Challenges On The Ground: Conducting HIV/AIDS Research With Men Who Have Sex With Men in Chennai, India

Peter A. Newman, Ph.D., University of Toronto

This narrative describes the author's experiences designing and implementing collaborative research projects focused on HIV/AIDS prevention and care with men who have sex with men (MSM) in Chennai, India. Various personal, logistical, methodological, and ethical challenges in launching and conducting research with a highly stigmatized and vulnerable population in the developing world are addressed, as well as negotiation of these challenges. In particular, field research with vulnerable communities need not dispense with rigor, while at the same time maintaining feasibility and flexibility and the utmost protection of participants and research staff. Research is presented as a tool to support advocacy, health, and human rights.

On September 2, 2004, the Delhi High Court dismissed a legal challenge to Section 377 of the Indian Penal Code. Plaintiffs filed the case in June 2001 after police arrested four gay and lesbian rights workers…for conspiring to commit "unnatural sexual acts" and possessing "obscene material" which was reportedly safer-sex educational materials construed as pornography. (U.S. Department of State, 2005).

India is home to the largest number of persons living with HIV/AIDS in the world—over 5 million (NACO, 2005; UNAIDS/WHO, 2004) and counting. India is also one of five countries in which the U.S. government has deemed HIV/AIDS a national security threat (NIE, 2000; Singer, 2002). In this day and age, speaking in the language of security and terror often marshals more public concern than a discourse of human rights and suffering.

Albeit officially dubbed a "heterosexual epidemic"—and indeed millions of heterosexual men and women are affected—HIV/AIDS is also ravaging men who have sex with men (MSM) in India (Chakrapani et al., 2002). Two recent studies in India document high risk behaviors among MSM (Dandona et al., 2005) and elevated risk for HIV (Go et al., 2004). Many of these men are very poor. Access to state-of-the art HIV/AIDS medications is as unlikely as winning the lottery, so they get sick and die very quickly. And they often die without psychosocial support, having to hide both their illness and their same-sex behavior for fear of social repercussions so severe that they supersede even their fear of death, loss of family, employment, friends, community, and life as they know it. They also are often victims of harassment and violence. Yet, of the over 600 government HIV serosurveillance sites—locales in which the National AIDS Control Organization (NACO) conducts HIV testing to estimate the impact of the epidemic around the vast landscape of India—only three were designated for data collection among MSM (NACO, 2005). And so, not surprisingly, HIV/AIDS in India remains a "heterosexual epidemic."

One may not commonly think of behavioral epidemiology or sexually transmitted disease (STD) screening as a sociopolitical endeavor—much less the realm of one trained in social work. Surveys and in-depth interviews are not commonly perceived as tools for social change. Nevertheless, the need for culturally competent interventions that address contexts of risk has been well documented in HIV-

prevention research, for example, among South Asian (Ratti, Bakeman & Peterson, 2000), Black/African American (Peterson, Bakeman, Blackshear, & Stokes, 2003), Latino (Diaz, 1998), and White (Seibt et al., 1995), MSM in North America, as well as one study among MSM in India (Asthana & Oostvogels, 2001). Targeted investigations such as these are needed to provide an empirical basis for culturally tailored interventions and to advocate for their being funded. Epidemiological and social behavioral research can be powerful tools to support the design and implementation of targeted interventions.

Epidemiological and sociobehavioral data, or lack thereof—as in the omission of MSM from government HIV/AIDS statistics—may construct one reality; but, it may also be used to provide sites for contestation. It should therefore come as no surprise that conducting HIV risk and prevention research among MSM in India is a contentious sociopolitical undertaking. We are met with challenges at every step—which continue to surpass anything I had envisioned; thankfully, so do the dedication and tenacity of my colleagues and our research staff.

