knowledge not only about HIV but our rights, skills, talents ...not forcing ourselves to do things just to earn money...drink or have bad customers that will force, hold or kiss us... maybe some of us may realize to go back to school and finish our studies so that we can get a better job. ”

-Female sex worker

“If they will ask me, they also need to have an idea how to help us get out of this kind of job...because if we learn how to earn money doing something else, that would be the easiest way for us to prevent having HIV.” **-Female sex worker**

Conclusion – Best Practices

- Explain role of the IRB; provide clear instructions on how to report unethical practices to the IRB.
- Employ community-based research assistants the participants 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.

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CAB & Interventions combined: HIV/STIs, health & human rights



Adapted from Community Life Competence Process (CLCP) (tested in 20 countries)

Acknowledgements

This research was supported by the Fordham University HIV Prevention Research Ethics Institute NIDA (R25DA031608-02), NIDA (T32DA023356), and R01DA028692-04S1.

The contributions of Peer Ed ME PAMAC-Q (a youth-led/peer educators NGO working on HIV and sexual & reproductive health and rights issues), Benilda de Guia, Jay Caparida, and Junelyn Tabelin in recruitment, data collection, and translation are greatly appreciated, as well as the support of Josefina Ferriols-Pavico, Executive Director of the Center for Environment and Sustainable Development (CESD), and Gerlita Enrera of Pinoy Competence.

We also thank Dr. Celia B. Fisher, Director of the Fordham University Research Ethics Institute, for her assistance throughout the research process and for reviewing drafts of this manuscript.

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