In the very first issue of Research for Sex Work, in 1998, Sue Metzenrath from Australia wrote: “For far too long researchers have been using sex workers as guinea pigs without any benefit accruing to sex workers as the result of research. Essentially academic careers are made on our backs. Further, some research has provided ammunition to those who want to suppress the sex industry and research findings have been used to support some of those arguments. In many countries sex workers already refuse to be involved in research because they can’t see anything in it for them. After all, why would sex workers give freely of their information and knowledge and then it is used to suppress their livelihood?”

Stigmatisation and discrimination are key factors that have an impact on sex workers’ lives as appears from the contributions in this 7th issue of Research for Sex Work on ethical issues in health care and research. It starts at government level. As long as there is no policy to decriminalise or legalise sex work it is hard to develop research and interventions that focus on the well-being of sex workers. An example of such counterproductive policies is seen in the campaign against social evils in Vietnam as described by Rosanne Rushing. However, Vietnam is not the only country with this approach. Other countries may not be as naïve in their terminology, but their policies are also leading to conceptualisation of sex work as a social evil, resulting in stigmatisation and unethical behaviour of government personnel.

When it comes to specific categories of sex workers this is often more outspoken, as described in the article by Chakrapani, Babu and Ebenezer about Hijra sex workers in India. Gaëlle Téqui from the French NGO Cabiria even writes that there is currently more discrimination in health care in France as described by Rosanne Rushing. However, Vietnam is not the only country with this approach. Other countries may not be as naïve in their terminology, but their policies are also leading to conceptualisation of sex work as a social evil, resulting in stigmatisation and unethical behaviour of government personnel.

Moving beyond STIs

On the positive side is the contribution from Gabriela Irazabal, who describes how the Argentinian sex workers’ union AMMAR fights discrimination in health-care settings. Other community-based organisations have found similar solutions. However, some practices remain unacceptable. Veronica Monet explains how sex-negative attitudes in the USA lead to biased views of policy makers and researchers, which in turn lead to practices like mandatory testing.

An important step would be to move beyond thinking that STI treatment is the primary goal of health care for sex workers and STI research the primary goal of sex work research, as William Wong and Ann Gray from Hong Kong stress in their article. They learned that research on aspects other than STIs and condom use is rare in Hong Kong and state that “it is time the health professionals and researchers review the ethics behind their research agenda and start to address those of sex workers instead of their own.”

Those who think that stigmatisation is absent at the level of social science research are proved wrong by Stephanie Wahab and Lacey Sloan who stress that the class differences between middle-class researchers and low-class sex workers have an overriding impact. Among others it leads to victimisation and problematisation of the behaviour of sex workers. Finally, Laura Agustin points out how that again leads to stereotyped answers from sex workers to researchers’ questions.

Real-life experiences of sex workers

A lot of these problems can be countered by proper conceptualisation of research for sex work and by adopting the methodologies that are most effective in visualising the real-life experiences of sex workers instead of producing biased stereotyped views of health workers, researchers and policy makers. For a solid conceptualisation of sex work in the context of today’s realities there should be scientific consensus in considering sex work to be a normal economic activity. It is not primarily a sexual activity, however eager the clients of sex workers are willing to believe that it is. Sex work is an economic activity that will attract certain groups of men, women and third-gender people more than others. That is a field of research in itself. It creates vulnerabilities and possibilities. The possibilities should be further explored to reach an
understanding of how they can play a role in the empowerment of sex workers. The vulnerabilities should be mapped, because they are directly linked to the risks of sex work, such as violence, drug use, disease, debt and exploitation. They include the following:

- Absolute – lack of protection
- Relative – exposure to higher than average risks
- Epidemiological – exposure to higher risks of HIV/STI infection
- Medical – inability to get optimal quality and level of care
- Human rights – exposure to discrimination
- Social – deprivation of some or all social rights and services
- Economic – inability to counterbalance risk of infection or access to care, and
- Political – inability to get full representation or lack of political power.

Such a conceptual framework will give the proper dimensions to future research and interventions. By looking at more factors than just ‘epidemiologic vulnerability’ (to STI and HIV infection), we will be much better able to grasp the realities of the complex world sex workers live in, and to promote their health and well being.

Community-based research

The chosen methodologies are equally important. The traditional way of thinking in science, where the complex reality is broken down into elements that are researched individually and are later put back together to form an overall vision is counterproductive because it will recreate the perspective of the researcher. There is a need to respect the perspectives of sex workers, because these reflect the realities in which interventions have to take place.

This can only be done in participatory community-based approaches. These approaches are based on a dialogue between sex workers’ experiences and needs and researchers’ scientific skills. Unfortunately, in a sex-negative world this often remains an ideal rather than being considered as the only obvious option. Funding agencies continue to support the kind of research that creates the virtual realities of middle-class researchers.

Fortunately, international organisations have understood the importance of the new paradigms, but without the promotion of a strong conceptual framework for research on sex work, we may not see quick changes. However, some promising examples can be found in this edition. The research-community partnership of the sex workers’ programme CAL-PEP and the California State University provides valuable lessons learned for similar projects. The collaboration between the WSH drop-in centre and the B.C. Centre for Excellence in HIV/AIDS on making antiretroviral therapy more accessible to HIV-infected sex workers, shows potential as well. A research project in Brazil hired a former sex worker as the principle investigator and involved sex workers in all study phases. Examples like these should be studied and documented, so that sex workers’ organisations and their research allies learn how to collaborate better for a common cause.

Taking action against discrimination

Another positive development is the fact that the number of community-based organisations that are not waiting for governments to take proper action against unethical treatment of sex workers is increasing. The majority of the contributions to the present edition come from that background. Kao Tha and her colleagues of the Cambodian sex workers’ organisation Women’s Network for Unity (WNU) describe their fight against a new anti-HIV medication trial that does not offer any post-trial health care to the women for treatment of longer-term side-effects. This example shows that WNU and other sex workers’ alliances world-wide no longer want to be guinea pigs for science. They demand ethically sound conditions for their involvement, and proper access to health care, not only during the research phase but also for a long time after research has been completed.

Finally, convincing doctors and researchers to take sex workers seriously and to treat them like normal citizens is not enough. In the end, society at large should also do the same. Gabriela Irrazabal writes as follows in her article on AMMAR’s destigmatisation work in Argentina: “The most significant task is not only to build self-consciousness and self-esteem among its members and to create a collective sense of identity, but also to generate a good atmosphere towards sex workers in this conservative society.”

Note


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26 Social evils and sex work in Vietnam – R. Rushing
29 Mandatory testing: The fear that feeds the falsehood – V. Monet
Although sex work has generated interest and intrigue among different disciplines since ancient times, there has been a swell of research focused on sex work-related issues since the 1980s. A dynamic discourse and inquiry related to sex work and the lives of people involved in the sex industry has emerged. This discourse has been informed by a range of competing forces, such as the initial scapegoating of sex workers as transmitters of disease following the onset of the AIDS epidemic, the feminist ‘sex wars’ on pornography and prostitution, international attention to trafficking issues, the founding of sex workers rights groups, and a growing number of sex workers involved in academic research. Consequently, practice and research around sex work reflect the challenges presented by these competing groups, values, agendas and perspectives. Some of these challenges, or ethical dilemmas, are described hereafter.

**Population and samples**

One of the challenges associated with researching sex workers is that it is nearly impossible to obtain a random sample. The illegality and stigma, among other forces, of sex work, has forced researchers to rely on non-random sampling methods such as convenience and snowball sampling. As some researchers fail to contain the population to whom they generalise findings, research on street workers is frequently presented as though it reflects and/or speaks to multiple sex work venues (e.g., escort, dance, SM, pornography).

While these methods have their strengths, they do not support generalising findings to broad communities of sex workers. First of all, inaccurate generalisations tend to perpetuate stereotypes and stigma such that ‘all’ sex workers are described as drug injectors, very poor, sexually abused, unresourceful, and dishonest ‘with a heart of gold’. If these images are supported/perpetuated by research and inform our understanding of sex workers, and if research drives practice and interventions, we can only conclude that services/interventions only reach and support certain sex workers and not others. How do agencies that view sex workers as victimised, poor and drug addicted support escort workers who may or may not have drug habits? Similarly, how do such agencies treat sex workers as the experts on their own lives? How do they interact with sex workers who do not perceive themselves as victims?

**Class discrimination**

Although some researchers have reported that street sex workers only consist 10-20% of all sex workers in North America, they are disproportionately represented in the social science and public health literatures. That is, most research on sex work focuses on street work. A possible reason for this type of disproportionate representation may be related to the heightened visibility associated with street (public) work. By disproportionately singling out street workers for inquiry, researchers make other forms of sex work invisible and shield them from the research gaze, in addition to political, law enforcement, moral and religious attention.
Ethical issues

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Consequences

Portraying all sex workers as victims or deviants also obscures issues of agency (personal will and ability to act) and sex work as legitimate work. Although there is a broad spectrum of discourse and perspectives on sex work, the social science research overwhelmingly adopts a radical feminist perspective that views sex workers as victims of male aggression. Consequently, social science does not reflect the diversity of lenses through which we can study sex work or the diverse realities of sex workers' lives. By continuously portraying and constructing sex workers as victims, researchers do not leave a space for the possibility that sex work may be empowering for some, disempowering for others, that individuals may freely choose sex work, nor does the limited lens leave a space for multiple and contradictory experiences. Another blow frequently dealt to sex workers by researchers and radical feminists has been the notion that sex workers ‘do not realise or understand that they [sex workers] are victims of exploitation’. According to domination theory, sex workers who claim to have chosen sex work are victims of ‘false consciousness’. False consciousness suggests that oppressed persons unconsciously internalise the dominant ideology. It further suggests that women have been taught to eroticise domination, and while they may believe they are giving consent, in reality, they are engaging in ritualised forms of domination that have become familiar.

Relationship to research participants

Traditional research methods that adhere to notions of objectivity assume the existence of one independent truth and reality to any given subject and experience. To discover the ‘truth’, researchers often attempt to maintain a distance between themselves and their subjects.

What are the issues to consider when privileged, white, Christian, middle-class academics study South East Asian and/or African sex workers?

The practice of maintaining a distance between the researcher and the researched is problematic because rather than recognise the dynamic, inescapable relationship between the researcher and the study participants, study participants are placed outside of the knowledge creation process. That is, if we accept the notion that there is such a thing as an objective observer in the social sciences, that observer (researcher) becomes solely responsible for defining the realities of those being studied. In this case, the knowledge creation process of research becomes a unilateral rather than collaborative process. Consequently, one of the ethical issues brought to the surface is that the detached, objective researcher is granted expert status on the study participants’ experiences. In addition, what he/she brings to the research process (as a researcher) becomes invisible. Through the distancing or creating an illusion of distance from the participants, researchers obscure the effects of their race, class, gender, values and agendas from the research process. What are the implications and issues to consider when privileged, white, Christian, middle-class academics study South East Asian and/or African sex workers? In addition, what are the consequences when we are not given the opportunity to think critically about who conducted the research and for what purposes?

Recommendations

The issues concerning research samples, class and gender discrimination, theoretical frameworks and researchers’ relationships to their study participants raised in this article highlight ethical concerns in

Girlfriends Talking

An example of a collaborative project between researchers and sex workers was Girlfriends Talking (GT), a program of People of Color Against AIDS Network (POCAAN), a Seattle-based HIV/AIDS prevention and education organisation. Girlfriends Talking was created as a part of a Center for Disease Control (CDC) study in the early 1990s. The study aimed to explore sex workers’ use of condoms with their clients compared to their primary/intimate partners. Girlfriends Talking was organised and run by an ex-sex worker of 25 years from Seattle. It provided HIV/AIDS education and prevention activities as well as weekly individual and group support to local female sex workers.

GT followed POCAAN’s use of a peer education model of HIV/AIDS prevention and education. That is, sex workers were hired to conduct HIV/AIDS outreach to their peers (in the streets, escort agencies, dance clubs and jail). One of the authors worked with GT for five years. During this time, GT organised a vigil, in response to the murders of two Seattle sex workers in 1994. The vigil aimed to honor and remember women in the sex industry who had been murdered and/or victims of violence. In addition, GT organised a conference for women in Seattle in 1997. The Girlfriends Talking project of POCAAN ended due funding cuts in December 2003.

