

# Stigmatization and Discrimination toward People Living with HIV/AIDS in a Coastal City of South India

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Nithin Kumar, MD<sup>1</sup>, Bhaskaran Unnikrishnan, MD<sup>1</sup>,  
Rekha Thapar, MD<sup>1</sup>, Prasanna Mithra, MD<sup>1</sup>, Vaman Kulkarni, MD<sup>1</sup>,  
Ramesh Holla, MD<sup>1</sup>, Darshan Bhagawan, MD<sup>1</sup>,  
and Avinash Kumar, MD<sup>1</sup>

## Abstract

**Background:** The HIV/AIDS scenario all over the world is complicated by the stigmatic and discriminative attitudes toward the HIV-infected individuals. **Methodology:** In this facility-based, cross-sectional study, 104 HIV-positive patients were assessed regarding their personal experience with HIV-related stigma and discrimination using a Revised HIV Stigma Scale. The association between stigma and factors such as socioeconomic status and gender was tested using chi-square test, and  $P < .05$  was considered statistically significant. **Results:** A large proportion (41.3%) of the participants were in the age-group of 26 to 35 years. Confidentiality of the HIV positivity status was maintained only in 14.4% of the participants. Compared to females (48.2%), more than half (51.5%) of the male participants had experienced HIV/AIDS-related personalized stigma ( $P > .05$ ). **Conclusion:** HIV-related stigma and discrimination are the major social determinants driving the epidemic, despite the advances in medical treatment and increases in the awareness about the disease.

## Keywords

HIV/AIDS, stigma, discrimination, health care, South India

## Introduction

HIV and its manifestation AIDS is one of the major global health issue, which has resulted in an epidemic of devastating proportions. The World Health Organization estimated that around 35.3 million people were living with HIV at the end of 2012.<sup>1</sup> In India, according to the National Aids Control Organization, the estimated burden of people living with HIV/AIDS (PLWHA) for the year 2012 to 2013 is around 2.1 million. In India, the HIV infection has been on a steady decline from a prevalence level of 0.41% in 2001 to 0.27% in 2011. However, India is still estimated to have the third highest number of PLWHA, after South Africa and Nigeria.<sup>2</sup>

All over the world, the problem of HIV/AIDS has been complicated not only by the alarming numbers but also due to the stigmatic and discriminative attitudes toward the HIV-infected individuals. HIV-related stigma and discrimination are described as the greatest barriers to the practice of safe and effective HIV prevention behaviors and facilitate the spread of HIV infections. It creates significant obstacles in the access of HIV care, treatment and support services and also in providing care and support to those living with HIV/AIDS.<sup>3</sup> The stigmatic attitude toward PLWHA is seen not only among general population but also among health care workers, coworkers at employment, and caregivers, thus directly affecting their treatment and care.<sup>4</sup>

HIV/AIDS-related stigma can be due to the fear of illness, fear of contagion, or fear of death and is characterized by rejection, denial, discrediting, disregarding, underrating, and social distance, which very often lead to discrimination and violation of human rights.<sup>5</sup> Stigma and discrimination, in addition to being a universal problem permeating boundaries, operate at multiple levels in our society, that is, within individuals, families, communities, institutions and media, and in government policies and practices.<sup>6</sup> Stigmatization associated with AIDS is underpinned by many factors, including lack of understanding of the illness, misconceptions about how HIV is transmitted, lack of access to treatment, irresponsible media reporting on the epidemic, the incurability of AIDS, and prejudice and the fears related to the number of socially sensitive issues including sexuality, disease and death, and drug use.<sup>7</sup> It can be expressed in a variety of ways ranging from rejection

<sup>1</sup> Department of Community Medicine, Kasturba Medical College (Manipal University), Mangalore, Karnataka, India

### Corresponding Author:

Nithin Kumar, Department of Community Medicine, Kasturba Medical College (Manipal University), Mangalore, Karnataka, India.

