



UNIVERSITY OF CALIFORNIA PRESS
JOURNALS + DIGITAL PUBLISHING

Confidentiality, Privacy, and Respect: Experiences of Female Sex Workers Participating in HIV Research in Andhra Pradesh, India

Author(s): Elizabeth Reed, Kaveh Khoshnood, Kim M. Blankenship and Celia B. Fisher

Source: *Journal of Empirical Research on Human Research Ethics: An International Journal*, Vol. 9, No. 1 (February 2014), pp. 19-28

Published by: [University of California Press](#)

Stable URL: <http://www.jstor.org/stable/10.1525/jer.2014.9.1.19>

Accessed: 07/03/2014 16:30

Your use of the JSTOR archive indicates your acceptance of the Terms & Conditions of Use, available at <http://www.jstor.org/page/info/about/policies/terms.jsp>

JSTOR is a not-for-profit service that helps scholars, researchers, and students discover, use, and build upon a wide range of content in a trusted digital archive. We use information technology and tools to increase productivity and facilitate new forms of scholarship. For more information about JSTOR, please contact support@jstor.org.



University of California Press is collaborating with JSTOR to digitize, preserve and extend access to *Journal of Empirical Research on Human Research Ethics: An International Journal*.

<http://www.jstor.org>

CONFIDENTIALITY, PRIVACY, AND RESPECT: EXPERIENCES OF FEMALE SEX WORKERS PARTICIPATING IN HIV RESEARCH IN ANDHRA PRADESH, INDIA

ELIZABETH REED

University of California, San Diego

KAVEH KHOSHNOOD

Yale School of Public Health

KIM M. BLANKENSHIP

American University

CELIA B. FISHER

Fordham University

ABSTRACT: FEMALE SEX WORKERS (FSWs) FROM Andhra Pradesh, India, who had participated in HIV research were interviewed to examine participant perspectives on research ethics. Content analysis indicated that aspects of the consent process, staff gender and demeanor, study environment, survey content, time requirements for study participation, and perceived FSW community support for research were key factors influencing whether FSWs perceived their confidentiality and privacy had been maintained, and whether they felt the study was conducted respectfully. Findings suggest that partnership with community-based organizations and investigation of participant's experiences in HIV prevention research can provide critical information to best inform research ethics protocols, a particular priority among research studies with highly stigmatized populations, such as FSWs.

KEY WORDS: female sex workers, research ethics, HIV prevention

Received: August 20, 2013; revised: September 16, 2013; revised: November 6, 2013

HIV INFECTION IS OF CRITICAL CONCERN IN India, where 2.3 million people are estimated to be living with the virus (NACO, 2010). In India, the epidemic is largely contained within subgroups most at risk for HIV, including female sex workers (FSWs), injection drug users, and men who

have sex with men. The southern Indian state of Andhra Pradesh is among the states with the highest rates of HIV (UNAIDS/WHO, 2005).

Ethically sensitive HIV prevention research design and implementation needs to be responsive to the multiple life challenges facing FSWs in Rajahmundry. Such challenges include stigma and discrimination associated with sex work (Liu et al., 2011; Wong, Holroyd, & Bingham, 2011), resulting in housing evictions, family and community rejection, as well as violence and harassment from police, clients, and others (Reed et al., 2010; Reed et al., 2011; Zalwango et al., 2010; Ntumbanzondo et al., 2006; Reed, Gupta, & Blankenship, 2012). Specifically, women have reported arrest by police, violence, and eviction by landlords upon their identity as a sex worker becoming known (Reed et al., 2010, 2011; Erausquin, Reed, & Blankenship, 2011). Additionally, FSWs face doubling burdens related to women's low social status, including limited access to education and economic opportunities, barriers to housing based on inability to secure financial loans or bank accounts (particularly without a male family figure present), domestic violence, and abandonment and financial neglect by husbands (Reed et al., 2010, 2011; Zalwango et al., 2010). FSWs in Rajahmundry also face dire economic circumstances as sole financial providers for themselves and their families and being burdened with husbands' or other family members' debts (Reed et al., 2010, 2011; Zalwango et al., 2010). Many of these social and economic burdens are cited as the factors leading to women's sex trade involvement (Reed et al., 2010; Zalwango et al., 2010).

Given the multitude of such challenges within the life contexts of women working as sex workers, HIV prevention researchers need to thoughtfully consider potential research risks confronting FSWs in this high HIV prevalence region. Recognizing the stigma and discrimination women report as a result of identification as a sex worker, issues of confidentiality, privacy, and respect have been prioritized by investigators and institutional review boards (IRBs; i.e., ethical review committees). While HIV prevention research studies conducted in this region are designed to follow standard ethical guidelines, such guidelines may

not be fully responsive to the values and expectations of the study population (Fisher, 2002, 2004; Fisher & Wallace, 2000; Fisher et al., 2008; Fisher & Goodman, 2009).