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Social scientists, who tend to be middle-class, often study those who are the most oppressed and marginalised in societies, because they are the most visible, accessible and/or financially needy. This ‘studying down’ phenomenon in a way protects the private lives of privileged classes, including high-class sex workers, while it further exposes those of marginalised classes.

Gender discrimination

Blatant gender discrimination pervades the study of sex workers. Although a heterosexual prostitution encounter typically involves a male (client) and female (worker), women have systematically been the ‘subjects’ of social research on sex work, as well as the targets of arrest. The gender discrimination in research on sex work is problematic, because: 1) it protects the customers’ lives from public attention by keeping their business private; 2) it leaves an impression that female (street) sex workers constitute a problem, which increases their chances of being targeted for arrest, prosecution or involuntary rehabilitation; and 3) it makes male and transgendered sex workers invisible.

Theoretical bias

Most research on sex work has studied sex workers in a way that portrays them as victims, deviants and/or criminals. These portrayals can be linked to the theories that inform and ground the research. The way that a ‘problem’ gets defined in research also informs how the data gets used, and for what purpose. Many studies labelling sex workers as victims or deviants have shaped therapeutic treatment programmes for sex workers. The notion that all sex workers need therapeutic intervention as a result of their involvement in the sex industry contradicts much of what we have learned through the activism and work of prostitutes’ rights organisations all over the world.

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research and health care. The research issues raised here are considered significant by the authors because, more and more, agencies that fund services, are requesting ‘evidenced-based practices’. That is, they request that agencies utilise interventions that are supported by research. If the bodies of research that practitioners draw from are not representative of the multiple identities and experiences of sex workers, how can we provide services that actually support those we intend to ‘help’? While it is relevant and important to know about the intersections of drugs, violence, poverty and disease in sex workers’ lives, we must also be able to recognise and draw upon the strengths and diverse experiences of those in the sex industry.

In consideration of the issues discussed, we present some recommendations for research on/with sex workers. These recommendations are consistent with feminist participatory research, and with recommendations made by the South Australian Sex Industry Network (SIN).1

1. Researchers must collaborate with the sex workers they seek to study. This collaboration must include all aspects of research design, theoretical framework, methods, and dissemination.

2. Researchers must be cognisant of issues of social, political, economic and personal power and seek to equalise power relationships with the sex workers they study. This can be accomplished by acknowledging that sex workers are the experts on their own lives; researchers are the experts on research methods, and we all stand to learn from one another.

3. Researchers must bring the results back to the sex workers they study to ensure that the researchers’ interpretation of the data is accurate.

4. Sex workers and sex work organisations are encouraged to hire their own researchers to conduct research of relevance to sex workers. Or, sex workers and sex work organisations are encouraged to obtain training or consultation that would enable them to conduct their own research.

Note
1. SIN, South Australian Sex Industry Network, is a sex workers rights organisation in Australia. Members of SIN attended the International Conference on Prostitution in Los Angeles in March 1997, and provided recommendations at a panel on research ethics. These recommendations were developed by SIN following negative experiences with academic researchers.

Personal story of a young South African researcher
As a female researcher I was able to build a special relationship with some of my female respondents. However, my position as an English-speaking, middle class, white, educated female who has been living in Europe for a number of years differentiated me from my respondents. Many sex workers regarded me as an ‘other’; they made assumptions about my past and my character and often called for proof of my personal investment and commitment before divulging their personal histories or experiences. Alternatively, they looked to me for validation, assistance or advice because they assumed that as an educated and relatively protected female I was better located to assist or advise them. Researchers have often been likened to pimps because they extract or ‘take’ information from the women without giving anything in return. In other words, the relationship between the researcher and the sex-worker is one-sided or parasitic. There have been times however, when I have been able to assist the women and girls directly. I have taken them to tuberculosis and family planning clinics, helped them track down their identity documents, provided them with condoms or bought them a meal or two. On the other hand, I have often felt handicapped in my attempts to assist these women directly. For example, one of my respondents was being threatened repeatedly by a local gang member, she refused to seek refuge at the local shelter and asked instead to reside at my home. This would obviously undermine the boundaries between researcher and respondent and would potentially place me in danger. After discussing her options with her, it was clear that staying with one of her regular clients for a few days was the best solution for her. Even though she was only sixteen years old, sex work was the best choice out of a bad set of options. There have also been times when I felt frustrated by my inability to give my respondents good advice. I have been asked repeatedly whether society will always label them judgmentally as prostitutes even after they leave the business. I found this a particularly difficult question to answer. On the one hand, it would be easy for me to advise them to rise above what society thinks, but to do so would be to ignore the painful reality of their lives and the constant denigration that they face from the police, the public, their families, peers and clients.

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ETHICAL ISSUES
Alternate ethics, or: Telling lies to researchers
Laura Maria Agustin

On the subject of ethics in sex work research, we usually think of the insensitivity and careerism of researchers whose interest is in obtaining information they will take credit for. This article points to another problematic area: the issue of whether those being researched are honest with researchers. After all, why should people who are being treated as objects of curiosity tell the truth?

We are all so surrounded by research projects that they seem to be a natural part of life, but what is research for? While often presented as pure advancement of knowledge, research is often integral to people's jobs, whether they work in government, NGOs or universities, and the audience for whatever they find out is first and foremost whoever paid for the research.

Institutional research projects are required to explain the investigator's ethical responsibility to the people researched. But the assumption is that once research begins, researchers will cooperate, freely telling researchers what they want to know. Those being researched are not usually given any choice about participating and they have also not been required to agree to an ethical standard of behaviour. Since no universal ethics exists, research subjects simply may not tell (all) the truth to researchers.

Sad stories, omissions and outright lies

When a person working in an ‘irregular’ trade is approached by a professional-looking person from the straight world, who is not a paying customer, he or she is naturally viewed with suspicion. In the worst case, the visitor may be working for the police; in the best case, be someone giving out free condoms or needles. Of course, researchers have to find a way to ‘gain access’ to their subjects, making friends with the head of an NGO or a bar or convincing a doctor of their good intentions, and thus may be introduced as an ‘ally’. This goes for those conducting any kind of research using any kind of methodology. But even if the person comes with a good introduction, how does it feel to have him or her move toward you with the intention of asking personal questions? In most cultures, such a situation does not occur naturally. A Nigerian sex worker in a Spanish park once commented on outsiders asking questions: “I don’t understand what they’re doing, they don’t have anything to offer. The others that come are doctors, they give us medicine, examinations. But these want to talk, and I don’t have any reason to talk to them.”

It has long been recognised that people who are considered ‘victims’ or ‘deviants’ are likely to tell members of mainstream society what they believe they want to hear. There are deeper reasons to keep personal secrets, too: “To be able to hold back some information about oneself or to channel it and thus influence how one is seen by others gives power [...], it leaves one open to coercion.”

It was one open to coercion, “...” But there are also researchers who second-guess people’s responses. Negre i Rigol describes an interview with Leonor, who presents her own getting into sex work as a rational choice. When she starts to talk about other girls who were raped and coerced, the interviewers “realise perfectly that Leonor is telling them about her own life for the first time”. Here interviewers are presented as omniscient, capable of seeing through lies. If Leonor saw this interpretation of her words, she might decide not to talk with researchers any more.

Ways around the problem?

No formula exists for avoiding these problems. Some people believe that using ‘insiders’ to contact the target group is the solution – people who have shared the same life of those under research. It sounds better having a sex worker do the interviewing of other sex workers, but other differences between ‘insiders’ can be more important than whether they have worked in the sex trade or not – class, colour, nationality. A Colombian woman once commented on a Colombian peer interviewer to me: “I wouldn’t tell her anything, she’s from Cali. You know how those women are.”

Ethics or self-protection?

There are other reasons to tell sad stories. When sex workers know that a certain health-care service may be at stake, or that they will get help only if they can present themselves convincingly as victims, it is not surprising when they tell stories that serve their own interests. Or, in the case of research for health promotion, workers may not want to talk about their own failures to use condoms or their own getting drunk – who does, after all? Or, in the case of research on ‘trafficking’, sex workers may not want to admit they thought boyfriends really cared about them, when it turned out they were only using them, or admit they paid people to fabricate false travel documents for them. It really does not matter whether their answers will be treated ‘confidentially’, because they simply may not want to talk about such intimate matters. To put it another way, keeping secrets may help sex workers gain independence or control over projects to help them. Talking about sexual risks with people who think it is wrong to ever take any risks may cause them to treat you as irresponsible. Admitting the desire to stay in sex work after getting out of the clutches of abusers can render you ineligible for victim-protection programmes. The best policy may be to omit certain information from responses or to put on the expected front. There are deeper reasons to keep personal secrets, too: “To be able to hold back some information about oneself or to channel it and thus influence how one is seen by others gives power [...] To have no capacity for secrecy is to be out of control over how others see one; it leaves
One researcher I know says she is perfectly aware that sometimes people are lying (or at least hiding something), and she tries to find out the truth by going back to the same point on different occasions to see if the ambiguities can be cleared up. Or, she may check one person’s story against another’s to see if they coincide. To her, it is a question of instinct: “It’s not so different from daily life, you ask yourself every day if people are telling you the truth and you acquire mechanisms for selecting information.”

Researchers need to understand that if their access to those researched comes from a particular agency then informants may be less than candid about that agency, or if access comes from a friend of a friend, who is the madam of a club, then those that work for the madam will probably not share their complaints about her with you.

The best way to avoid being lied to is to spend long amounts of time with the people under research. Participant observation for at least a year is a standard technique of anthropological ethnography: “My practice of noting conversations greatly helped me to establish how clients and sex workers lied to me about factual matters. I found that initially people lied to me considerably concerning where they lived. For a considerable amount of time Rita, one of my main informants, lied to me about her role as a madam. [...] It would seem that Rita did not want me to know that she was charging the other sex workers to use the flat because she did not want me to think that she exploited them.”

Beyond ‘the truth’
Is a failure to tell the truth to researchers ‘unethical’? Only if you believe that some universal standard of ethics exists and that it is better to be ethical than not. The version of ethics that is usually referred to in research is, like so much else, a thoroughly western one. But we should remember that other ethics exist and refer to values that make sense within particular cultures and subcultures. And, in fact, keeping secrets can be seen as another system of ethics. One of my favourite pieces of research was carried out in New York crack houses. The tape-recorded conversations of Puerto Rican crack dealers leave no doubt about their version of ethics: selling drugs, ripping people off and even rape come across as logical within their extremely disadvantaged world system. At the same time, dealers’ own positive values, such as the search for ‘respect’, come across, too. Do we know that they ‘told the truth’ to the researcher? We can only guess.

Notes

About the author
Laura Maria Agustin has done independent, NGO and academic research, mostly focused on migration and the sex industry. Zed Books will publish this research, called Leaving Home for Sex, in 2005. Laura runs an e-mail discussion list in Romance languages called IndustriadelSexo.

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Until recently, science and community collaborations have been rare. There is no tradition of collaboration and, besides, the community and scientific researchers come from two distinct cultures. However, increasingly community-based organisations and researchers realise they need each other, and collaborative research projects have been started. A case study of a successful collaboration between a community-based organisation (CAL-PEP) and a research institute (California State University) provides valuable lessons learned for similar projects. CAL-PEP (California Prevention Education Program) is a community-based AIDS service organisation working for and with sex workers and drug users. It was founded twenty years ago, as an offshoot of COYOTE, a sex workers’ rights organisation. Some 40% of CAL-PEP’s outreach staff are former clients: ex-sex workers and recovering drug users, and the large majority of staff are African American or Latina women, representing the communities that they serve. Initially, the idea was to evaluate CAL-PEP’s programme effectiveness, however, after elaborate discussions, other components were added to the research agenda. Staff stressed their need for a comprehensive study of why high-risk people are at high risk in the first place. In the end, the staff helped define half of the research questions and hypotheses. The interviewers were specifically hired and worked with the regular CAL-PEP outreach teams. Periodic meetings were held to identify problems and to work on solutions. The lessons learned from this research project and from other similar projects are:

1. There must be a common problem that both parties wish to address, and an agreement on what would constitute a solution. In this case, the common goal was to slow down, perhaps prevent, the spread of HIV/AIDS among hard to reach, high-risk groups.

