

A comparison in HIV-associated stigma among healthcare workers in urban and rural Gujarat

Kartavya J Vyas, Gulab R Patel, Deepak Shukla, William C Mathews

Abstract

The present study measures levels of stigma within health care settings in urban and rural Gujarat, in an attempt to understand how this may have contributed to the state's increasing HIV incidence. Two sites were studied: a rural hospital in Bardoli and an urban hospital in Surat. HIV-associated stigma among healthcare workers ($N=170$) was assessed using a Stigma Index. Overall, analyses suggest an increase in medical education was found to be associated with higher stigmatisation ($p<0.001$). Furthermore, a statistically significant difference between stigma scores of HCWs in rural and urban Gujarat was not observed.

Keywords: Stigma, healthcare workers, HIV-positive patients, India.

Résumé

Cette étude mesure les niveaux de stigmatisation dans des environnements médicaux situés dans les zones urbaines et rurales du Gujarat, afin d'essayer de comprendre comment la stigmatisation pourrait avoir contribué à l'incidence croissante du VIH dans l'Etat. Deux sites ont été étudiés : un hôpital situé en zone rurale à Bardoli et un hôpital urbain à Surat. La stigmatisation associée au VIH parmi les travailleurs de la santé ($N=170$) a été évaluée en utilisant un indice de stigmatisation. Globalement, les analyses suggèrent qu'une meilleure éducation médicale était associée à une plus forte stigmatisation ($p<0.001$). De plus, aucune différence statistiquement importante entre les résultats de la stigmatisation des travailleurs de la santé dans les zones rurales et ceux des zones urbaines du Gujarat n'a été observée.

Mots clés: Stigmatisation, travailleurs de la santé, patients séropositifs, Inde.

Introduction

Of India's over 1.15 billion population – one-sixth of the world's population – 5.7 million are infected with HIV. Since first being diagnosed in Chennai in 1986, the infection has seen a tremendous growth in both numbers and distribution in the urban and rural areas of southern and western India (Steinbrook, 2007). Until recently, however, research on HIV/AIDS stigma had been predominantly limited to the urban epicentres of India. Because of this, there is little information pertaining to how HIV/AIDS-related stigma and discrimination are affecting or contributing to the recent surges of the epidemic in rural India, specifically in Gujarat – a state on the verge of becoming one of the states in India with the highest prevalence (Basic Health Statistics, 2007; National Health and Family Welfare, 2009). The total number of HIV-positive cases reported to the Gujarat AIDS Control Programme more than doubled from 2002 ($N=2\ 528$) to 2006

($N=5\ 824$), with an average increase of 700 new cases per year (Basic Health Statistics, 2007).

In Surat, a mid-sized town in Gujarat of 2.5 million inhabitants, almost 15% of adolescent and young adult males visit sex workers for sexual gratification, and a negligible proportion among them use condoms. In the general population, 40% (1 million) live in various slum pockets and almost 80% (2 million) are poorly educated (Pallikadavath, Garda, Apte, Freedman & Stones, 2005). It is hypothesised that because of the high traffic of rural commuters to and from cities like Ahmadabad 255 km to the north (where 13% of commercial sex workers are HIV-infected) and Mumbai 263 km to the south (where 54% of commercial sex workers are HIV-infected and injection drug use is more accessible), the epidemic may build a stronghold here (Fung *et al.*, 2007; Madhivanan *et al.*, 2005; Pallikadavath *et al.*, 2005).

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Because most of the surrounding rural villages, like Bardoli 35 km to the east, are farming communities, men often travel to Surat to sell their produce in the markets. During this time, they leave their homes and wives and are more susceptible to engaging in high-risk behaviour. With stigma against people living with HIV/AIDS (PLHA) already pre-existent, and illiteracy an immense hindrance, understanding the interconnectivity of urban and rural areas and how this may promote high-risk lifestyles is very important in trying to tailor future interventions.

