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Original Article

A questionnaire survey of stigma related to human immunodeficiency virus infection/acquired immunodeficiency syndrome among healthy population

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ABSTRACT

Background and Objectives: Human immunodeficiency virus (HIV)-related stigma is present at all levels which act as critical barriers for effectively addressing it. This also influences the treatment uptake and under or nonparticipation in treatment available. In view of this, the present study was aimed to assess the stigma of otherwise healthy individuals of the community toward HIV infection/acquired immunodeficiency syndrome (AIDS). **Methods:** The study was conducted on 100 healthy individuals. Their responses were taken on a self-designed semi-structured questionnaire. **Results:** The results showed that there is more perceived stigma as compared to enacted stigma. Nearly 46% of the individuals feel that HIV-infected persons should be blamed for their illness and 41% individuals feel that they will feel ashamed if they have HIV. It was also seen that older adults (between 46 and 55 years) had more stigma as compared to the younger adults (between 16 and 25 years). The educated individuals still have stigma to a certain extent. Most of the individuals would like to tell their partner if they were diagnosed with HIV. Participants were divided into two groups on the basis of their level of education (<12 years of formal education and >12 years of formal education). Stigma related to HIV/AIDS was compared among these two groups, and there was no significant difference in the level of stigma in these distinctly different educational groups. **Conclusion:** There is still stigma present to a certain extent in the society in the educated and urban individuals. Level of stigma may not be significantly different in people with educational difference. Stigma needs to be addressed for prevention and better management of HIV/AIDS.

Key words: Education, human immunodeficiency virus infection;acquired immunodeficiency syndrome, stigma

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INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) caused by human immunodeficiency virus (HIV) is a major public health concern globally. As per the data of the United Nations, about 36.7 million people are living with HIV by the year 2015, globally.[1] Of this large population, more than half are living in eastern and southern African countries. In the year 2015, there are 1.1 million AIDS-related deaths across all ages.[1] However, in the recent years, there is scaling up of antiretroviral drug provision globally, resulting in 46% global coverage.[1]

India, being a heavily populated country, is having a great portion of population with HIV/AIDS. The annual report 2015–2016 of the National AIDS Control Organization (NACO) reveals the prevalence of HIV in adult population of India to be 0.26%.[2] Uttar Pradesh along with Andhra Pradesh and Telangana, Gujarat, and Bihar shares 47% of the total new infections in the country as found in the report.[2]

People living with HIV/AIDS (PLWHA) encounter enormous stigma and discrimination in the society. Prevalence of negative attitude of people toward PLWHA is very high.[3] Poor education and awareness play a major role with regard to the existence of stigma and discrimination associated with AIDS.[4,5] Faulty sociocultural beliefs and moralistic view toward sex may also influence stigma.[5]

Stigma stands as a major barrier between the patients and the health-care providers. Stigma results in underreporting or delayed reporting about the status of HIV/AIDS at health-care setups. PLWHA encounter stigma and discrimination at the family, community, work place as well as health-care settings.[3,6-9] Stigma and negative attitude toward HIV/AIDS result in the violation of fundamental rights of the PLWHA to lead a dignified life in the society and avail health-care facilities.[3] Providing factual information and addressing the myths among public in relation to HIV/AIDS help in reducing stigma and discrimination.[4]

PLWHA often have the fear of discrimination at work place and dying from the disease as seen in a study.[7] Considering the significant impact of stigma in the life of PLWHA, we had planned to conduct a study in a sample of healthy adults accompanying patients seeking health from a tertiary care center. It was assumed that the healthy adults, who approach health-care systems for various health issues, were more aware on the various aspects of health and illness than the healthy adults living in community.

SUBJECTS AND METHODS

The aim of the study was to assess stigma toward HIV/AIDS among healthy individuals. A questionnaire survey was done among the healthy individuals (caregivers of patients) attending the psychiatric outpatient clinic of a tertiary care hospital of North India, after obtaining informed consent. Participation in the survey was voluntary, and no incentives were given to the participants. Participants were briefed about the questionnaire before administration. A total of 100 healthy individuals (adults), 16 year old or above, were included in the study by convenient sampling. The relevant information (sociodemographic details and information about stigma related to HIV/AIDS) was collected in a predesigned and pretested pro forma. The collected data were subjected to appropriate statistical analysis.

