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Primary prevention lessons learned from those with HIV in Chennai, India

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Abstract

Background—As each HIV-infected individual represents a breakdown of HIV primary prevention measures, formative data from representative individuals living with HIV can help shape future primary prevention interventions. Little is known about sexual behaviours and other transmission risk factors of high-risk group members who are already HIV-infected in Chennai, India.

Methods—Semi-structured qualitative interviews were conducted with 27 HIV-infected individuals representing each high-risk group in Chennai (five men who have sex with men (MSM), five female commercial sex workers (CSW), four truckers and other men who travel for business, four injecting drug users (IDU), five married male clients of CSW, and four wives of CSW clients, MSM, truckers, and IDU).

Results—Themes relevant to HIV primary prevention included: (1) HIV diagnosis as the entry into HIV education and risk reduction, (2) reluctance to undergo voluntary counselling and testing, (3) gender and sexual roles as determinants of condom use, (4) misconceptions about HIV transmission, and (5) framing and accessibility of HIV education messages.

Conclusions—These qualitative data can be used to develop hypotheses about sexual risk taking in HIV-infected individuals in South India, inform primary prevention intervention programs, and improve primary prevention efforts overall.

Additional keywords

AIDS; education; MSM; sex workers; sexual behaviour

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Conflicts of interest
None declared.

Introduction

At the end of 2007, ~2.5 million (2.0–3.1 million) people in India were living with HIV.[1] Nationwide, risk groups include injecting drug users (IDU),[2] men who have sex with men (MSM),[3] female commercial sex workers (CSW),[4,5] male truck drivers and other men who travel for business.[6,7] In each of these risk groups for which there is prevalence data, HIV estimates far exceed the national adult prevalence of 0.36%. Among IDU, 8.71% are estimated to be infected; among MSM, the estimate is 5.69%; and among female CSW, it is 5.38%.[8] Bridge populations such as the male clientele of CSW may also pass the virus on to their wives.[9] The wives of other high-risk men (IDU, married MSM, truck drivers) are at increased risk for infection as well. Indeed, a truncated epidemic among monogamous married women in India has emerged, as wives often have little power over whether and when to have sex, and condom use is rare between spouses.[10]

Primary prevention – preventing HIV-uninfected individuals from contracting HIV – focussed on high-risk groups is key at this point in the epidemic.[11] However, as of August 2005, there were 965 targeted HIV prevention interventions underway in India[12] and only 31% of these focussed on the high-risk groups of female CSW, MSM and IDU.[13] In addition, a disproportionate number of prevention interventions aimed at high-risk groups focussed solely on condom distribution or psycho-education about behaviour change. [13] Recently, the scale-up of interventions targeting high-risk groups has intensified (e.g. Avahan).[14] However, novel, effective and sustainable interventions tailored for high-risk groups are still needed to reduce transmission rates. One method to develop effective prevention programs or augment existing prevention programs is to investigate how individuals with known HIV infection became infected. This information can be important for generating hypotheses regarding the culturally and contextually relevant variables that are most associated with sexual risk taking for at-risk groups because each individual is an example of the insufficient reach of current prevention programs.

Chennai is a city of 6.5 million in the state of Tamil Nadu, which carries one of the highest burdens of HIV in the country.[8,15] Development of novel, effective interventions that address new challenges in prevention is necessary for high-risk groups in Chennai. Studies of individuals from South India who are already HIV-positive, however, are few[16–18] and, to our knowledge, only one focuses on transmission risk behaviours.[19] Therefore, interviews from the present study are notable, as they provide information about the sexual behaviour and HIV knowledge of individuals living with HIV before and after diagnosis. The purpose of the present study was to examine how individuals from high-risk groups living with HIV in Chennai, India, became infected and to inform the development or augmentation of HIV primary prevention approaches in this setting. These interviews were originally conducted to gather information about developing a secondary HIV prevention program for individuals with HIV.[20] However, in doing so, we discovered additional important qualitative data relevant to primary *v.* secondary prevention. Accordingly, these data are described and summarised below.