Emails: nithin.gatty@manipal.edu; drnithin\_kumar@yahoo.co.in

and ostracism of PLWHA, compulsory HIV testing without prior consent, or protection of confidentiality at one end of spectrum to unprovoked violence against persons who are perceived to have AIDS or to be infected with HIV and quarantine of persons with HIV at the other end. Stigmatization might be in any form; however, at the end, it inflicts suffering on PLWHA and interferes with attempts to fight the AIDS epidemic.<sup>4</sup>

Despite the rise in prevalence of stigma and discrimination toward PLWHA and its recognition as a significant problem in combating HIV/AIDS epidemic, very few countries have prioritized activities to reduce or eliminate stigma and discrimination in their national HIV/AIDS programs.<sup>6</sup> Individuals and organizations have been constantly working to reduce HIV-related stigma and discrimination without any significant help from the government, nor is the program scaled up at a level to have a significant impact on HIV outcomes.<sup>8</sup> Overcoming HIV stigma and more pertinently discrimination are fundamental to addressing the HIV epidemic. The existing program should have an analytical framework within which the effects of stigma and discrimination can be studied, and a policy and program should be drafted and implemented to combat and overcome this significant barrier in HIV/AIDS control.<sup>8</sup>

The present study was undertaken to assess the HIV/AIDS-related stigma and discrimination faced by PLWHA, in the coastal city of Mangalore in the southern part of India.

## Materials and Methods

The port city of Mangalore is the administrative headquarters of Dakshina Kannada District in the state of Karnataka in southern India, comprising a population of 4.9 lakhs and a literacy rate of 94.03%.<sup>9</sup> The state of Karnataka has a HIV prevalence rate of 0.52%, which is way beyond the national prevalence level.<sup>2</sup> However, the HIV prevalence rate is 0.22% among the low-risk general population in the district. The prevalence is moderate at 8.33% in the high-risk men and low at 3.74% among the high-risk females.<sup>10</sup>

This facility-based, cross-sectional study was carried out in the teaching hospitals associated with Kasturba Medical College, Mangalore (Manipal University). Ethics committee approval was obtained from the Institutional Ethics Committee of Kasturba Medical College, Mangalore (affiliated to Manipal University), India, prior to the commencement of the study. The sample size of 104 was calculated using the expected proportion of stigma among HIV-positive patients, which was 60%, based on a previous study,<sup>11</sup> taking 15% relative precision and 95% confidence interval and accounting for a nonresponse error rate of 15%.

A total of 104 HIV-positive patients in the age-group of 18 to 65 years, who visited the teaching hospitals, were included in the study. The participants were clearly explained about the objectives of the study in their own language and were assured anonymity. A written informed consent was obtained from those participants who were willing to take part in the study. The data were collected by face-to-face interview held in

separate consultation room and in a manner that would not affect their scheduled consultation. The average duration of interview was about an hour.

A pretested semistructured proforma was used to collect the information which consists of 3 sections, namely, section A—general participant information, section B—information regarding discrimination at health care system, employment, and breach in confidentiality, and section C—information regarding stigma faced by PLWHA. The socioeconomic status of the study participants was assessed using Modified Kuppuswamy Socioeconomic Status Scale.<sup>12</sup> HIV stigma among PLWHA was assessed using a 10-item HIV Revised Stigma Scale covering 4 domains, that is, 3 items on personalized stigma, 2 items on disclosure, 3 items on negative self-image, and 2 items on public attitudes.<sup>13</sup>

The data were entered in and analyzed using SPSS version 11.5. The Revised HIV Stigma Scale was analyzed using a 4-point Likert-type scale, that is, *strongly disagree* = 1, *disagree* = 2, *agree* = 3, and *strongly agree* = 4. For the purpose of analysis, PLWHA responding to the items as *strongly agree* or *agree* were classified as those who had faced stigma and PLWHA responding to the items as *strongly disagree* or *disagree* were classified as those who had not faced any stigma. The results were expressed in proportions. The association between stigma and factors such as socioeconomic status and gender was tested using chi-square test, and  $P < .05$  was considered as a statistically significant association.