In other global contexts (often US based), studies with persons who inject drugs have investigated participant perspectives of and experiences in research, and have provided useful information for improving the ethical design and conduct of social and behavioral research with these populations (Fisher, 2010; Fisher et al., 2008; Scott, 2008; Davidson & Page, 2012). In contrast to this work among drug using populations, to date, there has been less empirical attention to research ethics relevant to experiences among FSWs. The existing, but limited, work on the topic of research ethics among FSWs has identified the issues of confidentiality, privacy, and respect as pertinent to this population; findings have indicated high levels of stigma and victimization as security challenges when conducting research among FSWs (Shaver, 2005; Ditmore & Allman, 2011). However, the majority of these studies have not been specific to research ethics pertaining to HIV research among FSWs. Furthermore, very few studies have occurred within high HIV prevalence Indian states, where a multitude of FSW-directed HIV social and behavioral research studies have been conducted. Additionally, the existing work among FSWs within this context, and elsewhere, has often been limited to studies focused on research ethics issues within vaccine or other HIV prevention trials (Suhadev et al., 2006; Ditmore & Allman, 2011; Berkley, 2008; Jayaraman, 2008; NIMH Collaborative HIV/STD Prevention Trial Group, 2007; Sahay & Mehendale, 2004; Thomas, 2004). In conclusion, less investigation on HIV research ethics issues (in India and elsewhere) has focused on the conduct of social and behavioral epidemiological studies, and this is particularly limited among FSWs.

The purpose of this research is to: (1) identify factors that have not been adequately considered or implemented in past research efforts in this region; (2) inform the implementation of future HIV prevention research efforts, considering specific cultural meanings of important ethical domains (confidentiality, privacy, and respect) in the region; (3) determine whether revision or reinterpretation is needed to existing research ethics protocols; and (4) guide the ethical conduct of work implemented in similar settings.

Methods

Semi-structured interviews were conducted with 30 FSWs recruited by word of mouth from Nari-Saksham, a community-based organization led by and serving FSWs based in Rajahmundry. Details of the methodology and study limitations appear at DOI: 10.1525/jer.2014.9.1.S1.

Results

Sample Characteristics. The average age of the sample was 37 years (range = 24–50). The majority of women (93%) had lived in the same town for over the past 10 years. Most reported having been married (73%): 13% were currently married, 37% were separated from husbands, 13% divorced, and 10% widowed (27% chose not to answer this question). The majority of women (60%) reported having a “temporary husband” (i.e., boyfriend or relationship partner). Most women reported working across multiple venues (73%), whereas 13% reported working in a rented room, and 6% each worked at home or in agricultural fields.

Types of Studies in Which Women Reported Participation. All women had participated in more than one previous HIV research study. Studies consisted of social and behavioral risk surveys collecting information related to women’s HIV risk (e.g., including information on demographics, sexual risk behaviors, type of sex work and information on clients, experiences with police, history of victimization, social support systems, access to services, and history of STD symptoms). Women also reported participating in qualitative interviews assessing women’s life histories and ongoing challenges across multiple domains. One study reported by women included HIV testing and provision of HIV results as well as a social and behavioral risk survey. While most studies were conducted by organized research entities (the Indian public health service and US-based entities such as the Ford Foundation and Gates Foundation), some women also discussed participating in smaller-scale research studies with local students and unknown entities not linked to a particular institution, though these were reported less frequently. Recruitment was generally through word of mouth, where women would hear about the research study from other women and seek participation. With some exceptions (which are discussed in more detail below), women reported that studies followed standard ethical procedures, including the provision of informed consent, assurance of confidentiality, and information on HIV, HIV/STI testing, and local support services. Given low literacy levels, consent as well as information on support services was usually provided orally.

OVERVIEW OF COMMON THEMES

Initially, the first five interviews were coded using an *a priori* code list created by the research team that was based on key domains of interest, including: women’s fear of loss of confidentiality and privacy; events where confidentiality and privacy were breached by researchers;

ways in which confidentiality and privacy could be ensured by research staff and the surrounding research environment; and how respect between participant and research staff was or was not established. Based on interview themes, initial codes were expanded to include: issues related to the gender of the interview facilitator; more specific negative and positive experiences reported from staff interaction with participants during the study process; the nature of respectful and nonrespectful interactions; and women's perceptions of the inclusion of sensitive questions within research surveys. In the following sections, we illustrate these themes through the words of our respondents.

