

Stigma and Discrimination faced by HIV-infected Adults on Antiretroviral Therapy for more than 1 Year in Raichur Taluk, Karnataka, India

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ABSTRACT

Aim: The aim of this study was to evaluate the stress and discrimination faced by human immunodeficiency virus (HIV)-affected adult patients on antiretroviral therapy (ART) for more than 1 year.

Materials and methods: A cross-sectional study was carried out among 170 adults on ART, reporting to the ART center of the District Civil Hospital, for more than 1 year in Raichur Taluk, Karnataka, India. Convenience sampling technique was followed. Descriptive statistics was performed (Chi-square test) using Statistical Package for the Social Sciences version 16.0.

Results: A total of 156 (91.8%) patients' families had knowledge about their seropositive status. Seventeen (10.9%) HIV-positive patients reported of change in the attitude of their family members. The main reasons for not revealing the HIV status were the internalized stigma and fear of rejection. Women faced greater discrimination from family, friends, and neighbors than men.

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Conclusion: It is necessary to not undermine the effect of rejection due to HIV. It is the only infection that has so many associated social and psychological norms which we need to tend at the earnest. Till date, there is an existence of condescendence toward treatment approach.

Clinical significance: The presence of stigma and the fear of being discriminated could be a major hurdle in the rehabilitation of these patients into the mainstream society. Furthermore, it serves as an existing challenge to ascertain these individuals to achieve overall health.

Keywords: Discrimination, Family, Friends, Human immunodeficiency virus, Stigma, Workplace.

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INTRODUCTION

Stigma is an essential aspect of the lives of people living with HIV/acquired immune deficiency syndrome (AIDS) (PLWHA). Although ART is available, there are no magic bullets against discrimination arising out of stigma that exists in both the urban as well as the rural setup across the world. It is a persistent and a pernicious problem, i.e., a hurdle to any steps taken for the betterment of the affected population. Logie et al² have enumerated different types of stigmas that contribute to discrimination against HIV and further contribute to the spread of the infection.

- Symbolic
- Felt/normative stigma

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- Enacted stigma
- Internalized stigma.

According to Florom-Smith and De Santis,3 HIVassociated stigma results in a number of problems. Most of the studies related to stigma have concentrated on the African nations. Abrahams and Jewkes⁴ stated that there was perceived stigma among African women who faced gossips and insults. A meta-analyzed article by Katz et al⁵ highlights that HIV-associated stigma underlines the social relationships and its exacerbation on the economic impacts of HIV. Rahangdale et al⁶ reported about discrimination against women in rural areas of India due to their seropositive status from society, neighborhood, family, and by health-care professionals. Nambiar has stated in her article that the nongovernmental organizations were not willing to take up targeted interventions related to HIV and other special groups due to the fear of stigma associated with working for such a population. In India, stigma in such cases is fanned further due to lack of awareness, traditional beliefs, and a moralistic sexual tag. 8 Stigma is a major barrier for the successful treatment of the PLWHA worldwide as highlighted by a number of studies. 9-18 We report the first study related to stigma in the North Karnataka Region of India, which is one of the most underdeveloped areas of the state and has a high prevalence of HIV/AIDS.

MATERIALS AND METHODS

Ethical clearance was obtained from the Institutional Review Board of Navodaya Dental College, Raichur, India, before the start of the study. Permission was also obtained from the head of the ART center, Raichur. One hundred seventy individuals above 18 years of age on ART for more than 1 year and who gave a voluntary informed consent were included in the study.

Convenience sampling was followed since it was difficult to obtain a sampling frame and go for a probability sampling technique due to confidentiality issues. The questions were pretested with a pilot study on 30 seropositive individuals. The time period of the study was 5 months (from December 2013 to April 2014). The participants were assured that their answers would not hinder their treatment at the center. No incentives in any form were provided to the people.