2. There must be an understanding that neither party can achieve the goal without the other.

3. There must be a partnership where the CBO director and the researcher(s) are equals in authority as co-investigators.

4. Each party must be fully involved in the planning, design, and execution of the project, as well as interpretation of results.

5. There must be a mutual agreement about the end product such as publications, reports, training manuals, staff enhancement and training. There must also be agreement as to who keeps equipment such as computers, software, and office furniture after the project is completed.

6. To build mutual trust, there must be regular meetings to address problems, a willingness to learn the concerns and limits of the other party, and flexibility in problem solving.

7. Researchers must understand that community collaborators have valid hypotheses, theories, and insights to contribute to the research, based upon their experience with their client population.

Even after following these guidelines as close as possible, unanticipated factors may arise that influence outcomes. Ways to prevent these are:

• Continuous training: In the CAL-PEP study, part of the success was continuous staff training. The regular staff meetings were used to train staff about research as well as to problem-solve and trouble shoot. This included two teams – the outreach staff and the interviewers. After the study, the staff went on to write research proposals and to receive funding for several subsequent grants with evaluation requirements.

• Visibility with staff: The extent to which the research and CBO partners are directly involved in the project also impacts research outcomes. In the case of CAL-PEP, there was a crucial level of visibility that was essential for team morale and provided another level of accessibility for problem identification and solution, and training. Staff was not left alone for very long without feedback and the opportunity to provide feedback. In the early stages of each project, close supervision proved to be essential.

The lessons learned by the research team can be used by other community-based organisations to shape and design their own collaborative research projects.

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Benefits of community-academic collaboration

For community partner organisations:
• Opportunity to shape the research project
• Gain access to other academic networks
• Identify gaps in knowledge of clientele and service delivery
• Develop a sustained research agenda
• Strengthen networks with like-minded partners

For academic researchers:
• Develop an understanding of how stigma is formed and perpetuated in society
• Gain access to emergency aid, if required
• Contact with non-judgemental outreach health services
• Opportunity to validate their life experiences
• Safe place to tell their story
• Linkage to new educational and employment opportunities
• Opportunity to work with a research team
• Strengthen networks with like-minded partners

For research assistants (sex workers):
• Opportunity to work with a research team
• Refugees for future employment/character reference
• Acquisition of skills and development of work habits essential to non-sex trade jobs
• Development of trust with respondents
• Crucial link to the hidden population
• Strengthen networks with like-minded partners

For respondents:
• Safe place to tell their story
• Opportunity to validate their life experiences
• Contact with non-judgemental outreach health and social services
• Access to emergency aid, if required
• Develop an understanding of how stigma is formed and perpetuated in society
• Opportunity to make a decent wage in the world

Typically, sex workers are used to provide information, some of which is very invasive and unnecessary, with no meaning and mostly asked only to satisfy the curiosity of researchers. Another common use of sex workers in research is to facilitate the access of researchers to respondents, as it is not easy to enter most settings. For a very long time we have been considered hard to reach and have been used to provide access to sex workers and sex workers’ neighbourhoods, exposing ourselves to several dangers, mainly acquiring us the mistrust of colleagues and attracting the attention of the police and other authorities.

Sex workers are also used to provide samples (blood, urine or even genital secretions) for testing. Donors have become very demanding, particularly since the HIV pandemic, to know the seroprevalence of sex workers in different regions of the world. In some extreme cases – but not rarely – the participants in this kind of research do not have access to the results of their tests and do not benefit from participating in this kind of research. Furthermore, this type of research has contributed to an increase in the stigma against us, as some figures have been used to justify the idea that sex workers are ‘vectors’ of HIV from ‘higher to lower incidence populations’.

Most international ethical guidelines regarding research in human beings do not apply to sex workers. Basically, people who participate in any kind of research must understand the objectives, risks and benefits and several research projects with sex workers simply ignore this very basic principle. Sex workers who participated in research often just say that “some people came here to ask some questions”. It is not common to see sex workers taking part in ethical committees or participating in the whole process of research design.

Informed consent?

One basic principle in research with human beings is the informed consent form, a document that the respondent must read (or must be read out to), in which the most relevant information about the study is provided, including the objectives, risks and benefits. The person must understand and sign this form, usually keeping a copy with contact information from the researchers and the principal investigator. As said above, several researchers do not make sure that the participants understand the objectives, risks and benefits. Some are very formal and are only interested in collecting data. They make people sign the informed consent form without making sure that they understand what they are signing. It is not a rare occurrence that this document is simply not provided. Another common mistake is to not share the results of research. A good example of this happened in the late 1980s, in Rio de Janeiro, when a group of 33 male sex workers were tested for HIV without informed consent or counselling and the results were announced in an important scientific journal. This attracted the attention of the media and created panic among the group, causing loss of clients and several other problems.

An alternative approach

In 1999, Horizons/Population Council decided to fund a study to evaluate the impact of the community development model to reduce the vulnerability to HIV and other STIs of sex workers in Rio de Janeiro, Brazil. One of the highlights of the study (concluded in June 2004) is the inclusion of sex workers in all different phases. As a start, the principal investigator (and the author of this article) is himself an ex sex worker and a sex workers’ rights activist. Further, sex workers have been actively participating in all phases, from the design of the research to the production and distribution of the reports.

Members of the Grupo Fio da Alma participating in an art workshop
The Tenofovir trial controversy in Cambodia

Can a trial be considered ethical if there is no long-term post-trial care?

Kao Tha, Chuon Srey Net, Sou Sotheavy, Pick Sokchea and Chan Sopheak

The Women’s Network for Unity (WNU) was established in June 2000 by a group of sex workers for sex workers. It provides a foundation for support and builds solidarity and self-empowerment among sex workers. Our network provides a space for women to come together, share ideas and discuss the collective challenges we face. We have over 5,000 members across Cambodia. WNU has been involved in some advocacy with the media and parliamentarians over the past few years on issues ranging from sex workers’ right to work, trafficking, violence against women and changes to the Law on Prostitution.

The first ever Cambodian sex worker-planned and run press conference was held in Phnom Penh on March 29, 2004. The network expressed its opposition to an experiment which is recruiting healthy female sex workers to test an anti-HIV drug, Tenofovir DF, and find out if it is safe to use on HIV-negative women and whether it would reduce the risk of HIV infection. Similar drug trials are starting soon in Ghana, Cameroon, Nigeria and Malawi. These trials are conducted by researchers from the University of California, USA, and the University of New South Wales in Australia. They are funded by the Bill and Melinda Gates Foundation and the American National Institute of Health. The researchers are looking for 960 Cambodian sex workers who are HIV-negative to take a pill once a day for one year in exchange for free medical services, counselling and $3 per month. Testing is due to start in the summer of 2004.

The WNU is against the use of sex workers for experimentation in a poor country like Cambodia, especially when the drug has only been tested on healthy monkeys—never on healthy humans. Side-effects of the drug when given as AIDS treatment are diarrhoea, nausea, tendency to major liver and kidney

Steps taken
A first step towards the inclusion of local sex workers was a workshop, organised in Rio de Janeiro in March 2000, to discuss the protocol and design of the research and to review the informed consent forms. This presented a unique opportunity to have these documents written in a language comprehensible to the study participants; not only sex workers but also ‘third parties’, such as business owners and the police. The group of sex workers also participated in several workshops to refine the instruments, making sure that all questions were understood and were not too invasive or irrelevant.

After the selection of the interviewers, a schedule for collecting data was developed, which involved always having a sex worker working together with the interviewer. The function of the sex workers was more than just to facilitate access to the respondents. Their involvement was also to make sure that the respondents understood the aims of the study and its risks and benefits. As intervention was a strong component in the study, regular meetings were organised between the study staff and the local sex workers organisation. The study had three rounds of data collection, and each time the results were available, the team made sure that these were shared with the sex workers. At the end of the study, a large workshop was organised in Rio de Janeiro to interpret the data and these contributions have been included in the final report. The group of sex workers produced three publications as part of the intervention, with the technical support of the study team. A fourth publication revealing the main achievements is to be produced and will be distributed throughout the study area.

This research project shows that sex workers do not always have to be ‘subjects’ of research but that they can be partners. It shows that it is not too difficult to reduce the ethical deviations generated by sex work research by including sex workers in the whole process.

Notes

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Many sex workers worry about being the first healthy humans to test the drug and are worried about the side-effects of taking a drug for prevention purposes: “They said they don’t want to try the drug because they are poor and they are sex workers... If they fall ill, who will look after their mothers, children, sisters or brothers? If the researchers are so sure that this drug is safe for HIV-negative women to take, in the short and long term, why won’t they commit to insurance for us and our families? If we get sick or can’t work it can be the difference between life and death for our families”.

**What WNU wants**
The network wants insurance against possible side-effects of Tenofovir for 30 or more years and not just health care for the duration of the trial. When the researchers are finished and leave Cambodia who will take responsibility for sex workers and their families who may be suffering longer-term side-effects? WNU believes that all sex workers who participate in the trial have the right to ask questions and be fully informed about the risks and to demand better medical and financial protection. Must poor sex workers in Cambodia take the risk of taking Tenofovir, withstand the side-effects, sacrifice health and income for $3 month and no longer-term guarantees?
If our members agree to take the risk, which may one day benefit people in richer countries and the drug company, then we deserve adequate protection for our future lives and our families. The high cost of this drug means that, even if it is successful in preventing HIV, Cambodian sex workers will never be able to afford it.

**Increased risk-taking**
WNU also warns that women involved in the trial will not know if they are taking the drug or a sugar placebo and may mistakenly think that condom use is not necessary – or they will take risks with clients to increase their income. We believe that even if experiment participants are given counselling and confidence, many young women will still believe that they are safe from HIV infection as long as they are involved in the experiment. Condom use is working well amongst sex workers for HIV prevention – it is married women who have the highest increase in HIV infection in Cambodia and this is usually contracted from their husbands.

WNU plans to continue outreach activities to its members on this issue and have further meetings, workshops and press conferences to negotiate protection of our members’ health and human rights. We welcome other sex workers from around the world to tell us of similar experiences and especially from those in Ghana, Cameroon, Nigeria and Malawi to find out what is happening to the women there.

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The Hijras in India are born as biological males who reject their ‘masculine’ identity in due course to become identified either as women, or not-men, or in-between men and women, or neither men nor women. In current terminology, they could be considered to be male-to-female transgenders/transsexuals. In India, Hijras have existed as communities for centuries. They are given different names in different languages. In the Tamil language which is spoken in South India they are called Aravanis or Alis. Though they are ‘tolerated’ by Indian society they are not ‘accepted’ and are discriminated against in various settings. In this article the authors discuss the discrimination faced by Aravanis involved in sex work by the public health system in the state of Tamil Nadu, India.

Those males who identify themselves closely with women often leave their birth families at a very young age and join the Hijra communities. They are doubly stigmatised and looked down upon by society. First, because of their transgender status – their cross-dressing or feminine appearance – which is often ridiculed. Second, because of their presumed occupation (sex work). It is true that lack of education, lack of other job opportunities and lack of economic/emotional support from their families compel many Hijras to enter into sex work for survival, or sometimes, to pay for sex change operations.

Because of this, the Indian public considers all Hijras as sex workers even though not all of them are. As a result of this misconception, Hijras have to face discrimination, and physical and sexual violence. Since the arrival of HIV/AIDS in India, they have also been blamed for spreading the disease. Being known to be HIV positive further increases the discrimination faced by Hijra communities; HIV-positive Hijras then have to face a triple stigma.

**Facing discrimination**

Hijras face discrimination in various ways in the Indian health-care system. Discrimination could be due to their transgender status, presumed/real occupation (sex work) or HIV status. In most instances, it may not be possible to point out the reason for discrimination. Much of the following discussion is based on the focus group discussions and in-depth interviews done by the authors and also documentation of experiences shared by Aravanis in South India.

Many Aravanis have a low socio-economic status and if they fall ill they attend public hospitals since free medical care is available there. Discrimination starts there right from the beginning: at the registration desk in the outpatient department. The staff at the reception counter enquire about the complaints of patients and refer them to the appropriate specialty outpatient department after registering their details for the hospital records. Most Aravanis are dressed as women. They can choose to have their male sexual organs left intact, or to have them completely removed in an emasculating operation, which is called castration.