India

India, as a developing country, presents challenges for anyone raised in the countries of the developed North. After five years and a dozen sojourns across swaths of the vast Indian terrain, I have become accustomed to obstacles presented by intermittent natural disasters and a tenuous infrastructure. We, in the North, take for granted the electricity, heat, and hot water almost invisibly pumped into our homes much less abundant, clean food, drinkable water, indoor plumbing and a fairly reliable public transportation and highway system. As one who has cursed out the New York MTA for 20-minute subway delays and re-routings of the E train on the F line, decried two-plus hour delays on the congested freeways of Los Angeles and the streetcars of San Francisco with the constant detachment of the overhead power lines, I never dreamed that what I thought to be the 3-hour-late Friday noon train to take me on the 18-hour journey from North Bengal back to Calcutta was in fact the noon train scheduled to leave the day before, on Thursday. My train would arrive in another few hours—if we were lucky.

I got "smart" on the next trip and we rented a four-wheel-drive jeep cum driver; however I had made a huge presumption—that there were in fact roads.

Not so.

My Indian colleagues explained that each year monsoon damage wreaks such havoc on the roads that they require more repair than is possible or affordable, compounded by the problems of government corruption that waylay funds. Yet, after a few trips these natural disasters and unreliable infrastructures became woven into my expectations.

Technological salves help a bit. My two-pound, battery powered, wireless laptop printer obviates my reliance not only on the availability of local hardware and ink, but on electricity. On one of my trips in rural North Bengal, I had deliberately scoured the surroundings and located a shop that would print from disk, replete with a giant Xerox machine that looked like it could survive a war. What I neglected to plan for were the lightening storms that knocked out all the electricity. Now, when I need a consent form at a moment's notice, technology can come to the rescue.

But technological gadgetry only goes so far. Much more importantly, I learned to smile, even laugh, in the vein of my Indian colleagues. The alternative is to pull one's hair out and, probably, not to work in India or the developing world, at least not doing field research with disenfranchised communities.

But this is not my story. This is where my story begins.

Beginnings

My research program in India began to take shape after two years of contact and visits with various stakeholder communities in South India, afforded by my collaborations on other HIV/AIDS research projects on the Indian subcontinent (Jana, Basu, Rotheram-Borus, & Newman, 2004; Newman, 2003; Thilakavathi et al., 2003). In the course of designing and implementing a multi-site community intervention trial of an HIV-prevention program among female sex workers in Calcutta and North Bengal, as well as a behavioral risk assessment among STD clinic attendees at a government hospital in Chennai, I sought out contacts in MSM communities. Even these contacts I did not seek out immediately, knowing that "homosexual behavior" is criminalized in India; and there are not gay community centers or bars in which to easily seek out allies or learn the lay of the land, even less so in the socially conservative South. Gradually, I began to cultivate local allies and met an avid, newly trained STD physician devoted to working with MSM and interested in gaining sociobehavioral research experience.

Many of the public health and government officials I met along the way either did not have much of an interest in the health and well-being of MSM, were simply unaware of this population or any health crisis, or were afraid of the various risks to their own careers. However, I did have the good fortune to meet some very highly placed Indian officials and professionals with an earnest interest in the health and well-being of all human beings, including MSM, who offered support in the form of personal contacts, business cards (an important entrée in India), and encouragement to pursue this line of investigation.

To this day, whenever I travel for my research in India, I carry the business card presented to me by a former head of the Indian Council of Medical Research—akin to the head of the U.S. National Institutes of Health—in hopes that if I ever get in trouble, I will produce his card and will be magically rescued.

Before embarking on any research in collaboration with community agencies, I made several visits to their sites, met with volunteers and clients, sat and talked extensively with a very helpful Community Advisory Board (CAB), and embarked on field trips with the staff to the public areas where they conduct outreach to MSM. My entrée through Dr. Venkatesan was key, as he was highly respected by staff and clients alike, as was my openness to listening and learning. The suitcase full of condoms "smuggled" across the border that I provided to the Director of the Social Welfare Association for Men (SWAM) was not enough, we both knew, to even make a dent in the need; but I believe my good faith at having followed through on my promise—perhaps aided by the uniqueness of multi-colored, flavored condoms—was duly noted.

Without local contacts, and a willingness to wait, observe, listen, and learn—and drink lots of *chai* (Indian spice tea)—I would have no program of research in India, at least not one along the lines of my own design and interest. I also do not take for granted that being a tenure-track academic at a large research university, and perhaps more so with an appointment in Canada, I am afforded a fairly secure home base to which to retreat and recoup. Even some of my American colleagues have been forced to become newly cautious with the interference in scientific investigations, including a crackdown on HIV/AIDS and sex research, that is the policy of the Bush administration (United States House of Representatives, 2003). Most vulnerable, however, are my Indian colleagues who have no place to retreat.