Confidentiality and Privacy

Most participants reported that when they were first approached to participate in the study, they were fearful that the information they provided would be shared with outside entities (e.g., often police, other community members). Prior to these HIV prevention studies, little attention was dedicated to the FSW community in terms of their health and social needs. Until the initiation of these multiple HIV prevention research studies (and subsequently, the local community-based organization of FSWs), women were not aware that so many other women were also working as FSWs in the local area. Thus, the initiation of HIV prevention research and sudden interest in the well-being of women working as sex workers appears to have been met with initial skepticism, as well as interest, from the FSW community.

PUBLIC EXPOSURE AS A SEX WORKER

For many women, their first experiences participating in HIV research were accompanied by fears of being identified as a sex worker by local media, police, and other study participants either intentionally by research staff or unintentionally revealed based on the locale in which they participated.

I had the fear that these people might give my interview to the TV and newspapers.

All the women were scared that ... people would hand us over to police after.

I had the impression that the interviewers say [that they keep our responses confidential] ... but they would discuss about our responses with others as soon as the participants go away.... Suppose another woman comes after me, though the interviewer does not disclose my name, she would definitely say to others, "That woman was like that ... she used to do like this."

Women commonly reported that they felt most confident that their sex worker identity would not be revealed when participating in studies conducted by entities that were known and trusted.

We (I) would not go if unknown people invited me into studies. Since I know these people, I participated because of the trust that I had on them.

... if some unknown persons come, how can we give interview to them?... I would first learn about the team and the organization they come from. Then only I would participate in the interview.

Once at the site, some concerns about confidentiality were alleviated after the consent form was read by the interview facilitator, especially when it was emphasized that the survey or transcribed interview would not contain any identifying information.

After reading the consent form, we came to know that except [for] our ID numbers, our names would not be written ... since all these were told beforehand, we got confidence that they would keep confidentiality of us.

[The researcher conducting the interview told me] "I do not know who you are and you do not know who I am. Apart from that we do not write your name." She [interviewer] showed the papers... She told, "We will seal these papers and put them in a locked file. ... No one can make out that the interview is yours." All these things gave us confidence. That is why we believed them.

INCIDENTS WHEN PRIVACY WAS NOT ENSURED

Women noted incidents when the physical location of the study infringed on their ability to keep their sex work private.

Some people [research studies] are conducting interviews at the hotspots under the trees in front of others. Some women are complaining, "It is not good when they talk where ever we were ... under the trees etc in front of others. This is not a good way."

I was scared a little while entering into the hotel [where the study was being conducted] as I thought that people might think why I was going to the lodge. ... If they come to my house my husband ... Once my husband suddenly came home while the study was on. He thought that I was talking to my staff and ignored us. If the study is conducted in a hotel, he might be suspicious for spending hours together in the hotel. [woman was afraid that her husband would find out that she is working as a sex worker.]

Women also reported incidents when their own or others' medical privacy were violated by study staff.

Then the counselor informed them that they have HIV. ...She is supposed to inform one after the other privately. She [HIV testing counselor] looked at four women who sat on a bench and said, "You have HIV; you have HIV; you have HIV."

They [survey staff] would make the women sit in a group [focus group session] and ask, "Do you have HIV? Did you go for CD-4 test? Since how long are you with this disease? Since how long are you in sex work profession?" What is meant by confidentiality? They should ask these privately.

... the staff used to enter the room during the interview.

It is different if we are asked separately like how you are asking now. If they ask [personal questions] in front of others [in a focus group], how can I answer [privately]? ... It would be better if people come and talk to us [about these personal topics] privately [one-on-one interviews].

Respect for Persons

Women described a number of factors related to their study participation that influenced their sense of being respected during study participation. These included interactions with staff, disrespectful questions which they had not anticipated from the description of the study, perceived lack of relevance of questions to improving the lives of sex workers, and aspects of the social and physical environment in which the study was conducted, including long waiting-times.

RESPECT AND STUDY STAFF

When asked what they would most prefer in an interview facilitator, women reported that they desired interview facilitators who treated them as an equal, indicating respect. Not surprisingly, this sense of equality and respect was also reported to determine the level of openness and honesty in women's responses.

When a sex worker is invited, she should not be ill-treated. They should say to us, "Amma ... [term indicating respect and being one of the same] whether you know me or not, we are here to talk to you." We will tell our problems only when they talk affectionately with us. They should have a kind heart. If they [researchers] talk to us only for their salaries ... if they say, "I am asking this ... you have

to answer like this." Naturally we will think of giving false responses ... thinking that they are working only for [the money].

