

The methodological and practical concerns of conducting an integrated bio-behavioural survey with female sex workers: Lessons from the field

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BACKGROUND

Globally, HIV prevalence among female sex workers (FSWs) is higher than in the general population, making HIV research among FSWs an important undertaking. However, due to the stigma associated with sex work, FSWs are a hidden population difficult to engage in research studies. This formative research study considered methodological practices that were acceptable and suitable to FSWs and that would ensure optimal participation in the South African Health Monitoring Study (SAHMS), an integrated biological-behavioural survey (IBBS).

METHODS

The study was conducted in Durban, Johannesburg and Cape Town in 2013. Through purposive sampling, 91 FSWs participated in focus group discussions. Twenty-one researchers and stakeholders working closely with FSWs and FSWs themselves participated in in-depth interviews. Data was collected using a semi-structured qualitative interview guide.

RESULTS

Respondent-driven sampling was cited as the preferred recruitment method. Participants provided recommendations on IBBS study procedures, study logistics and the disposition of study staff. The majority of participants were confident that FSWs enrolled in IBBS would be willing to test for HIV, as well as accept the use of biometrics and laptops. Participants' concerns about confidentiality and study staff attitudes were cited as common barriers to participation.

CONCLUSION

Participation of FSWs in an IBBS is important to determine HIV prevalence and inform prevention strategies. Using a participatory approach to engage FSWs in research studies can help ensure ethical research implementation, inform methodological best practices and increase recruitment and participation. Including FSWs in the planning and implementation of surveys can contribute to their sense of community empowerment.

Key words: Participation; research, methods; HIV; female sex workers; IBBS

BACKGROUND

HIV prevention and care programmes have focused largely on general populations at the expense of key high-risk populations such as sex workers, men who have sex with men, and people who inject drugs (WHO, 2016). Until recently, female sex workers (FSWs) were underrepresented in surveillance studies in most of sub-Saharan Africa due to stigma, discrimination, and criminalisation of sex work, as well as the perception among many in the scientific community that FSWs are an inaccessible population (Baral, 2012; Richter, Chersich, Temmerman, & Luchters, 2013; Gould & Fick, 2008, Scheibe, Drame & Shannon, 2012; Scorgie et al., 2013). The paucity of rigorous studies on FSWs makes it difficult for researchers, programme planners, and scholars to gain much-needed insights regarding this population.

Several studies have highlighted challenges to engaging marginalised and vulnerable populations such as FSWs in research (Magnani, Sabin, Saidel, & Heckathorn, 2005; Remple, Johnston, Patrick, Tyndall & Jolly, 2007; Schwartländer, 2001). These challenges include difficulties in recruitment or sustained participation, often due to mistrust and feelings of exploitation expressed by members of the study population (Urada & Simmons, 2014; Fisher Wallace & Fenton, 2000; Fisher et al., 2008; Oransky, Fisher, Mahadevan, & Singer, 2009). Studies by Gerassi, Edmond and Nichols (2017), Jeffreys (2009) and Shaver (2005) argue for a person-centered, participatory approach to research with FSWs. In practice, this translates into the involvement of FSWs in the steps of the research process such as research planning, question formation, methodology development, and data collection and analysis. Some studies have researched best practices for engaging FSWs and other key populations in research, but these have been conducted outside of Africa (Sinha, 2017; Goldernburg et al., 2015; Goldernburg, Brouwer, Jimenez, Miranda & Mindt, 2016; Reed, Fisher, Blankenship, Khoshnood, 2017). This study fills a gap in the literature by considering methodological best practices for FSWs in South Africa.

The South African Health Monitoring Study (SAHMS) was an integrated biological-behavioural survey (IBBS) of HIV and associated risk factors conducted among inner-city FSWs in Durban, Johannesburg and Cape Town in 2013-2014. Prior to IBBS implementation, researchers conducted a formative assessment to consult FSWs on the appropriateness of operational plans, including community entry and mobilisation, recruitment methodology, study procedures and logistics, to ensure their optimum participation in the IBBS. Ultimately, 2180 FSWs in the three cities participated in the IBBS—exceeding the target sample size of 1500 (500 per site). Results have been published in the South African Health Monitoring Study, Final Report: The Integrated Biological and Behavioural Survey among Female Sex Workers, South Africa, 2013-2014 (UCSF, Anova Health Institute, & WRHI,

2015). In this paper, we focus on the SAHMS formative assessment findings that informed our engagement with FSW communities on the operational plans, which likely contributed to the successful recruitment and implementation of the IBBS.