## Results

A total of 104 PLWHA were interviewed to assess their personal experience with regard to HIV/AIDS-related stigma and discrimination. A large proportion (41.3%,  $n = 43$ ) of the study participants were in the age-group of 26 to 35 years, were males (53.8%,  $n = 56$ ), and married (63.5%,  $n = 66$ ). The sociodemographic characteristics of the study participants are shown in Table 1.

Table 2 depicts the HIV/AIDS-related discrimination faced by the study participants with respect to breach of confidentiality. The mandatory written informed consent was not obtained from 5.8% ( $n = 6$ ) of the study participants, and 29.8% ( $n = 31$ ) of the participants were not given any pretest and posttest counseling. HIV-positive status was revealed by health worker/doctor in 63.5% ( $n = 66$ ) of the study participants. Confidentiality of the HIV positivity status was maintained only in 14.4% ( $n = 15$ ) of the participants.

Refusal of treatment due to HIV-positive status was faced by only 1.9% ( $n = 2$ ) of the study participants, and 3.8% ( $n = 4$ ) experienced delays in the provision of the treatment. Table 3 shows the HIV/AIDS-related discrimination experienced by the study participants in the health care system.

Only 3.8% ( $n = 4$ ) of the study participants had faced any kind of discrimination at their workplace due to their HIV status. Of the 15 participants whose HIV status was known at their workplace, 7 (46.6%) participants themselves revealed their HIV status. Around 40% ( $n = 6$ ) of the study participants

**Table 1.** Sociodemographic Characteristics of the Study Participants.<sup>a</sup>

Characteristics	n (%)
Age group, years	
18-25	03 (02.9)
26-35	43 (41.3)
36-45	39 (37.5)
46-55	13 (12.5)
56-65	06 (05.8)
Gender	
Male	56 (53.8)
Female	48 (46.2)
Religion	
Hindu	82 (78.8)
Muslim	07 (06.7)
Christian	15 (14.5)
Socioeconomic status	
Upper middle	04 (03.8)
Lower middle	13 (12.5)
Upper lower	73 (70.2)
Lower	14 (13.5)
Marital status	
Single	21 (20.2)
Married	66 (63.5)
Divorced	01 (0.9)
Widowed	16 (15.4)

<sup>a</sup> N = 104.**Table 2.** HIV/AIDS-Related Discrimination Faced by the Study Participants with Respect to Confidentiality.<sup>a</sup>

Variables	N (%)
Consent obtained for the test	
Yes	98 (94.2)
No	06 (05.8)
Pretest and posttest counseling done	
Yes	73 (70.2)
No	31 (29.8)
Reaction after finding out the status	
Sad	78 (75.0)
Guilt	01 (01.0)
Angry	05 (04.8)
No reaction	14 (13.5)
Other	06 (05.8)
Status revealed by	
Counselor	29 (27.9)
Doctor/health care worker	66 (63.5)
Relatives	08 (07.7)
Others	01 (00.9)
Privacy maintained when the status was revealed	
Yes	97 (93.3)
No	07 (06.7)
Confidentiality maintained when the status was revealed	
Yes	15 (14.4)
No	89 (85.6)

<sup>a</sup> N = 104.

reported a change in the behavior of their coworkers after learning about their HIV status Table 4 summarizes the HIV/AIDS-related discrimination faced by the study participants.

**Table 3.** HIV/AIDS-Related Discrimination Faced by the Study Participants with Regard to Treatment.<sup>a</sup>

Variables	n (%)
Refusal of treatment as a result of HIV status	
Yes	002 (01.9)
No	102 (98.1)
Delay in treatment as a result of HIV status	
Yes	004 (03.8)
No	100 (96.2)
Pay extra for health care services as a result of HIV status	
Yes	004 (03.8)
No	100 (96.2)

<sup>a</sup> N = 104.**Table 4.** HIV/AIDS-Related Discrimination Faced by the Study Participants in Employment.<sup>a</sup>

