

**HIV/AIDS in rural India: context and health care needs**

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## **Summary**

Primary research on HIV/AIDS in India has predominantly focussed on known risk groups such as sex workers, STI clinic attendees and long-distance truck drivers, and has largely been undertaken in urban areas. There is evidence of HIV spreading to rural areas but very little is known about the context of the infection or about issues relating to health and social impact on people living with HIV/AIDS. In-depth interviews with 19 men and women infected with HIV who live in rural areas were used to collect experiences of testing and treatment, the social impacts of living with HIV and differential impacts on women and men. Eight focus group discussions with groups drawn from the general population in the four villages were used to provide an analysis of community level views about HIV/AIDS. While men reported contracting HIV from sex workers in the cities, women considered their husbands to be the source of their infection. Correct knowledge about HIV transmission coexisted with misconceptions. Men and women tested for HIV reported inadequate counselling and sought treatment from traditional healers as well as professionals. Owing to the general pattern of husbands being the first to contract HIV women faced a substantial burden, with few resources remaining for their own or their children's care after meeting the needs of sick husbands. Stigma and social isolation following widowhood were common, with an enforced return to the natal home. Implications for potential educational and service interventions are discussed within the context of gender and social relations.

## **Introduction**

The Indian National AIDS control organisation (NACO) estimates that there were between 3.97 and 4.58 million HIV cases in India in 2002. Although the overall HIV infection rate in India is stated to be less than 1% among the adult population in the age group 15-49, representing about 505 million using the 1991 age structure and the 2001 census population, sentinel surveillance data indicate significant variation across the states. Spread to 'low risk' groups such as general antenatal clinic attendees is also evident (NACO, 2004a). In the context of AIDS care, 81% of the 135 HIV positive women seen in a south Indian facility were housewives rather than sex workers or intravenous drug users (Newmann *et al.*, 2000). Husbands are thought to be the main source of infection for this group (George *et al.*, 1997). Thus transmission via sex workers and long distance truck drivers has now extended the epidemic into populations who might have been considered to be at low risk of HIV infection, apart from being in a marital sexual relationship (Singh & Malaviya, 1994; Rao *et al.*, 1999; Bryan *et al.*, 2001; Venkataramana & Sarada, 2001).

While there is evidence that HIV is appearing in rural areas of some states, very little is known about the context of this spread or about the needs of people living with HIV in these areas. Given the social context of gender relations in rural areas where women have little autonomy in the family, it is hypothesised that HIV would pose a much greater burden to women than to men. A greater understanding of the gender differentiated context of the disease, in other words, of the differing needs, impacts and consequences for men and women living with HIV/AIDS is needed to inform service and education interventions.

Rural Maharashtra was selected as the study context as it is easily accessible to urban commercial centres that are a focus for men seeking work as short-term

migrants, visiting as truck drivers or visiting for entertainment, all circumstances where contact with sex workers can occur. According to the 2001 Census, Maharashtra's population was 96.7 million with 42.4% residing in urban areas (Census of India 2001, <http://www.censusindia.net/results/rudist.html>). The state is one of the epicentres of the HIV epidemic in India. As of April 2004, more than 16,000 people were reported to be living with AIDS in Maharashtra as a whole (including the Municipal Corporation area of Mumbai) which represents the second highest number of any state the country (NACO, 2004c). The seroprevalence of HIV among women attending antenatal clinics in the state in 2002 was 1.25% (NACO 2004a). Comprehensive state level data on the extent of the HIV epidemic in rural areas are currently lacking. However, there is evidence of spread to the rural hinterland of Maharashtra from the metropolitan areas of Mumbai and Pune where the epidemic has been concentrated. For example, in Pune district 1.2% HIV seroprevalence was noted in a sample of 1,251 rural women (Kunte *et al.*, 1999).

Lack of knowledge about HIV and its prevention is a key factor placing the general population at risk, with early evidence of significant knowledge deficits in India (Pais, 1996). More recently a large-scale sample survey of about 90,000 married women in the reproductive age group showed the overall awareness of the existence of HIV among rural women to be around 30% (IIPS & ORC Macro, 2000). Again, from a 2001 "national baseline survey" of 21,267 men and 21,267 women in the age group 15-49 conducted by NACO, 65% of women and 79% of men in rural India had heard of the disease (NACO, 2004b). Thus knowledge levels appear to be increasing among the rural population; it should however be noted that different sampling approaches were used for the two surveys above, limiting their comparability.