METHODS

Research design

To conduct the formative assessment, we used qualitative methods, including focus group discussions (FGDs) and key informant interviews (KIIs), to explore and understand the context in which FSWs live and work. The formative assessment used the constructivist paradigm which suggests that individuals experience multiple socially constructed realities in their social world (Chilisa & Kawulich, 2012). This paradigm enabled researchers to understand individual experiences and how participants create meaning, which informs their unique understanding of the world (Creswell, 2014). The formative assessment sought to capture an understanding of FSWs, researchers and stakeholders' perspectives of methodological best practices that encourage research participation.

Sampling technique

Purposive sampling was used to recruit study participants. The selection of the initial contacts was guided by the national coordinator of a sex worker organisation who assisted in identifying FSWs in each city who would be willing to participate in the study. Purposive sampling was followed by a chain-referral of sex workers into the study. Furthermore, the authors purposefully sampled and interviewed stakeholders and researchers from various organisations working with the sex worker community in each city.

Sample

A total of 11 FGDs were conducted with 91 FSWs, including four FGDs in Durban (39 participants total), three FGDs in Johannesburg (27 participants total), and four FGDs in Cape Town (25 participants total). A total of 21 KIIs were conducted, five in Durban (three FSWs, one researcher and one stakeholder), nine in Johannesburg (four FSWs, three researchers and two stakeholders), and seven in Cape Town (five FSWs, one researcher and one stakeholder). Because seven FSWs participated in both an FGD and a KII, the total sample size of FSWs was 96.

Data collection and procedure

A semi-structured interview guide consisting of two sections was used to collect data. The first section included demographic information; origin of FSWs in the three cities; the different types of sex work; where and when they work; and challenges they face in doing sex work and accessing health care. The second section focused on the feasibility of conducting an IBBS. Questions

asked about the process of community entry and mobilisation; study procedures such as informed consent; duration of the study; HIV testing; use of biometrics (a fingerprint scanner) to prevent double counting of participants); use of laptops; willingness to answer questions on sexual behavior; and logistics of the IBBS such as study office location, office hours, and study staff. Participants were also asked to choose the appropriate recruitment strategy for FSWs. They could choose between respondent-driven sampling (RDS), which is peer-to-peer recruitment of study participants through the use of invitation cards, and time-location sampling (TLS), which utilises an ethnographic understanding of a population based on a random selection of venues, day and times where they are most likely to be present.

Interviews were conducted first with researchers and stakeholders to provide a general understanding of the sex worker community. These were followed by FGDs and KIIs with FSWs. All sessions were conducted in the participant's preferred language which included isiXhosa, isiZulu, and English. Interviews lasted approximately 45 minutes for KIIs and 120 minutes for FGDs. Two researchers with a tertiary education conducted both the FGDs and KIIs; while one facilitated the other took notes. Sessions were also recorded with participants' consent. Data were collected between January and February 2013.

Data analysis

The first author transcribed and translated the data verbatim from isiZulu and isiXhosa to English. Data were analysed using a thematic approach. The authors coded the data, and after extensive consideration of the coded transcripts, the authors reached a consensus about the emerging themes. The analysis followed the six steps outlined by Braun and Clarke (2006) to translate and transcribe the data, familiarise oneself with the data by reading and re-reading, generate codes from the data, generate themes from the codes, define and refine the identified themes, and employ the identified themes in the final presentation of study findings.

Ethical considerations

All participants provided written informed consent. Ethical permission was obtained from the Ethical Review Board of the University of Cape Town, South Africa (IRB number 00001938). Personal identifiers were removed to ensure anonymity.

RESULTS

The majority of FSW participants were street-based black isiXhosa- and isiZulu-speaking South African FSWs between the ages of 19-60 years (Table 1). Foreign FSWs were from Zimbabwe, Zambia and Lesotho. The education attainment of most FSWs was up to secondary level schooling, which most did not complete. Two participants had no schooling, and very few FSW participants

had undergone tertiary education. All researchers and stakeholders had undergone tertiary education and had experience working with FSWs.

Table 1. Demographic information of FSWs in focus groups discussions and key informant interviews in South Africa.