... the way how you sat close to me to talk. They should also sit and talk pleasantly. Some people sit away from us because we are sex workers.

They should treat us equal to them ... they should not discriminate us as sex workers. They should adjust with us with a feeling of equality.

A staff member's disposition and manner when interacting with women was reported to be an important factor in women's feelings of being respected during the study process. Many women reported positive experiences with research staff.

They treated the participants respectfully. The women who were employed to interview us ... treated us like sisters. Sometimes, they would get tears when we were giving our responses.

They were very good with me. Even during two or three hours of interview duration, they treated with love and kindness. We felt like talking continuously with them.

Participants reported instances when staff were insensitive or had not been adequately trained to work in a respectful way with this particular population.

They did not know how to ask questions. The questions were like ... do you use condoms with your husband? Do you use them while sleeping with him (client) ... do you convince him [client] when he was drunk ... do you also drink etc. They were laughing while asking these questions.

Yes, she [interview facilitator] got several phone calls. I was interviewed by a young girl.... They appointed young girls from the [data entry] staff ... [the participant felt that the facilitator, who was a data entry staff member, was not trained to conduct the survey interview and, thus, did not conduct the study professionally in a respectful and mature manner.]

When I asked to find out if my card number was nearing [when participant would be interviewed] and asked if I can go down to attend some work, the staff member would say, "Your number has not come yet. Go and sit. You people come for money and at the same time you cannot wait."

In terms of the interview facilitators' ability to build respect and rapport, women overwhelmingly stated that they were more comfortable with female facilitators.

We cannot talk [about everything] with men. If they ask about STI symptoms..., how can we say that we have STI symptoms?

If the interviewer is female, we can talk affectionately. If the interviewer is male, we feel shy. We cannot talk like that with men.

There is difference talking to the women interviewer. How can we inform the male interviewers that we were beaten here and there? How can we tell them that we slept with this man and that man? How can we tell that I used condom during the last encounter? How can we tell them? Can we discuss these things with men? I cannot.

Notably, in response to whether they preferred a female or male facilitator, women also provided examples of when male facilitators engaged in activities that were demeaning to their dignity and betrayed their trust. Several women noted issues with one male study investigator who returned as a client with friends after the research was completed. Another scenario included a male posing as a study investigator, promising women to provide reimbursement in return for photos and sexual activities, but then left suddenly without fulfilling these promises.

he [research interviewer] developed affair with a community outreach worker. He also took his friends to the women [sex workers] ...just like a broker. That is not a sensible thing.... He took his friends to that area [later that night.]

One man came [for a survey].... I served him [had sex] with the hope of getting loan to start a shop. ... next day he packed the things and went away. We signed on the papers. We gave our photographs. That is the reason, why I stopped believing others ... because they are deceiving like this.

Women also indicated feeling disrespected as a result of interview facilitators who appeared to prioritize their own monetary needs over the responsible implementation of the research. For example, in many studies, interviewers were paid by the interview, and thus, research staff were perceived to be motivated to maximize the quantity of surveys conducted rather than on spending time on explanations and building rapport with women.

The interviewer read out the consent form hurriedly to start the interview and asked her to sign because there was no time.

They were only concerned with their target. They would say, "Bring four more women. If we get

another ten of them, we can reach our target." That was their style.

Women also reported incidents when interviewers asked offensive questions. In these scenarios, it was unlikely that the questions women report being asked were part of the questionnaire. However, this aspect was not clear to women while participating in the study, and regardless, women felt very disrespected as a result.

She asked, "When the man has a wife, why should you sleep with him?"

[repeating what the facilitator said], "When you have a lover ... why do you need temporary husband? Is it not enough to have a husband?"

RESPECT AND SENSITIVE SURVEY QUESTIONS

Many women also noted that they felt disrespected by some of the questions in standardized surveys and this made them question the motivations of the study staff.

No woman will give answer to such questions. ...If you ask the women about the number of encounters they do, they may get upset and may feel that you people are discriminating against their profession.

If the women are asked such questions like how many condoms does a woman use ... how many encounters she does ... it would be upsetting. If the woman is a secret sex worker ... she would feel bad you know? Women ...would say, "Why is that they are paying to get answers for these questions?"

Women reported that if staff were able to establish a rapport or explain the context and need for such questions, then this was helpful.

First time I was scared and thought ... why she was asking such shameless questions. I started looking down to hide my face. Then she told me, "... do not feel scared or shameful. I am also a woman like you. I too serve my husband the same way. That is why I could ask you." After she told that, I did not feel that she is someone out of my community. I felt like she was my friend or fellow sex worker. Later I got used to it.

