Chapter 4
Sex Workers Involved in HIV/AIDS Research

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This case study shows that equitable relationships between researchers and research participants are about a lot more than informed consent. For instance, the higher level of research literacy among the sex workers that was achieved in the Majengo clinic is a model for others to follow.
Doris Schroeder.

Abstract This case study is written as a personal story by an outside support worker starting to engage with sex workers, a vulnerable and stigmatized population in a Nairobi slum. We hope the shared experiences will give better insight into the difficulties faced by members of this key population as they eke out a living. It is also a positive case study, not one of exploitation, despite sex work being illegal in Kenya.

Keywords Clinical trials · Sex workers · Kenya · Women · Empowerment

My Experience Visiting Majengo

I took an assignment with the Sex Workers Outreach Programme (SWOP), a leading sex workers' health organization in Kenya that promotes the health, safety and wellbeing of sex workers, as well as affirming their rights as workers and as people. The programme is funded by CDC-PEPFAR[1] through the University of Manitoba, Canada. I began my assignment by visiting the Majengo slum where SWOP runs a health clinic targeting sex workers living in and working from these informal settlements.

I am Kenyan with a background in social work and public health. My public health interest is in HIV prevention, while my social work interest is in

[1]The US President's Emergency Plan for AIDS Relief, as implemented by the Centers for Disease Control and Prevention in the USA.

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D. Schroeder et al. (eds.), *Ethics Dumping*, SpringerBriefs in Research and Innovation Governance, https://doi.org/10.1007/978-3-319-64731-9_4

interventions. My hope is to build a strong foundation to improve the health and well-being of vulnerable and stigmatized communities such as LGBTs (lesbian, gay, bisexual and transgender persons) and sex workers.

I have lived in Nairobi for the greater part of my life, but like most Kenyans I had never visited a slum in Kenya. I was prepared for the unexpected, but it was like going to a different world. What struck me first were the overcrowding and the variety of activities that the residents engaged in for survival. The area is densely populated; it felt like being in a city within a city. The road we tried to drive along to access the slum was full of people selling second-hand shoes, clothes and household items. We had to stop and wait for close to ten minutes for the hawkers to clear a path – like parting the Red Sea – so that we could get into the clinic compound. I took a walk with a health worker from the Majengo sex workers clinic to meet some of the sex workers who live and work in the area. We saw dirty alleys, open sewers and lots of trash. There were women doing laundry on the sidewalks, and some sitting beside their doorsteps. Men were going in and out of the houses or just walking around, many looking as if they had been drinking heavily. I saw hardly any children; those I did come across were playing outside unsupervised. The more fortunate children were presumably attending school in other parts of the city, while many of the rest were at the dumpsites, trying to earn money by scavenging for recycling companies. The houses were small and squeezed together, poorly built with rusted metal roofs.

The sex workers to whom I was introduced on the narrow pathways and by the doorsteps were friendly, saying "Hello!" and "Karibu!" (welcome). One of them ushered us into her tiny room. She had been doing sex work since she was a teenager and now looked to be in her mid-50s. She was skinny; I think she weighed no more than 40 kg. Her single room was small and cramped, with no space for a kitchen area or a living room. But two beds were squeezed in. One of the beds, she said, was her "office … where I service my clients, and the other one is where I sleep when not working". Hanging on top of her bed was an assortment of underwear in different styles and colours. She smiled and said, "Some of my clients prefer me to wear different colours and shapes of underwear, so I keep this for them."

Seeing the Majengo slums and experiencing something of the life there was an eye-opening experience that I will not forget for the rest of my life.

About Majengo

The Majengo slums are about three kilometres away from Nairobi's central business district. One of the oldest slums in the country, it is located between Gikomba market (the biggest mitumba, or second-hand clothes market, in East Africa) and Eastleigh, a commercial hub that is now known as Little Mogadishu due to the huge number of Somali immigrants living in the area. Majengo can be traced back to

colonial times in the 1920s, when it was occupied by East African railway builders and those serving them.