Demographics	Frequency (Percentage)		
Age group	Durban	Johannesburg	Cape Town
19-23	9 (23%)	2 (6%)	1 (4%)
24-28	12 (31%)	4 (13%)	4 (13%)
29-33	7 (18%)	11 (35%)	5 (19%)
34-38	5 (13%)	7 (23%)	8 (31%)
39+	6 (15%)	7 (23%)	8 (31%)
Education level			
No school	2 (5%)	0 (0%)	0 (0%)
Primary school	2 (5%)	0 (0%)	0 (0%)
Secondary school	27 (69%)	22 (71%)	22 (85%)
Matric	6 (15%)	8 (26%)	3 (11%)
Tertiary	2 (5%)	1 (3%)	1 (4%)
Language			
IsiZulu	28 (72%)	10 (32%)	1 (4%)
IsiXhosa	4 (10%)	12 (39%)	18 (69%)
Sesotho	4 (10%)	5 (16%)	1 (3%)
Other	3 (8%)	5 (16%)	6 (23%)
Race			
Black	37 (95%)	31 (100%)	21 (81%)
Coloured	2 (5%)	0 (0%)	5 (19%)
Indian	0 (0%)	0 (0%)	0 (0%)
White	0 (0%)	0 (0%)	0 (0%)
Country of origin			
South Africa	38 (97%)	24 (77%)	25 (96%)
Zimbabwe	0 (0%)	6 (19%)	0 (0%)
Lesotho	1 (3%)	1 (3%)	0 (0%)
Zambia	0 (0%)	0 (0%)	1 (4%)
Total	39 (100%)	31 (100%)	26 (100%)

During the formative assessment, participants provided suggestions on community entry and mobilisation, recruitment strategies, study procedures and study logistics, which are the major themes for this results section.

Community entry and mobilisation

Participants in all three cities emphasised that researchers needed to engage with organisations that work closely with FSW peer educators to gain community entry. These peer educators are often resourceful in helping researchers access the community and mobilise FSWs to participate in research studies.

'For us to participate in your study we need to know who you are. You cannot just come to us on your own, we will look

at you and ignore you. Others will say nasty words to you. Come to us through our organisation.’ (FGD1, FSW, Durban)

Recruitment strategies

The majority of participants in all three cities selected RDS as the preferred method of recruitment.

‘I think the first one [RDS] will work best, for instance when I get the cards I will give it to people that I know and I will convince them to come. But the other one [TLS] where you are going to them yourself is going to be a flop, because they will either be busy working or drinking.’ (FGD1, FSW, Cape Town)

Some FSW participants expressed that both methods could work because they cater to different types of FSWs working under different circumstances. Some felt that TLS could work best among hotel- and brothel-based sex workers because they may not have the time to go to the study site. RDS could work for street-based FSWs because they have flexible working hours and can make time to come to the study site and participate.

‘No I want to say that both methods would work. The one for invitation cards [RDS] will work for street-based sex workers, and the second method [TLS] will work for the indoors because it involves going to them.’ (FGD1, FSW, Cape Town)

Study procedures

Informed consent

Participants were told that they would have to read and sign informed consent. A researcher from Johannesburg suggested that the informed consent form should be ‘short and easy to read, as well as simplified and explained to participants who cannot read.’

Duration of the study

Participants in all cities felt that 2-3 hours was too long a period to participate in all study procedures. However, willingness of FSWs to participate in the study was highly dependent on monetary incentives and whether they felt that the incentive made up for time spent.

‘As long as you give them an incentive they will come, they want money. We attend support group once a month for 5 hours but because we get money for transport and food we come.’ (FDG1, FSW, Johannesburg)

One incentive for participation may be having access to HIV testing. One FSW expressed her genuine appreciation for research studies by recognising their importance in encouraging HIV testing as well as effecting social change.

‘Well in my opinion, I support surveys, especially the ones that provide HIV testing; people are afraid to test. For example, I am HIV positive and I was afraid to test, but eventually I participated in a survey and that’s when I found out that I

was HIV positive. If I did not participate in that survey, I could have probably been dead by now. So, I find that participation in surveys is very helpful.’ (FGD2, FSW, Cape Town)

HIV testing

The majority of participants from all the cities expressed confidence in FSWs’ willingness to test for HIV. This was partly due to exposure to HIV testing through research programmes providing direct service delivery.

‘Most of the ladies are used to being tested at the clinic. Wits [Wits Reproductive Health and HIV Institute] normally does a lot of studies so they are used to participating in research.’ (KII, stakeholder, Johannesburg)

‘No, they won’t have a problem. I will do it [HIV testing] first; I will be the first example so when they see us test they will be encouraged to test.’ (KII, FSW, Cape Town)

Biometrics

Participants were asked about the willingness of FSWs to use biometrics. Participants in all cities indicated that FSWs would need to be taught how the biometric works. Some FSWs, especially those who have been involved in criminal activity, would associate the scanning of fingerprints with being arrested.