Women reported that, over time, as a result of discussion within the FSW community, women increasingly perceived that such questions were meant to address challenges in women's lives, and as a result, did not perceive these questions to be out of disrespect.

That was in the beginning. But later when we came out [and discussed among our community members]

we felt that they were for our benefits. When we gave a thought on the questions ... then we realized that the researchers wanted to know what kind of difficulties sex workers are facing.

Earlier when we were not aware of that [the purpose of the questions], we felt shy. Sometimes we used to feel bad because of such questions. Gradually we started feeling good because we realized that the people ask us all these only for our well-being.

RESPECTFUL STUDY ENVIRONMENT AND ORGANIZATION

Women commonly indicated that the overall study environment influenced their feelings of respect and privacy. Factors related to women's level of physical comfort during study participation were noted as facilitating an environment of respect.

As soon as we went there, they offered chairs. When there were no chairs, they offered mats to sit.

They provided tea and talked about the study. We have not faced any inconvenience. It benefitted us.

In contrast, women reported separate bathrooms for study staff and participants in one research study, making them feel disrespected.

Though they came to conduct a research study on us, they looked down upon us. That was my observation. There were two wash rooms. One was kept entirely for staff and the other was for us. Do you think it (HIV) would be transmitted by sharing the toilets?

Women commonly reported long waiting periods for study participation, and the need for better organization for women to be able to participate in a timely way. Such study logistics that involved a significant amount of women's time spent waiting made women feel disrespected.

We used to sit and wait for our turn.... When the time was over, they used to say, "Today it's over ... there is no time ... your interview cannot be taken now ... come tomorrow."

I was taken to the office by 10:00 am and made to sit till 2:00 pm. Now they are saying that there is no time.

The women would lose Rs.1000 [approximately \$16] by losing those clients who would pay Rs.300 each. The women would lose Rs.1000 just for two hundred rupees [study reimbursement money].

Notably, in some instances, long waiting times also threatened women's ability to maintain privacy regarding their study participation.

The women had to spend four or five hours. Then their husbands used to hit the women by saying, "You said that you would return in an hour. What were you doing all these hours?" I have seen two to three women with injuries.

Discussion

The current paper builds on an expanding number of studies examining ethical challenges in the design and conduct of HIV prevention studies, particularly among highly stigmatized populations (Fisher et al., 2008; Fisher, 2010; Fisher & Wallace, 2000; Norris, Jackson, & Khoshnood, 2012; Simon, Mosavel, & van Stade, 2007). Overall, participant responses illuminated aspects of the consent process, staff gender and demeanor, study environment, survey content, and administrative organization and monitoring that were key factors influencing whether FSWs perceived their confidentiality and privacy had been maintained, and whether they felt the study was conducted respectfully. Findings highlight that investigation of participant's experiences in HIV research can provide critical information to best inform the responsible development of research ethics protocols, a particular priority among research studies with highly stigmatized populations, such as FSWs. Findings also reinforce the importance of such investigation as a first step in the design of research studies, particularly among marginalized groups. Such research is of particular concern in the context of India, where increasing HIV social and behavioral research is being conducted among FSWs in order to halt the expanding HIV epidemic in this region. Furthermore, findings highlight that conducting research in ways that are informed by the ethics-relevant values and sensitivities of FSWs is critical to ensure the scientific and social value of the data collected.

Regarding issues of confidentiality and privacy, this study illuminated specific participant fears related to breaches in confidentiality and privacy that might lead to incarceration, community stigma, or partner violence as well as procedures that mitigated those fears. In particular, participant comments underscored the utility of the consent process as well as ensuring a private study site location for increasing FSW trust in investigators' commitment to protecting confidentiality and privacy as well as reassurances regarding how these can be maintained. These findings parallel other non-HIV related studies on research ethics among FSWs, as well as research ethics studies among other marginalized groups (Shaver, 2005; Hardon et al., 2012; Duncan et al., 2009).

Study findings related to women's perceptions of respect are new to the literature on HIV research ethics

among FSWs, and particularly within the context of India. However, studies in other global contexts among other stigmatized groups (e.g., drug-using populations) have documented similar challenges in ensuring respect during study participation. For example, Fisher et al. (2008) reported incidences when participants perceived study staff to be solely motivated to make money for their own benefit. Women's preference for female interview facilitators, as reported in the current study, has also been reported in previous literature among other marginalized populations, though with some mixed results, likely based on the context and population (Lamb & Garretson, 2003; Reed et al., 2008). However, one previous study (non-HIV related) among FSWs reported more generally that discomfort or distrust during study participation had implications for the validity of the data collected (Shaver, 2005). Current study findings related to respondent negative reactions to sensitive questions have also been identified as a challenge in research among drug-using populations (usually U.S.-based research) (Fendrich, Lippert, & Johnson, 2007). This work emphasizes the challenges in asking sensitive questions among hidden populations involved in stigmatized or illegal behavior.