While knowledge about HIV is more prevalent in urban areas a complete understanding cannot be taken for granted: among sexually active men, nearly 70% did not know that condom use could prevent HIV/AIDS infection (Sharma *et al.*, 1997) and 65% of female college students interviewed in Pune city did not know that condom use could prevent HIV transmission (Singh *et al.*, 1997). Although married women in coastal areas of Maharashtra had awareness about transmission of HIV, awareness about prevention measures was very low (Hirve & Sathe, 1999). Knowledge among urban women may have risen substantially in recent years, reaching 90% according to the 2001 survey (NACO, 2004b).

The objective of the present study was to obtain primary data about HIV in a rural context, gathering information about the circumstances of HIV transmission, how HIV status was communicated, treatment decisions, the social and family response, and social, health, and economic needs. Among the general rural population the aim was to characterise knowledge and attitudes about HIV. A final aim was to consider potential educational, health and social interventions within the context of gender and social relations in this setting.

## **Methods**

Approval for the study was obtained from the Ethics Committee of the KEM Hospital Research Centre, Pune. Fieldwork was carried out in four villages within outreach areas of the Rural Health Programme of KEM Hospital from October to December 2001. The relationship with hospital outreach service provision was considered vital on ethical grounds: programme staff members had a thorough knowledge of the area and were known to the village population in a context of service provision.

The methods of data collection adopted in this research were focus group discussions and in-depth interviews. Focus group interviews are the most appropriate methods to understand general view of the villagers about HIV and AIDS as it brings together different people and gives the opportunity to verify some of the facts about HIV and AIDS in the village. It also generates hypotheses and ideas that could be further examined in the in-depth interviews with HIV-positive people. Focus group participants were drawn from the general population and groups were facilitated by community health workers from KEM hospital staff. They contacted participants for the focus groups, explained the study, arranged venues for discussion and arranged refreshments for the participants. No effort was made either to include or exclude HIV positive individuals from the focus groups, in which any person in the village aged 20 years and over was eligible to participate. As women may not have been willing to discuss sex related issues in the presence of men, separate focus groups were conducted for men and women, with one of each per village, giving a total of four male and four female groups. On average focus group interviews took about two hours. Trained and experienced staff from KEM Hospital Research Centre moderated all the focus group discussions and on average 12 participants took part in each. A

specially assigned person took detailed notes of the discussions and later transcribed and translated them into English. The transcriptions of focus group discussions were read repeatedly, coded, and analysed for themes and patterns with the aid of Ethnograph software version 5.0.

Nineteen in-depth interviews were conducted among HIV positive men and women, including ten women and nine men. In-depth interviews were considered the most appropriate method for this part of the because of the ability to provide complete privacy to the respondent. Eligible individuals were those known to the study team from an earlier project and the status of other village residents was not known. It is therefore important to note that this might not have been a representative sample of all HIV-positive people in the village nor could it be representative of rural Maharashtra as a whole. None of those approached declined to be interviewed. Interviews were conducted at the KEM rural hospital in Vadu, situated about 20 kilometres from the study villages, by trained research centre staff. It was decided not to interview at homes because of the risk of a breach of confidentiality. On average each interview took about an hour and half. Interview notes were later translated, transcribed into English and analysed as described above.

Although participants in the in-depth interviews co-operated with the interviewers in providing responses, these were often not as full or detailed as one would generally expect in in-depth interviews. Women recently widowed were naturally reluctant to discuss the events that had led to their husbands' death. Some respondents, especially women, became distressed during interviews and manifested this by crying, while men tended to remain silent. Where such signs of distress were encountered it was necessary to interrupt the interview, and if it was possible to

continue, to take an alternative less distressing line of questioning for the remainder of the interview.