Method

Setting

The Y.R. Gaitonde Centre for AIDS Research and Education (YRG CARE) is a non-governmental organisation (NGO) based in Chennai, India. YRG CARE provides HIV information, education, voluntary HIV counselling and testing (VCT), and care and support to those infected with HIV, including antiretroviral (ARV) treatment. The medical centre offers psychosocial and medical care for more than 8000 individuals living with HIV. This study was approved by the institutional review boards at YRG CARE and at Miriam Hospital, a teaching hospital of Brown University.

Participants

All participants for this study underwent an informed consent process and signed an informed consent form. All participants ($n = 27$) were recruited from the YRG CARE clinic or community outreach efforts, were HIV-infected, and were either currently on ARV treatment or had been on ARV in the recent past. Participants belonged to one of six risk groups: five female CSW, four IDU, four male truck drivers, five married men who were clients of CSW, four married women, and five MSM, all *kothis*[A]

Demographic information about the sample is presented in Table 1.

Interview

Some participants are individuals receiving HIV care at YRG CARE. These participants were approached by a nurse or staff member and invited to join the study while waiting for their appointment; each potential participant was informed that a refusal to participate in the study would not affect their care at YRG CARE. To attain representation from all of the risk groups, other participants were recruited through community outreach efforts. These participants were scheduled for an interview at YRG CARE's associated outreach centre located in central Chennai, not at the clinic. Each interview occurred one-on-one with a gender-concordant counsellor at YRG CARE. Interviews lasted approximately 1 h and participants' time was reimbursed with food coupons. Interviews included questions on HIV knowledge and education (e.g. 'What did you know about HIV and AIDS before you were infected?') stigma ('Have you ever felt that you were treated differently by others?') communication and disclosure, HIV testing (e.g. 'Why do you think that people who think they might be HIV-positive delay getting tested?'), barriers and facilitators to safer sex, the role of women in Indian society, and issues specific to each risk group.

Interviews were semi-structured; interviewers introduced the broad topics listed above and had a list of probes available. The interviewer probed for additional information only after the participants' initial response on each question. All interviews were conducted in one of the local languages (Tamil or Telugu), tape-recorded, transcribed verbatim and translated into English.

Analysis of qualitative data

Interview transcripts were entered into NVivo (2002) for qualitative analyses. Transcripts were read multiple times, a codebook was developed and all 27 transcripts were coded using the codebook definitions. Two coders rated each interview and discrepancies were resolved by consensus.

Results

Interviews of HIV-infected individuals yielded five main themes related to HIV primary prevention. These included (1) diagnosis as the entry into HIV education and risk reduction, (2) reluctance to undergo VCT, (3) gender and sexual roles as determinants of condom use, (4) misconceptions about how HIV is transmitted, and (5) framing and accessibility of HIV

[A] In India. MSMs are not necessarily considered to have a separate sexual orientation. Rather, *kothis* are the receptive partner and construct their social roles as feminised males, whereas *panthis* are the insertive partner and do not see themselves as either homosexual or non-masculine. *Kothis* are the visible MSMs within society and are not necessarily considered to be 'men', *per se;* rather, they are *kothis.*

education messages. Below, each theme is explicated and sub-themes are explored with relevant quotes from interviewees.

