



HHS Public Access

Author manuscript

AIDS Care. Author manuscript; available in PMC 2018 July 01.

Published in final edited form as:

AIDS Care. 2017 July ; 29(7): 914–918. doi:10.1080/09540121.2016.1271935.

Why female sex workers participate in HIV research: the illusion of voluntariness

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Abstract

The purpose of this study was to examine factors influencing the motivation for and perceived voluntariness of participation in non-intervention HIV research among female sex workers (FSW) in India. FSW (n=30) who participated in non-intervention HIV studies in the previous three years were recruited from a local community-based organization. Semi-structured qualitative interviews focused on women's personal and economic motivations for participation and their perceptions of the informed consent process. Interviews were audio-recorded, translated, transcribed, and reviewed for common themes. Content analysis indicated that while many women reported willing participation, reports of obligatory participation were also a common theme. Obligations included money-related pressures and coercion by other FSW, social pressures, not wanting to disappoint the researchers, and perceiving that they had a contractual agreement to complete participation as a result of signing the consent form. Findings suggest a need for additional efforts during and following informed consent to prevent obligatory participation in HIV research studies among FSW. Findings emphasize the importance of integrating ongoing participant feedback into research ethics practices to identify issues not well addressed via standard ethics protocols when conducting HIV research among vulnerable populations.

Keywords

HIV; female sex workers; research ethics

Introduction

There are 2.3 million people living with HIV in India (NACO, 2010). Female sex workers (FSW), in particular, are among the most affected subgroups, and the state of Andhra Pradesh has one of the highest prevalence rates (UNAIDS, 2005).

Ethically sensitive HIV prevention research must be responsive to FSW challenges, including stigma and discrimination due to women's identity as a sex worker becoming known (Erausquin, Reed, & Blankenship, 2011; Reed et al., 2010, 2011), which may result in housing evictions, marginalization, and violence from police, clients, and others (Wong, Holroyd, & Bingham, 2011; Reed, Biradavolu, Gupta, Devireddy, & Blankenship, 2011; Reed, Gupta, Biradavolu, Devireddy, & Blankenship, 2010; Reed, Gupta, & Blankenship, 2012). It is imperative that informed consent procedures adequately communicate risks associated with study participation and participant rights. It is also important to assess the degree to which monetary or other incentives may unduly influence participation. Although HIV prevention research studies follow standard ethical guidelines, they may not be fully responsive to the specific realities of FSW populations (Fisher & Goodman, 2009; Fisher, Oransky, Mahadevan, Singer, Mirhej, & Hodge, 2008).

Studies investigating research ethics among FSW have focused primarily on biomedical HIV prevention trials (e.g. Berkley, 2008; Brown, Daytvan, & Fisher, 2015; Ditmore & Allman, 2011; Suhadev, Nvamathi, Swaminathan, Venkatesan, Raja Sakthivel, Shenbagavalli, Suresh, & Fahey, 2006), and are limited for social and behavioral epidemiological studies, indicating an important gap in the literature (Reed, Khoshnood, Blankenship, & Fisher, 2014; Urada & Simmons, 2014). Thus, the purpose of this study was to examine motivations for research participation and understanding of participant rights among FSW involved in social and behavioral epidemiological studies for HIV prevention.

Methods

Semi-structured interviews were conducted in 2012 with 30 FSW recruited by word of mouth from Nari-Saksham, an FSW-led community-based collective in Rajahmundry, Andhra Pradesh. Eligible FSW participated in at least one HIV study in the previous three years.

Procedure

FSW were recruited through existing connections with Nari-Saksham leaders. A short screening form was used to determine eligibility, asking about past study involvement (e.g. number, study type, blood testing). All participants approached were eligible and agreed to participate in the interview. Participants were provided written consent, which was required by the local IRB. Interviews took about 90 minutes and were conducted in Telugu by a trained interviewer. Interviews focused on motivations for study participation, voluntariness, and perceptions of informed consent and participant rights. Women described personal research experiences and general sentiments in the local FSW community. Participants also completed a short demographic survey.

Facilitators provided information on local HIV services. All participants received reimbursement (Rs.300, approximately \$7) for their time. Interviews were audio-recorded, translated and transcribed. The study protocol was approved by Institutional Review Boards at the University of California, San Diego and the VHS-YRG Care Medical Centre in Chennai, India.