RESULTS

A total of 100 healthy adults had participated in the survey. The mean age of the participants was 36.99 ± 12.38 years. Approximately, half of the participants were below the age of 35 years. Majority (77%) of the participants were males and 70% of the total participants were educated above the intermediate level (12th standard). The mean years of education of the participant group with education above 12th standard (n = 70) was 15.99 (standard deviation [SD] = 1.21). Participants with education ≤12th standard (n = 30) had 10.33 (SD = 1.18) mean years of education. The difference in the years of education between these two groups was statistically significant ($P < 0.0001$). Participants were divided into two groups on the basis of their level of education (<12 years of formal education and >12 years of formal education). Stigma related to HIV/AIDS was compared among these two groups, and there was no significant difference in the level of stigma in these distinctly different educational groups [Table 1].

More than two-third of the participants were married and belonged to urban population. Most (90%) of them were Hindus and 60% belonged to joint family type.

Among the participants, 22% feel that persons infected with HIV should feel ashamed of themselves. Seven percent of the participants feel that HIV-infected people deserve it. Only 1% of the participants thought about socially outcasting HIV-infected individuals, whereas 95% disagree to it. One-fifth of the participants say that HIV-infected persons are not a part of the community. Thirteen percent of the participants question the moral values of HIV-infected persons. A large mass of participants (45%) blame HIV-infected persons for their illness. Only 5% of the participants believed that uneducated people exclusively get infected with HIV, whereas 2% participants believed that only poor people get infected with HIV. Fifteen percent of the participants were reluctant to talk and work with an HIV-infected person. Most of the participants (95%) were agreeing to help people infected with HIV. All participants agreed to disclose their HIV status, if get infected with HIV, of which 9% will disclose their status to a doctor, whereas 23% to their close relative, 40% to their friends, 50% to their parents, and 77% to their

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Table 1: Stigma related to human immunodeficiency virus/acquired immunodeficiency syndrome with respect to the level of education

Questions on stigma	Responses	Number of participants	Education		Test of significance
			<12th standard	>12th standard	
Should HIV-infected persons feel ashamed	Yes	22	7	15	1.000
	No	74	22	52	
Those who have HIV, deserve this only	Yes	7	2	5	1.000
	No	84	24	60	
Should HIV-infected persons be thrown out of the community	Yes	1	1	0	0.2813
	No	95	26	69	
HIV-infected persons are not a part of the community	Yes	20	9	11	0.0913
	No	76	18	58	
HIV-infected persons are not moralistic	Yes	13	3	10	1.000
	No	78	21	57	
HIV-infected persons should be blamed for their illness	Yes	45	14	31	1.000
	No	48	14	34	
Only uneducated persons get infected with HIV	Yes	5	3	2	0.1465
	No	91	25	66	
Only poor people get infected with HIV	Yes	2	1	1	0.5064
	No	96	28	68	
Would you like to talk to and work with an HIV-infected person?	Yes	77	21	56	1.000
	No	15	4	11	
Would you like to help an HIV-infected person?	Yes	95	29	66	1.000
	No	2	0	2	
I will be ashamed if I have HIV	Yes	41	11	30	0.6463
	No	49	16	33	
I will not allow my child to play with an HIV-infected person	Yes	26	10	16	0.3119
	No	70	18	52	
Should HIV-infected persons get treated by doctors?	Yes	97	28	69	0.2959
	No	1	1	0	
Should HIV-infected persons be married?	Yes	21	6	15	1.000
	No	61	16	45	
Will you give permission to an HIV-infected person to work at your place?	Yes	76	20	56	0.3849
	No	18	7	11	
If you get to know that a close friend of yours has HIV, will you keep the same relationship with him/her?	Yes	80	21	59	0.03091
	No	12	5	7	

HIV: Human immunodeficiency virus

partner (numbers are not mutually exclusive). Feeling ashamed, if acquired HIV infection, was expressed by 41% of the participants. Twenty-six percent of the participants had shown their reluctance to allow their children to play with HIV-infected person. Eighty percent of the participants said that if their close friend gets infected with HIV, it will not affect their relationship. Nearly 76% of the participants agreed to allow an HIV-infected person to work at their place. However, only 21% of the participants agreed in favor of the marriage of a HIV-infected person. Majority (97%) of the participants expressed their view that a HIV-infected person should get treated by doctors.