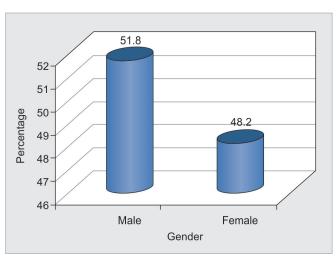
RESULTS

The study included 170 HIV-positive people from 19 to 60 years of age, average age of 37.17 ± 8.21 years, of which 88 (51.8%) were males and 82 (48.2%) were females (Graph 1). They came from the rural part of Raichur, and 95.3% of the participants belonged to the lower class. Only 3.05% were unmarried. Thirty-nine patients had visited the dentist before, of which 17 (43.6%) were males and 22 (56.4%) were females.

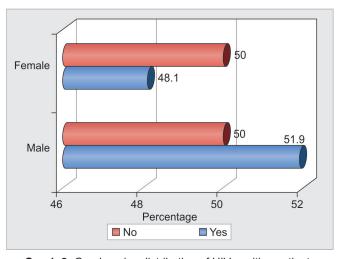
Forty-three (25.3%) of the 170 participants isolated themselves to avoid any form of uncomfortable questions or comments by relocating to a distant village. Fifty-one (30.0%) of the 170 participants reported of voluntarily avoiding functions and get-togethers, while older men reported staying indoors and not going to meet friends and relatives since long.

Change in Attitude of Family Members against the HIV-positive Patients

Among the 170 HIV-positive patients, 156 (91.8%) patients' families had knowledge about their seropositive status and 14 (8.2%) had yet not revealed their status to their family (Graph 2). One man (1.1%) of the 88, who was a physician, had not revealed his status to his wife before marriage, leading to his wife and two children becoming

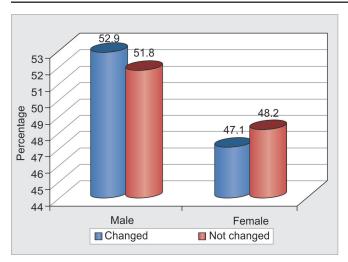


Graph 1: Distribution of the HIV-positive patients based on their gender



Graph 2: Gender-wise distribution of HIV-positive patients based on their family awareness about their HIV status





Graph 3: Gender-wise distribution of HIV-positive patients based on the change in the attitude of family members toward their status

HIV positive. One woman (1.2%) out of the 82 reported suicidal attempts due to depression.

The attitude of 17 (10.9%) of the 156 HIV-positive patients' family members had changed [8 (47.1%) females and 9 (52.9%) males] (Graph 3). There was no significant difference in the attitude of family members with respect to the gender of the participants ($\chi^2 = 0.019$, df = 1, p = 0.89).

Out of these 17, 2 (11.7%) were not permitted to mingle with them as before, one each (5.9%) was given separate isolated rooms and faced indifferent attitude, and 13 participants (76.5%) faced discrimination in more than one form. There was no statistically significant difference between the male and female participants with respect to discrimination by their respective family members ($\chi^2 = 0.008$, df = 1, p = 0.93).

Among the 8 women of the 17 whose family had knowledge about their seropositive status, 4 (50.0%) reported that they were held responsible for the HIV-positive status of their spouses and 2 (25.0%) of them were thrown out of the house, and their husbands had got married again. One woman reported being thrown out of the house with her children after the death of the spouse even though the family was highly educated and knew that she was not to be blamed and economically quite strong to support her. Although the married couples were happier and open about their status, those who were single faced the worst situation. A young unmarried participant had not revealed his status to any one as he was afraid of problems related to marriage and community neglect.

One woman (7.1%) of the remaining 14, who had not revealed her status, was associated with the education department. Although she was educated, she had a fear of mockery and losing her job. All the women

covered their faces while traveling to the center to avoid recognition.

Change in Attitude of Friends against the HIV-positive Patients

Table 1 shows the gender-wise distribution of HIV-positive patients based on the knowledge of their friends about their HIV-positive status.

The main reasons for not revealing the HIV status were the internalized stigma and fear of rejection. Thirtyone (18.2%) of the 170 had revealed their status to their friends. Four (12.9%) out of these 31, faced discrimination. One (25.0%) participant said that it was no longer possible to mingle with friends as before. One (25.0%) participant could neither mingle nor share food with friends as before, while two (50.0%) faced all these along with a problem of refusal to stay in the same room (Graph 4).