Variables	n (%)
Anyone at workplace know your HIV status (n = 53)	Yes 15 (28.3) No 38 (71.7)
Who at workplace know your HIV status (n = 15)	Friend 02 (13.3) Everyone 04 (26.6) Employer 06 (40.0) Manager 03 (20.0)
How people at workplace got to know your HIV status (n = 15)	People, friends, neighbors, family members told 06 (40.0) Revealed by myself 07 (46.6) Blood test for job eligibility 02 (13.3)
Any change in their behavior after finding out your HIV status (n = 15)	Yes 06 (40.0) No 09 (60.0)
Discrimination faced at workplace as a result of your/your family member's HIV status (n = 104)	Yes 04 (03.8) No 100 (96.2)

<sup>a</sup> N = 104.

More than one-third (35.9%, n = 37) of the study participants were a member of the HIV-positive network. Almost all the participants (n = 100, 96.2%) were of the opinion that the existing programs on HIV/AIDS control was effective in combating HIV-related stigma and discrimination.

On analyzing the modified 10-point HIV stigma scale, 53.8% (n = 56) of the study participants had experienced personalized stigma. Table 5 shows the association of stigma among the study participants with gender and socioeconomic status. Compared to females (48.2%, n = 27), more than half (51.5%, n = 29) of the male participants had experienced HIV/AIDS-related personalized stigma ( $P > .05$ ). No significant association was found between socioeconomic status and experiencing stigma.

Table 5 shows the association of presence of stigma among study participants with gender and socioeconomic status. Majority (83.1%, n = 45) of the study participants who

**Table 5.** Personalized Stigma with Respect to Gender and Socioeconomic Status.<sup>a</sup>

Characteristics		Stigma (n = 56), n (%)	No Stigma (n = 48), n (%)	Chi-Square	P Value
Gender	Male	29 (51.8)	27 (56.3)	0.207	.649
	Female	27 (48.2)	21 (43.7)		
Socioeconomic status	Upper middle	02 (03.6)	02 (04.2)	0.9	.8
	Lower middle	06 (10.7)	07 (14.6)		
	Upper lower	39 (69.6)	34 (70.8)		
	Lower	09 (16.1)	05 (10.4)		

<sup>a</sup> N = 104.**Table 6.** Disclosure Stigma with Respect to Gender and Socioeconomic Status.<sup>a</sup>

Characteristics		Stigma (n = 54)	No Stigma (n = 50)	Chi-Square	P Value
Gender	Male	33 (61.1)	23 (46.0)	2.38	.122
	Female	21 (38.9)	27 (54.0)		
Socioeconomic status	Upper middle	02 (03.7)	020 (4.0)	0.046	.9
	Lower middle	07 (13.0)	06 (12.0)		
	Upper lower	38 (70.4)	35 (70.0)		
	Lower	07 (12.9)	07 (14.0)		

<sup>a</sup> N = 104.

experienced stigma due to disclosure status belonged to a lower socioeconomic status. No significant association was found between experiencing stigma due to disclosure and gender and socioeconomic status ( $P > .05$ ) (Table 6).

## Discussion

Stigma and discrimination is the oldest and the most negative and harmful social responses commonly seen among those infected with tuberculosis or leprosy. AIDS-related stigma and discrimination have been associated with the disease since the outbreak of the pandemic. Rapid advancement in HIV treatment and testing has resulted in the transformation of the HIV/AIDS from an acute debilitating infection to a chronic disease and by virtue of early diagnosis and initiation of antiretroviral therapy (ART) has resulted in the increase in life span of the HIV-infected individual. However, this prolonged life span of individuals with HIV/AIDS is riddled with discrimination and burdened by the unique effects of stigma, especially among the high-risk groups.<sup>14</sup> It creates a significant barrier toward the uptake of HIV/AIDS-related services including HIV Test and Counseling and ART. AIDS-related stigma is a common phenomenon in any part of the world and can occur in any setting and context including the family, community, workplace, and health care settings.<sup>15,16</sup>