The main issues discussed in the focus groups and interviews were: knowledge of HIV/AIDS; modes of HIV transmission; knowledge of the 'window' period; knowledge of symptoms of HIV/AIDS; knowledge of HIV/AIDS cases in the neighbourhood; history of AIDS in the village; HIV as a socially sensitive secret disease; reasons to keep the disease secret; whether or not the prevalence of the disease is increasing; the profile of HIV infected people; how villagers had contracted HIV infection; how infection could be prevented in the village; treatment for HIV/AIDS; the cost of treatment; health problems; health needs; economic problems; social problems; secrecy; stigma; sexual relations; and possible interventions.

### **The study population and the social context**

The selected villages were within a range of 50 kilometres from Pune city, two located on a major highway and the other two from interior areas of the same district. The two villages located near highways were slightly larger than the other two located in interior areas. In total, the population of these four villages was around 31,000. All four villages had easy access to Pune city either by bus or by private jeep. Compared to villages located in interior parts of Maharashtra, particularly in the tribal and forest areas, these villages were developed and have easy access to important commercial centres in Maharashtra. This distinction is important because both are referred as rural in the literature, in the Census for example. In the study villages agriculture was the major occupation of the population. Some men were employed in the cities of Pune, Mumbai, and Ahmednagar mostly as semi-skilled workers. Men from agricultural households visit cities to sell their produce. There is an increasing trend of male

migration from these villages to cities of Pune and Mumbai for semi-skilled employment, both short and long term. Diminishing agricultural land and development with focus on non-agricultural livelihood in the state (Human Development Resource Centre, 2002) may be contributing to migration and urbanisation with profound implications for the well-being of both rural and urban residents in Maharashtra.

The profile of the HIV positive individuals interviewed in this study was as follows. All but one of the women was aged 30 or below compared to five of the nine men. All respondents had some schooling. Only three of the men but none of the women had been educated to college level. All others had schooling up to 10<sup>th</sup> class. Seven of the women worked as labourers and three were not working. Of the men, four were truck drivers or helpers, two worked in the city and three worked in agriculture. Seven women were widows, two were married and one was separated. Seven men were married, one unmarried and one separated. Nine of the women had children. Six women lived in the parental home while four lived with their in-laws or husband. All the HIV-positive people interviewed had some farming land, either their own or under family ownership. In relation to caste, two men and one woman identified themselves as belonging to a 'scheduled caste' while the others belonged to the majority caste group in the village.

Gender relations that set the worth of one sex relative to the other are embodied in social institutions such as marriage and family. Understanding these institutions is important to understand gender relations. The institution of marriage and family in the study villages resemble with that of the general pattern observed in Maharashtra, with patrilineal and patrilocal systems of inheritance and residence (Karve, 1965). In such system inheritance of property rights are passed through the

male lineage. In the patrilocal system a woman lives with her husband in her husband's home after marriage. Women can impose authority within the husband's family only after she gives birth to a live child, particularly a son. Karve (1965) notes that woman settles in her husband's family only after she has given birth to a few children. In patrilocal societies the status of widows in the family is low. In the present study where widowhood could occur early in married life due to HIV infection the consequent disadvantage could be magnified. Dreze and Sen (2002) argue that disadvantage with widowhood is mainly due to gender inequalities. Further, in patrilineal societies there exists inequality in conjugal relations. Dube (1997) notes that in patrilineal societies the husband's exclusive right over the wife's sexuality is unquestioned. Women thus have no power to make men use barrier contraceptive methods such as the condom which could prevent both pregnancy and sexually transmitted infections.

Dube (1997) reports that the status of women in terms of nutrition in Maharashtra is generally low. For example, customarily a girl is not given milk to drink; girls and women are generally provided with unimportant and less expensive food; and they eat last in the family. In poor households this discrimination would be acute and women tend to eat much less food compared to men. Thus, the role of women is articulated socially as that of food givers. Linked to this is the expectation that women should think of the comfort of others, without being bothered about themselves.