If Aravani sex workers have a non-urogenital complaint and if they look like ‘real women’, they may be registered as females and sent to see physicians in the medical department. However, if they have come for urogenital complaints, even cross-dressed Aravanis are often registered as males and referred to the STI department. This happens regardless of whether they have been castrated or not. The reasons often cited by the STI physicians are that Aravanis are ‘basically males’ and women physicians might be too embarrassed to examine non-castrated Aravanis. Many Aravanis find this unacceptable since they want to be registered as females. However, some just accept this practice and convince themselves that at least they are being given some kind of medical care in the government hospitals.

**Medical staff’s attitudes**

Many Aravanis have mentioned that the physicians do not know anything about them and do not treat them like other patients. They are often addressed in a disrespectful manner and staff frequently use male pronouns which they find very offensive. Non-castrated Aravanis often do not want to show their male genitalia even in an STI clinical examination. Similarly, many Aravanis might be reluctant to show their ano-rectal area. In both cases, they might have to endure abusive language from the examining physician or assisting paramedical staff. One Aravani sex worker told us that she was told: “If you can widely open your ‘back’ during sex, why you pretend to be a shy person?”

Another problem is that doctors sometimes force Aravanis to show their anal and genital STI lesions to medical students so they can learn about certain STIs. This happens without consent. Aravani sex workers also face discrimination and derogatory remarks from the nursing
Aravani sex workers in Tamil Nadu

In Tamil Nadu, most Aravanis wear women’s clothes, and they may or may not have undergone sex change surgery. They have a low social status in society and usually end up in low-paid jobs, such as domestic work, selling vegetables or flowers, prostitution etc. A research study conducted by Chakrapani et al in 1999 among Aravani sex workers in Chennai, the capital of Tamil Nadu, revealed the following:

**Living situation** - Many Aravanis enter into sex work at a very young age. They had run away from their biological family, joined other Aravanis and, as they had no financial support, they resorted to part-time or full-time sex work. Those who are more feminine and younger usually earn more money through sex work than middle-aged Aravanis, who have difficulties in attracting clients. Some Aravanis stay single, others live with their male partners, but most live in groups together with other Aravanis or their ‘mother’. A ‘mother’ is a senior Aravani who has adopted another Aravani as ‘daughter’ through a ritual called madi-kattuthal. If they have boyfriends, called Panthi (meaning ‘real man’) their relationships may be unstable, as many Panthis will be married or will get married in the near future. Very few Aravanis manage to live as a couple, as most Panthis will not be able to resist societal pressure to marry a woman.

Work situation - Aravani sex workers usually pick up their clients near wooded areas, and sex takes place on the spot. Unlike in Calcutta and Mumbai, brothels employing Aravanis are very rare in Chennai. Most of their clients have a low socio-economic status and consequently, earnings of sex workers are relatively low.

Sexual behaviour - Because sex change operations in India are not available in the government hospitals and do not include vagina construction, sex between Aravanis and their male partners includes ‘high sex’, oral sex, masturbation and anal sex. Condoms are mainly used for anal sex and rarely for oral sex. Condoms also seem to be less used with regular clients or Panthis. Some Aravanis reported having unprotected anal sex with their clients if they were offered more money. Others acknowledged that they did not use condoms if their client looked clean or if they liked the person. Water-based lubricants were almost never used, increasing the risk of STI infection through anal sex. The sex workers either did not know about lubricants or said these were not affordable. HIV and STI prevalence among Aravani sex workers in Tamil Nadu is not known, as no specific studies have been conducted among them. However, it is clear that they are especially vulnerable to HIV and STI infection.

Violence - The level of violence towards Aravani sex workers is high. Most often this concerns violence by the police or local gangsters; however, clients may also force sex workers to have unprotected sex and might beat them after the sex act. A few incidents of gang rape and domestic violence have been reported.

The interviewed Aravanis stressed that they have a need for assistance with regards to their planned emasculation surgery and complications following that procedure. They also expressed the need for non-judgemental sexual health services, information about hormonal therapy and sex change operations, and assistance from the government and NGOs in finding other jobs.


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staff. One said: “That nurse was preparing to give me two shots of penicillin injection on my ‘back’ and I was very afraid of the pain and asked her to inject smoothly. She immediately replied that since I have experienced pleasure through my back now I have to experience pain from the injections in the back. This was in front of other patients and I felt very bad about myself at that time.”

Aravanis are admitted to the male ward of the hospital in such situations.

**Emascation**

As sex change surgery is not provided in government hospitals and the majority of Aravanis cannot afford to pay the fees of private plastic surgeons, they resort to unqualified medical practitioners for this operation. Some are operated on by older Hijras (called Thai Amma in Tamil Nadu), which is in fact an old custom. Rarely, some Aravanis even resort to doing the castration themselves. Consequently, due to bad surgical procedures adopted by unqualified persons, many Hijras develop post-operative complications, especially urological problems.

These complications would have been avoided if free or affordable sex reassignment surgery had been offered in the government hospitals. Those Aravanis who approach urologists for treatment of these complications often have bad experiences. They might not receive proper and prompt treatment even for post-operative (post-emasculation) wound infections. There may also be an unusual delay in getting a second opinion from plastic or general surgeons. Often the urologists will try to get rid of ‘that case’ by saying that plastic and general surgery colleagues should take over the patient.

**Living with HIV/AIDS**

HIV-positive Aravanis face severe discrimination. One HIV-positive person, aged 35 years,

Many Aravanis have mentioned that the physicians do not know anything about them and do not treat them like other patients.

had a block in the urinary tract following self-emasculation. Through a hole made in the lower part of the abdomen and using a special catheter, urine was drained in a government hospital in Chennai. Even though she was eligible for reconstruction of the urethra, the urologists said that she could not undergo that procedure because of her HIV status. She was thus forced to remain with the catheter for almost three years, changing the catheter
by herself periodically. After pressure from community organisations and after providing protective materials (through an NGO), the urologists finally agreed to do the reconstruction.

Thus, we have seen that Aravanis in sex work face discrimination in the Indian health-care system in various ways: from general physicians and nurses, from co-patients and from medical specialists.

**Recommendations**

Anti-discrimination laws to prevent discrimination against Hijras and other marginalised groups need to be seriously considered. Currently, the Indian legal system is silent on the issue of sex change operations. But emasculation is considered a criminal offence - whether done by oneself or another person and irrespective of consent having been given. The legal status of sex change surgery should be clarified and this surgery should be offered in government hospitals so that Hijras would not need to go to unqualified medical practitioners for having their sexual organs removed. This can prevent complications resulting from bad surgical procedures by quacks.

Furthermore, HIV status of Aravani sex workers (or any person) alone should not prevent the health-care providers from providing necessary medical or surgical treatment. Finally, it is crucial to provide training on transgender/transsexual health issues to the health-care providers so that the quality of medical care given to the Aravani community can be improved.

**Notes**

1. Since the Tamil term Ali is considered derogatory, the term Aravani was coined by Ali activists to refer to them. However, most Aravanis identify themselves as Kothi. The Kothi identity is shared by both Aravanis and feminine homosexual males in India.

**About the authors**

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**Argentinean sex workers taking care from themselves:**

**The experience of AMMAR**

Gabriela Irrazabal

“We are tired to go to the doctor’s and see how they put two pairs of gloves to check us up.” This is the way a poor female sex worker describes her regular visits to the gynaecologist's in a public hospital in Argentina. Discrimination and unethical behaviour of health-care personnel towards sex workers in this Latin American country is very common. The Argentinean sex workers union AMMAR has fought this type of behaviour by identifying and contacting ‘friendly hospitals’ in the framework of a comprehensive health promotion strategy.

Receiving public medical assistance in this Latin American country is not an easy task. If you want to make an appointment with a doctor you have to get up in the early hours. The procedure is very simple: you arrive at the hospital at dawn, stand in the long queue and wait, if you are lucky, for three hours. Then, you will receive a ‘number’ so that the receptionist can call you and make an appointment for you for the next month. On the one hand, this chaotic situation can be explained by the fact that the public health sector is not getting enough money from the national budget, and, on the other hand, by increasing unemployment rates. Nowadays, at least 16% of the Argentinean population is unemployed. That is why many people have recently started using the public health system instead of the private sector. So, as a result of the high unemployment, hospitals are flooded with patients and do not have much input or materials available to provide good-quality health services.

The situation might be worse if you are a sex worker. Not only because of the mechanism described above, but also because of the alleged likelihood of spreading diseases, which leads many doctors and nurses to treat sex workers differently than other patients.

**Unionising against unethical behaviour**

The Argentinean sex workers union AMMAR (Asociación de Mujeres Meretrizas de la República Argentina: Argentinean Female Sex Workers Association) was founded ten years ago when some sex workers from Buenos
Aires stood up against police harassment. Not long after its inception, the CBO started health campaigns among street-based female sex workers. As STIs were a big problem for these women, the leaders started walking around Buenos Aires' streets to hand out condoms and explanatory leaflets. These leaflets were full of pictures so that anyone could understand them. They also contained a lot of (condom) advice: ‘wear them always’, ‘use them even if he pays you more’, ‘take care of yourself’, etc. The objective of this campaign was to create greater health consciousness among sex workers.

Moreover, AMMAR's leaders encouraged sex workers to go for HIV testing. After talking to many of them, they discovered that the women did not want to take the test because they refused to go to the hospital. In fact, they felt that they were not treated in a good way there: they felt discriminated and stigmatised. It seemed like few doctors wanted to do medical check-ups, and the ones who did, took many security precautions, such as wearing two pairs of gloves and mouth caps. These women were treated differently from other patients and that is how they felt.

One doctor said, “Although there is a permissible legislation that allows prostitution, we need to say that prostitution is immoral and human filth, moreover, it is a huge crime against people's psychology, ethics and physical health, and finally, it is also discrimination, and subordination by women prostitutes to men,” when he was asked about his feelings towards sex workers. Even though quotes like this represent the most conservative ideas, it is believed that these ideas influence health-care personnel's behaviour toward sex workers. That is why AMMAR says that women avoid going to the hospital or for HIV testing and neglect their personal care. Furthermore, due to these circumstances some women never find out that they have caught a disease.

Friendly institutions
To overcome the resistance to hospital visits and HIV testing, AMMAR had to develop a comprehensive strategy to increase sex workers' health consciousness. Some components of this strategy are:

1. Prevention campaigns - Several STI prevention programmes and campaigns have been conducted since 1998, first, in Buenos Aires, and later in other cities such as Rosario, Mendoza, Córdoba and Salta.
2. Peer education - A peer education programme has been set up, which allows several women to receive information on health care and STI prevention. After these lessons the women have been in charge of distribution of this information to their peers in the street.
3. Research - An investigation was conducted for PAHO (Pan-American Health Organization) to inform this international organisation on the socio-economic situation of street-based sex workers, and a survey was carried out among 300 female sex workers to determine the HIV incidence rate among them.
4. Support - Free psychological assistance has been offered to their members and a weekly group meeting where women can share their thoughts and experiences has been organised.

Finally, an important component of the strategy has been the establishment of a network of 'friendly institutions', where women can go to in order to take care of their health. After several interviews with members from public and private institutions such as hospitals, government organisations and NGOs, several agreements with doctors were made so that women can visit the hospital at a specific day and hour, find ‘friendly doctors’ there and avoid unpleasant situations due to discrimination.

Taking stock of a decade of work
After many years of intense work, AMMAR has grown a lot. There are offices all over the country now and the organisation is actively involved in the Latin American and Caribbean Network of Sex Workers. At the moment, the main focus of interest is to challenge societal
Discrimination of sex workers in health-care settings in France

Gaëlle Téqui

In France, health access is currently deteriorating despite what started out as a reasonably good social security system. This is not surprising, as the two-year-old right-wing government has enforced a repressive zero-tolerance model of society and a tough budgetary policy. New laws have been enacted in the last two years, such as the law on domestic security, which provides that the penalty for passive or active soliciting in the streets is a two-month prison sentence and a 3,750 euro fine. Migrant women tried on this charge run the risk of being deported whether they have a residence permit or not. This new law on domestic security, in force since March 2003, has led to sex workers being harassed, frightened, sued, fined and jailed; compared to delinquents, threatened, sent back to the realms of marginality and permanently exposed to violence.

Since January 2004, a new law on immigration has been in force which, among other things, toughens the conditions for obtaining residence permits and makes deportation easier and faster. At the same time, reforming the social security system is being looked into.