Studies have documented HIV/AIDS-related stigma in many different settings, such as within the family, workplace, community, and healthcare settings (Rathod, 2004). Nonetheless, the healthcare sector may be the most conspicuous of the environments listed. Because of negative attitudes from many healthcare workers (HCWs), infected patients may feel embarrassed and anxious to reveal their serostatus, fearing even worse reactions from family members and co-workers. Therefore, it has been hypothesised that the fear and anxiety that many PLHA endure daily could be traced back to traumatic experiences in healthcare settings (Rathod, 2004).

The most commonly reported manifestations of stigma within this setting include: a refusal to treat or admit HIV-positive patients, the tendency to neglect patients, the habit of testing for HIV without consent, and breaches of confidentiality (Horizons Final Report, 2006). A large-scale study of 884 HCWs in New Delhi concluded that ward staff – including paramedical, administrative, and cleaning employees – harboured the most disdain toward PLHA, followed by nurses and doctors (Horizons Final Report, 2006). This mindset was reflected in poor care of patients both physically and psychologically. For instance, PLHA were often isolated (given separate arrangements outside the ward), were restricted in their movements around the ward or room, and were treated with unnecessary use of protective gear (gowns, masks, etc.). Furthermore, use of plastic sheeting to wrap dead bodies and reluctance to provide transport for the body were commonplace actions. It is hypothesised that this may discourage many PLHA from receiving treatment from healthcare professionals, and that they then solicit care from local mystics or simply take over-the-counter medications to treat opportunistic illnesses (Horizons Final Report, 2006; Zelaya *et al.*, 2007).

The objectives of the present study were to identify the general manifestations of stigma against PLHA in healthcare settings, and to measure specific HIV-related attitudes and risk perceptions among doctors, nurses, and ward staff working in both urban and rural settings in Gujarat.

Materials and methods

A cross-sectional survey of HCWs was conducted from August to October 2008, in two healthcare settings. In Surat, a public university-based 800-bed hospital staffed by 380 doctors, 200 nurses, and 396 ward staff was selected as the urban site. Conversely, a private 200-bed hospital 35 km east in Bardoli staffed by 80 doctors, 62 nurses, and 75 ward staff was selected as the rural site.

A convenience sample of HCWs – doctors, nurses, and ward staff (paramedical, administrative, and cleaning) – were asked anonymously to complete a Stigma Index comprised of 18 statements pertaining to healthcare access, testing and counselling, confidentiality, infection control, and quality of care. All responses to questions were on a 3-point Likert scale: agree, don't know, and disagree, with a maximum score of 54. All HCWs employed in each department of both hospitals were invited to participate in the study. Interested participants were asked to complete the questionnaire within one week. These were collected after the given time period. This instrument was created and validated by Mahendra and colleagues in 2006, and is designed specifically to measure HIV-associated stigma among HCWs in India (Horizons Final Report, 2006). With an internal consistency reliability of 0.742, the Stigma Index was developed through a review of national and international literature, a selection process by specialists in HIV-associated stigma in India, and a baseline survey of 884 healthcare workers in New Delhi (Horizons Final Report, 2006).

Several changes were made to the study protocol by respective healthcare facilities due to the sensitive nature of certain statements in the questionnaire. Thus, the ethics committee removed statements 5 and 8 from the Stigma Index before distribution, and stigma score calculations were done without these two statements.

Demographic information was gathered from each participant regarding: age, sex, employment category, and HIV status. Questionnaires contained no participant identification information. The instrument was made available in English and Gujarati, and was back-translated to ensure equivalency of items. Written consent was obtained from each HCW participant. All documents were gathered and kept in an off-site safe after each collection day. The data were analysed using SPSS version 17.0. The statistical tests used to assess the strength of the associations between variables included Chi-square (for categorical variables), independent samples t-test (for continuous variables), and Cronbach's alpha (to test the internal consistency reliability of both instruments). Ethics approval for the study was granted by the University of California, San Diego Human Research Protections Programme, the institutional review boards of both rural and urban study hospitals, and the Gujarat State AIDS Control Society.