A more recent survey provides evidence of continuing female disadvantage in Maharashtra, particularly in rural areas. The 1998-99 National Family Health Survey of Maharashtra, a representative sample survey of 5,391 ever married women in the reproductive age, asked each woman a series of questions about women's status and

autonomy, defined in terms of education, work participation, and exposure of mass media. In rural Maharashtra 56% women were illiterate; 43% women were not regularly exposed to media; and 33% were working in family farming or business. The survey also had questions that could measure women's autonomy and empowerment in terms of participation in household decision making; their freedom of movement; and access to money they can spend as they wish. The study showed that in rural Maharashtra only 29% of women made decisions on obtaining health care for themselves; husbands made this decision in 46% of cases. Only 9% of women made decisions about purchasing jewellery or other major household items; husbands made this decision in 36% of cases. Only about 15% women decided about going and staying with parents or siblings; husband made this decision in about 47% of cases. In the same survey about 18% of rural women reported being beaten or physically mistreated by their husbands (IIPS & ORC Macro, 2000). A report based on the above data gave Maharashtra among other states in India among the lowest rating for women's empowerment (Kishor & Gupta, 2004). The gender differentials discussed above have tremendous implications for the transmission of HIV and care of AIDS patients.

## **Findings**

### *HIV/AIDS knowledge*

Participants in all of the four focus groups in this study had heard about HIV and AIDS and knew that it was a disease. However, the differences between HIV and AIDS and the technicalities of the disease were often unclear. For some, AIDS was a disease and HIV was a virus, for others both were the same, and a few others believed that HIV and AIDS were different but could not say how. Although health workers from the Rural Health Programme work in these villages, television was reported to be the major source of information about HIV.

The focus groups identified heterosexual contact with an HIV positive person as the prime mode of HIV transmission. The groups mentioned sexual union outside marriage, particularly with sex workers as the key channel of HIV transmission. Other routes of transmission were identified including injection needles and shaving blades contaminated by HIV infected blood, mother-to-child transmission during pregnancy through breast milk from an HIV positive mother, and blood transfusion using HIV contaminated blood. Other beliefs expressed were that HIV could be transmitted through mosquito bites, flies sitting on wounds, using the clothes of a HIV infected person, sitting close to someone, through the mouth of a person who died of HIV, through food and water, through the saliva, and through fumes from cremation of a person who died of AIDS. Thus, beliefs about HIV transmission reflected both current scientific knowledge and ideas that had no scientific basis. In general, the views of HIV positive individuals interviewed in this study more strongly reflected current scientific understanding. However, some misconceptions were also expressed, such as the view that spread could occur through proximity to an HIV infected person.

There was awareness among the focus group participants that there is a time lag between the time of HIV infection and the onset of visible signs of the disease. This was reported to be a gradual process over a few months to several years. However, only a few focus group participants reported that there could be a time span during which an HIV infected person would not test positive for HIV. A few believed that if contracted through sex then the virus takes more time to appear in the blood compared to direct transfusion of HIV infected blood to a previously non-infected person.

Focus group participants knew some symptoms of AIDS, most commonly mentioning fever, cough, loose motions, vomiting, eating less, weight loss, tuberculosis, and 'poor health'. A few reported that HIV patients get black marks on their face and that boils appear on their body. The focus group participants had views about roughly how many people had died and how many could be living with HIV/AIDS in the village. There were thought to be two to three such people living in each village, and a similar number were thought to have had died of AIDS in each village. When asked how they knew that these were indeed HIV/AIDS cases, a majority of the participants responded that they could tell this from the appearance of the person. Thus HIV positive people are identified in the village only when their condition has deteriorated so as to be obvious.

Although focus group participants could not say how many new HIV cases were occurring in the village they thought that the number had been increasing in the previous few years. The increase was attributed to greater mobility of people, particularly of young people to the cities. Some of the focus group participants mentioned that the first AIDS death in the neighbourhood had occurred 4-5 years

previously. All this information, however, did not lead them to consider HIV/AIDS as a major cause for concern or an important problem for the villagers in general.

#### *HIV transmission*

Male HIV positive respondents interviewed in the study reported contracting the infection from sex-workers. They had been facilitated by their employment, which had involved travelling to cities or short-term stays for business.