‘Well you need to explain to them how it works because the fingerprint scanner will remind them of the mofotouch [fingerprint device] that the police use and that one generates their personal information. I personally have not used the fingerprint scanner but there was a study that was being piloted here the other time and they were using the fingerprint scanner and it worked, so just explain to them that it isn’t connected to the police or any law enforcement.’ (KII, researcher, Cape Town)

Use of a laptop to record survey responses

Participants felt that FSWs are familiar with laptop computers and would not have a problem with their use in the study. However, their only concern was with having their picture taken without permission.

‘We are used to computers, we don’t mind answering questions from a laptop; the worst thing FSWs can see is a camera, they hate camera.’ (FGD3, FSW, Johannesburg)

Willingness to answer questions related to sexual behaviour

Opinions were mixed as to whether FSWs would respond openly and truthfully to questions about sexual behaviour during IBBS. Some researchers and stakeholders suggested that the informed consent process should make it clear why these questions are being asked and how knowledge gained would benefit the FSW population. Some FSWs suggested that it would also be beneficial to have FSWs ask these questions because FSWs would likely be more willing to open up to a fellow

sex worker.

'... It is important to make it clear why you asking questions on sexual behaviour just so it's easier for them to respond.' (KII, researcher, Johannesburg)

'Well the thing is FSWs trust us, so if we ask them such questions they respond and are comfortable knowing that what they tell us remains confidential. But if you walk up to them and start asking them questions without us, they will get suspicious and not respond to you because they will think that maybe you want to write an article about them or put them on TV. But we as sex workers, they trust us and so respond to us freely because they know us and we have never exposed them.' (KII, FSW peer educator, Johannesburg)

Study logistics

Office location

In suggesting the location of the study office, participants considered the centrality of the area in relation to public transport, as well as safety, familiarity and anonymity.

'Your office should be in town because it's easier for most of us to get there; make sure it is in one of those busy buildings with other different offices because we don't want people noticing that it's only sex workers who come there.' (KII, FSW, Durban)

Office hours

The proposed office hours for Durban and Johannesburg were Tuesdays to Thursdays from 10:00 to 16:00. Most participants said that on Mondays sex workers are tired from the weekend and Fridays are busy days when they see the most clients. Cape Town differed slightly, as participants proposed Mondays to Thursdays because Mondays are usually quiet for business and FSWs are more likely to need money and therefore be willing to participate in the study.

Study staff

Participants were asked whether FSWs would prefer male or female interviewers and counsellors. Most FSWs stated that the gender of the study staff was not important, but what mattered was staff attitudes toward FSWs. Furthermore, both FSWs and researchers mentioned that having FSWs as part of the study staff may help to ensure that participants feel confident that the study office is sex-worker friendly. Some participants felt that study staff should be proficient with the local languages spoken in each city.

'You need to have well-trained staff people who are not judgmental who understand sex work issues, so someone outside from the sex-work community will not be a problem. However, it is always advantageous to have trained sex workers as part of the research but in essence people who are nice and

empathetic.' (KII, researcher, Johannesburg)

DISCUSSION

While the SAHMS survey ultimately included widely accepted recruitment methods and practices to reach FSWs, the engagement between researchers and FSW community stakeholders provided each with critical information about the other's practices, habits, and needs from the survey. Participants in our formative assessment suggested that involving sex worker organisations would be helpful in facilitating community entry. This finding was similar to a study conducted in Guatemala among FSWs that utilised an HIV prevention organisation which served sex workers to train outreach workers on how to gain entry into the sex work community and appropriate ways to recruit sex workers into the study (Goldenberg et al., 2016). Similar to our findings, Grassi and colleagues (2016) and Asthana and Oostvogels (2006) emphasised that researchers should consider partnering with community-based organisations as well as members of the target population. Peers make entry into the target population possible and give voice to their fears and concerns.

Our study sample's preference for RDS is consistent with the findings of others (Gerrassi et al., 2017; Heckathorn, 2011; Johnston et al., 2006; Okal et al., 2016) that have established this methodology as a best practice for HIV surveillance with key populations. However, it cannot be taken for granted that RDS will work with these populations without substantive community engagement. Grassi and colleagues (2017) suggest that diverse strategies of recruitment may be beneficial to ensure representation of various subgroups.