Results

Among HCWs who participated in the study in Surat (N=170), 55 were doctors (52%), 36 were nurses (34%) and 14 were staff members (13%). The mean age of Surat respondents was 31 years (SD 10) and the majority were male (53.3%). Among HCWs who participated in the study in Bardoli, 8 were doctors (12%) and 57 were nurses (88%). The mean age of Bardoli respondents was 34.1 years (SD 12) and the majority were female (89.2%). All participants reported that they were HIV-negative.

The percentage of endorsements for each statement based on employment category and healthcare setting is summarised in

Table 1. Proportion of HCWs in Surat and Bardoli agreeing with statements related to care of PLHA

Statements	% Endorsement ²				
	Surat			Bardoli	
	Doctors N=55	Nurses N=36	Staff N=14	Doctors N=8	Nurses N=57
Attitudes towards PLHA					
People living with HIV/AIDS have a right to decide who should know about it*	91.2	97.1	100	87.5	63.2
People with HIV/AIDS should still be able to marry, as long as both partners know about it	50.0	68.6	35.5	50.0	50.9
HIV-positive women should not get pregnant.	73.5	65.7	29.0	87.5	78.9
HIV/AIDS spreads due to immoral behaviour	83.6	55.6	78.6	87.5	84.2
Men who get HIV/AIDS get what they deserve ¹					
Sex workers are the ONLY women who have to worry about getting HIV/AIDS*	0	8.3	7.1	0	5.3
Men who go to sex workers or use drugs are the only men who have to worry about getting HIV/AIDS	5.5	5.6	7.1	12.5	8.8
A woman who gets HIV/AIDS gets what she deserves ¹					
Would you be willing to share a meal with an HIV-positive person?	92.7	63.9	85.7	75.0	96.5
If you knew that a foodseller had HIV/AIDS would you buy food from him?	89.1	75.0	78.6	87.5	96.5
Would you be willing to move into a home if the neighbour was HIV positive?	87.3	86.1	92.9	100	89.5
If you found out that a co-worker has HIV/AIDS would you be willing to work with him/her?*	98.2	100	92.9	100	94.7
Attitudes toward healthcare-related practices					
Patients' blood should never be tested for HIV without their consent	78.2	88.9	100	50.0	89.5
Patients who test positive have the right to decide whether or not their relatives should be informed	67.3	61.3	78.6	75.0	68.4
When a person tests positive, the doctor should inform the patient's partner	81.8	94.4	85.7	100	98.2
The need for consent is exaggerated. HIV tests should be handled like any other blood test*	34.5	77.8	21.5	100	98.2
HIV/AIDS patients should be made to pay for gloves, AIDS kits, and other infection control supplies	89.1	83.6	78.6	50.0	82.5
All pregnant women should be tested for HIV*	94.5	94.4	92.9	100	100
Patients with HIV/AIDS should be kept at a distance from other patients	18.2	61.1	29.0	25.0	61.4
Clothes and linen used by HIV patients should be disposed of or burned*	92.7	100	71.4	100	100
Overall score	34.2	35.0	31.1	34.6	34.4
		34.1 (SD 3.4)		34.5 (SD 3.3)	

¹Statements were removed from questionnaire by the ethics committee.

²Defined as participants agreeing to specific statements in the HCW questionnaire.

*p<0.05.

Table 1. In the first 12 statements, 'attitudes towards PLHA', designed to capture information pertaining to respondents' perceptions of PLHA and their level of tolerance concerning physical contact and societal interaction, with a maximum possible score of 30, HCWs in Surat produced a mean stigma score of 18.3 (range 14 - 24, SD 2.0), while those in Bardoli produced a mean stigma score of 14.3 (range 10 - 20, SD 2.0). In the next 8 statements, 'attitudes towards healthcare-related practices', designed to reflect respondents' perspectives on how medical care and treatment should be given to PLHA, including concerns over medical costs and consent regulations, with a maximum possible

score of 24, HCWs in Surat displayed a mean stigma score of 17.8 (range 10 - 24, SD 2.5), while those in Bardoli displayed a mean stigma score of 19.3 (range 16 - 22, SD 1.4). Overall, in Surat, the mean score was 34.1 (range 24 - 43, SD 3.4). Conversely, in Bardoli, the overall mean score was 34.5 (range 27 - 46, SD 3.3). The HCW questionnaire resulted in a Cronbach's alpha value of 0.396.