*I think I got the disease from sex workers whom I used to visit during my trips to Bangalore. At that time I used to have sex with whomever was available. I was working as a truck driver. For about one to one and half years I used to go there and used to have sex about three or four times a month [40 year old HIV positive man]*

Reported circumstances of women's HIV infection reflected the prevailing gender relations within couples and families. Men did not reveal their HIV status to their wives until they were ill to the extent of being bed-ridden; some men even died without revealing their status to their wives. One of the women in the study reported that, following advice from his doctor, her husband had used condoms during sex immediately after discovering his status, but he had gradually stopped doing this and the couple subsequently had unprotected sex. She could not persuade her husband to use a condom for fear of being beaten. Almost all of the HIV positive women interviewed reported being infected by their husbands. Many of the children of these women were also HIV positive as a result of breast-feeding.

*I got the infection from my husband ..... he used to go 'out' and that is how he got it....in the last days when he was dying he made me sit by him and told me that he went out with other women and that is why he*

*got this infection. He told me that he was sorry...[23 year old HIV positive widow]*

Focus group discussion participants identified travel to the city as the main source for HIV infection in the area. There was specific mention of visits to sex workers by youngsters during festivals, especially during the 10 days of the Ganapati festival, and by long distance truck drivers, jeep drivers and businessmen in the course of their work in the cities.

*Testing: experiences and resulting knowledge*

In the majority of cases HIV testing had been recommended when a doctor was consulted for opportunistic infections. Most testing had been carried out in Pune city, but most had taken more than one test. While considering that the study was based on recall of consultations that had occurred some months before, there was evidence that in the majority of the cases HIV tests were done without adequate counselling. An instance was reported where clinic staff asked a woman embarrassing and taunting questions regarding her sexual relationships in the course of giving her an HIV test result. Sometimes those interviewed recalled receiving misleading information regarding the test results, especially in the case of women who were usually accompanied to the consultation by a male member of the family such as the husband, father, or brother. On such occasions women who tested positive were told things like 'there is some problem in your blood', 'there is some fault' and 'you will be alright'.

The current knowledge of HIV positive men and women was limited with regard to treatment options for opportunistic infections, care to be taken to avoid infecting other people, and the prevention of maternal-to-child transmission. HIV infected people believed that they could infect other family members with simple

physical contact, that sex should be avoided in order to reduce the impact of the disease on themselves, and they reported approaching quacks or traditional healers claiming to have treatments to cure HIV.

Almost all participants knew that HIV/AIDS has no complete cure. However, some ways to treat the disease so as to prolong life were known to them, including ayurvedic and other traditional medical practices as well as Western medicine. They also believed that if treatment was taken regularly there could be useful relief of some of the symptoms. This knowledge came from advertisements in newspapers and through information exchanged by local people. Some were aware of far away places for treatment such as the south Indian cities of Chennai in Tamil Nadu and Cochin in Kerala. Knowledge regarding anti-retroviral treatment was very limited.

#### *Process of revealing HIV positive status*

Focus group participants expressed the view that there were no direct ways of identifying the HIV status of a person in the village until he or she developed signs of full-blown AIDS. Interviews with HIV positive men and women showed that they concealed their HIV status for as long as possible, and from as many people as they could. There was a pattern in the process of revealing HIV status to others. Generally, it was those who accompanied the person for testing who first knew about the result. In the case of a married woman her husband would be the first to know and her parents would come to know about the disease often before her in-laws because of the economic and social support expected from her parents. Sometimes a woman would not know her own HIV status for a long time as neither the doctor nor her relatives revealed the results to her.

*After he [my husband] died I came to know about his disease. People used to say that he got something from outside. That time my blood was not tested....[23 year old HIV positive widow]*

Men in general tended to conceal their HIV status more than did women. There were cases in this study where husbands did not reveal their HIV status to anyone, including their wives. Sometimes economic needs also forced people to let their HIV status be known to others in order to get money for treatment. In general, there was a view that there was no reason to tell another person about one's HIV status when it was certain to be unwelcome news. Rather, it was considered better to let people know about it only when it became obvious. Revealing one's HIV status to those outside the family had greater social costs than benefits.