Thus, a secure home base, the ability to travel, and a strong trusting relationship with collaborators in South India have provided

an essential foundation to enable me to undertake a risky program of international research.

Program of Research

Two research projects are presently in the field in Chennai, India—a "small" Indian city of about six million people. Two pilot projects have already been completed. Both current projects are collaborations between me, Dr. Venkatesan Chakrapani, and local community agencies serving MSM.

One project, the idea for which was initiated by my Indian colleagues, is an in depth qualitative needs assessment and behavioral risk evaluation among HIV-positive MSM in Chennai. We have just completed 90 minute long, in-depth, semi-structured interviews with 15 HIV-positive MSM, and three key informant interviews with service providers. Participants were recruited through local community agencies, using purposive and respondent-driven sampling. We received small funding from Family Health International, Dr. Venkatesan's MacArthur fellowship, and piggybacked on my project funded by the Connaught Foundation in Canada.

The second, Canadian funded, project is a cross sectional, 30-minute survey of 200 MSM randomly selected from public sex environments (PSEs) in and around Chennai. We assess HIV/AIDS knowledge, attitudes, and practices, as well as contexts of risk behavior, experiences of paid sex, violence and nonconsensual sex, and preferences for HIV-prevention interventions. After a year of planning, hiring, creating a training and procedures manual, staff training, constructing and pre-testing a questionnaire, and mapping out the sampling frame from February to April 2005, our very able local research staff has completed 200 interviews in Tamil.

Methodological and Ethical Challenges in the Field

Much as the road to our program of research has been long and interesting, the challenges in implementing our studies have superseded my expectations. Next, I will discuss methodological and ethical challenges in the field in the implementation of these two studies.

Sampling. Constructing a sampling frame of MSM in Chennai is a difficult endeavor. For one, male-to-male sex is criminalized (U.S. Department of State, 2005); the very criteria on which one is basing eligibility for one's study could land a potential participant in jail. Perhaps even more powerful than criminalization, both HIV/AIDS and "homosexuality" are highly stigmatized in India. Thus, MSM and MSM living with HIV/AIDS are not easy-to-reach populations; there is a substantial investment, based on survival, in *not* revealing either one's sexual orientation or one's HIV status.

Male-to-male sexual behavior in India is also characterized by a complex web of identities and practices, many of which do not conform to Western constructs of sexual orientation or identity (Asthana & Oostvogels, 2001; Chakrapani et al, 2002). For example, many, if not most MSM at risk for and living with HIV/AIDS in Chennai do not self-identify as "gay" or "*Kothi,*" a local self-identification among some MSM who tend to adopt the receptive role in anal sex. "*Panthis,*" a label ascribed by *Kothis* and one not adopted by the *Panthis* themselves, do not self-identify as other than heterosexual given their role as the insertive partner in anal sex; and many *Panthis* have wives and children, as do some *Kothis* (Chakrapani et al, 2002). In short, there is no uniform, readily identifiable "gay" community.

In each of the two studies in the field, we have addressed challenges around sampling in different ways. For our qualitative needs assessment, we wanted to ensure diversity among our participants. For one, many MSM in India are married. Persons living with HIV/

AIDS also exist across a disease spectrum. We consciously aimed to include a range of MSM, married and unmarried, younger and older, HIV+ and with full blown AIDS, and those who engaged in commercial sex and those who did not, to increase the breadth of our sample.

For our survey, our aim is to generalize our findings to the population of high risk MSM in Chennai. To that end, we chose a rigorous sampling strategy focused on public sex environments (PSEs). Clearly, not all MSM attend PSEs, but those who do are at elevated risk for HIV infection. Additionally, those MSM who attend the very limited community service agencies for MSM are not representative of the larger MSM population, most of whom would never attend such an agency due to fear of disclosure of their same sex behavior.