One of the effects of such action is increased discrimination toward migrants and marginalised groups including sex workers. As some 60% of the country's sex workers are migrants, the sex work community is severely affected by these laws.

The French social security system France is a country where everyone is entitled to health insurance, provided they have a work contract. If not, and if someone earns less than about 550 euros per month, he or she can benefit from CMU (Couverture Maladie Universelle, Universal Health Coverage) which is coverage free from any form of prepayment. Foreigners and asylum seekers who have been living on French territory for more than three months and earning less than the above-mentioned sum, are also entitled to CMU. As for illegal immigrants, there is a special arrangement called AME (Aide Médicale d'État, State Medical Assistance) which entitles them to free health care in public hospitals.

Theoretically CMU is thus a right. But in practice, first time applications to subscribe to CMU at the Social Security counters are an assault course. That is where the discrimination begins. Employees at these counters are highly inquisitive and if an applicant is well dressed, he or she is liable to be reproached for having enough money to afford nice clothes and jewellery. It leads quite often to resignation and an end to the procedure. Since 2002, immediately after the eventful presidential elections which brought the right-wing government into power, Members of Parliament have suggested health system reforms to cut down public spending. These all target foreigners and people with little or no wages and their right to health care, making it more difficult for them to have access to decent medical care. Since January 2004, Members of Parliament have been attacking the general health insurance system by limiting repayments. They even plan to cancel the right to AME. In this climate, access to medical care in hospitals, but also in private doctors' consulting rooms, becomes worse, as the following examples show.

Health care in hospitals Sex workers who have to undergo hospital treatment are quite often victims of discrimination, especially if they are migrants, transvestites or transsexuals. Migrant sex workers who fall victim to attacks or who need emergency care for another given reason, usually have to wait longer in emergency rooms, as if they deserve to suffer more than local people. Sometimes, it can lead to risky situations such...
as, for example, a woman from Sierra Leone who was the victim of an attack. She bore a deep and long knife cut on her arm, the pain and seriousness of which had been underestimated. Without the intervention and insistence of one of Cabiria's outreach team workers who accompanied the woman, she might have been forced to undergo much more complicated medical treatment involving a potentially lethal infection instead of simple stitches.

Another example of discrimination toward migrant sex workers is that of a Moldavian woman, giving birth after nine months of pregnancy. When she arrived at the hospital, her cervix was dilated considerably more than a French woman who was also waiting to be taken in to deliver. After consulting both women and telling each about the extent of dilation, the doctor decided to give priority to the French woman without giving any reason.

We have also noticed an increase in unsolicited examinations for African women. Many of them are prescribed blood tests for HIV although these were not requested by them. Another sad example is that of a French sex worker who, after having been raped and examined at the hospital, was refused a shower and had been given the post-exposure tri-therapy treatment against HIV too late.

As for transvestites and transsexuals, they are usually very poorly received in hospitals because of their physical appearance or due to the gender difference in their identity papers.

Health care at private doctors' surgeries
The first difficulty sex workers have to deal with in some doctor's surgeries is the practitioner's curiosity. Regardless of how it becomes known, once the doctor knows that the person is a sex worker, his or her behaviour generally changes. A permanent suspicion of STI infection hangs over the patient. If a female sex worker is a migrant, then many doctors automatically think that she is a victim of trafficking and that her ailment is not serious but simply due to stress.

If the sex worker is from Africa, then he or she is suspected to be HIV positive. One doctor for example said, seeing spots on the skin of a sex worker's baby: "You come from Africa and you are a prostitute, so your baby is bound to be HIV positive!" In that particular case, the baby just had a rash. Consultations take less time and sometimes health problems are not detected, such as the blindness of a four-month old albino baby regularly taken to the same doctor by its mother.

How Cabiria deals with it
While two of our objectives are to promote health and to empower sex workers these tasks are complicated by gender, racial and class discrimination. To fight this, we have developed the following strategy:
1. Accompaniment - We nearly systematically accompany people to their appointments to avoid any mistreatment or infringement of rights. All sex workers, regardless their nationality are affected by this if they rely on the CMU. It is then obvious that they do not have a work contract and are part of this cross-section of poor and/or excluded people, and/or foreigners. It is a form of double discrimination: first, they are from a lower class, and second, they are immoral by the nature of their activities. Medical staff often dislike sex workers and they do not hesitate to show it.
2. Referral - As a result of the stigmatisation and discrimination, it is difficult for sex workers to have their type of activity revealed, and to deal with those in the medical and legal professions, the police and other institutional staff. Fortunately, Cabiria's President is herself a Medical Doctor and we often refer sex workers to her so that they can receive a judgement-free diagnosis, medication and treatment.
3. Monitoring - Since May 2003, we have been compiling a journal documenting all the kinds of repression that sex workers have been facing. This logbook shows a real increase in cases involving violence and discrimination. The French population seems to think that there is impunity and that they have the right to trouble and disrespect sex workers because the government does so. Therefore, we encourage people to read this journal and to support us in denouncing what is compiled in it.
4. Campaigning - To address general repression and discrimination of (migrant) sex workers we started a campaign in 2002 against the new municipal orders and the domestic security law proposed by the government. Since then, we have organ-
Health-care projects and the risk of NGO goal displacement

Wim Vandekerckhove

A lot of NGOs active in the field of sex work provide health-care-related services for sex workers. Notwithstanding the necessity of these services as well as the good intentions of those providing them, engaging in the provision of such services can cause goal displacement for NGOs. This article identifies a number of such potential goal displacements from a European perspective and gives some suggestions to address these.

That sex workers have a right to health-care access and that they are often deprived of that right because of their legal, financial or social status, are two non-debatable facts. In this sense, providing health-care services for sex workers is a necessity, and many NGOs have taken up that role. However, because of the socio-political context in which they operate, providing health services for sex workers can easily divert an NGO from its original and claimed goals and principles. The identity of an NGO is constituted by the goals and principles it explicitly sets itself to serve. These refer to an ethical and political state of civil society. In other words, an NGO serves a ‘good cause’: for example the empowerment of sex workers.

Now, to realise that ‘good cause’ an NGO has to develop activities and set strategies for campaigning and service delivery - find funding, create alliances, identify opponents, develop arguments - but has to do that within a socio-political power field in which opportunities have
to be acted upon. The ethical risk for an NGO is then that acting upon apparent opportunities causes the organisation to serve a different end than the explicitly stated ‘good cause’. The organisation then is no longer the one that the leading people, the employees, volunteers or even society thinks it is. When this is the case, goal displacement has occurred.

The funding trap
Engaging in services related to health care might be tempting for sex workers support organisations because of government funding. If a governmental agency – regional, national or international – decides to fund projects for sex workers, the first and most likely projects to be funded are health-care projects, especially those focusing on STI prevention. Whatever the political or public opinion might be with regard to sex work, access to health care is regarded as a fundamental human right in Europe. Funding health-care projects in no way obliges governments to take or change their position on sex work. In Europe, all national governments fund health projects aimed at sex workers, whether they criminalise buyers of sexual services, are abolitionist, or have regularised sex work as a legitimate business. Norway is funding such projects although it is shifting towards criminalising clients; Belgium is funding health projects while it is gradually shifting towards decriminalisation.

For an NGO, a health-care project might be the main or even sole form of funding. But because of the existing laws on sex work and the moral sentiments with which the issue is laden, engaging in health care-related services can constitute ethical risks of goal displacement for NGOs. Some of these risks are described below.

1. Health-care projects can become the source of legitimisation for NGOs
Health services are transparent in terms of specifying activities and measuring results. What kind of medical check-ups have been carried out, how many, where and when is easy to report on. They can easily be budgeted and accounted for. This is important for funding governments. They know what they are paying for. For NGOs, registration – even anonymous – in terms of numbers and activities as well as in terms of allocated costs is fairly straightforward. Through reporting on delivered health services, an NGO can show it is working hard and working well. The increasing demand for NGOs to be accountable might lead NGOs to overemphasise their health project in relation to other - less measurable - projects they run or goals they pursue.

2. Health projects can distort the discourse of an NGO
Health-care projects often narrow down the health issue to an HIV/STI issue. In the early 1980s, HIV/AIDS took the place syphilis had up till the 1970s. Given the current alarm on the HIV epidemic, governments cannot afford not to fund HIV prevention projects. As such, it is a tempting funding channel for NGOs. However, tapping into it reinforces a 19th century discourse that regards sex workers as ‘spreaders of diseases’. That discourse is still alive today in justifying health projects for sex workers. It is still used in lobbying for government funding in the sense that health-care projects for sex workers equals preventive health care for the population. It is obvious that such a discourse distorts empowerment of sex workers. When NGOs take up that discourse to get their project funded – and taking it up increases their chances of getting funded - then they reproduce the stigma of sex work as dangerous, threatening, unhygienic and unhealthy.

Furthermore, a project or health service will be regarded as successful when it is able to report a high number of medical screening, vaccinations, condom distribution and treatments. But for sex workers such results are actually bad news, for the message it speaks reinforces the stigma of sex workers as an unhealthy and unhygienic group of people. But being able to report strong results - read: a lot of very unhealthy sex workers - strengthens the argument for more funding. Finally, the reduction of the health issue regarding sex work to HIV and STI prevention and care, diverts the attention for other health issues sex workers face, for example the lack of access to regular health care for (migrant) sex workers, or the risk of physical abuse sex workers face. In an extreme case, using funds from an HIV/STI project to promote healthy nutrition or physical safety, or to spend time talking about social issues with sex workers, might be seen as fraudulent. For example, this was one of the arguments in the withdrawal of government funds allocated to the Belgian NGO Payoke for an HIV/STI prevention project. The targets of that project were considered too wide – as it also included social assistance - and the government only wanted to finance ‘strictly medical actions’.
Female sex workers have always been considered as reservoirs, if not ‘vectors’, for the transmission of STIs by the medical establishment in Hong Kong. Several studies have been published concerning infection rates and STI prevention efforts among sex workers. However, what is still being ignored by many health professionals and researchers is that sex workers might have more health-related problems than just STIs. Many women have to deal with a myriad of socio-economic problems, among which poverty, drug use, social marginalisation and organised crime. They are heavily stigmatised and ostracised. Sex workers are often forced to work underground and away from their local communities. With the closer integration and high volume of cross-border travel between China and Hong Kong in recent years, this workforce is constantly ‘supplied’ by mainland Chinese women with little education and negotiating power. Due to their illegal working status, they do not get any protection from the police, nor are they able to report crimes committed at or outside work without the risk of being faced with criminal charges or deportation. Therefore, many are living in sub-optimal health conditions. For those people, access to health care is then only possible through the NGO project – which usually has limited funds and a highly insecure funding situation.

4. Health-care projects can depoliticise an NGO

Most NGOs start up as ethico-political actors. As such, many of their activities are advocacy-related, and their service delivery is an exponent of their advocacy. As with any government funding, funding health-care projects can make an NGO dependent on that funding. If the delivery of health services becomes the main or sole source of funding for an NGO, service delivery will be its central focus, and its advocacy role will become marginal. A specific risk with regard to health projects is that performing well – getting the results one is accountable for – makes it a technical rather than a political issue. To argue that access to health care is a human right is a political argument. But organising outreach in function of contacting more sex workers to register and to refer to health services calls for a technical rationality. In this sense, health-care projects can depoliticise an NGO.

NGOs should be careful not to distort their discourse into narrowing down the health issue into an HIV/STI issue

Sticking to one’s mission

Concluding this brief analysis, it seems important that NGOs make their mission as ethico-political actors explicit and position their projects – including health-care projects – within that mission statement. Doing so might form a barrier against the gradual marginalising of their advocacy role. Secondly, NGOs should be careful not to distort their discourse into narrowing down the health issue into an HIV/STI issue. Third, NGOs should maintain non-health related projects. If no funding can be obtained for these projects, an effort should be made to have these projects carried out by volunteers. In order to balance the amount of attention different projects get, it is advisable to also have volunteers on the Board. Fourth, less measurable projects can be reported on through questionnaires on the attitudes of the target group towards those projects. In all their activities, NGOs ought to be wary of depoliticisation.

As far as governments and donors are concerned, there is a need for argumentation picturing social, non-controlling projects as a human right. To generate discourses linking sex work with the concepts of social health (the ability to keep healthy interactions with friends, family, neighbours or co-workers) and citizenship for example, still seems to be a continuing task for activists and academics.

