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# A COLLABORATIVE METHODOLOGY FOR INVESTIGATING THE ETHICAL CONDUCT OF RESEARCH ON FEMALE SEX WORKERS IN THE PHILIPPINES

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## Introduction

Designing research in an ethical, nonexploitative manner that investigates concerns around privacy, confidentiality, and voluntariness is imperative for female sex work populations (Shaver, 2005; Urada & Simmons, 2014). Some community-led interventions, especially those focused on empowerment, education, and economic independence, have been effective with female sex workers across the globe (Biradavolu et al., 2012; Kerrigan et al., 2006; Swendeman et al., 2009; Sherman et al., 2000). To avoid disillusionment among sex workers and their managers when they do not see positive changes resulting from research, designing and adapting interventions is a critical research aim for this population.

This article is a companion publication with “Social and Structural Constraints on Disclosure and Informed Consent for HIV Survey Research Involving Female Sex Workers and Their Managers in the Philippines” (Urada & Simmons, 2014), a study examining the contextual factors that influence participants’ disclosure of sensitive topics in nongovernmental survey interviews and their consent to participate in HIV prevention intervention research. However, the collaborative methodology in this study may be useful for research carried out with female sex workers in other similar contexts. This paper focuses on the collaborative aspects of the methodology in the aforementioned study. The more general methodological approach is summarized in the companion paper noted above.

This qualitative study explored the ethical issues of female sex workers’ participation in HIV prevention research. The study’s main findings included the following. Informed consent was constrained by perceived government coercion and skepticism that research

results would translate into community benefits. Disclosure was also constrained by distrust; sex workers did not trust that confidentiality would be maintained. They also felt many of the survey questions were intrusive, particularly those that were meant to elicit information about substance use and sex work. Structural constraints imposed by police also played a significant role in nondisclosure. Police raids were common, and sex workers and managers were frustrated by the government’s inability to stop police from using condoms as evidence of prostitution. In conclusion, HIV interventions must move beyond didactic prevention workshops, include female sex workers in intervention design and implementation, and aim to reduce social and structural constraints on participation.

As indicated in the main paper, our methodological aims were to be as transparent and participatory as possible, without causing harm to participants through heightened visibility or extensive time commitments. Sex work is highly stigmatized and illegal in the Philippines, as is common elsewhere, and women commonly do not disclose sex work to family members. The sex workers who participated in the study were also especially concerned about losing clients and the money they generated. Even the relatively small fees for work permits from the health department were difficult for women to pay. Collaboration with our community advisory boards and the Peer Ed ME PAMACQ (Peer Educators Movement for Empowerment of Pasay, Manila, Caloocan and Quezon City) enhanced recruitment efforts, the development of rapport with the female sex workers and their managers, and helped to produce relevant findings and continued collaboration.

## Participatory Methods

Peer Ed ME PAMACQ (Peer Educators Movement for Empowerment of Pasay, Manila, Caloocan and Quezon City) is a peer-driven nongovernmental organization of young people that provides peer educator training and

HIV awareness to youth in the Metro Manila area of the Philippines. Hosted by the parent organization, the Center for Environment and Sustainable Development (CESD), PAMACQ is also affiliated with Pinoy Competence (a consortium of individuals and NGOs). An example of an innovative community participatory project conducted by PAMACQ was their successful resource mobilization around delivering HIV prevention and reproductive health messages via community events through the help of Barangay officials and health department staff and physicians. PAMACQ was also involved in the Peer Educators Youth Movement (PEYM), which implemented an Asian Development Bank-funded Community Life Competence Project (CLCP). PAMACQ led a two-day training for youth in which participants shared and identified their concerns and acted out their dreams for their community. At the end of the training, participants joined PEYM and worked on behalf of PEYM's HIV and AIDS advocacy. They also participated in human rights activities such as supporting the Reproductive Healthcare Bill in the Philippines. For the current study, PAMACQ interviewers recruited and interviewed participants, and provided feedback on the research design and interpretation of the results.

The former survey interviewers/peer educators, including former street sex workers, were also PAMACQ members of the peer-driven organization affiliated with this project. The former interviewers were selected for the community advisory board (CAB) if they were survey takers in the previous study (Urada et al., 2012, 2013) and if they were available (all were available except for one who now resides outside the country).

### Community Advisory Board Meetings

Three community advisory board meetings were held prior to the current ethics study. The first CAB meeting was held with the former interviewers of the survey study (Urada et al., 2012, 2013), who discussed their experiences around surveying the sex workers and managers in the past. The second CAB meeting was held with seven NGO members, academics, and government health department officials, who reviewed and gave feedback on the proposed study's design. A third CAB meeting was held with five academics and NGO workers, who provided insights into designing an intervention and how to incorporate participant feedback into the design. This CAB included new academic members who did not attend the other CABs and who engaged in dialogue specifically about designing an

intervention with the NGO based on the findings of this ethics research project.

In the first CAB, interviewers for the prior survey research gave input on which female bar/spa workers and managers to interview and their reasons for the selections. Their familiarity with bars/spa workers and managers enabled them to recruit participants for this study across different types of venues. However, due to the mobility of the women and the closure of several venues, locating women from the previous survey study was not always possible. Therefore, they also recruited women who had not been previously interviewed, but had experienced being a research participant in other studies (e.g., government HIV surveillance studies).

All three CABs (health department officials, managers, former female sex workers and peer educators/interviewers, nongovernment organizations, Philippines university consultants) were audiotaped with the participants' consent and were used to elicit feedback about the proposed research questions, interview guide, consent, and the interpretation of results. CAB participants critiqued the interview questions/vignette, consent process, recruitment, and methods of the current study. During the research process, consultation and debriefing ensured the results were valid prior to dissemination.