Diagnosis as the entry into HIV education and risk reduction

Prior to diagnosis, risk behaviours are common and occur in a context of minimal HIV prevention information—The most common point of entry into HIV education was diagnosis. Almost unanimously, participants reported that they learned about HIV and its prevention at the point of their diagnosis or as part of their HIV post-test care. Prior to diagnosis, most participants reported knowing ‘nothing’ about HIV or simply that it was a ‘dreadful disease’ with no cure. Likewise, they reported that before receiving an HIV diagnosis, they knew little or nothing about how HIV is spread (e.g. unprotected sex, sharing needles) or how HIV cannot be spread (e.g. toilets, food, sneezing). Several participants also reported hearing about condoms but not knowing how to use them before diagnosis. One participant spoke about his prior knowledge of HIV:

> I did not know about HIV (AIDS) at all. That is why I was ‘playful.’ I came to know about it only in the past 15 months. Now I feel very shameful [and] sad… Before. I did not know about this. I did not know as what HIV was.’ (33-year-old married man, businessman; duration of treatment, 15 months)

Participants reported that their HIV education and knowledge increased greatly at or after diagnosis. At the interview, most participants could accurately report basic information about HIV (i.e. HIV infection progresses to AIDS; one cannot tell if someone is HIV-infected by looking at them) and modes of transmission such as unprotected sex and sharing needles. Participants often cited their HIV counsellors, doctor or NGO workers as their primary source of information. Doctors in particular were cited as significant sources of instruction; doctors’ orders to use condoms or to be adherent to ARV were reported to be taken seriously and followed faithfully. In speaking about how she learned about HIV, one woman reported:

> ‘I knew some information about HIV and AIDS even before my marriage…But I was under the impression that whoever gets this infection would die immediately. But now I am very clear about this: it is wrong to say so. I got this information through counselling, different NGOs like SIP+ [South India Positive Network] and Gurukulam. They have given us a second life. Their counselling has made us understand that we need not feel dejected and lead an isolated life but we can lead a normal life.’ (35-year-old married woman, candle maker; duration of treatment, 2.5 years)

Currently, changing risky behaviours begins only at diagnosis—After diagnosis, most participants reported a significant drop in risky behaviours such as unprotected sex or sharing needles. For instance, married men and women often reported abstinence or using condoms after one or both partners tested positive. Several CSW stated that they now insist that their clients use condoms, often to the point of refusing to have sex with them if the client objects. Truck drivers and MSM, likewise, reported beginning to use condoms and minimising risky situations, such as having multiple sex partners, patronising CSW or becoming very intoxicated. IDU reported that they often continued to inject drugs, but refused to share needles. For instance, this IDU spoke of refusing to share needles post-infection:

> ‘He should not use the same needle used by me. He should dispose of the needle. He should use a new needle. I will not give him [my used needles]. I buy my syringes. Even if they need money, I will give them [some] to buy new syringes.

> But I will never [share] my needles. I always have a stock with me. (32-year-old unmarried IDU, unemployed; duration of treatment, 18 months)

In some cases, it was apparent that behaviour change included negative compromises. For instance, one participant (MSM, *kothi*) stopped commercial sex work after his infection and restricted his sexual activity to those known to him and, as he made clear in other portions of the interview, had sex only with a condom. However, for him and many other individuals who rely on sex for income, leaving sex work reduced economic opportunities and options.

> 'After my HIV infection, I have reduced having sexual relationships with others… I would have sex only with loved ones. I would not get money from them. And they will not give money for having sex with me. Because of my infection, I am not getting money for my profession.' (24-year-old MSM (kothi), unemployed former CSW; duration of treatment, 8 months)

As HIV-positive individuals, most participants now consider themselves and, in some cases, their immediate social circles, to be well informed about HIV, but perceive the general public as having low levels of knowledge or perceived risk:

> 'Though they know, most of them are not careful. They are not bother[ing] about getting this infection. Only after the infection they regret their action. That happened to us. But we did not know about the infection. But many of them know but still they are not careful at all. What can we do?' (27-year-old married woman, housewife; duration of treatment, 6 months)

Reluctance to undergo VCT

Voluntary testing occurred only under urgent circumstances—Most of participants tested because they were symptomatic, tested in conjunction with tuberculosis diagnosis, or had a very sick spouse. In the case of several CSW, however, other CSW urged them to get tested before symptoms appeared. None of those sampled reported using VCT services as part of a regular health care routine or without a significant suspicion of infection. Instead, testing seemed to be used as a confirmation of illness; thus, behaviour change and risk reduction were delayed until this point as well.