Notes

1. For arguments pro and contra special health services for sex workers, see for example Research for Sex Work 2 (1999): www.med.vu.nl/hcc.
2. The Ghapro team works together with an NGO – the Ketelpatrouille – to contact African migrant sex workers. It is important to note that the Ghapro team works on an annual government-funded budget of 80,000 euro, while the Ketelpatrouille receives no funding at all, but is allowed to use a house owned by the city.

About the author

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Female sex workers in Hong Kong: Moving beyond sexual health

William Wong and Ann Gray

Female sex workers have always been considered as reservoirs, if not ‘vectors’, for the transmission of STIs by the medical establishment in Hong Kong. Several studies have been published concerning infection rates and STI prevention efforts among sex workers. However, what is still being ignored by many health professionals and researchers is that sex workers might have more health-related problems than just STIs. Many women have to deal with a myriad of socio-economic problems, among which poverty, drug use, social marginalisation and organised crime. They are heavily stigmatised and ostracised. Sex workers are often forced to work underground and away from their local communities. With the closer integration and high volume of cross-border travel between China and Hong Kong in recent years, this workforce is constantly ‘supplied’ by mainland Chinese women with little education and negotiating power. Due to their illegal working status, they do not get any protection from the police, nor are they able to report crimes committed at or outside work without the risk of being faced with criminal charges or deportation. Therefore, many are living in sub-optimal health conditions. For those people, access to health care is then only possible through the NGO project – which usually has limited funds and a highly insecure funding situation.
According to the literature, nearly half of the ten studies conducted among Hong Kong-based female sex workers and their clients until February 2003, not one mentioned issues other than HIV/STI incidence and prevalence, sexual behaviour and condom use. A literature search in medical journals showed that of the ten studies conducted among Chinese sex workers and on their willingness to seek medical attention.

Health risks of sex workers
A literature search in medical journals showed that of the ten studies conducted among Hong Kong-based female sex workers and their clients until February 2003, not one addressed other issues than HIV/STI incidence and prevalence, sexual behaviour and condom use. According to the literature, nearly half of the sex workers attending the government STI clinics between 1999 and 2000 were found to have STIs. Of them, hepatitis B transmission tended to be ignored in the literature. Hepatitis B is far more infectious and far more common among sex workers than HIV; however, few data are available. A small sample of 100 sex workers attending a clinic in 1995 showed that they had 1.5 to 2 times more Hepatitis B surface antigen (HBsAg) and HBeAg antibodies in their blood than other people. One study showed that female sex workers who were drug users were perceived to have a lower level of control over the use of condoms with their clients. The proportion of female sex workers who reported ‘always’ using condoms in Hong Kong has grown steadily (from 40% to 75%). However, condom use in oral-genital sex with clients remained low (around 30%) as well as condom use with regular partners (8-30%).

Holistic approach
As stated before, HIV and other STIs are not always the sex workers’ prime concern. With the recent outbreak of Severe Acute Respiratory Syndrome (SARS), sex workers were caught in a difficult dilemma. On the one hand, they were exposed to a large number of clients across society and had little say in who walked through their doors. The nature of their work involved close personal contact and it was impossible for them to follow the government’s recommendations regarding personal hygiene and protection. On the other hand, they had to continue to make a living with their work. In addition, social marginalisation and stigmatisation had caused delays and even stopped some of the most resource-deprived women from seeking proper medical care and treatment. These clashing interests could be a potential ‘time-bomb’ in the spread of SARS or any infectious disease in the community. In many countries, services aimed at sex workers have adopted an increasingly holistic approach in which STIs and HIV prevention is only part of a broader health and economic programme. Specialist outreach clinics have been employed in other countries with great success. These clinics take services to the places where sex workers work, they are open at the hours suitable to them and they enable them to take up risk-reduction strategies relevant to their needs. In Hong Kong such an approach is only gradually developing. Previously, the main funding for NGOs had been secured for HIV prevention programmes only but the experience from working with female sex workers in Hong Kong has shown an urgent need for an integrated service centre.

Quality of life
Until recently, no research from Hong Kong had attempted to look into the life-styles of sex workers and how their work may interact with their health and well-being. For example, the time they spend waiting for clients is usually very long. This restricts them from doing any outdoor exercise or cooking at home, thereby encouraging unhealthy life-styles such as smoking or gambling. As some women work on the street, there will be an added risk of lack of personal safety and exploitation by gangsters.

Of the 89 women, 3 have been abused, 7 beaten, 20 refused payment by their clients
Action for REACH OUT and the Chinese University of Hong Kong carried out a survey among 89 street sex workers to explore their quality of life (QOL) using the WHOQOL Measure, and to assess various life-styles including diet, exercise, sleep and leisure activities. The survey found that sex workers’ psychological health and environmental domain, defined by personal safety, home environment, access to health care, opportunities for

About Action for REACH OUT

In 2002, Action For REACH OUT (AFRO) set up an integrated community health drop-in centre for female sex workers. AFRO is a service organisation working with and for sex workers in Hong Kong. The drop-in centre offers them counselling, information and referral for drug and alcohol-related, mental, sexual and emotional health issues as well as for family and legal problems. This is consistent with the World Health Organization’s description of sexual health as “the integration of the somatic, emotional, intellectual and social aspects of sexual well-being in ways that are positively enriching and that enhance personality, communication and love”. Underpinning the effectiveness of the services provided by the centre is a clear understanding of the realities of the sex industry, so research also becomes an important element of the project. The centre also offers part-time employment and on the job training in office work and beauty care for those who are interested in exploring future or alternative career opportunities. The clinic described above and a legal advice clinic are now integral parts of the project.
acquiring new information and skills, were significantly worse than that of 89 local subjects matched by sex and age.¹

Stress and distress

The majority of female sex workers (90%) admitted experiencing stress, and financial problems was the most cited cause. A quarter of women had considered and had attempted suicide. Almost half of them worked seven days a week and many for more than ten hours per day. Most women (78%) worked and lived in the same place, and shopping, eating out, playing mah-jong and karaoke were the top four pastimes. Of the 89 women, 3 have been raped, 7 beaten, 20 abused, 14 robbed and 18 refused payment by their clients. During the 2003 SARS outbreak, 19 women out of the 33 respondents who were working in Hong Kong at the time were scared of being infected, but only 5-6 of them wore masks and washed their hands more frequently. The rest chose to do nothing, tried to select healthy clients or reduced the workload.

The diverse health concerns of sex workers are also visible in the first results of a new outreach clinic at the AFRO drop-in centre, which was set up by AFRO and the Chinese University of Hong Kong in 2003. In this clinic, basic health checks and counselling services are provided for two hours every month. In the last six sessions, we had 28 patients attending the clinic. Their complaints ranged from physical health problems (14) and STI-related issues (9) to severe depression (2).

Conclusion

The sex trade is an open secret in Hong Kong and an inseparable part of social and economic life. It is estimated that Hong Kong has 200,000 female sex workers of a total population of 6.8 million people. However, the literature review shows that our understanding of the health of sex workers is very unbalanced and the emphasis is often on sexual health. Sex workers are a sector of the population no different from the rest of the population except for the fact that they may have more specific health risks and require greater sensitivity. It is time health professionals and researchers review the ethics behind their research agenda and start to address those of sex workers instead of their own. There are very few NGOs working for sex workers in Hong Kong (a place often regarded as ‘well-developed’ and wealthy) and they should be actively involved in shaping the research directions which were previously dominated by academic institutions alone.

Our research on the quality of life and lifestyles exposed a number of weaknesses, such as poor psychological and physical health as well as lack of access to the health services and lack of legal protection, for which further actions and services are required. There is no affordable medical service or psychological counselling and support currently available for sex workers. Our experience with the new outreach clinic at the AFRO drop-in centre confirms our argument that their health needs are not necessarily related to STIs and that proper health care and health promotion for sex workers are urgently needed.

Except for these special services, education of medical students and health professionals in Hong Kong’s regular health services is necessary. Health professionals working with sex workers must learn to accept commercial sex as the occupation of their patients and approach their health holistically. Further training for doctors to overcome barriers to discussing sensitive issues such as sex, STIs and condom use are needed at both undergraduate and postgraduate levels. Also, medical personnel need to be made more aware of their otherwise discriminatory and stigmatising behaviour towards sex workers. In an event of a life-threatening infectious epidemic such as SARS, sensible and acceptable precautions such as hand washing or avoiding wet kisses should be encouraged. Last but not least, vaccines against hepatitis B should be offered to all sex workers free of charge.

World Health Organization’s Quality of Life (WHOQOL) Project

Since 1991, WHO has developed two questionnaires for measuring the quality of life (the WHOQOL-100 and the WHOQOL-BREF). These instruments have many uses, including use in medical practice, research, audit, and in policy making. The WHOQOL is currently available in over 20 different languages and is being tested in several countries. In 2003, WHO also developed a draft questionnaire to assess the QoL for people living with HIV/AIDS.

The definition of QoL, adopted by the WHOQOL Group is: “an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment.”

Some principles of the WHOQOL are: 1) it includes all the facets of life mentioned in the definition; 2) it should be applied by the subjects themselves and not by a doctor or researcher. A number of studies have demonstrated that physicians’ ratings of the QoL of their patients with chronic illness are significantly different to patients’ self-rated QoL; 3) instruments need to be culturally sensitive, comprising items which address culturally relevant issues and use culturally relevant language.

More information: www.who.int/evidence/assessment-instruments/qol
Notes
2. See the side-box on page 22.

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Expanding HIV treatment options
for female sex workers in Vancouver's Downtown Eastside
Janice Duddy

In many female sex workers' lives HIV/AIDS is not a priority and often sits far down the list after eating, finding a place to sleep, and getting money for their next fix if they are drug users. On the streets of Vancouver's Downtown Eastside (DTES) the ethics of ARV distribution have been challenged by the practical issues of getting sex workers to care enough about their health and creating a programme that is easy and accessible. Recently, work was started to change the current situation for female sex workers in the DTES area. Although the road ahead is long the first steps have been made.

It is important to understand that Vancouver's DTES neighbourhood is unlike any other place in Canada, and perhaps in North America. There are approximately 16,000 long-term residents living in the DTES. It is Canada's poorest neighbourhood with a concentration of crime, sex work, and drug addiction unlike anywhere else in the country. In 1997 the Health Board declared the DTES a medical emergency due to the incredibly high HIV infection rates, the highest in North America.

HIV/AIDS in the DTES
A disproportionate number (40%) of DTES residents are aboriginal (Native American). In fact, 70% of Vancouver's total aboriginal population lives in the DTES, and 70% of the DTES sex workers are aboriginal.1 As the HIV/AIDS epidemic in British Columbia has drastically changed since it began in the early 1980s, aboriginal people, and women in particular, have become one of the fastest growing populations becoming infected.2 Accurate estimates on the burden of HIV infection and the number of individuals who are eligible for ARV treatment in the DTES are not available. For argument's sake, it is estimated that there are 4,000 to 5,000 active injection drug users (IDUs) in the area. Of these, between 30% and 40%, or about 2,000 people, are HIV positive. If half qualify for treatment than it can be assumed that approximately 1,000 people should be on ARVs. The drug treatment programme at the British Columbia Centre for Excellence in HIV/AIDS currently distributes ARV medications to about 250 people with postal codes in the DTES. This means that there is a significant under-utilisation of ARVs in the community.

Reaching out to women
Cost to individuals is not a factor in the under-utilisation. Since 1992, under its drug treatment programme, the B.C. Centre for Excellence in HIV/AIDS has distributed ARVs at no cost to HIV-positive people in British Columbia. While Canada has public health care, it is a provincial rather than a federal responsibility. Therefore, not all provinces have the same policy as British Columbia. While provincial health insurance pays the majority of medical cost it does not always pay for prescription treatments. However, patients may qualify for some drug support through social assistance.

The Maximally Assisted Therapy (MAT) pro-
WISH found varied reasons for not taking HIV medications to women in the DTES.