To ensure confidentiality and trust from participants, CAB members insisted that interviews of the bar/spa workers and managers should not be tape recorded, that the place/venue and time of the interview be kept confidential, and that it take place at a location where only the interviewer and research participant could hear each other. Participants distrusted research in general and feared their identities would be disclosed; all declined to be audiotaped. Both female bar/spa workers and managers believed tapes could be used as evidence for police to raid their establishment, or would leave them vulnerable to blackmail. Therefore, notes were recorded by hand instead, with one person conducting the interview while another simultaneously transcribed the interview. Note takers aimed for verbatim transcription, but given the time constraint of simultaneous transcription, verbatim transcription was not always possible. However, immediately after the interview, the note taker, with the assistance of the interviewer, completed the transcription as accurately as possible. The location of the interview was left up to the respondent; most chose to be interviewed at the clinic, at their workplace, or in a restaurant, rather than at home where family may not know the nature of their work and where they would be uncomfortable answering questions about sexual behavior. In addition, most of the female bar/spa workers did not want their

manager present during the interview because this would limit their answers to “safe answers”; they often “kept secrets” from their managers and were concerned about their image. However, some participants preferred being interviewed in the venues with their managers present because they felt safer having their co-workers and manager around. Others preferred the clinic if they were given a private room to be interviewed in, and still others preferred meeting at a restaurant.

### Vignettes

At first, this study only intended to collect opinions of the sex workers and their managers about the vignettes so that participants would not have to disclose sensitive information or talk about themselves directly. However, following the recommendations of the CABs, the participants were also encouraged, if they felt comfortable doing so, to talk about themselves or people they knew.

The vignettes were developed by the first author, based on previous experiences working in the field with female sex workers in the Philippines, as well as the average profile of the previous survey participants. In addition, Mary Ann’s age was changed from under 18 to 18 years old based on the CAB’s suggestion because it is illegal to work under 18 years of age in a bar/spa or nightclub.

#### *Entertainer Vignette: Mary Ann*

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 the research participant to a corner of the room and shows her the 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.

#### *Manager Vignette Example: Mrs. Bautista*

Mrs. Bautista is a manager at a 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 at a table. The interviewer shows her this consent form [show consent form], and says, “During this interview, I will ask you questions about your work. This is a voluntary survey. Please answer as truthfully as you can. Your answers are confidential and will be used to make recommendations for improving AIDS prevention programs and services in the Philippines. Please ask me to skip any questions you do not wish to answer.” The interviewer then begins to ask her questions on this survey [show survey] about her workplace, such as whether there is a rule about condom use, if condoms are offered at the establishment and at what price, and if she supports the workers’ condom use.

The CAB members agreed that the use of these vignettes and interview guides rather than structured surveys were more likely to elicit responses. In addition to recommending additional interview questions (e.g., related to how they would like to participate in various parts of the research and intervention), the CABs discussed having participants share stories beyond just asking them to respond to the vignettes. They hoped participants would still discuss people they knew, such as their co-workers, even if they elected not to self-disclose.

The following were interview guide domains (research and consent challenge areas) and sample questions for the sex workers and managers:

- *Perceived Barriers to Disclosure of Information on Surveys.* Why might Mary Ann/Mrs. Bautista not feel comfortable answering certain survey questions? Are there certain conditions under which she might consider answering these questions more truthfully?
- *Perceived Barriers to Informed Consent for the Survey.* How was the consent process conducted? Respect: How much do participants feel respected by the interviewer and/or research? Trust: How much do participants trust the research and researcher and/or interviewer (e.g., confidentiality breaches)? Understanding/comprehension: How much did the woman understand the consent form?
- *Perceived Barriers, Benefits, and Risks to Consenting to Be in the Intervention Project.* What do you think Mary Ann/Mrs. Bautista feels about the manager and female bar/spa worker participating in an intervention together? What are the necessary conditions for Mary Ann and other entertainers to participate in an intervention?
- *Perceived Barriers to Participating in an Intervention Project.* Trust: Concerns about conditions and confidentiality breaches during the intervention. What do you think Mary Ann/Mrs. Bautista may understand about HIV prevention interventions and the goals of the project? What do you think they might understand and want from the research?

As a result, the questions in the interview guide changed over time as saturation of themes occurred and to elicit fuller responses in interviews. The interviewing became an iterative, participatory process (Srivastava & Hopwood, 2009) as the authors gathered feedback from the interviewers and questioned them further after interviewers turned in transcripts on an ongoing basis.

Study results illustrated how female sex workers and managers perceived barriers to respect, trust, and/or disclosure that largely stemmed from risks in the structural environment and the historical and situational context of research conducted in Metro Manila. Viewing these issues in terms of the Belmont Report's principles of respect for persons, beneficence, and justice was a central aim of this study (US Department of Health and Human Services, *Belmont Report*, 1979, 1998). Beneficence is the practice of making efforts to help and do no harm (*Belmont Report*, 1979, 1998; Fisher, 2011).

Justice dictates that selection of subjects in research must be fair and equitable (*Belmont Report*, 1979, 1998). Participants who are already burdened with risks should not bear the burden of participation for others out of convenience.

## Conclusions

The inclusion of participatory and iterative methods between the CAB members, interviewers, and researchers led to more complete answers on sensitive topics that were otherwise difficult for the trained peer educators to probe and for the researchers to determine alone. Furthermore, the results of the study were shared with the interviewers and CAB members. The CAB members were composed of NGOs, academicians, and five groups of sex workers (N=100). In keeping with the desires of the female bar/spa workers and managers, interventions were conducted during these five CAB meetings. The interventions entailed "dream-building" activities and plans for follow-up meetings via the nongovernment and peer organizations involved in the project.

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## Authors' Biographical Sketches

**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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