#### *Social impact of HIV: social stigma*

Focus group discussions indicated that a man's infection with HIV was invariably viewed by others as linked to his past contact with sex-workers. This was reported differently in the case of housewives whose behaviour was vouched for positively. Focus groups reported that these women were usually considered victims of their husbands' immoral character and sympathy was expressed for them. However, individual merits would come to be submerged under the overall immorality of the family and eventually the neighbourhood would look down on them all. Under the circumstances the most appropriate behaviour would be not to let others know about one's HIV status until it was obvious, and the in-depth interviews showed that people did exactly that. Focus group participants confirmed that the only HIV positive people they knew were those with visible signs of serious illness attributable to AIDS. Thus, in the early stages, HIV infected persons are not identifiable and hence difficult to

stigmatise. In instances where HIV status was known, social stigma and discrimination were reported.

*.....people do not invite me....family members do not treat me well.  
They do not let me touch anything, mix with them, do not let me cook  
for my son. I was admitted for TB. After I came home they asked me to  
stay separate. They gave two rooms for me... When neighbours came to  
know about my HIV, they asked my family members to keep me  
separate. They do not come to my house. My relatives do not come to  
my house. They do not touch me. ....Sometimes the landowners think  
before calling me for labour work [28 year old HIV positive widow]*

Once the physical signs of AIDS became apparent there was a complete social and physical isolation of the individual. This was not so much associated with the social stigma attached to the immoral behaviour of the person, but with fear of infection. At this stage of the disease people were less concerned about the cause of the disease, particularly the individual's previous behaviour. Even the patient's own children, usually very young, were forbidden from touching or going close for fear of infection. Usually a separate room was given to the HIV infected person when the disease reached the final stage. Focus groups reported that people who died of HIV/AIDS were cremated without traditional rites as people wanted to cremate the body as quickly as possible because of fear of infection. Often the mouths of people who had died of HIV/AIDS were filled with cloths to stop viruses from spreading. These behaviours were not, however, viewed as relatives' disrespect for a person of supposedly immoral character, but rather fear of spread of the disease.

*HIV: impact on women*

Gender relations in the family and society play an important role in mediating the social impact of HIV infection. Among couples, the pattern of social and economic impact was determined by who was infected with HIV first. As indicated above, this was usually the husband. When husbands were infected with HIV earlier than wives, the impact on wives might include among others: a lack of economic resources left after caring for a sick husband; a higher risk of having HIV positive dependent children; a risk of being removed from their deceased husband's family; a risk of being stigmatised for longer periods of time; becoming a widow and taking shelter at the parental home.

In-depth interviews illustrated that when a husband contracted HIV infection, the family typically used all the economic resources to treat him, eventually leaving very little for the wife and children. This involved using all their savings, selling assets, and taking loans. In one case a wife's parents sold their property to treat their HIV infected son-in-law. Thus, husbands had the economic support of the family and the services of their wives. Since husbands utilised most of the economic resources and plunged some families in to debt women had few economic resources to seek medical care for themselves and HIV positive children, and to manage their day-to-day expenses. Furthermore, while husbands received physical help from their wives while suffering from HIV related illness, wives had no one to physically support them, adding to their sufferings.

*I took him to a private doctor. He was a little better. He used to talk a little. Then he was admitted in Sassoon hospital for a week. It did not help either... Again I took him to a private doctor.. He was admitted there for two days..... we brought him home. We used to bring*

*medicines for him. He died a day prior to Sankranti [23 year old HIV positive widow]*

Women face the threat of divorce or separation from husbands when they are found to be HIV positive. Two instances were reported where the wives were HIV positive and their husbands were said to be HIV negative. In both cases the circumstances of infection were not disclosed and study investigators were not able to document the discordant status. In one case the husband had indicated his desire to divorce and re-marry. In the other, the man already had two wives, one known to be HIV positive and the other thought to be negative.

The ultimate impact of a husband getting the disease first is that the wife would become a widow leading to her removal from the husband's family. Some women had had to leave their deceased husband's house and return to their parental home as their husband's relatives considered them and their children too much of a social and economic burden.