The WISH drop-in
There are many challenges that female sex workers face when accessing health services, as seen in the drop-in centre society. WISH is a nonprofit organisation open most nights of the week. It is the only organisation open to female sex workers after regular business hours. It is a place where women can find refuge from the street, eat a hot meal, have a shower, and relax. WISH also offers on-site nursing, referrals to detoxification centres, rehabilitation houses, and shelters. The NGO serves up to 150 women in a night and over 400 different workers after regular business hours. It is a safe, supportive environment within which they can express their needs and concerns. Based upon the comments of the sex workers, Planned Parenthood has begun discussions with Stepping Stone to initiate the process of making this organisation an outreach site. It will be able to provide anonymous HIV testing, hepatitis B, and syphilis testing, hepatitis A and B vaccinations, and group educational sessions on a bi-weekly basis. The sex workers who participated in the focus groups were very open and honest in their belief that the presence of Planned Parenthood would be well accepted at Stepping Stone, and they all stated that they would be glad to share their positive experience in the project with other sex workers.

The location of the HIV testing site proved to be very important to the sex workers. Some women liked the idea of coming to the Planned Parenthood premises for testing as they felt that it would offer an extra measure of confidentiality due to the broad range of services offered at the clinic. "Yeah, I think here wouldn't be too bad either [for testing] though because Planned Parenthood, you know, it's...who knows what you're here for. Everybody that walks in that door could be getting birth control, anything you know, so..." The majority felt however, that they would be more comfortable if HIV testing and education services were offered at Stepping Stone, an organisation that provides support services to sex workers. Not only does the organisation itself provide a physical space in which the women feel safe, the support of fellow sex workers allows for an emotional environment within which they can express their needs and concerns. Based upon the comments of the sex workers, Planned Parenthood has begun discussions with Stepping Stone to initiate the process of making this organisation an outreach site. It will be able to provide anonymous HIV testing, hepatitis B, and syphilis testing, hepatitis A and B vaccinations, and group educational sessions on a bi-weekly basis. The sex workers who participated in the focus groups were very open and honest in their belief that the presence of Planned Parenthood would be well accepted at Stepping Stone, and they all stated that they would be glad to share their positive experience in the project with other sex workers.

Anita Keeping, coordinator of the Anonymous HIV Testing Program at Planned Parenthood Metro Clinic, Halifax, Nova Scotia, Canada.

Responding to the need: moving forward with client-focused services in Canada
The Planned Parenthood Metro Clinic in Halifax, Canada, has been promoting sexual and reproductive health for over thirty years, especially among vulnerable populations, including sex workers. The NGO has operated an anonymous HIV testing programme since 1994. During the latter part of 2003, Planned Parenthood carried out an assessment to examine the need for voluntary counseling and testing services among sex workers. As part of the data collection process, two focus groups with female sex workers in the Halifax area were done. The women who participated in the focus groups revealed useful information regarding how and where HIV testing should take place. For them, discussing past experiences with testing in traditional healthcare settings, which were less than positive, gave them insight into what they did not want in terms of testing. Of primary concern was the judgemental attitude presented by some health-care providers, who sometimes treated the women with disdain. The location of the HIV testing site proved to be very important to the sex workers. Some women liked the idea of coming to the Planned Parenthood premises for testing as they felt that it would offer an extra measure of confidentiality due to the broad range of services offered at the clinic. "Yeah, I think here wouldn't be too bad either [for testing] though because Planned Parenthood, you know, it's...who knows what you're here for. Everybody that walks in that door could be getting birth control, anything you know, so..." The majority felt however, that they would be more comfortable if HIV testing and education services were offered at Stepping Stone, an organisation that provides support services to sex workers. Not only does the organisation itself provide a physical space in which the women feel safe, the support of fellow sex workers allows for an emotional environment within which they can express their needs and concerns. Based upon the comments of the sex workers, Planned Parenthood has begun discussions with Stepping Stone to initiate the process of making this organisation an outreach site. It will be able to provide anonymous HIV testing, hepatitis B and syphilis testing, hepatitis A and B vaccinations, and group educational sessions on a bi-weekly basis. The sex workers who participated in the focus groups were very open and honest in their belief that the presence of Planned Parenthood would be well accepted at Stepping Stone, and they all stated that they would be glad to share their positive experience in the project with other sex workers.

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In an attempt to examine the possibility of using an organisation like WISH as a partner in dispensing HIV medications, the B.C. Centre for Excellence in HIV/AIDS partnered with WISH to initiate a needs assessment study late in 2003. A survey of 159 women at WISH found varied reasons for not taking HIV medications. The women feared the side-effects of the drugs. They did not know enough about the treatment. They could not make regular medical appointments. They could not take medications every day, and feared that others might suspect that they were HIV positive. Following this initial survey, further research is underway. It was found during the survey that women were not self-reporting their HIV status, thus an additional questionnaire is being formulated that will allow women to give consent so that researchers can link with participants’ medical records. Through these linkages, researchers will be able to validate/verify self-reported information through previous medical testing, HIV/HCV infection rates, viral loads, CD4 counts, and previous uptake of ARVs. This data will allow researchers and medical professionals to more adequately monitor health indicators and identify intervention needs. Also, a series of focus groups are being created to allow women to have input in what they see as an effective method of anti-retroviral distribution for female sex workers and ‘street involved’ women in the DTES. Some different ways that have been identified to distribute medications include: at WISH, at a health clinic for women only, daily delivery to home or room, delivery on the street, and at a community pharmacy. These will be further explored during the focus groups.

Reasons for not using ARVs
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A holistic framework
Using the data collected from these sources and in partnership with a community advisory board, it is hoped that a successful HIV/AIDS treatment programme will be created for these women. Although the women who use WISH services agreed that an ARV programme would be beneficial, many of them repeated...
that an HIV/AIDS programme designed for female sex workers in the DTES must be created within a larger framework that deals with health and wellness in a holistic manner. Sex workers need to be treated as complete people. They experience many complicated, interconnected, and sometimes diverging health and wellness concerns that need to be acknowledged and acted upon. Their risk of HIV/AIDS would be reduced and the success of HIV treatment would improve if they could improve all aspects of their lives.

It is clear that HIV/AIDS is not the only challenge female sex workers in Vancouver face. Their lives are full of uncertainty; they face violence, addiction, poverty, illness, disease, depression, and insecurity everyday. Their health and wellbeing is continually threatened. For many, HIV/AIDS does not top their list of concerns. Understanding this reality is important.

Ethical responsibility

Community members, service providers, medical professions, and researchers have an ethical responsibility to find ways to protect these women and to keep them healthy. Steps are now being taken to create a treatment programme that is flexible enough so that female sex workers can feel confident in accessing services, while staying stringent enough to protect the integrity of the drug treatment. While HIV/AIDS drug therapies are very complicated and demanding, it is imperative the patient takes the medication every single day. Public health concerns arise due to the fact that patients who do not fully adhere to therapy are more likely to develop multi-drug-resistant virus types, which they could then pass on to others.

Female sex workers, a group that has been disproportionately affected by the AIDS epidemic in Vancouver, are not accessing life-saving drugs. Given that current programmes are not working, it is unethical for service providers to simply ‘stay-the-course’.

Hopefully this new partnership between the B.C. Centre for Excellence in HIV/AIDS and the WISH Drop-In Centre Society will use innovation, creativity, and input from female sex workers to create the space needed for women to access treatment.

Notes
1. C. Benoit and D. Carroll. Marginalized voices from the Downtown Eastside: Aboriginal women speak about their health experiences. The National Network of Environments and

About WISH

The aim of WISH (Women’s Information Safe House) is to increase the health, safety and well being of women working in the sex trade in the DTES.

The drop-in centre is open Sunday through Friday from 6 to 10 pm. On a nightly basis, staff and volunteers serve hot meals, dispense make-up, hygiene items, and clothing, and provide showering facilities. Further, WISH offers medical services to women who often avoid going to regular health clinics. Street nurses come in twice a week and the Health Van stops by the centre every night. For women whose addictions and lifestyles result in multiple infections, illnesses, and injuries, these services are vital.

WISH also offers referrals to detoxification centres, rehabilitations houses, and shelters for up to 150 women per night. For those who want to find other jobs, the ‘Women Helping Women Transition Program’ offers training to women who are generally considered to be unemployable.

Throughout the six-month course, the participants are given a small weekly honorarium while gaining valuable work experience through volunteer training and various courses.

Three times a week, the activities centre is open for women to learn computer skills, borrow books, write letters, journals, and poetry, engage in arts and crafts, or just ‘hang out’. The facilitators also provide tutoring for those who are attempting to upgrade their education. Springing from the Literacy Programme is the Women’s Advisory Group. Comprised of WISH participants, this group has a vital say in formulating and implementing WISH policies. Several WAG members sit on various committees (Program & Policy, Communications, Volunteer etc.) with volunteers and Board members. It is our hope that, in a few years, women from WAG will become members of the Board of Directors and take a stronger role in the running of the Society.

More information: WISH, wishvolunteers@telus.net, www.wish-vancouver.net

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“I was an IV drug user for many, many, many years and I have scars. And when I go to get just blood work done, you know, I’m watching them and laughing, okay, because they’re doubling up the gloves. I see how they look at me right, they embarrass you without saying anything. Just the way they look at you, you know, even you’re handled in a way differently.”

Participant focus group conducted by Planned Parenthood Metro Clinic, Halifax, Canada

More information: WISH, wishvolunteers@telus.net, www.wish-vancouver.net
Until recently, the national ordinance on HIV/AIDS stated that sex work in Vietnam is considered a social evil. The current approach applied by the Vietnamese government in dealing with sex work, drug use and gambling is known as the ‘social evils’ approach. Social evils are taken to be behaviours or persons that negatively affect society. The consequences of this approach for sex workers can be severe, as this article will show.

The constant threat of arrests works against the trust that NGOs are trying to establish

sex workers who have migrated to the city. Most of them have migrated illegally, without official permission of the government, and therefore have restricted access to social services and support networks. Furthermore, they have become a ‘social evil’ through their line of work, which also affects their ability to access assistance.

While HIV/AIDS rates in Vietnam are relatively low in comparison to other South-East Asian countries, the rates continue to increase steadily. Ministry of Health statistics as of October 2003 report over 73,600 HIV-positive people in Vietnam with 11,254 clinical AIDS cases and 6,325 reported deaths. The actual numbers are suspected to be significantly higher than reported.

According to the National AIDS Standing Bureau, there are several reasons for the increased expansion of the HIV/AIDS epidemic in Vietnam: “the evils of prostitution and drug use have been controlled to some extent; nevertheless, these vices are still developing secretly. This is the main and direct reason causing the transmission of HIV/AIDS in Vietnam at present and also that is the possible cause for a booming epidemic in sentinel areas.” Therefore, the government believes that the epidemic in Vietnam could be contained by preventing prostitution and drug use.

Social evils interventions

The social evils approach to sex work and drug use comprises repressive interventions such as rounding up of sex workers and drug users and placing them in forced rehabilitation centres. If the government and/or police decide to conduct a ‘social evils round-up’, arrested sex workers will be placed in these rehabilitation centres.
Health promotion and harm reduction

The rehabilitation centres continue to use the government's anti-social evils approach when dealing with their residents. However, more recently NGOs such as Family Health International (FHI) have been working with the government and the centres' staff to include a harm reduction approach when working with both sex workers and IDU residents. Residents are taught about HIV/AIDS and prevention skills as well as safe injection and safer sex practices.

From the outside of the walled compound, the Binh Dinh 05/06 centre resembles a boarding school. It is clean and has beautifully tended gardens. Within the compound there are staff offices, a building for the women (sex workers) and a building for the men (IDUs). The residents' rooms (commonly shared by two or three residents) are clean and simple. There is also a building for vocational training and for meetings. Further back in the centre is a building for residents living with HIV/AIDS. The Binh Dinh centre was the first to be included in FHI's Health promotion and harm reduction model developed by FHI in Binh Dinh. In addition, the government IEC unit has insisted on using ex-IDUs and people living with HIV/AIDS in the development of the interventions.

Instead of locking sex workers up in closed institutions, governments such as that of Vietnam would better serve sex worker populations by taking a holistic, public health and human rights-based approach

‘Peer education for risk reduction and support for people living with HIV/AIDS’ project. Staff were open to working with FHI and to learning about a harm reduction, public health-based approach. A public health approach to illicit drug use and sex work focuses on health promotion and disease prevention, and contains measures such as safer sex education, condom promotion, needle exchange facilities etc.