Analysis

Survey data were analyzed descriptively to characterize the sample. Interviews were analyzed using content analysis (Ryan & Weisner, 1996). All interviews were independently coded by two investigators and compared for agreement before finalization. No new codes emerged after two-thirds of the interviews were coded, suggesting content saturation was achieved.

Results

The average age of the sample was 37 (range = 24–50). The majority of women (93%) lived in Rajahmundry for the past 10 years. Most had been married (73%); 13% were currently married, 37% were separated, 13% divorced, and 10% widowed (27% did not answer). Most women (60%) reported having a boyfriend or partner. Women worked across multiple sex work venues (73%); 13% reported working in a rented room and 6% each worked at home or in agricultural fields.

All women had participated in more than one previous social and behavioral HIV research study involving quantitative surveys, with some studies including HIV testing. Most studies provided financial reimbursement. The majority of studies were conducted by organized research entities (e.g. Indian public health service); smaller scale research studies with local students and unknown entities were reported less frequently. With some exceptions (discussed below), women reported that studies followed standard ethical procedures.

Most women reported willing participation in research studies, citing an interest in contributing to positive community change, but their motivation for research participation was more complex. Importantly, scenarios of obligatory participation also emerged as a theme, including financial and social pressures, coercion by other FSW, not wanting to disappoint researchers, and perceptions of a contractual agreement to participate as a result of signing the consent form.

Motivations for Participation

While women acknowledged that financial incentives were a benefit of the research, some women reported that their participation in HIV research also stemmed from a desire to gain knowledge and to be part of a larger effort to improve conditions for FSW communities in India and abroad (Table 1).

Women felt that research participation would provide personal and community benefits, but also felt pressured to ensure larger benefits to other FSW. The implication was that it would be disrespectful to the larger FSW community to refuse participation. Motivations also included financial pressures (i.e. dire economic needs and debt). Some women reported

coercion to participate by madams or more senior FSW who wanted a percentage of their study reimbursement.

Voluntariness

FSW reported feeling uncomfortable answering sensitive questions, but continued because they felt it was disrespectful or a sign of poor character to quit early. Importantly, study completion indicated their integrity and resolve, though women also feared researchers would focus efforts elsewhere if FSW disappointed them, suggesting that FSW believed research would lead to subsequent improvements for FSW (Table 2).

Informed Consent and Contractual Obligation

Women also reported continuing with studies, despite discomfort, because they perceived that the consent process and signing the consent form provided a guarantee or contract of participation. (Table 3)

Discussion

This study is among the first to document motivations of FSW to participate in social and behavioral HIV prevention research, highlighting ways to improve future ethics protocols. Findings indicate that true voluntariness in research is complex and difficult to achieve among FSW in India. Although women reported participating in research because they wanted to give back to their community, they also faced significant personal and community pressures. Misunderstandings of the informed consent process may also threaten the ethical conduct of research with FSW.

Our findings suggest that economic vulnerability may underlie a sense of urgency to participate in research, despite attempts at compensation that is not coercive. Studies with other stigmatized groups have reported similar findings (Davidson & Page, 2012; Fisher, 2010; Fisher & Goodman, 2009; Emanuel, 2005; Klitzman, 2005). Community-driven financial pressures may also play a role. Respondents reported that madams or more senior FSW took women to participate in research, charging commission on study reimbursements. Although our previous work demonstrated the importance of including the community early in the development of research ethics protocols (Reed et al., 2014), current study findings suggest that community *support* of research projects may also create *pressure* to participate. Future related studies must develop effective strategies for ascertaining voluntariness in study participation, in lieu of economic vulnerabilities and the potential for coercion by others.

Findings also suggest that the consent form may be interpreted in some contexts as a contract requiring participation (e.g. "*giving my word*" to participate in full). Although studies have shown limitations of the informed consent process to communicate participant rights, particularly in HIV treatment trials (Chiasson, Kass, Chengeta, Mathebula, Samandari, 2011; Jefford & Moore, 2008), ours is among the first to document that informed consent, and the signature requirement, can be perceived as a contractual agreement for study completion. While women confirmed that the facilitator explained their rights to stop at any time, some participants saw withdrawal as a sign of disrespect or lack of

personal commitment, while others thought that signing the consent document guaranteed completion. In future studies, verbal consent may lessen such misunderstandings; however it may not be sufficient alone to ensure participant understanding of their rights.