Best Practices

The utility of the consent process in addressing concerns related to a breach of confidentiality: Regarding confidentiality and privacy, findings emphasize the importance for future research protocols, especially within the consent form, to carefully consider and describe safety implications and protections for FSWs to participate in HIV research (e.g., given that women feared that their identification as a sex worker could lead to victimization, eviction, arrest, etc.).

Careful consideration is needed when asking sensitive questions: Regarding the issue of respect, findings underscore the importance for study staff to explain the rationale behind sensitive questions and how the data will be used in order to make participants more comfortable answering the questions and less suspicious of the researcher's agenda. Beyond training facilitators to be extremely sensitive to these questions and to develop a rapport with women, future protocols may benefit by including written explanations in the survey (for facilitators to read directly to women) that provide the reasons for these questions and how the data will be used to benefit the community. Furthermore, findings emphasized the importance of including community engagement to elicit support from the beginning of study design and implementation, and ultimately, increasing transparency and participant

understanding of study motivations, and improved respect felt among participants.

Other logistics, such as staff payment, can contribute to the ethical conduct of research: Furthermore, our respondents' comments illuminate aspects of study implementation outside of the written protocol (e.g., staff payment methods) that require additional attention to ensure the responsible conduct of HIV research involving marginalized populations. Findings from the current study suggested that the way in which staff were paid (e.g., if they are paid by the survey or interview or have a fixed payment based on time worked) may have implications for the quality of staff interactions with participants (e.g., whether staff spend time to build rapport or provide needed explanations).

Preferred female gender of the facilitator: Furthermore, current study findings indicating scenarios where women participants' respect and dignity was betrayed by male study facilitators, highlight the need for further consideration of the gender of study staff hired for projects collecting sensitive data (particularly data related to sexual behaviors) among highly stigmatized groups of women in India as well as in other global contexts. Women's reported discomfort with men also has implications for the scientific validity of interviews if the FSWs are uncomfortable providing sensitive information to male facilitators.

Need to address burdens on women's time: Findings related to women's reports of long wait times for study participation are also of critical importance to needed improvements in study protocols, especially if the long duration of time spent on study participation interferes with women's ability to make sufficient money required for food and other essentials. Our previous work has documented how economic burdens create an urgency in women's work and are associated with increased inconsistent condom use (i.e., agreeing to unprotected sex trades in order to make more money) and STI among women (Reed et al., 2010). Thus, it is imperative that future studies consider wait times in their protocol development in order to minimize the monetary sacrifices women need to make in order to participate in research studies.

Overall, in terms of best practices, while the ethical principles of confidentiality, privacy, and respect have been prioritized in research protocols with stigmatized groups, including FSWs, our findings suggest that community feedback early on and during study implementation may likely improve adequate response to unanticipated ethical problems. Community feedback and involvement appear to be critical to tailor ethical protocols, as well as other study procedures (e.g., including staff payment methods), to be most responsive to

ethical challenges, particularly when conducting research on sensitive issues (e.g., HIV, sexual behavior) among stigmatized populations.

Research Agenda

Interviews of study staff can elucidate the challenges and motivations involved in their work, and thus better inform future hiring and training protocols, and suggest methods of paying research staff that yield the most ethical staff behavior.

Educational Implications

Training of staff should be designed to ensure that they are sensitized to the unique challenges in female sex workers' lives and understand that ensuring respect is a top priority of research (e.g., beyond survey completion rates). The violations of confidentiality and privacy, described by our respondents, have important implications for additional training needs among medical and research staff.

Acknowledgments

This research was funded by the Fordham University HIV Prevention Research Ethics Training Institute (National Institute on Drug Abuse Training Grant # 1R25DA031608-01, Principal Investigator, Celia B. Fisher). We would like to acknowledge the contribution of the interview facilitator, Arshathunnisa Sultana Begum, for her immense dedication to this work. We would also like to acknowledge Yvonne Kodl and Amanda Borsky for their contributions in coding the interview data. We are grateful for the women who participated in the study for their critical feedback, time, and effort.

Author Note

Please direct communication to: Elizabeth Reed, University of California, San Diego, Department of Medicine, Division of Global Public Health, 9500 Gilman Drive, Mail code 0507, La Jolla, CA 92093. E-MAIL: lizreed@ucsd.edu.