In her book *The Comforts of Home: Prostitution in Colonial Nairobi*, White (1990) describes how cattle epidemics, locusts, famine and drought swept through Kenya in the 19th century. A lack of food and the spread of disease, including smallpox, in central Kenya caused the death of an estimated 70% of the population.

After the famine, the Nairobi economy began to boom in the mid-1920s, with men and women from neighbouring districts arriving to sell agricultural products. Many ended up staying in Majengo. Sex workers became Kenyan's "urban pioneers", and were among the first residents to live in Nairobi year-round. They frequently came from strong families (White 1990:9). Many were able to send money home to bolster rural family incomes, which were racked by upheavals. Prostitution emerged as an identifiable category of women's work, taking three forms:

- Watembezi prostitutes (from the Swahili word *kutembea*, "to walk") offered brief sexual services along the streets.
- Malaya (the term means "prostitutes" in Swahili) offered more prolonged indoor domestic and sexual services.
- Wazi wazi ("open") prostitutes sat in front of their houses, calling out their prices raucously and aggressively.

For some women, sex work was casual and intermittent: "He was hungry for sex and I was hungry for money" (White 1990:85). For others, it was the only way to survive: "[W]e were hungry, we had to go with men to get money, or have no money" (White 1990:79).

Majengo, also known as Sofia Town, was once an entertainment spot for British soldiers who frequented the village to watch cultural performances by mostly female groups. During the colonial era, Majengo grew into quite a popular area, but without the provision of adequate shelter. Its population today is estimated to be more than 150,000 people of all ages and different ethnicities. It is divided into the four smaller settlements of Sofia, Mashimoni, Kitanga and Digo. The women continue to sell sex, filling a gap for men whose wives, girlfriends and families remain back home in rural Kenya. In addition, men from other countries continue to visit Majengo for sex.

The Majengo Clinic

The Majengo Clinic is a medical facility for low-income and medically underserved communities. Within a larger compound there is a special clinic, also known as the Special Treatment Centre (STC), that has offered sex workers a safe space since the mid-1980s. For a long time it was the only public health centre in Kamukunji, Nairobi, providing sex workers and their clients with treatment for sexually

transmitted infections (STIs). With funding from the Canadian government and the assistance of the public health authority of Nairobi City Council, researchers from the universities of Oxford, Nairobi and Manitoba worked to improve existing resources and provide basic outpatient medical services to the Majengo community of female sex workers. In the mid-1980s, the World Health Organization (WHO) designated their operations as a WHO collaborating centre for sexually transmitted diseases (STDs). Among the common ailments treated were classic STDs, malaria and typhoid. Currently, the clinic offers comprehensive HIV prevention and treatment services, birth control methods, gynaecological examinations, and TB tests and treatment, in addition to supporting the management of assorted HIV/AIDS-related opportunistic infections. It also serves as a research facility for the collaborating researchers, who run two HIV-integrated activities: HIV research and HIV care and treatment. More than 5,000 sex workers receive care at the clinic, 3,200 of them enrolled in clinical research studies.

Majengo Research

The Majengo Observational Cohort Study (MOCS) started in the late 1980s, and is a long-term cohort study of disadvantaged female sex workers in Nairobi. The study, as expected, has contributed to the development of several candidate vaccines against HIV.

HIV research studies started when Dr Frank Plummer, a Canadian scientist who was the principal investigator undertaking research on STIs in Majengo, discovered that about two-thirds of women visiting the clinic had tested positive for the virus in 1985. This changed the focus of his research from general STIs to include the epidemiology of HIV in Africa.

Plummer and his team later discovered that a small number of the women had apparently developed immunity to the HIV virus despite long-term exposure through sex with infected clients. This led to other studies aimed at understanding the epidemiology and immunobiology of HIV and the risk factors associated with its spread. Blood, cervical, vaginal and saliva samples were drawn from women in this cohort, with their consent. One of the key findings was that when some of the "HIV-resistant" women took breaks from sex work – for example, to visit family or pursue alternative employment – temporarily stopping their exposure to HIV, they rapidly lost their immunity and became significantly at risk of HIV-infection on resuming sex work.