Our local research staff along with SWAM mapped the universe of PSEs (about 50) in Chennai. We then stratified PSEs by those that were predominantly commercial and those predominantly non-commercial and randomly sampled ten of each type. Within these twenty sites, we used time-space sampling (MacKellar et al, 1996; Stueve et al, 2001) to estimate and map out the flow of men at these sites by days of the week and hours of the day in order to draw a representative sample among PSE-attending men. We then randomly selected among time-space units within the sites that were selected and targeted these units for our recruitment efforts.

An effective field research protocol must be created with backups, alternative scenarios to address the inevitable exigencies that befall the best laid plans. Two such events are notable in our survey of PSEs.

The December 26th *tsunami* wrought devastation on Indonesia and Thailand; the more localized devastation in India was less reported. Two of our recruitment sites in Chennai were deluged. Thankfully, none of our staff or participants was hurt, though many local fishermen were never to be found. Perhaps, more mundanely, we had to re-write our intricate sampling plan as the beaches that were hit would be "down" for a while as PSEs where we recruit high-risk MSM. Well beyond sampling issues, the *tsunami* brought home the realization that as much as I do my ethical best to protect our research staff, and myself, from foreseen trouble, there is much that is simply out of my control. (I happened to be on the east coast of southern Thailand when the *tsunami* hit the western Andaman coast.)

The second and more formidable challenge to our research protocol plan involved dangers to research staff conducting recruitment.

Recruitment. Several concerns present in trying to recruit a highly vulnerable and stigmatized population. The first is the challenge of identifying potential participants. A second is the challenge of mitigating any risks to participants due to research participation.

A recent UNAIDS (2001) study of stigma and discrimination faced by people living with HIV in India provides a case in point; only 1½ pages out of the 70-page report address "gay and other homosexually active men." The authors note that "[d]espite numerous attempts over several months, eliciting the voluntary participation of HIV-positive gay men in this study proved unsuccessful" (UNAIDS, 2001, p. 56).

For our in-depth qualitative study of HIV-positive MSM, we conducted recruitment through local community agencies serving this population. All recruitment was done by word of mouth only; no written materials were printed or distributed, nor were any study identifiers posted at any interview or research site. Participants were recruited either through contact with someone at a community agency for MSM living with HIV/AIDS, or by participants asking their peers if they wished to participate. In the latter case, the potential

participant had to make the first contact with the research staff.

Within two weeks we had a sample of 15 participants across a range of MSM living with HIV/AIDS. I am not under the illusion that I personally could have conducted that recruitment, but our staff, known and trusted among many MSM and persons living with HIV/AIDS, had entrée to the population. The level of ongoing stigma, harassment, blackmail, and violence reported by participants, however, suggests the problematic oversight in the UNAIDS report. In fact, several of our participants reported they had an easier time finding acceptance among their families in being HIV-positive than in disclosure of their sexual orientation (Chakrapani, Newman, Shunmugam & Melwin, in press).

Our survey recruitment required outreach at PSE's. PSE's are fairly dangerous everywhere (Frankis & Flowers, 2005). They are particularly dangerous in Chennai, where there continue to be documented reports of harassment and violence against both the men who frequent these sites and the outreach workers conducting HIV prevention (Human Rights Watch, 2002; Kumar, 2000; PUCL-K, 2001; U.S. Department of State, 2005). Indeed, data from both of our studies documents blackmail, harassment, sexual assault, and violence faced by MSM. It is one thing to collect data from participants reporting past incidents and to read published reports:

> *Physicians for Human Rights (PHR) has learned of the detention, arrest, and harassment of 4 colleagues in Lucknow, Uttar Pradesh, India...These men were detained for six weeks without bail and recently released on August 20 but will now face trial on charges of conspiring to commit obscenity and sodomy. PHR believes, as does over 400 organizations, however, that these HIV/AIDS workers were only doing their job, that is, developing and distributing health education materials for males who have sex with males. This is not the first time health workers have been detained in Uttar Pradesh (Human Rights Watch, 2002).*

It is another matter when one's own research staff and potential participants are endangered. In the late stages of recruitment, I received the following email from our project director:

> *Tue, 29 Mar 2005 05:59:10: By this time we should have completed 180 interviews. A few of our recruiters are facing some practical difficulties in recruiting the participants from certain cruising sites; i.e., an unknown person has been murdered in North Chennai, an area very close to two of our recruitment sites. There has been a severe raid by the police at those sites. I have asked the recruiters to stop, temporarily, recruiting participants from those sites and to continue with rest of the sites.*

I immediately inquired further about the incident, and made clear that the safety of our research staff was our preeminent concern, not the sampling protocol. I asked for further clarification of what happened, and received the following response:

> *Thu, 31 Mar 2005 05:19:46: ...the murdered person was a MSM. The murder took place in a ceremony that had been organised by a kothi... Severe raid here means all the kothis who attended the*

ceremony had been taken into police custody for enquiry. The cruising sites in and around North Chennai have been ransacked by the police men and many MSM who visit those sites had been arrested by the police as suspects.

In his well intentioned zeal to adhere to our detailed recruitment protocol, the project director wished to resume data collection at the sites in question. I replied that we must suspend any further data collection at the two sites. In so doing, I wanted to protect, to the extent possible, our research staff conducting recruitment. I also did not want to contribute to any possibility of having any MSM attend the site in hopes that they might be recruited for the study and incentive. I also wanted to assert responsibility so that any alteration in our research plan was squarely on my shoulders. I immediately altered the recruitment protocol by substituting two additional locales and explained that we would use this event as an opportunity to adjust for overrepresentation among non-commercial PSE attendees. In this way, the project director and staff could continue the study and not have a feeling of failure in eliminating the two sites that posed imminent danger.

Data collection. Of utmost importance in both of our studies in the field is ensuring and maintaining the confidentiality of participants and not placing them at additional risk by virtue of study participation. Accordingly, in both studies, interviews were conducted in private rooms at one of three safe community venues known to our research staff. Perhaps more notably, we worked with my University Ethics Review Board (ERB) to revise requirements; following the letter of the law, or usual practice, could place participants at risk, that which the ERB is charged with mitigating. For one, participants were asked only to place an "X" in the box on the consent form: no signatures or initials were required. Understandably, MSM who are at risk of police blackmail and violence are wary of having their confidentiality broken; thus, a request for a signature in an otherwise anonymous survey is seen as suspect.

Indeed as reported in our running project log, the project director wrote, "One of the recruiters mentioned that some participants feared being caught on camera in the room where they had been interviewed." In previous studies we had opted against using audiotape recorders with headphones that would enable respondents to listen to and answer sensitive questions by placing checkmarks in boxes rather than having to respond to an interviewer; some participants feared their responses were being monitored through the tape recorder.

Second, a copy of the consent form was retained at the study site; copies were not distributed to individual participants. In a setting in which MSM are often harassed by police or "rowdies" for carrying condoms—as a sign that they are going to engage in sex, or that they are going to solicit sex for money—being caught with a consent form that indicates MSM or HIV risk presents a potential danger. Indeed, our data revealed sexual assault and violence at the hands of police, and participants' fears of carrying condoms (Chakrapani et al., in press):

> *Policemen took me to police station and during the night one policeman asked me to come to the bathroom...he had sex with me in the back...I did not have condoms at that time since I was only in my underwear. I also could not talk about condoms. Even if we just show condoms they will beat us on our hands with the lathi [police stick].*

Third, given the danger of PSEs, we decided not to attempt to conduct even brief screening interviews in these environments. Both potential participants and research staff could be placed at additional risk in having to remain longer in the PSE than they would otherwise. At the same time, it is usually preferable to conduct one's data collection as proximal as possible to recruitment to increase one's response rate and, thus, the validity of one's data. Furthermore, our sampling plan required not only that visits to sites be scheduled as determined by our time-space sampling, but that research staff enumerate the approximate number of men on site at a given time and, in view of our target for recruitment, approach every nth man (e.g., every 3rd or 5th man) to ask if he would be interested in participating. We wished to avoid having research staff approach only their friends, or more attractive men, or those who arrived on site first, or last—each of which might bias the sample. If we then allowed anyone who happened to appear on site to participate in an interview, our rigorous sampling could be easily negated. In order to try to ensure that only those asked to participate would be interviewed, we gave MSM who agreed to be interviewed a small, discreet card (with no mention of HIV/AIDS or MSM) with a deadline for a study interview, and research staff accompanied those who wished to the interview site. In this way, we both avoided undue risk for study participants and research staff and followed through on a rigorous sampling plan in a risky field project.