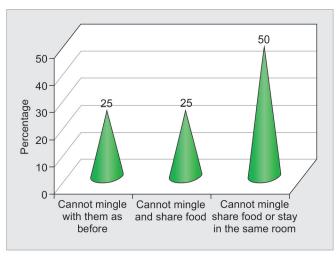
Change in Attitude of People at Workplace against the HIV-positive Patients

Out of the 82 women involved in the study, 9 women (11.0%) had revealed their HIV status at their workplace. One woman of the nine (11.11%) reported of not being provided with water to drink at the workplace, four women (44.4%) had lost work, and they were subjected to verbal abuse. Sixteen men (18.2%) out of 88 had revealed their status at their workplace, but none reported of any

Table 1: Gender-wise distribution of HIV-positive patients based on the knowledge of their friends about their HIV-positive status

Friends knowledge			
about the HIV status	Male n (%)	Female n (%)	Total n (%)
Yes	17 (54.8)	14 (45.2)	31 (100)
No	71 (51.1)	68 (48.9)	139 (100)
Total	88 (51.8)	82 (48.2)	170 (100)

 $\chi^2 = 0.032$, df = 1, p = 0.86



Graph 4: Distribution of HIV-positive patients based on the type of change in the attitude of their friends

Table 2: Gender-wise distribution of HIV-positive patients depending on the change in the attitude of their workplace colleagues after revealing their HIV-positive status

Workplace colleague			
awareness	Male n (%)	Female n (%)	Total n (%)
Changed	00 (0.0)	4 (100)	4 (100)
Not changed	16 (76.2)	5 (23.8)	21 (100)
Total	16 (64.0)	9 (36.0)	25 (100)

 $\chi^2 = 5.48$, df = 1, p = 0.01

change in the attitude of their colleagues. No statistically significant difference was found between the males and the females with respect to the change in the attitude at their place of work ($\chi^2=1.23$, df = 1, p = 0.20). Table 2 shows the gender-wise distribution of HIV-positive patients depending on the change in the attitude of their workplace colleagues after revealing their HIV-positive status, which was statistically significant.

Discrimination from dentists was reported by 3.52% (6 out of 170) of participants.

DISCUSSION

Infection with HIV/AIDS is considered as a devastating global health problem posing severe challenges in low-and middle-income countries. There are a lot of challenges that the people suffering from HIV face (Fig. 1). It is easy to enumerate them but difficult to actually be in their shoes. These individuals irrespective of their background or the people among whom they stay are subjected to a number of psychological stresses. Human immunodeficiency virus is not only just a disease affecting the body but also the mind of the patients leading to depression, suicidal tendencies, and loss of interest to

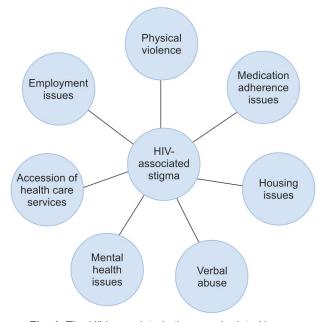


Fig. 1: The HIV associated stigma and related issues

live a life that takes away the interest of the patients from self-care resulting in neglect and further complications. The present study participants reported of discrimination by family, friends, and at workplace in different forms. A few even reported of such behavior by dental practitioners. Our findings are consistent with that of the study in rural Bagalkot, India, 14 though the participants faced less discrimination in this study due to the lack of disclosure. We found social discrimination as prevalent in our study similar to the study among the rural and tribal people of Maharashtra. 19 There was no association of age with discrimination unlike the findings of a study among older US adults above 50 years who faced depression due to stigma.²⁰ Less social support for people on ART was suggested by Pearson et al.²¹ Furthermore, the past studies have associated stigma with delay in seeking treatment.²² The people of Raichur faced lesser discrimination compared with the study population in Africa,²³ where 23.8% faced discrimination form family/spouse, 18.8% were excluded from social gatherings, and 15.5% faced family activity exclusion. There was a great amount of internalized stigma in this study, which could be a prime reason for the nondisclosure of the participants, as suggested by Tsai et al.²⁴ Since most of the individuals used avoidance as a coping mechanism, it could lead to a greater negative psychological impact. 11,12 The social rejection faced by the participants in this study was in the form of not sharing food, water, or room. Such mentality existing in the HIV-free population was highlighted by others as well. 9,16,19,25-28 A few participants reported of depression and one had a suicidal tendency, so HIV-associated discrimination could be a serious cause of depression. A study in Thailand showed that emotional and social support was inversely related to depression and directly related to stigma.²⁹ Such an association was also suggested in different studies across the world. 15,17,21,22,30 The fear of losing jobs, verbal abuse, and family and social rejection was main reasons for nondisclosure in the study population, same as other studies. 8,31 According to Mbonu et al,²⁸ stigma and resultant depression could be a major cause for more risky behavior among the people. It is essential to deal with the internal stigma since it affects the individual's adherence to ART, quality of life, and their social experiences directly. 13,17,18,32