Majengo Research Participants

"Prostitutes" is what they called them in the past. Then they were known as commercial sex workers, and now the term is sex workers. "I don't know what they will call them next," said one of the Majengo clinic workers during my visit. "Sex worker" is the term used by researchers and policymakers and includes female, male and transgender adults aged over 18 years who sell consensual sexual services in return for cash or payment in kind, and who may sell sex formally or informally, regularly or occasionally. It's a word used by people who think the word "prostitute" is impolite or offensive.

Sex work is classified under Kenya's Penal Code as illegal (Laws of Kenya 2014), and it entails a stiff penalty. It is seen as an "immoral activity" rather than a form of labour, and many believe that sex workers deserve to be punished.

At first sex workers were nervous to register with the SWOP clinic, because they feared that their personal information would be shared with the Kenyan law enforcement agencies. Once they were assured that the information gathered through unique identifiers and biometric tools was for research purposes and would not be shared with any third party, they registered in droves. They also signed informed consent documents for the different research studies undertaken. In return, the SWOP team provided and continues to offer free health care including HIV management. One of the reasons why the clinic has a good record on research ethics is its engagement work with the community that is involved in the research.

Research Literacy Among the Sex Workers

The research has built up long-term relationships between the researchers and the women sex workers through peer leaders and educators who engage in dialogue and negotiations with the scientific investigators about the terms and conditions for participation in the research. Over time, these activities have helped to develop and formalize a "community" among the sex workers that did not previously exist. The partnership has enabled a wide range of benefits in the research cohort and wider community, such as health education, free distribution of condoms, and the provision of free treatment for a range of STIs. In addition, it has led to effective referral for other health care requirements, such as non-communicable diseases, cancers and surgical procedures including hysterectomy. Such services would probably not otherwise have been available to these women.

These peer educators are themselves sex workers. They educate women about their rights, promote behavioural change, distribute condoms and provide referrals to health clinics. Peer educators also address workers' concerns, whether about personal issues, services offered, or the research they are a part of. They are the gatekeepers of the sex workers' community.

Education about condom use has given sex workers the confidence to negotiate this with their clients. Over time, 100% condom use has been achieved with casual clients, but regular clients still remain a challenge. Peer educators have also been active in the provision of general information on the research consenting process. Capacity building on the consent procedures undertaken over the years by the SWOP team seems to have borne fruit. Sex workers currently involved in the pre-exposure prophylaxis (PrEP) studies[2] have stated that they are not subject to any pressure in deciding whether to participate in any of the research projects. "We are free to refuse to consent to any research, be it from SWOP or any other," stated one of the participants. "Consent is voluntary and has always been voluntary at the Majengo clinic," said a sex worker who was also a peer educator.

Ethical Concerns and Benefits

The sex workers have long been collaborating with researchers from Kenya, South Africa, Europe and Canada. The Majengo clinic has also been providing better health care than is offered at other public health facilities. There are obvious issues around informed consent and the possible exploitation of the sex workers in the studies that constantly have to be dealt with. For example, do the sex workers really understand what they are consenting to, or do they trade participation for access to better and free health care? The peer educators, in my judgement, are influential. Do they therefore play a big role in the willingness of sex workers to participate in the studies? Does the collective opinion of the sex worker community on particular studies have a major influence on individual willingness to participate, thus diluting autonomy and self-determination?

These issues have been raised before – for example, in a newspaper article headed "Sex slaves for science?" (Nolen 2006) and in *Benefit Sharing: From Biodiversity to Human Genetics* (Schroeder and Cook Lucas 2013) – and they demand answers. In addition, Andanda and Cook Lucas (2007:9) have stated that:

> In the Majengo case, the original, routine issues of negotiation and decision-making related to the conduct of the research studies only involved researchers and administrators from the relevant universities and institutions. … There was no formal inclusion of representatives from the sex workers in any of these negotiations.