> 'Only when they suffer due to loss of weight and then they [get] diarrhoea, the doctors will ask them to get their blood tested. So that is when most of them get tested.' (42-year-old married IDU, unemployed; duration of treatment, 4 months)

Stigma deters testing—When asked why HIV-positive people might delay testing even if they suspect they are ill, some participants stated that the general public may be unaware of the availability of HIV testing. Most participants, however, cited fear, a preference for not knowing, or a dread that their relationships with partners, families and their community would be jeopardised. Almost universally, participants stated that others in their communities equate testing with infection.

> 'They have a fear that the society will talk wrong about them and they may lose their jobs. In a government job, if they come to know that a person is HIV-infected, they ask him to leave the job. In a family, if the father is infected by HIV, no one will come forward to marry his daughter. So no one comes forward for testing. Only when the infection becomes very severe people visit the doctor.' (39-year-old CSW, living with a partner; duration of treatment, 2 years)

Another participant agreed:

> 'Many of them are scared to know about HIV testing. Very few of them will come voluntarily for testing. Not even 5% of the population will be ready to come for

> voluntary testing. The balance 95% of them will get tested only if they are asked to get tested by the doctor. They do not have an interest in coming for voluntary testing. They are scared. They are worried that others will treat them badly. Even a person infected with cancer will disclose it but the [HIV-] infected person will not have the courage to disclose it.' (39-year-old married man, unemployed; duration of treatment, 4 years)

Many participants, in addition to focussing on attitude change among individuals, called for NGO, the government and the media to take responsibility in reducing stigma and encouraging testing. Many participants saw a direct line between reducing stigma and increasing VCT uptake:

> 'Awareness among people will lead to removal of stigma. Once the people are aware, there will be less stigma. So as the stigma is less, more people will come forward to get tested. So there will be no problem in disclosing it. So if they know their HIV status, they will be careful and not pass it on to others.' (34-year-old widow, counsellor; duration of treatment, 3 years)

Gender and sexual roles determine condom use

Initiation of condom use often raises suspicion and distrust. The specific interpretation, however, varies based on the gender and sex role of the individual initiating the condom use. For instance, among CSW and MSM, initiating condom use is often interpreted as a disclosure of HIV infection. Among married men and women, condom use raises suspicions of engaging in commercial sex work, patronising CSW or engaging in other infidelity.

Married women also agreed that they do not have sufficient power to insist on condom use or to purchase condoms. Indeed, many married women spoke of being unable to choose whether or when they have sex. Speaking for herself and other married women, one participant stated:

> 'We do not have a say in this. We have to satisfy their needs. If I was able to make a decision, I would not have got this infection. Whenever they call, we have to go to bed. We might be tired, we might not be interested, but we have no choice. We have to act according to their wish and do all they tell us to do.' (27-year-old married woman, housewife; duration of treatment, 6 months)

Among CSW, initiation of condom use is dismissed by clients as an inappropriate request given the perceived role of the CSW as a service provider and the resulting power differential between the partners. For example, one CSW stated:

> 'Now I am not going out as I was earlier because no one accepts using condoms because they won't get satisfied by having sex with a condom. They say "We pay you so that you satisfy us and when you can't satisfy what is the use of paying you? Instead of that, we can give that money to our wife and have sex with her whenever we want."' (39-year-old woman living with a partner, CSW; duration of treatment, 2 years)

Some participants, however, discussed recent empowerment of some women to demand condom use from their partners.

> 'Now women are coming forward. If we go to a lodge [a lodge is the equivalent of a hotel that charges hourly rates] then women force us to use a condom. They do not want to have sex without using a condom. They are bringing condoms with them. If we are not willing to use a condom, they are not willing to have sex. Before it was not like that, but the present situation is like that.' (42-year-old married male IDU, unemployed; duration of treatment, 4 months)

Misconceptions about HIV transmission

Although participants were largely accurate in reporting facts about HIV they had learned through post-diagnosis education, common misconceptions remained. The most common mistake was the belief that HIV is spread through a certain type of person (e.g. CSW, 'illicit relationships,' eunuchs) rather than through specific behaviours (i.e. unprotected sex and sharing needles). Several participants believed that they and others could protect themselves simply by refusing sex with CSW or 'outsiders'.