Overall, an increase in medical education was found to be associated with higher stigmatisation, where ward staff were found to have the lowest stigma scores (31.1) ($p=0.001$). When

asked if HIV/AIDS spreads due to immoral behaviour, doctors were more likely to agree than nurses in both healthcare settings ($p=0.043$). Nurses from both sites also endorsed fewer discriminatory attitudes than doctors, and nurses in both sites were more likely to agree that consent is always needed before testing for HIV than doctors ($p=0.021$). Nevertheless, HCWs in Bardoli nearly unanimously agreed that the need for consent was exaggerated ($p<0.001$). In addition, nurses in Bardoli were more willing to purchase food from an HIV-positive foodseller (96.5% v. 75.0%) or move into a home next to a PLHA than nurses in Surat (89.5% v. 86.1%) ($p=0.023$). Regarding medical costs, urban doctors were significantly more likely to agree that HIV-positive patients should have to pay for infection control supplies and AIDS kits than rural doctors ($p<0.001$). In relation to age, younger respondents were more likely to agree that HIV-positive women should not get pregnant ($p<0.001$). Expectedly, age was positively correlated with stigma scores ($p=0.002$).

Discussion

Our analyses suggest that HIV-associated stigma is just as prevalent in rural Gujarat as in urban Gujarat. However, ward staff produced the least stigmatising score of all groups. In direct contrast to previous findings in other Indian regions (Horizons Final Report, 2006; UNAIDS, 2001), these findings suggest there is an inverse relationship between medical education and stigma scores in Gujarat. In support of this revelation, ward staff were more likely to defend the need for consent before testing for HIV than nurses, followed last by doctors. In addition, of all HCW participants, ward staff were least likely to agree that clothes and linen used by HIV-positive patients should be disposed of or burned. This reflects both the fear HCWs have regarding contracting HIV through occupational exposure, and the strength of stigma even within professional Indian communities. Similar results were found in a study conducted by Kermodé and colleagues in 2005, in which knowledge of HIV transmission and perception of risk were not associated with willingness to provide care.

Furthermore, routine HIV testing is not being employed. Instead, patients are tested based on lack of response to 'marker diseases' such as tuberculosis, diarrhoea, and persistently swollen lymph nodes (Zelaya *et al.*, 2007). Despite extraordinary past initiatives, outside of the antiretroviral therapy centres of both hospitals there is a great need for a review of HIV/AIDS treatment and care, specifically with emphasis on the need for consent and confidentiality; when it is appropriate to test for HIV; and protocol in relation to patient turnover (Solomon, Chakraborty & Yepthomi, 2004). Moreover, to advocate good medical practice yet lack supplies evidently forces doctors to push medical costs onto patients, thereby discouraging testing for HIV and treatment. Much of this cost is for fumigating operation theatres or labour rooms; double and triple-gloving for staff; and AIDS kits for all staff assisting in surgical procedures (Solomon *et al.*, 2004). Such procedures are not required and amount to discriminatory practice. Discontinuing such practices may be able to reduce hospital costs and lessen the burden on PLHA to pay for unnecessary tests, AIDS kits, infection control supplies, or new clothes and linen (Mignone, Washington, Ramesh, Blanchard & Moses, 2007).

Traditional sociocultural attributes of India in many ways define a woman's role as being dependent on having children. The pressure to bear children is so intense that a woman must choose between having children at the risk of infection by her husband or remain childless. She often chooses the former. As a result, three quarters of HIV-positive women in India were found to be infected within a few years of marriage (Pallikadavath *et al.*, 2005; Solomon *et al.*, 2004). Such attributes of traditional Gujarat are in many ways contributing to secrecy around HIV, where testing is either discouraged or unknown among many inhabitants (Zelaya *et al.*, 2007). This of course is carried over into the daily interactions among HCWs and PLHA to produce an environment where HIV stigma gains immense strength.