*My husband was sick when I was pregnant. I stayed with my mother for eight months after my delivery. Then I came to my husband's house. But he was sick. Hence my father-in-law sent me back to my mother with my small child. I have been staying with them since then [29 year old widow]*

#### *Impact on sexual life*

In-depth interview participants of both sexes reported that being HIV positive was seen as the end of sexual activity, within or outside marriage, often on the basis of medical advice. Only one participant was able to relay advice he had received from a doctor about condom use; others did not report receiving any advice on how to have marital relations safely. Participants of both sexes voiced the opinion that sexual

relations would adversely affect their own health status and that they should therefore abstain. It was unclear how this opinion had arisen.

*I have not had any sexual relations with my wife for a couple of years.*

*She is not in good health and I am HIV positive, so we do not have sex at all.... [ 29 year old HIV positive male]*

#### *Perceived and actual needs of HIV infected people*

The anticipated health problems of HIV infected people reported by the focus groups were recurring fever, chronic cough associated with tuberculosis, and loose motions. It was reported in the discussions that these observations were either based on what they had seen or heard from other people. However, interviews with HIV positive study participants did not indicate these health problems to be current, as those interviewed were in the asymptomatic phase.

The perceived needs of HIV infected people were broadly expressed by focus group participants as needs for medicine or treatment, for personal health care, for moral support to sustain treatment, and for nutritious food to sustain good health. Among health needs, provision of medicine to HIV infected people was thought to be very important. However, without moral support and good diet the role of medication was felt to be rather limited. Among in-depth interview participants the greatest social need was for interventions to educate people about the disease, particularly to reassure everyone that it would not spread by touching or normal social contact. They believed that such interventions could reduce social stigma and discrimination.

Most HIV infected people interviewed in this study were poor by the standards of the study villages and although not currently very ill, spent a major share of their disposable assets on medical treatment. There were families who had sold or

mortgaged their land for treatment, spending between Rs 4,000 and Rs 50,000 for treatment (US\$ 88 to 1,100), often in response to AIDS related illness in a husband who had since died. Current expenditure on medicines and doctors' fees was in the range Rs 400 to Rs 1,000 per month (US\$ 9-22), and multiple HIV tests were often taken at up to Rs 400 each. The average daily wage was between Rs 100 and Rs 150 and work was normally irregular. Thus, the money spent on HIV testing and treatment was substantial as a proportion of available resources even among those not currently suffering an AIDS related illness.

*Possible routes to prevent HIV transmission*

According to the focus group participants, the major way to stop HIV infection among the village population was preventing people from having sex with sex-workers. Participants felt that it is very important that people, particularly the illiterate, know about how one gets HIV infection, how one can prevent it and the social, economic, and health consequences of having the disease. While focus groups of women emphasised the need to prevent men from having relationships with sex-workers, men stressed the provision of information about how one can prevent HIV infection. This topic came up indirectly however: as sex outside marriage was socially unacceptable in this setting, any strategy that advocates condom use to prevent HIV infection in an illicit relationship could not be mentioned during the focus groups. Thus while most focus group participants were aware that condoms could prevent infection only a few suggested it for either marital or non-marital relationships.

## **Discussion**

The present study has provided primary data about the responses of a rural community and the HIV-positive individuals within it to the spread of the epidemic. The detailed findings cannot be generalised outside the study setting but illustrate the social and health impact of the disease at village level. Social conditions in rural areas are characterised by poverty, gender inequality, and illiteracy, which magnify the harmful impact of infection. Any strategy to deal with HIV infection in rural areas in India must, therefore, include interventions to mitigate these inequalities. Improvements in the status of women are particularly important if the destructive impact of HIV on the whole family is to be reduced. Specifically, women need to be empowered with adequate knowledge and resources to negotiate the terms of their sexual relationships.

Poverty dominated the lives of the in-depth interviewees in this study, either as a consequence of their family's pre-existing low economic and caste status or destitution as a result of the disease of those previously at the margins of economic stability. In the African context poverty coexisting with rapid social change are thought to underlie a pattern of marital instability and migration that can be seen as proximate determinants of the epidemic (Boerma *et al.*, 2002). To date the dynamics of poverty and impoverishment in relation to the spread of HIV have been analysed only to a limited extent in India, but the overall context of poverty cannot be ignored in any proposed intervention strategies. It must be realized that in settings where poverty is prevalent, the degree to which individual health beliefs and behaviour can be summoned to improve access and compliance are significantly compromised by forces beyond the individual's control (Farmer, 1996). On the other hand, while much of the experience described in the present study was negative, there is potential to

draw on the family structures and social networks within rural society so as involve the wider community in care and support, as has been emphasised in the urban context (Bharat & Aggleton 1999).