Our study participants highlighted the importance of incentives. The use of incentives in research is highly contested; it has been viewed in some instances as a form of coercion (Oransky et al., 2009, Sinha, 2016). However, incentives are also justified in that they compensate participants for their time (Sinha, 2016). To harmonise the balance between coercion and compensation, IRBs in most African institutions provide guidance on what incentives to give. One participant in this study saw an added benefit of having the opportunity to test for HIV to know their status and receive health care. Similar findings were reported by Goldenberg and colleagues (2015).

Informed consent informs participants about the aims of the study, procedures, risks and benefits of participation as well as ensuring voluntary participation. A suggestion from this study was that the consent forms should be short and easy to read. To encourage truthful responses on questions about sexual behaviour, participants suggested that researchers explain the usefulness of this information during the informed consent process. According to Sinha (2017), informed consent should be thoroughly understood by interviewers and participants as a process, and not merely the signing of the form.

This assessment confirmed the idea that study staff may encourage or hinder participation. While FSWs in this study were not particular about the gender of the staff, they emphasised how important it is that study staff are respectful and non-judgmental. Similarly, in a study by Reed and colleagues (2014), participants described respect as being treated as equals by interviewers. Body language was an indicator of respect; participants sensed when interviewers were uncomfortable or viewed them with disdain. The tone of voice and manner in which sensitive questions were asked was also used by participants to ascertain respect and determined whether FSWs responded openly to interview questions. As reported in this study and others, participants felt that having members of the FSW community as study staff may bolster trust in the study. Urada and Simmons (2014) found that participants felt that knowing the interviewer or study coordinator increased their confidence in the confidentiality of the study. Goldenberg and colleagues (2015) found that FSWs were much more comfortable participating in projects with former or current sex workers as study staff. However, this finding may not apply in some contexts or instances where FSWs are not open about their involvement in sex work.

Participants in this study preferred that the location of the study office be in a familiar and easily accessible area, discreet from the public. Similarly, Reed and colleagues (2014) found that the physical location of the study office was important as participants felt that it could either expose or protect them. In Reed's (2014) study, participants mentioned that they were hesitant to participate if the study was being conducted at a hotel or if the study targeted the locations where they worked, for fear that community members would notice that the study engaged only with sex workers.

FSWs were not opposed to the use of biometrics; however, they suggested that peer educators from sex worker organisations should explain how they work. According to Blankenship and colleagues (2010), it is important for researchers to cater to the needs of FSWs who fear public visibility and create opportunities for those to participate in research without jeopardising their right to privacy.

This assessment is subject to several limitations. The findings from this study cannot easily be generalised to represent the knowledge or practices of FSW populations generally, as they are drawn from qualitative research with a purposively recruited sample. During focus group discussions, some participants' responses could have been influenced by what their peers were saying or the responses of facilitators. The formative assessment participants were largely street-based FSW who were relatively easy for study staff to recruit. Therefore, opinions and practices of hotel-, brothel-, and escort-based sex workers may not be represented. Similarly, the views of metropolitan FSWs, of whom this assessment was mainly comprised, may not be shared by FSWs working in smaller provincial cities or on transportation routes across South

Africa. Participation in this study was largely from black South African FSWs and may lack insights from FSWs of other race groups.

Nevertheless, this paper highlights the importance of informing research of vulnerable populations such as FSWs with their views and opinions. Future studies could consider taking the participatory approach further by building capacity for sex workers to be more directly involved in the planning of research studies, data collection and analysis as well as consulting with them in the write-up and dissemination of research results. Engaging FSWs in the research process could prove to be an empowering tool for FSWs, creating a sense of ownership and responsibility towards common issues of concern as well as ensuring the sustainability of interventions and enabling their participation in research on more equal terms with researchers than is currently possible.

CONCLUSION

The engagement of FSWs in research is paramount in response to the HIV epidemic. Challenges of research with FSWs include their being difficult to access because of stigma and their reluctance to participate in studies due to fear of their confidentiality being compromised. This study provides some insight into the methodological and practical concerns that future studies can consider before engaging in this type of research. We recommend a participatory approach to research with FSWs to create a sense of involvement and empowerment among FSW communities in HIV research.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests. The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the funding agencies.

AUTHOR'S CONTRIBUTIONS

TL conceived and designed the study. NFM and KM collected data, NFM transcribed interviews, analysed data, interpreted findings and drafted the manuscript. MG, TL, KM, HS, JM contributed to analysis and interpretation of findings, as well as preparation of the manuscript. All authors reviewed and approved the final version of this manuscript.

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