In the framework of the peer education project, the 05/06 centre staff and the resident IDUs and sex workers were trained in HIV prevention, risk reduction and peer education skills. Other activities included focus group discussions, advocacy meetings with local authorities and topic talks and forum education for residents about healthy living and safer behaviours. The peer educators use real-life stories written by themselves, drama and music, to convey safer sex and harm reduction messages to their peers, and also to other people outside the centre. For example, Binh Dinh centre residents have written a play about sex work and they have presented it in the local community and schools. Further, a documentary film entitled ‘Thirst for Life’ about the Binh Dinh centre and about a stage show developed by a resident and acted out by centre residents was presented at the 15th International Conference on the Reduction of Drug Related Harm in Melbourne, Australia, in April 2004.

One step forward, two steps back

According to FHI Vietnam the new national HIV/AIDS strategy that was approved in March 2004 no longer includes the use of the term ‘social evils’. The strategy addresses new issues of harm reduction, and stigma and discrimination. Although it is a good sign that the Ministry of Health has dropped the use of the term and takes a more public-health focused approach, it might take a lot of time before the social evils viewpoint will really disappear. The Department of Social Evils still exists. Notwithstanding, the government is actively working with NGOs towards making real and positive changes for a public-health model. They are interested in training all rehabilitation centres in using the model developed by FHI in Binh Dinh. In addition, the government IEC unit has insisted on using ex-IDUs and people living with HIV/AIDS in the prevention of the interventions.

Also outside the centres, NGOs are working to assist the government in adopting a public health approach in working with sex workers. DKT International, a condom social marketing organisation, has been working with the authorities in advocating condom sales and condom use in ‘hot-spot’ areas, such as bars, karaoke venues, hotels and truck stops. Other organisations such as World Vision International help the women adopt safer sex practices and provide HIV/AIDS education and prevention.
While these NGOs have been relatively successful, the constant threat of arrests works against the trust that they are trying to establish. Even if the government bodies working on HIV prevention understand the importance of a less stigmatising and discriminatory approach, round-ups still occur on a regular basis, which is potentially undermining any positive efforts. All of the NGOs working with sex workers must lobby the government in order to obtain permission to work with the women. However, it is generally ‘one step forward, two steps back’ as while the NGOs may make some ground with government authorities, the police (a separate entity) continue to conduct round-ups. Advocacy is also conducted with police; however, this has not been very effective or successful so far.

To many, the term ‘social evil’ conjures up negative images. Evil can mean immoral, sinful and wicked. To place these terms and labels on anyone, most notably girls and women, only serves to discriminate against, rather than empower them. In working with sex workers, governments (especially those with a social evils approach as in Vietnam) and organisations must realise the importance of ethical and sex worker-inclusive interventions. NGOs must continue to advocate and work with the government for these interventions to occur. Instead of locking sex workers up in closed institutions and notifying their families of the reasons behind the arrest, governments such as that of Vietnam would better serve sex worker populations by taking a holistic, public health and human rights-based approach. Programmes like those implemented by FHI and DKT which help sex workers, drug users and people living with HIV/AIDS to adopt safer practices and to share their stories with others may help bring about a positive change.

Notes

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Sex work in Vietnam
As sex work is illegal in Vietnam, brothels are not officially recognised. Sex work is conducted from two main venues. The first is from an entertainment venue such as a karaoke bar, hotel, or restaurant; the women who work here are considered ‘indirect’ sex workers. They are commonly younger, prettier and fairer skinned. Karaoke-based sex workers are defined as women who meet their clients in entertainment establishments such as karaoke bars, coffee and tea bars, and beer bars. They work in various establishments selling drinks or food, but earning much of their income through sex work with clients they meet at the establishments. Approximately 70% of all soliciting takes place in these entertainment establishments.

The second venue is street-based; these women are categorised as ‘direct’ sex workers. Generally, the women begin work at an entertainment venue and move (within a year or two) to direct sex work as they begin to ‘mature’ and become less attractive to clients.
Any discussion of legalising or decriminalising prostitution in the United States inevitably leads to the controversy surrounding mandatory testing of sex workers for STIs and HIV. Although the sex workers' rights organisation SWOP-USA (www.swop-usa.org) is launching a tri-city (San Francisco, Berkeley and Oakland in California) effort to decriminalise prostitution is currently illegal in the United States, with the exception of a few licensed brothels in rural counties of the state of Nevada.

According to the Nevada State Health Division AIDS Program, sex workers in Nevada's licensed brothels must be screened for chlamydia, gonorrhoea, syphilis, and HIV prior to working. If they are found positive for chlamydia, gonorrhoea or syphilis, they cannot begin work until they are adequately treated, followed-up, and test negative on a subsequent test. Testing positive for HIV bars them from working for life. Once sex workers begin working in the Nevada brothels, they are tested weekly for chlamydia and gonorrhoea, and monthly for syphilis and HIV.

Many US states have laws pertaining to the mandatory testing of individuals convicted of ‘sex crimes’, including prostitution. The details can be found on the National Conference of State Legislatures’ website: www.ncsl.org/programs/health/mandtest.htm. If sex workers are found to be HIV positive they are barred from work, and if they do not give up prostitution, they can be severely punished, as Karen Bastow wrote in 1995: “Under a California law requiring mandatory testing, if a prostitute tests positive, subsequent prostitution convictions carry three-year sentences, whether the prostitute practiced safe sex or not. […] In another US state, a Florida, an HIV-positive prostitute was charged with manslaughter despite the fact that all her customers tested seronegative and she had used condoms consistently.”

Test and tax
To the majority of laypersons (and consequently the bulk of the voting population) mandatory testing seems like the least that should be expected from sex workers whether they work legally or not. It is a foregone conclusion that prostitutes spread disease and therefore need to be controlled in some manner if public health safety is to be maintained. In fact, many otherwise liberal individuals and groups will champion the opportunity to test and tax prostitutes as major incentives to legalise.

It matters little that scientific data do not support the common belief that sex workers are major contributors of STIs in the USA. The Centers for Disease Control have conducted several tests for HIV seropositivity in sex workers and consistently conclude “risk factors for AIDS in female prostitutes may be similar to those in other women living in these [tested] geographic areas.” In other words, although the US government would love to prove otherwise, US sex workers spread no more disease than US housewives and college girls. Some evidence even supports the contention that the presence of sex workers decreases the incidence of STIs, as Rita Brock and Susan Thistlethwaite point out in their book Casting Stones: “When the Chicken Ranch, the famous Texas brothel, was closed, the number of gonorrhea cases in the general population rose substantially. Venereal disease also rose substantially when brothels were closed from 1917 to 1920. U.S Department of Public Health statistics have been consistently expected from sex workers whether they work legally or not. It is a foregone conclusion that prostitutes spread disease and therefore need to be controlled in some manner if public health safety is to be maintained. In fact, many otherwise liberal individuals and groups will champion the opportunity to test and tax prostitutes as major incentives to legalise.

Many US states have laws pertaining to the mandatory testing of individuals convicted of sex crimes, including prostitution
testing for HIV, whether mandatory or voluntary, means little when it comes to the prevention of disease. Although an unnamed male performer was tested for HIV every three weeks, adult movie producers were forced to shut down when he tested positive for HIV. About 45 actors, actresses and other persons who had had sex with this performer, put themselves on voluntary quarantine as a result. Dr Jonathan Fielding, director of public health and health officer for Los Angeles County, said that the discovery shows that screening programmes are not perfect and the only way to prevent AIDS is not to have unprotected sex.

As any health-care professional knows, there is a window between infection and seroconversion when no amount of testing can guarantee that HIV will not be spread during sexual contact. Whether prostitution is linked with the increased spread of disease or not, mandatory testing will never be a solution. Mandatory testing is illogical and unscientific due to seroconversion rates as well as current statistics which establish the practice as ineffectual in preventing the spread of disease. In addition, mandatory testing has the net result of discouraging targeted populations from seeking medical intervention because of the fear and stigma that it inculcates. Compound this with the false sense of security that can and does lead tested individuals to engage in unprotected sex and testing becomes a sure fire formula for disaster. So why does the myth of mandatory testing persist?

Violation of civil rights
If one reviews all the instances where mandatory testing has been successfully introduced, an interesting pattern reveals itself. Mandatory testing has been applied to smaller disenfranchised portions of the population including immigrants, boxers, military personnel, prison inmates, persons convicted of sex crimes including prostitution, and legal brothel workers. Attempts to test the general population in specific instances such as marriage have been short-lived as the voters recognised it for the huge violation of their civil rights that it is. Mandatory testing for HIV was recommended for health-care providers (including dentists and surgeons) early on when the public was more fearful of AIDS. Of course it never happened. The medical community is far too powerful to consent to losing their rights to privacy. However, some doctors are currently crying out for the mandatory testing of patients, particularly pregnant mothers and their newborns.

I can only observe how typical it is that predominately male doctors wish to exert control over the lives and bodies of women in the name of public health. I do not think it is any accident that the public feels a need to control the lives and bodies of women employed in the sex industry either. For all the proclaimed interest in preventing the spread of disease, no one is suggesting that we mandatorily test the men who purchase sexual services, let alone all men who have sex of any kind with anyone. Does one really need to point to the obvious sexism? If mandatory testing makes medical sense for vaginas (which it does not), then it must make medical sense for penises as well. One cannot deny that a population of government-inspected sex workers might be a comforting thought for the consumers of sexual services. So, while mandatory testing may serve some function as a marketing ploy for brothel owners and the governments that tax them it cannot be promoted as a public health measure.
Online resources on sex work and health

Making Sex Work Safe
Cheryl Overs and Paulo Longo, Network of Sex Work Projects, 1997
English: www.nswp.org/safety/msws
Spanish: www.nswp.org/pdf/HTSS.PDF

Sex workers: Part of the solution. An analysis of HIV prevention programming to prevent HIV transmission during commercial sex in developing countries
Cheryl Overs, Network of Sex Work Projects, 2002
English: www.nswp.org/safety/SOLUTION.DOC (9 MB file)

Practical guidelines for delivering health services to sex workers
Rudolf Mak (ed.), EUROPAP, 2004
English: www.europap.net/dl/guidelines/layoutENG.pdf
Spanish: www.europap.net/dl/guidelines/layoutSPAANS.pdf
French: www.europap.net/dl/guidelines/layoutFR.pdf
Also available in 9 other European languages (check out: www.europap.net/guidelines.html)

Hustling for Health: Developing services for sex workers in Europe
European Network for HIV/STD Prevention in Prostitution (EUROPAP/TAM PEP), London 1999
English: www.europap.net/dl/archive/publications/H4H%20UK_version.pdf
Spanish: www.europap.net/dl/archive/publications/H4H%20ESP_version.pdf
Also available in 9 other languages (check out: www.europap.net/manual.html)

Sex work and HIV/AIDS
Unaid Technical Update, June 2002
Also available in French, Spanish and Russian

Sex work in Asia
WHO Regional Office for the Western Pacific, July 2001
English only: www.wpro.who.int/document/FINAL-Sex Work in Asia.doc

Prostitution et Sida
Infotheque Sida/AIDS Infothek, journal of the AIDS Info Docu Switzerland, Vol. 12, no. 6, 2000
French: www.aidsnet.ch/download/00-6f.pdf

Services in the window. A manual for interventions in the world of migrant prostitution
Transnet – Transnational Empowerment of Local Networks project, 2001
English: http://transnet.exclusion.net/handbook/en.asp (pdf)
Also available in Italian and Russian (check out: http://transnet.exclusion.net/handbook)

Where women have no doctor: A health guide for women
Chapter 20 on health care for sex workers
A. Bums, R. Lovich, J. Maxwell and K. Shapiro, The Hesperian Foundation, 1997
English: www.managingdesire.org/Hesperian/wwhnd20.pdf

Research for Sex Work
No. 1: Peer education, 1998
No. 2: Appropriate Health Services for Sex Workers, 1999
No. 3: Empowerment of Sex Workers and HIV Prevention, 2000
No. 4: Violence, Repression and Other Health Threats. Sex Workers at Risk, 2001
No. 5: Health, HIV and Sex Work: the Influence of Migration and Mobility, 2002
No. 6: Sex work, HIV/AIDS, public health and human rights

All back issues of Research for Sex Work can be accessed through www.med.vu.nl/hcc
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Acronyms
NGO: non-governmental organisation
CBO: community-based organisation
STI: sexually transmitted infection
IEC: Information, Education and Communication
ARV: antiretroviral medicine
IDU: injecting drug user