DISCUSSION

The present study was designed to assess the stigma toward HIV infection/AIDS among otherwise healthy individuals of the community, who had current exposure to the health system of a tertiary care hospital for consultation for psychiatric illness of their close ones. In our study, it was seen that most of the participants were educated and belonged to the urban background where people are more sensitized toward HIV/AIDS. Despite this, it was seen that there is stigma still present in the general population to a variable extent.

It was observed that 22% participants still agree that PLWHA should be ashamed that they have HIV while there were 75% participants who did not agree to it. Feeling ashamed for own HIV was more common among people between 46 and 55 years of age and least among people between 16 and 25 years of age.

Ugarte *et al*., in their community-based study reported a much higher percentage (86%) of participants agreeing that individuals who are HIV positives should be ashamed of themselves and not only that even the professionals working with them should also be ashamed.[10] However, the

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percentage of individuals accepting that PLWHA should be ashamed was much less than the ones reported in the above-mentioned studies.

A study by Dahlui *et al*., assessed stigma and discrimination related to HIV/AIDS in Nigerian population and it was observed that 50% of the population agreed that PLWHA should be ashamed of themselves and were liable for bringing HIV/AIDS to the community.[4] In this survey, 95% of the individuals were in favor of not throwing HIV-infected individuals out of the community for their illness. Almost 20% feel that HIV-infected persons should not be a part of the community. There were 76% of the individuals who did not agree with this. Majority of the individuals (35%) were in the age group of 26–35 years who agreed while majority of the individuals (31.6%) were in the age group of 16–25 years who did not agree with this.

Community bias toward PLWHA has been observed in the form of labeling and shaming.[11-13] However, various accounts of extreme forms of discrimination are also reported in many studies which include exclusion from social functions, expulsion of children of HIV-positive parents from schools, boycotting social visits to homes, physical isolation, and denial of last rites and burial plot upon death.[12-14]

In the report on the socioeconomic effect of HIV-AIDS, it was reported that approximately 25% of the PLWHA have not disclosed their status in the community. Of those who have disclosed their status, about 10% have reported discrimination mostly in the form of isolation and neglect. They have also been subjected to other kinds of discrimination such as teasing, social boycott, and not allowing their children in Anganwadi centers. In some cases, they have also been refused houses for rent.[15]

However, in the study by Ugarte *et al*., with a sample of 520 individuals, 86% of the respondents agreed that HIV-positive individuals should be asked to leave the community.[10] The reported percentage is much higher than that reported in our study.

In a study of school adolescents in New Delhi, 37% participants reported to believe that HIV/AIDS is a punishment from the God and 30% reported to believe that PLWHA deserve their condition.[16]

Most respondents expressed agreement with negative judgments toward HIV-positive people, including "HIV is a punishment from the God" and PLWHA "are immoral;" these beliefs were more prevalent in females than in males.[10] In our study, the moralistic value of persons infected with HIV/AIDS was not questioned by most of the participants (78%). There were only 13% of the individuals who felt that HIV-infected persons are not moralistic. Maximum individuals who feel this were between 36 and 65 years of age (61%), males (84.6%), graduates (46.2%), Hindu (84.6%), married (84.6%), and belonged to urban background (61.5%). It suggests that belief regarding morality of persons infected with HIV/AIDS may not be a gender-specific issue. Other reasons may attribute to its existence.

A major finding was that 46% of the respondents feel that HIV-infected persons should be blamed for their illness. This indicates that still a larger portion of healthy adults blame the PLWHA for their illness.

Maximum (26.7%) individuals participated in our study, who agreed HIV-infected persons are not moralistic, were in the age group of 46–55 years while maximum (29.2%) individuals, who did not agree with this, were in the age group of 16–25 years. In the Indian society, HIV infection in men is often viewed as associated with immoral behaviors.[12,13] Thus, men are labeled with "loose moral character." Women are also not treated differently as they are often viewed as the ones responsible for bringing the infection to the family.[13]

Most participants of our study did not think that HIV to be an illness of the uneducated (91%) and the poor people (96%). Nearly 77% of the individuals were not hesitant to interact with HIV-infected persons, of whom majority were 16–25 years of age, while 15% of the individuals expressed their reluctance to interact with them and majority of them were between 46 and 55 years' age group. Most of the individuals (95%) would like to help an HIV-infected persons. Maximum individuals (28.4%) belonging to the age group of 16–25 years would like to help HIV-infected persons while only 5.3% individuals belonging to the age group of 56–65 years would like to do the same. Almost 97% of the individuals think that the HIV-infected persons should get treated by doctors. This shows that there is decreased enacted stigma in the individuals.