Authors' Biographical Sketches

Elizabeth Reed is an assistant professor in the Department of Medicine, Division of Global Public Health, at the University of California, San Diego. She has focused her research to better understand the social, economic, and structural factors contributing to HIV and gender-based violence among women and girls globally. In terms of her contributions to the current manuscript, she was the recipient of the research funding as a Fordham HIV Research Ethics Training Institute fellow, and thus, led all investigation, analyses, and writing.

Kaveh Khoshnood is an associate professor of epidemiology at the Yale School of Public Health. His research interests include the epidemiology, prevention, and control of HIV/AIDS and tuberculosis among drug users, prisoners, and other at-risk populations in the United States and in resource-poor countries. Dr. Khoshnood was a primary mentor for Dr. Reed for the research ethics training fellowship and contributed conceptually, methodologically, and directly to the writing of the current manuscript.

Kim M. Blankenship is Professor and Chair in the Department of Sociology and Director of the Center on Health, Risk and Society at American University. Her research and publications focus on race, class, and gender analyses of health, with an emphasis on HIV/AIDS. Dr. Blankenship contributed conceptually, methodologically, and directly to the writing of the current manuscript.

Celia B. Fisher is the Marie Ward Doty Endowed University Chair and Professor of Psychology, as well as founding Director of the Fordham University Center for Ethics Education and the Principal Investigator of the NIDA-funded Fordham University Training Institute on HIV Prevention Research Ethics, which funded the research presented in this manuscript. Her research focuses on ethical issues and the well-being of vulnerable populations, including ethnic minority youth and families, active drug users, college students at risk for drinking problems, and adults with impaired consent capacity. Dr. Fisher contributed conceptually, methodologically, and directly to the writing of the current manuscript.

References

- BERKLEY, S. (2008). HIV vaccine trials in India. *Nature Biotechnology*, 26(5), 495.
- DAVIDSON, P., & PAGE, K. (2012). Research participation as work: Comparing the perspectives of researchers and economically marginalized populations. *American Journal of Public Health*, 102(7), 1254–1259.
- DITMORE, M. H., & ALLMAN, D. (2011). "Who is Helsinki?" Sex workers advise improving communication for good