> 'We should stop the ladies standing on the road and calling us to have sex. We should stop them completely. Then only the lorry or truck drivers would not get this infection… Because of these women, the truck drivers are getting this infection.' (29-year-old truck driver, unmarried; duration of treatment, 1 year)

Others attempted to correct such misconceptions:

> After my infection people, started talking that I got this infection because of my illicit sexual relationship and I only made them understand that my infection was not due to the illicit sexual relationship; it was because of unprotected sex.' (35-year-old woman living with a partner, CSW; duration of treatment, 5 years)

Framing and accessibility of HIV education messages

Prevention messages must be accurate and non-stigmatising—Some participants cited the media (newspaper, billboards, adverts at movie theatres, television ads) as a helpful tool in prevention and education. Others, however, were quick to criticise the media as providing limited and stigmatising information:

> 'More than giving information about how it spreads, the messages make the people treat the infected as untouchable and they try to isolate them. Sufficient awareness is not there. It is due to the wrong messages which are given to the people. Instead of giving them positive messages, the negative message reaches the people. When they know that a person is infected, there is no sympathy; instead, there is hate. This is mainly due to the wrong propaganda. The people hate us due to the large number of advertisements. That is the major cause.' (39-year-old married man, unemployed; duration of treatment, 4 years)

Prevention messages must be accessible—Some participants found current prevention and education messages to be culturally mismatched. Others found linguistic uniformity to be a problem in a country with many regional languages. One participant expressed frustration with condom packaging:

> We tell them to use [a condom] but not many know [how] to use condoms and, if you see, it is given in English and Hindi. How many of us know these two languages? So what is the use of this? So it should he given in Tamil. (35-year-old married woman, candle maker; duration of treatment, 2.5 years)

Literacy is also a challenge in Chennai and throughout India. Some participants spoke of seeing or taking part in street plays with HIV prevention and education themes. They expressed confidence that public performances and other non-written messages would help others change their behaviour.

Discussion

Even with the recent downward estimation of the number of people infected with HIV in India, prevalence remains high in Chennai and South India, and the epidemic continues to evolve in this region.[11] By extension, recommendations for the most effective approach to prevent new infections continue to shift as well. In order to remain current with the ever-evolving epidemic, it is important for researchers to remain rooted close to the ground and to listen to those who live with the virus on a daily basis. Qualitative information from those who are already infected with HIV is necessary to lay the groundwork for future culturally appropriate prevention interventions.

Our findings suggest two overlapping areas of focus for continued primary prevention research: (1) innovative methods of scaling up education and testing, and (2) continued stigma reduction. First, making education and testing more timely and accessible may be one method that is consistent with the qualitative results above. As these interviews suggest, despite efforts to educate community members and prevent HIV, accurate HIV education is most often provided *after* an individual is diagnosed as HIV-positive. While prevention counselling is an important aspect of HIV care, if this information is provided as part of the HIV-positive person’s entry into care, it comes too late for primary prevention. According to the participants in this study, doctors and NGO do an excellent job educating newly diagnosed individuals about topics such as condom use, transmission and behaviour change. While this information is necessary and helpful, provision of accurate prevention information and opportunities to test should occur well before seroconversion. Researchers have recently become more creative in the dissemination of HIV prevention information by ‘bundling’ the information with other services;[21] e.g. malaria, tuberculosis or malnutrition prevention services;[22] and other health-care services such as prenatal care [23] or substance abuse treatment.[24] Such bundling – embedding or piggybacking HIV prevention and education within other services to create synergistic advantage – may increase accessibility, cost-effectiveness and effectiveness.[21] Combining HIV prevention messages and direct offers of HIV testing with regularly utilised services increases the likelihood that information will reach at-risk individuals before seroconversion.