While writing this case study, I asked one of the peer educators about the inclusion of sex workers in decision-making in the past. She confirmed that inclusion and genuine partnership had not been emphasized previously, but she added: "Now we are enlightened, this would not happen at the moment without our consent. We must be part of the decision-making". The long-term engagement of the clinic with research participants in the spirit of ethical research has therefore,

[2]Pre-exposure prophylaxis, or PrEP, is a way for people who do not have HIV but who are at substantial risk of getting it to *prevent* HIV infection by taking a pill every day.

over time, led to improvements in the positioning and negotiation skills among the peer leaders/educators. This is easily noticeable on the ground. Other factors noted include:

- The women's health has improved because of their access to education and high-quality care, which has reduced HIV incidence, the disease burden and mortality.
- Important findings about HIV infections are shared with the sex workers' community as they emerge. This has a great impact on the health of sex workers generally, since both partners now practise evidence-based interventions and programming. This will become even more prevalent as a greater understanding of novel prevention strategies emerges, and as these strategies are adopted.
- Sex workers involved in the studies have increased their self-worth and agency by becoming valued partners in the research and by developing a sense of community among themselves. It is important not to romanticize this, because the women's lives are fraught with difficulty, but it has to be noted that sex workers have been able to counter assaults on their self-worth due to the illegality of sex work in Kenya by developing a new emphasis on their rights. Bandewar et al. (2010) argue that participation in the MOCS has improved and enriched sex workers' lives, because community engagement activities have helped create a community that did not exist independently. Majengo sex workers – as part of the growing sex workers' movement in Kenya – have formed an association called the Kenya Sex Workers Alliance (KESWA). This is a local chapter of the global sex worker alliance, whose mandate is to train sex workers about their human rights. "Sex work is work!" is an everyday slogan among the Nairobi sex workers.

Poor enrolment in the ongoing PrEP demonstration project, despite a huge number of potential at-risk HIV-negative participants from the cohort, presents some real food for thought. In my discussions with the sex workers' representatives, they pointed out that community education, demand creation and advocacy for PrEP among the sex workers were done poorly. The researchers and policymakers had not fully engaged the community in promoting the project. Therefore uptake of the novel intervention, despite its potential, will remain poor so long as the sex workers' community is not educated and involved in the grass-roots advocacy processes. Inclusion and the community buy-in and support are crucial to progress. This finding also confirms that the Majengo sex workers do indeed practice self-determination in the consenting process.

Conclusion and Looking Forward

At a recent TRUST[3]-sponsored high-level meeting in Nairobi, the peer educators' demands for inclusion went a notch higher. They insisted on being part of the ethics board that approved any research study involving sex workers. They also asked to be included in the technical working group to advise on issues concerning sex workers.

The ethics concerns for a group of sex workers from the Nairobi slums are obvious. I would like to end with two observations. First, to be considered vulnerable in a research context does not mean to be weak or to need others always to speak for one. Many of the sex workers I have met are very clear when expressing their concerns and suggesting ways forward. Second and very important, sex workers have increased their self-worth by participating in past and ongoing studies. They are now more empowered to make their own choices, whether these choices concern the way they receive their health services from SWOP or their decisions about participating in research projects.

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[3]TRUST is a European Union project with the main goal of catalysing a global collaborative effort to improve adherence to high ethical standards in research around the world. http://trust-project.eu/.

Author Biography

Anthony Tukai is a behavioural scientist with an interest in HIV prevention and interventions among vulnerable and stigmatized groups. Anthony has worked with several non-profit organizations in the UK and the US. He currently lives in Kenya, working to improve the health and well-being of lesbian, gay, bisexual and transgender communities and sex workers. Anthony works in Nairobi for Partners for Health and Development in Africa.