This study has several limitations. Participants may have been reluctant to report negative research experiences, fearing it would discourage future research investment in this region. All women provided criticisms of their research participation, however, so we believe women felt free to answer questions openly. Our findings may be most generalizable to the experiences of FSW who belong to similar sex work collectives. Additionally, all study participants reported involvement in more than one research study, indicating a higher level of research literacy than may be representative of the broader FSW community. Finally, study findings are most applicable to FSW in this geographic region, but may inform research with similar populations in other low and middle-income settings.

In summary, our findings have implications for the development of future HIV research protocols among FSW. We highlight the limitations of expert-driven ethical decision-making in developing protocols that are responsive to the needs of marginalized communities (Buchanan, 2008; Fisher, 2010; Reed et al., 2014; Simon, Mosavel, & van Stade, 2007). Findings point to the need for ongoing community feedback to tailor ethical protocols to local challenges, especially when conducting research on sensitive issues among stigmatized populations.

Acknowledgments

We would like to acknowledge the contribution of the interview facilitator, Arshathunnisa Sultana Begum, for her interview skills and 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.

Funding

This research was supported by the Fordham University HIV Prevention Research Ethics Training Institute under a grant provided by the National Institute on Drug Abuse Training Grant (# 1R25DA031608-01, Principal Investigator, Celia B. Fisher); and also supported by the National Institute of Mental Health (#K01MH099969, Principal Investigator, Elizabeth Reed).

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Table 1

Motivations for Participation in HIV Prevention Research Studies

<p>Personal and Community Benefits: “The Women Come with Hope...”</p> <p>a) It was not only for money but also with the idea of learning new things</p> <p>b) The women come with a hope that the researchers would do something for their well-being.</p> <p>c) My voice would go to far off places.</p> <p>d) They would say, “Though you face problems... though you dislike... if you take a step now, the others would benefit in the future...”</p> <p>e) <i>They would mobilize us and made us participate in the study.</i> [Participant was referring to efforts in the community to foster collective action to improve safety and health among FSW, saying these same efforts were used to pressure women to participate in HIV prevention research studies.]</p>
<p>Personal Monetary Incentives: “We need the money you know”</p> <p>f) I signed it with fear.... I was getting Rs.250/-. Why should I miss that? My household condition is poor. If I eat one meal... it is difficult to get the other meal the same day.</p> <p>g) My financial situation was ...bad... I had to pay electricity and cable bill... we need money you know?</p> <p>h) My intention to participate in the study is to pay the money lender.</p> <p>i) What if we do not have money? Where can I get money for installments [interest for debts]? ... That is why I signed the form.</p>
<p>Monetary Community Coercion: “I had to give commission.”</p> <p>j) I was forced [to participate in the study] and they [madams] took money from me. When I got Rs.250/-, they took Rs.100/- from me.</p> <p>k) I had to give commission [pay another FSW a portion of the study reimbursement] for my participation. I paid commission for my participation.</p>

Table 2

Voluntariness in HIV Prevention Research Studies

Voluntariness: “They would not quit.”	
a.	You read it out and the people in the earlier interviews also read it out. They read, “If you do not like you can quit... if the questions hurt you, you can quit.” When they said so, how would we think of quitting? ...When our sex workers think of doing a thing... they would not quit it until they complete it. Our community would not take back step. But if you see the non-community [non-FSW]... you can find them quitting in the middle. That is their character. But our community does not have that character. If they start a thing... they would never take a back step until they complete it.
b.	But if I quit in the middle, ...no one would call us [in the future to participate in other studies].
c.	We usually control ourselves because we feel that it does not look respectful to discontinue.
d.	[Study facilitator] told me that I can quit the study if I cannot answer But I told her that I was not among such persons to quit I went there with a strong mind.

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Table 3

Informed Consent in HIV Prevention Research Studies

<i>Informed Consent Form and Contractual Obligation: "I signed the form."</i>	
a.	I thought, "Since I am signing, I would have to answer the questions without fail." ... I was told that I can quit. But how can we quit without manners? ...I thought that I should complete the interview because I signed the form.
b.	If I do not like or the issues are not comfortable for me to talk about, I would decide whether to participate in the study in the beginning. How can anyone quit the study just because the questions are not comfortable even after going through the consent form thoroughly? He/she would refuse to answer that particular question. ...In my opinion, it not a good practice.

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