Steward et al³³ found that HIV-infected people on treatment who experience discrimination and who believe stigma against them are more likely to report symptoms of depression. In addition, experiences of discrimination and hearing stories about others being mistreated because of HIV correlate with the perception that stigma is more prevalent in the local community. These perceptions are in turn associated with efforts to avoid disclosure of one's HIV status and with reports



of depressive symptoms. It is not necessary for stigma among local community members to change before a patient on treatment can experience improvements in mental health. By challenging HIV-positive individuals' own hostile attitudes toward the disease, it may be possible to improve their overall psychological health.

Patients try their best to conceal their infection status from their near and dear ones because of the fear of stigma. People fear that they might be ostracized from the society if their infection status is revealed.³⁴ This adds to the existing debilitating state of these patients and pushes them to substance abuse. 15 The stigma associated with this was large even in the educational faculty. The assistant intern accompanying the research worker was discouraged by his colleagues stating that he may catch HIV. A few patients who were a part of this study had walked out before seeking treatment from the dental college to which they were referred due to the indifferent attitude of the postgraduate students assigned to these patients. The past Indian studies in the metropolitan cities of Mumbai and Bengaluru have reported the prevalence of such tendency among the health-care professionals.¹⁰ Tzemis et al¹⁸ suggest education as a means to remove this stigma. They found that higher education was associated with low stigma among Canadian population. As Azodo et al³⁵ put it correctly, public perception of the HIV epidemic has culminated in heightened and persistent public anxiety. This anxiety is attributed to the high mortality rate of AIDS, and it is a fact that there is, to date, no proven vaccine or cure for this mentality.

Limitations

- We used a convenience sampling, and hence the data cannot be extrapolated to all the population
- Since India, especially rural India, is still lacking in many fronts, the same mentality cannot be held true for urban population of another place
- There is always a chance of responders bias in this study as we relied wholly on the answers of the participants, some may have overrated or underrated the experiences, and also due to the fact that there were no closed-door counseling rooms for the people
- Discrimination by the health-care professionals could be also underreported by the participants.

CONCLUSION

This study highlights the presence of HIV-associated stigma in Raichur. It is essential to understand that, since this place is one of the most backward regions, there is a scope for a lot of health promotion to be carried out. Health-care professionals have been also neglecting these patients for long, and hence their adherence and faith

on the faculty have been on a slow but definite decline. Priority has always been treating the infections and a CD4 count of HIV patients, but the psychological impact has never been an area of concern in the Indian setup. It is necessary to not undermine the effect of rejection due to HIV. It is the only infection that has so many associated social and psychological norms which we need to tend at the earnest. Till date, there is an existence of condescendence toward treatment approach. Counseling at any center in India hardly is of a quality type, and main focus is on achieving numbers on paper. Some self-reflection on the part of the National AIDS Control Organization, National AIDS Research Institute, and the Health Ministry of India is essential. As health-care professionals, we too are failing the patients in the forefront. No special training or lectures are given to students related to the psychological aspects of handling a special group of patients. A lot needs to be done.

Public Health Significance

The comprehensive treatment plan for any HIV-associated group should also involve community participation as highlighted in this study. There is a need for a more humanitarian approach rather than a business approach toward these people. Words can do wonders that should always be remembered. Furthermore, the role of the future health professionals needs to be tailor made for an upliftment of the dwindling stature of the profession.

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