Another aspect of data collection, behavioral research on HIV risk, is often bounded by the veracity of participant self-report. One cannot follow someone into the PSE much less their bedroom to document sexual practices and (non)condom use. In order to increase the reliability of our data, we also collected blood samples, on a voluntary basis, to test for syphilis. We made a decision not to make this a requirement of participation, as the Indian staff and CAB reported that some men, who might otherwise respond to survey questions, may be loathe to undergo a blood test. Some men also may fear a loss of confidentiality in returning to get their test results. Two-thirds of participants underwent blood testing: 14% of these had syphilis, documenting high risk for HIV infection.

A related issue of opting to test for syphilis, not HIV, was due to a variety of factors. For one, HIV testing is more expensive and we had a very limited budget. Second, HIV is infinitely more stigmatized and the potential damages wrought by any breach of confidentiality more damaging. Another important concern that we made available in our study budget was that anyone who tested positive for syphilis could receive treatment, paid for by the study. We were in no position to provide that in the case of an HIV-positive test result; at most, we could refer men for counseling and whatever treatment may be provided by the local government hospital, which does not provide state-of-the art HIV/AIDS therapies. Nevertheless, having syphilis suggests high risk for HIV, both in documenting potential routes of exposure and increasing the physical risk of HIV infection. Thus, all men in the study were referred for free, confidential HIV testing on a voluntary basis.

Conclusion

I remain aware that what motivates my continuing desire to conduct field research among MSM and male sex workers in India, even as it is ostensibly focused on HIV prevention and care, is a deeper human rights agenda. Access to condoms may be necessary but is clearly an insufficient condition to effect HIV prevention. The issues when one engages in sex for survival—with a twofold increase in payment for not using a condom; or when one is subject to police

harassment for even carrying a condom—are well beyond knowledge and attitudes. The risks of a disease that might cause one to be symptomatic in several years, in the context of more immediate risks due to harassment and violence, may render HIV/AIDS less of a concern. Indeed, the very concept of high risk in application to HIV/AIDS implies that in the absence of HIV one is safe. This is clearly not the case for many MSM in India.

The ability to marshal effective HIV prevention is constrained by the myriad social determinants of risk. This is the larger agenda of our long term project: to ensure basic human rights for MSM in India. Down the road, we can help to mitigate the impact of various risks—harm reduction on a community or societal scale—but our vision is nothing less than the decriminalization and destigmatization of sex between men, as well as a contribution to the recognition of HIV/AIDS as a crucial health issue in India overall.

Conducting field research on HIV/AIDS and its prevention may seem worlds away from clinical social work practice, but parts of my MSW education continue to serve me well. Listening skills, the upholding of high ethical standards, and the ability to negotiate among an array of sometimes competing agendas are all skills that are central to social work practice. Furthermore, social work teaches the importance of parallel process. The very process and experience of implementing our research studies offers profound insights into the lives and perspectives of our participants, an important layer of data beyond the content of more traditional data sources. Natural disasters, police harassment, fear and murder, all of which impinged on our research staff conducting recruitment and data collection, serve to powerfully corroborate the data from our participants in qualitative interviews and survey questionnaires. They maintain thorough records of these daily challenges, both for ongoing safety and training purposes, and as a source of invaluable data.

I am energized as I continue to work with my Indian colleagues to implement community-based studies in and around Chennai: from epidemiology, to sociobehavioral determinants of risk, to needs assessments for men at risk of and living with HIV/AIDS. We are giving voice and listening to many MSM. We are helping to get the word out, in India and around the world, about the discrimination and risks faced by MSM. And we are also contributing to the growth of a cadre of trained recruiters, interviewers, data analysts, and behavioral researchers in India who will support the ongoing struggle for human rights among gay, lesbian, bisexual, and transgender persons, as well as persons living with HIV/AIDS in India.

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Peter A. Newman, Ph.D., is a Professor the University of Toronto, Faculty of Social Work. Comments regarding this article can be sent to: p.newman@utoronto.ca.