While the general level of knowledge about HIV, its mode of transmission and means to avoid infection is rising in rural India, correct and incorrect knowledge about HIV coexist as discussed above. The findings in this study are also consistent with those from multivariate analysis highlighting variations in knowledge about HIV and AIDS in relation to educational and socio-economic status within a given population. For example, in the populous north Indian states of Uttar Pradesh and Madhya Pradesh television watching and educational status were predictors of knowledge about AIDS among rural women (Pallikadavath *et al.*, 2003).

There are problems inherent in interventions aiming to link knowledge provision to existing reproductive and child health programmes because of limits on which categories of women can such programmes. For example, the family planning service infrastructure is highly developed throughout India with local staff in regular contact with rural communities. However, the large numbers of women who have been sterilised or are postmenopausal would not be accessible to health education messages about HIV through such services (Pallikadavath & Stones 2003). In addition, such linkage highlights the problematic gendered issues around promoting safe sex messages in a society where women's reproductive capacities are highly valued (Baylies 2001). Most critically, in order for knowledge enhancement provided by these services to have an impact on behaviour, women would need to be empowered in other ways to discuss such issues with their partners.

The service needs of HIV positive people and indeed the wider community identified in the present research include access to professional and confidential HIV

testing and post-test advice at anonymous locations, and professional help to deal with AIDS at the village level. In particular there is a need to assure access to supportive care and means of preventing opportunistic infection that overcome gender and societal constraints to reach rural women, children, and the poor. Emphasising the vulnerability of the Indian population to the spread of sexually transmitted infections including HIV, Hawkes and Santhya (2002) reviewed the challenges faced by public and private components of the health system as well as the key role being played by non-governmental organisations especially in information and communication, and in the care of people living with AIDS.

With regard to voluntary counselling and testing, the sensitivity of the condition means that assurance of confidentiality is essential. At present, most HIV testing is offered by government hospitals associated with medical colleges that are reasonably well placed to provide such confidentiality. However, this study has illustrated the difficulties experienced in accessing such services and being adequately counselled following a positive result, especially for women. Thus far formal comparisons of different models of provision for voluntary counselling and testing have not been undertaken, such as advice and testing at rural health centre level versus provision at a more anonymous distant site supported by information materials to enable access.

Once full-blown AIDS develops, the imperative for secrecy cannot be maintained and the pressing need is for care in the home. Given the stigma and fear associated with the disease, supportive care models need to be tested, either strengthening the existing rural health outreach infrastructure or by developing a cadre of specialised health workers. The latter model has shown good results in the cases of malaria and leprosy control in rural India but has not been formally evaluated

in the context of AIDS care. Recent reductions in the price of antiretroviral drugs together with new-found donor commitment to invest in drug treatment programmes will require a specific focus on service delivery models in rural areas. There is a risk that the already destitute and marginalized rural victims of the epidemic will have great difficulty in availing of such services as are made available. Furthermore, medical expertise for initiation and monitoring of antiretroviral therapy and dealing with adverse effects is at a premium, necessitating close liaison with specialist centres. Such liaison is already under way with KEM Hospital in the rural area used for the present study but may be wholly unrealistic in other parts of India: a recent study of rural health services in Rajasthan described public services of low quality co-existing with unqualified private providers (Banerjee *et al.*, 2004). On the other hand, political decentralisation with reservation of seats on village governing councils for women and members of 'scheduled castes' and 'scheduled tribes' has led to greater provision of public goods for these under-served groups, indicating that social dynamics in rural communities are responsive to such policy interventions (Chattopadhyay & Duflo 2004).

### **Acknowledgement**

This study was funded by the UK Department for International Development through the 'Opportunities and Choices' programme based at the University of Southampton.

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