There are some inherent limitations to the present study. When responding to questions regarding patient care, many HCWs may have felt the need to give responses that were socially acceptable or within hospital guidelines (social desirability bias). Furthermore, despite the fact that there is no reason to expect that the attributes of the participants should differ from those of non-participants, the convenience sample was not representative of all HCWs in urban and rural Gujarat (selection bias), so the findings should only be generalised with caution. Finally, the low Cronbach's alpha value of the Stigma Index (0.396) emphasises the multidimensionality of the questionnaire and is a serious limitation in measuring stigma as a single construct. This is illustrated by the point that HCWs in Surat exhibited higher stigmatising attitudes against PLHA, while also endorsing lower stigmatising attitudes towards healthcare-related practices, than HCWs in Bardoli.

The effects of HIV-associated stigma continue to hinder progress made in prevention, and harm reduction interventions. Being one of the first to measure HIV-associated stigma among healthcare workers in Gujarat, this study has provided important information regarding how pervasive stigma is throughout all levels of the healthcare sector in both rural and urban areas. Nevertheless, further research is needed concerning the efficacy of awareness campaigns in rural communities and their impact on reducing familial and societal stigma. These findings, in addition to future research, will provide information on how better to tailor preventive and awareness interventions in urban and rural Gujarat.

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References

- Basic Health Statistics (2007). Basic Health Statistics 2005-2006. Health and Family Welfare Department of Gujarat.
- Fung, I., Guinness, L., Vickerman, P., Watts, C., Vannela, G., Vadhvana, J. *et al.*, (2007). Modelling the impact and cost-effectiveness of the HIV intervention programme amongst commercial sex workers in Ahmedabad, Gujarat, India. *BMC Public Health*, 7, 195.
- Horizons Final Report (2006). Reducing AIDS-related stigma and discrimination in Indian hospitals. Population Council. New Delhi, India.
- Kermodé, M., Holmes, W., Langkham, B., Thomas, M.S., & Gifford, S. (2005).

HIV-related knowledge, attitudes, & risk perception amongst nurses, doctors, & other healthcare workers in rural India. *Indian Journal of Medical Research*, 122, 258-264.

Madhivanan, P., Hernandez, A., Gogate, A., Stein, E., Gregorich, S., Setia, M. et al., (2005). Alcohol use by men is a risk factor for the acquisition of sexually transmitted infections and Human Immunodeficiency Virus from female sex workers in Mumbai, India. *Sexually Transmitted Diseases*, 32, 685-690.

Mignone, J., Washington, R.G., Ramesh, B.M., Blanchard, J.F., & Moses, S. (2007). Formal and informal sector health providers in southern India: Role in the prevention and care of sexually transmitted infections, including HIV/AIDS. *AIDS Care*, 19(2), 152-158.

National Health and Family Welfare (2009). Division of HIV/AIDS Prevention. Health and Family Welfare Department of Gujarat.

Pallikadavath, S., Garda, L., Apte, H., Freedman, J., & Stones, R.W. (2005). HIV/AIDS in rural India: Context and health care needs. *Journal of Biosocial Science*, 37(5), 641-655.

Rathod, U.L. (2004). The control of HIV/AIDS in a migrant dominant city: An experience of a western Indian city. Abstract presented at the 15th International AIDS Conference, July 11-16, Bangkok, Thailand.

Solomon, S., Chakraborty, A., & Yepthomi, R.D. (2004). A review of the HIV epidemic in India. *AIDS Education and Prevention*, 16(Supplement A), 155-169.

Steinbrook, R. (2007). HIV in India – A complex epidemic. *New England Journal of Medicine*, 356(11), 1089-1093.

UNAIDS (2001). India: HIV and AIDS-related discrimination, stigmatisation, and denial. Best Practice Collection. Geneva, Switzerland.

Zelaya, C.E., Sivaram, S., Johnson, S.C., Srikrishnan A.K., Solomon, S., & Celentano D.D. (2007). HIV/AIDS stigma: Reliability and validity of a new measurement instrument in Chennai, India. *AIDS Behavior*, 12(5), 781-788.

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