- participatory practice in clinical trials. *Health Education Research*, 26(3), 466–475.
- DUNCAN, R. E., DREW S. E., HODGSON J., & SAWYER, S. M. (2009). Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. *Social Science & Medicine*, 69(11), 1691–1699.
- ERAUSQUIN, J. T., REED, E., & BLANKENSHIP, K. M. (2011). Policing and HIV risk among female sex workers in Andhra Pradesh, India. *Journal of Infectious Disease*, 204(Suppl 5), S1223–S1228.
- FENDRICH, M., LIPPERT, A. M., & JOHNSON, T. P. (2007). Respondent reactions to sensitive questions. *Journal of Empirical Research on Human Research Ethics*, 2(3), 31–37.
- FISHER, C. B., & WALLACE, S. A. (2000). Through the community looking glass: Re-evaluating the ethical and policy implications of research on adolescent risk and psychopathology. *Ethics and Behavior*, 10, 99–118.
- FISHER, C. B. (2002). Participant consultation: Ethical insights into parental permission and confidentiality procedures for policy relevant research with youth. In R. M. Lerner, F. Jacobs, & D. Wertlieb (Eds.), *Handbook of applied developmental science* (Vol. 4, pp. 371–396). Thousand Oaks, CA: Sage.
- FISHER, C. B. (2004). Ethics in drug abuse and related HIV risk research. *Applied Developmental Science*, 8, 90–102.
- FISHER, C. B., ORANSKY, M., MAHADEVAN, M., SINGER, M., MIRHEJ, G., & HODGE, D. (2008). Marginalized populations and drug addiction research: Realism, mistrust, and misconception. *IRB*, 30(3), 1–9.
- FISHER, C. B., & GOODMAN, S. J. (2009). Goodness-of-fit ethics for non-intervention research involving dangerous and illegal behaviors. In D. Buchanan, C. B. Fisher, & L. Gable (Eds.), *Research with high-risk populations: Balancing science, ethics, and law* (pp. 25–46). Washington, DC: APA Books.
- FISHER, C. B. (2010). Addiction research ethics and the Belmont principles: Do drug users have a different moral voice? *Substance Use & Misuse*, 46(6), 728–741.
- HARDON, A., VERNOOIJ, E., BONGOLOLO-MBERA, G., CHERUTICH, P., DESCLAUX, A., KYADDONDO, D., ET AL. (2012). Women's views on consent, counseling and confidentiality in PMTCT: A mixed-methods study in four African countries. *BMC Public Health*, 11, 12:26.
- JAYARAMAN, K. S. (2008). HIV vaccine controversy. *Nature Biotechnology*, 26(3), 256.
- LAMB, M. E., & GARRETSON, M. E. (2003). The effects of interviewer gender and child gender on the informativeness of alleged child sexual abuse victims in forensic interviews. *Law and Human Behavior*, 27(2), 157–171.
- LIU, S. H., SRIKRISHNAN, A. K., ZELAYA, C. E., SOLOMON, S., CELENTANO, D. D., & SHERMAN, S. G. (2011). Measuring perceived stigma in female sex workers in Chennai, India. *AIDS Care*, 23(5), 619–627.
- National AIDS Control Organization (NACO), Government of India. (2010). Ministry of Health & Family Welfare Department of AIDS Control. Retrieved from www.nacoonline.org/upload/HomePage/NACO%20Press%20Release%20on%20HIV%20Estimates.pdf.
- NIMH Collaborative HIV/STD Prevention Trial Group. (2007). Ethical issues in the NIMH Collaborative HIV/STD Prevention Trial. *AIDS*, 21(Suppl 2), S69–S80.
- NORRIS, A., JACKSON, A., & KHOSHNOOD, K. (2012). Exploring the ethics of observational research: The case of an HIV study in Tanzania. *AJOB Primary Research*, 3(4), 30–39.
- NTUMBANZONDO, M., DUBROW, R., NICCOLAI, L. M., MWANDAGALIRWA, K., & MERSON, M. H. (2006). Unprotected intercourse for extra money among commercial sex workers in Kinshasa, Democratic Republic of Congo. *AIDS Care*, 18(7), 777–785.
- REED, E., SILVERMAN, J. G., RAJ, A., ROTHMAN, E. F., DECKER, M. R., GOTTLIEB, B. R., ET AL. (2008). Social and environmental contexts of adolescent and young adult male perpetrators of intimate partner violence: A qualitative study. *American Journal of Men's Health*, 2, 260–271.
- REED, E., BIRADAVOLU, M., GUPTA, J., DEVIREDDY, V., & BLANKENSHIP, K. M. (2011). The role of housing in determining HIV risk among female sex workers in Andhra Pradesh, India: Considering women's life contexts. *Social Science & Medicine*, 72(5), 710–716.
- REED, E., GUPTA, J., BIRADAVOLU, M., DEVIREDDY, V., & BLANKENSHIP, K. M. (2010). The context of economic insecurity and its relation to violence and risk factors for HIV among female sex workers in Andhra Pradesh, India. *Public Health Reports*, 125(Suppl 4), 81–89.
- REED, E., GUPTA, J., & BLANKENSHIP, K. M. (2012). Migration/mobility and risk factors for HIV among female sex workers in Andhra Pradesh, India: Implications for HIV prevention. *International Journal of STDs and AIDS*, 23(4), e7–e13.
- SAHAY, S., & MEHENDALE, S. (2004). Addressing ethical concerns in the Indian HIV vaccine trials. *Indian Journal of Medical Ethics*, 1(4), 109–112.
- SCOTT, G. (2008). "They got their program, and I got mine": A cautionary tale concerning the ethical implications of using respondent-driven sampling to study injection drug users. *International Journal of Drug Policy*, 19, 42–51.
- SHAVER, F. F. (2005). Sex work research: Methodological and ethical challenges. *Journal of Interpersonal Violence*, 20(3), 296–319.
- SIMON, C., MOSAVEL, M., & VAN STADE, D. (2007). Ethical challenges in the design and conduct of locally relevant international health research. *Social Science & Medicine*, 64, 1960–1969.
- SUHADEV, M., NYAMATHI A.M., SWAMINATHAN, S., VENKATESAN, P., RAJA SAKTHIVEL, M., SHENBAGAVALLI, R., ET AL. (2006). A pilot study on willingness to participate in

- future preventive HIV vaccine trials. *Indian Journal of Medical Research*, 124(6), 631–640.
- THOMAS, J. (2004). Unmet ethical concerns of the proposed preventive HIV vaccine trials in India. *Indian Journal of Medical Ethics*, 1(3), 87–88.
- UNAIDS/WHO. (2005). *AIDS epidemic update*. Retrieved from www.unaids.org/epi/2005/doc/report_pdf.asp.
- WONG, W. C., HOLROYD, E., & BINGHAM, A. (2011). Stigma and sex work from the perspective of female sex workers in Hong Kong. *Sociology of Health & Illness*, 33(1), 50–65.
- ZALWANGO, F., ERIKSSON, L., SEELEY, J., NAKAMANYA, S., VANDEPITTE, J., & GROSSKURTH, H. (2011). Parenting and money making: Sex work and women's choices in urban Uganda. *Wagadu*, 8, 71–92.