Besides shifting the timing of HIV education to well before seroconversion, these interviews suggest that future research may continue to improve HIV education in a variety of cultures. Participants in the current study emphasised that decisions around condom use were tied to one’s gender or sex role, with women and *kothis* describing an inability to be proactive about safer sex. It is possible that developing workable strategies for disempowered groups and targeting condom promotion to those in power (i.e. married men, CSW patrons) may help shift this imbalance, as would information and testing for couples, peer groups and the community, not just individuals. However, previous research has shown that information alone is not usually sufficient to change behaviour.[25] Instead, multiple levels of influence – couples, peers, community and society – should be considered,[26,27] as should gender-based tailoring of interventions and the inclusion of skills training,[28,29] such as how to use a condom and how to negotiate condom use with a reluctant partner.

A second key area identified in the transcripts is the importance of stigma reduction. HIV stigma has received much attention in recent years yet remains problematic, as it keeps individuals from accessing the services that are available,[1,30,31] as well as impacting disclosure[32] and creating a complex interplay with uptake of treatment.[33] These interviews suggest that several barriers may remain. Items discussed included limited information about sexuality provided to women, conflating HIV status with personal morality, and misunderstandings about transmission routes. For example, some participants stated that stigma was perpetuated by the belief that HIV was spread by a certain demographic, most often CSW, as opposed to through unprotected sex with an HIV-infected person. In summary, the current study suggests that stigma reduction may continue to be a valuable goal for researchers, NGO and other advocates of people living with HIV and AIDS.

Limitations of this study include the small number of participants interviewed and the small number of individuals representing each risk group. A strength of the study includes the diversity and range of risk groups included; however, tailored recommendations for each risk group would require a larger number of survey participants. Additionally, in this cultural context, health professionals are deeply respected; therefore, being interviewed by a YRG CARE staff member may have led participants to offer socially desirable answers.

In conclusion, by gathering information from individuals who are already HIV-positive, researchers and interventionists can learn, from the ground up, what factors are contributing to the spread of HIV in Chennai, and how innovative and effective interventions can be designed to protect women and men in identified risk groups as well as the general population.

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Table 1

Demographic characteristics of the sample ($n = 27$)

One participant is a former truck driver who currently works as a clerk due to poor health. Within risk groups, he was classified as a truck driver, but his current profession is reflected in this table

	Total ($n = 27$)		**Men ($n = 18$)**		**Women ($n = 9$)**	
	n	**% total**	***n***	**% total**	***n***	**% total**
Profession						
Housewife	1	4			1	11
Sex worker	5	19			5	56
Truck driver	3	11	3	16		
Counsellor outreach	3	11	1	6	2	22
Clerk	2	7	1	6	1	11
Coolie	2	7	2	11		
Farmer	1	4	1	6		
Sales	1	4	1	6		
Professional	3	11	3	16		
Unemployed	3	11	3	16		
Unreported	3	11	3	16		
Education						
None	1	4			1	11
Up to 4th standard	4	15	3	17	1	11
5th to 8th standard	9	33	8	44	1	11
9th to 12th standard	6	22	4	22	2	22
Bachelor’s	4	15	3	17	1	11
Postgraduate degree	1	4			1	11
Unreported	2	7			2	22
Sexual orientation						
Heterosexual female	9	33				
Heterosexual male	13	48				
MSM	5	19				
Kothi	4					
Unknown	1					

	Total (*n* = 27)		Men (*n* = 18)		Women (*n* = 9)	
	n	**% total**	***n***	**% total**	***n***	**% total**
Marital status						
Married	14	52	11	61	3	33
Unmarried	7	26	7	39		
Widowed	1	4			1	11
Separated	3	11			3	33
Living with partner	2	7			2	22