The Global Network of People Living with HIV/AIDS, International Community of Women Living with HIV/AIDS, International Planned Parenthood Federation, and the Joint United Nations Program on HIV/AIDS conceived the People Living with HIV Stigma Index with an aim to collect information from different countries about the experiences of stigma and discrimination faced by PLWHA. In India, the study was conducted in the state of Tamil Nadu in 2010 to 2011,

involving 1594 PLWHA and was the first of its kind to quantify the stigma and discrimination experienced by PLWH in the state. The People Living with HIV Stigma Index study in countries like Estonia, Poland, Moldova, Ukraine, and Turkey have reported that a significant number of PLWHA seek testing and access care late because of their fear of discrimination.<sup>17</sup>

The present study tried to assess the HIV/AIDS-related stigma and discrimination faced by the PLWHA in the coastal city of Mangalore in Karnataka, which is one among the South Indian states with a very high prevalence of AIDS.

Stigma and discrimination in hospitals can range from condescending attitudes toward PLWHA by the health provider to delay or refusal of treatment. The health care provider's belief as an individual with HIV, as well as the institutional factors, contributes to AIDS-related stigma and discrimination in health care settings.<sup>18</sup> With respect to discrimination faced by PLWHA in health care system, our study findings were encouraging. Written informed consent was obtained from 94.2% of the participants prior to HIV testing. The first regional documentation of AIDS-related discrimination in Asia carried out by the Asia Pacific Network of People Living with HIV/AIDS in India, Thailand, Indonesia, and Philippines reported that the major area of discrimination was in the health care sector, with majority of the people not having received any pretest counseling.<sup>19</sup> This reflects upon the training provided to the HIV counselors prior to being employed in the Integrated Counseling and Testing Centre. In our study, 70.2% of the participants were given pretest and posttest counseling. HIV counseling and testing services play an important role in prevention of HIV infection among people, since they gain access to accurate information about HIV, along with undergoing an HIV test in a confidential environment.<sup>20</sup>

People who are found to be HIV positive are also provided with psychosocial support by the trained HIV counselors.<sup>20</sup> In our study, 75% of the participants felt sad when they came to know about their HIV status because of the fear of stigma associated with HIV. In a study in Zimbabwe, 41% of the participants were depressed when they discovered their HIV status.<sup>21</sup> Similar observations were made in a study from South Africa where 49.2% of the participants blamed self for their condition, 47.5% felt ashamed of their HIV-positive status, and 14.8% had suicidal ideations.<sup>22</sup> Thus, the role of counselors become very important and not providing pretest or posttest counseling will facilitate the spread of infection and inhibit the development of coping behavior and thereby decreasing the quality of life among those whose results are positive.

In our study, 1.9% of the participants were refused treatment, whereas 3.8% of them had delay in receiving treatment because of discriminative attitude toward them at the health center. In a study conducted in Bangalore, India, of the 13 clinics visited by the investigators, 9 refused to admit dummy HIV-positive patients, while 4 accepted on certain conditions. In Mumbai, of the 24 clinics, 15 refused, 8 accepted with conditions, and only 1 accepted unconditionally.<sup>23</sup> In the HIV Stigma Index study conducted in Tamil Nadu, India, 6% of the PLWHA irrespective of their risk category were denied health care services at least once.<sup>17</sup> A study conducted in Vietnam also found that stigma and discrimination were commonly encountered in public health care facilities.<sup>24</sup> In the study in Mumbai and Bengaluru, 89% of doctors, 88% of nurses, and 73% of ward staff reported that they would discriminate against PLWH in professional situations that involve likelihood of fluid exposure; and 57% of doctors, 40% of nurses, and 71% of ward staff stated that they would do so in low-risk situations as well.<sup>23,25</sup> A study conducted in New Delhi, India, revealed 4 types of discriminatory practices carried out by health care workers in the hospital setting which included testing patients for HIV without their consent, disclosing test results to relatives and other health care workers without the consent of patients, labeling of HIV-infected patients' belongings or files, and unwarranted use of precautions to prevent transmission.<sup>18</sup> Similar observations were reported from studies outside India. In studies from Swaziland among Men who have Sex with Me (MSM), participants reported being fearful in seeking health care because of stigma and discriminative attitudes shown toward them by the health workers.<sup>26,27</sup> In a study in South Africa, 6.6% of the participants were forced to submit to a medical or health care procedure, and 5.3% of the participants were denied health insurance. Health care services, family planning services, and sexual and reproductive health services were denied for 5.5%, 6.4%, and 10.5%, PLWHA, respectively.<sup>22</sup> Similar observations were made in another study from South Africa, Nigeria, and Bangladesh.<sup>28-30</sup>