Our study revealed that 41% of the participants will be ashamed if they are diagnosed with HIV. This shows the strength of perceived stigma among these individuals. Despite feeling comfortable to help and interact with an HIV-infected person, they still carry the fear of feeling ashamed if they themselves are diagnosed with HIV. Widespread perceived stigma may be the major reason for such distribution.

It was seen that 26% of the respondents will still not allow their children to play with an HIV-infected person. Nearly 21% of the participants think that HIV-infected persons should not go for marriage. It was observed that 18% of the individuals will not give permission to an HIV-infected person to work at their place while 6% are not sure. Finally, 12% of the individuals will not keep the same relationship with a close friend who is found infected with HIV and 8% were not sure about it. The above-mentioned stigma

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and discrimination are also reflected in the findings from various studies with varied samples ranging from adults from general population, health providers, and pregnant women. The studies reported that between one-third and half of the respondents, including health providers, blame HIV-infected people for their infection, display fear of infection from casual contact with them, express intentions to avoid them in daily life, endorse denial of their right to marry, and support their isolation in health settings. More than one-third of the respondents in the study by Porter refused to dine and work with HIV-positive people.[17]

In a sample of educated youth, 90% harbored at least one negative view toward PLWHA, for example, "HIV-infected people should kill themselves," 42% supported secluding them, and 31% favored their ban from attending classes.[18] In a study of school adolescents in New Delhi, 84% were willing to talk to them while only 12% were comfortable shaking hands with them.[16] Among general population, respondents of the National Behavioral Surveillance Survey-BSS (NACO, 2006), 56% said they would allow PLWHA to stay in the same village while a higher percentage (63%) supported a separate care center and only 44% would allow PLWHA to be treated with other patients.[19] One study examined stigma in terms of denial of rights of PLWHA to marry and have children. Nearly one-third of the pregnant women (29%) attending a prevention of parent-to-child transmission program believed that PLWHA should not marry, 31% believed that they should not have children, and 39% supported mandatory testing for pregnant women and for premarital couples.[20]

It was seen that there is more perceived stigma as compared to the enacted stigma. This shows that people feel more stigma than that is actually present in the society.

Subramanian *et al*., reported the above finding among 33% of PLWHA with significantly more HIV-positive women reporting perceived stigma (41%) than positive men (28%).[21] In another study, 71% of HIV-positive people did not report any instance of discrimination. However, in the sample, perceived stigma was found to be higher than internalized stigma, and all the three forms of stigma were associated with greater levels of depression.[22] Perceived stigma as well as internalized stigma was reported in higher degree in various studies.[21,23] Our participants were caregivers of patients suffering from mental illnesses, which is again highly stigmatized in the society. Due to being victimized by stigma, they can empathize better for PLWHA. It can explain the relatively low level of perceived stigma in our sample population.

It was also seen that younger age group (16–25 years) felt lesser stigma as compared to the older age group (46–65). The younger age group is more acceptable to these things. The education system also includes these things from the beginning while the older age group has not known these things.

We had divided the study population into two groups (group with >12 years of education and group with <12 years of education). There is significant ($P < 0.0001$) difference between these two groups in terms of years of education. However, the level of awareness, attitude toward PLWHA, and perceived and internalized stigma among these two educational groups were not different. Probably, factors other than education have a significant influence in this regard. An anticipation in this regard can be – high effectiveness of intense campaigning programs, in bringing down the stigma to a significant extent irrespective of the status of education. Hence, it may be recommended to strengthen the educational campaigns for reducing stigma in other illnesses, which will reduce the attitude of the society irrespective of the educational status.

Thus, it can be said that it is important to address the stigma and discriminatory practices of the educated group and those living in the urban areas also. Present programs mainly focus the rural areas and the uneducated groups.

Some methodological limitations of this study such as small sample, study population consisting of caregivers of psychiatric patients, may affect the generalizability of the results. As these data are cross-sectional, they do not establish a cause-effect relationship.

CONCLUSION

Stigma still persists towards HIV infection/AIDS in the society. Level of stigma may not be significantly different in people despite educational differences. Stigma needs to be addressed for prevention and better management of HIV/AIDS. Still, there is a long way to go to eradicate stigma.

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Conflicts of interest
There are no conflicts of interest.

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