In our study, 71.7% of the participants had not revealed their HIV-positive status at their workplace probably because of the fear of discrimination and losing their job. Among those whose status was known to their employers and coworkers,

46.7% had self-disclosed, probably because of their self-esteem and urge to live freely without any guilt, whereas 13.3% participants had to disclose because of a blood test for job eligibility. HIV status of the remaining 40% of the participants was disclosed by friends/relatives who might have leaked the information so as to humiliate them or sensitize them. According to 2006 United Nations Development Programme study in Asia, evidence of stigma was rampant in the workplace, with 74% of employees not disclosing their status to their employers for fear of being discriminated and 26% disclosed their HIV status, of which 10% of them were prejudiced.<sup>31</sup>

In our study, 35.9% of the participants were members of positive network group and rehabilitative centers in Mangalore. It has been observed that most of the study participants who were members of some positive network were much more discriminated in many spheres of life before joining the network. In a study in Tamil Nadu, India, it was reported that being a member of HIV networks offered positive benefits to general men, women, and commercial sex workers.<sup>18</sup>

In contrast to other studies, males were slightly more stigmatized than females in our study. The reason for this might be that in our study area, males are usually the breadwinners of the family. Hence, they are more likely to encounter stigma when compared to females who are mostly confined to their houses. According to the study in Mumbai, India, HIV-positive women were common witnesses of maximum negative responses.<sup>32</sup> Among those who disclosed their HIV status, 61.1% were males and 38.9% females. According to a study done in Chennai, 85% of women faced disclosure stigma when compared to 86% of men.<sup>33</sup> Lower socioeconomic class participants were stigmatized when compared to others. A study conducted in Tanzania also showed that HIV-positive individuals of lower socioeconomic status were more stigmatized than others.<sup>34</sup>

HIV-related stigma and discrimination are thought to be the major sociostructural determinants of the epidemic, and it can have extremely negative impact on the lives of PLWHA. Stigma, discrimination, and human rights violations are intimately linked, reinforcing and legitimizing each other. Preexisting stigma not only predisposes these vulnerable individuals to greater HIV/AIDS-related stigma and discrimination but also critically reinforces stereotyping and status loss of all with HIV/AIDS, regardless of how they may have acquired the infection.

Based on the study findings, we can conclude that the tackling of stigma and discrimination should play an equally important role for combating the HIV epidemic along with its treatment. It acts as a barrier for seeking health care among PLWH, both preventive and curative, and thus fuels the already growing problem into public health crisis. Elimination of stigma and discrimination in the day-to-day activities of PLWHA will encourage them to come forward seeking counseling and treatment, thereby improving the quality of life, since in the era of highly active anti retroviral therapy, HIV has become a chronic disease and ART has increased the life expectancy of HIV-positive patients.

As the study was conducted among a select group of HIV-positive patients attending hospitals, whose experiences with regard to the stigma and discrimination were captured, we may not be able to generalize the findings to other groups of HIV-positive patients.

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### Authors' Note

Ethics committee approval was obtained from the Institutional Ethics Committee of Kasturba Medical College, Mangalore (affiliated to Manipal University), India, prior to the commencement of the study. NK and BU conceived the study. DB, AK, and NK was involved in data collection and helped in review of literature. RT, NK, and PM analyzed the data statistically, made the tables, wrote the results, and contributed to the review of literature. RT, BUK, VK, and RH contributed to the introduction, materials and methods, and discussion of the article. NK and BU reviewed and edited the article. All the authors reviewed and edited the manuscript for intellectual content and approved the final version of the manuscript.

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