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A QUALITATIVE STUDY ON EXPERIENCE OF STIGMA AND DISCRIMINATION IN HEALTH CARE SECTOR AMONG PLHA ATTENDING VCTC OF NEW CIVIL HOSPITAL AND GSNP+ OF SURAT

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ABSTRACT

Introduction: Within health care settings, HIV-related stigma is a recognized barrier to access of HIV prevention and treatment services. The current study was undertaken with the objective to study various forms of stigma and discrimination towards PLHA in health care sector.

Methods: Total 30 PLHA were selected from VCTC of tertiary care hospital and GSNP+ in Surat city. Information on stigma and discrimination gathered through in-depth interview.

Results: Stigma and/or discrimination were experienced by 36.7% respondents and 13.3% experienced harassment from health care staff. As per 13.3% respondents, they were charged extra by private practitioners. Change of treatment modality from invasive to oral was observed by 13.3% respondents. Practice of taking extra precautions while treating PLHA was experienced by 44.4% respondents. Due to fear of stigma and/or discrimination from health care staff, 26.7% respondents were hiding their status while seeking medical care and 16.7% were avoiding doctor/hospital, and taking the drugs over counter for minor illnesses.

Conclusion: Present study concluding that various forms of stigma and discrimination do exist in health care sector towards PLHA. Although stigma is a pervasive and daunting problem in the health care setting, much can be done to address its causes and consequences.

Key Words: Stigma, Discrimination, HIV positive persons, Health care sector

INTRODUCTION

Stigma is a common human reaction to disease. Throughout history many diseases have carried considerable stigma including leprosy, tuberculosis, cancer, mental illness and many STDs. HIV/AIDS is only the latest disease to be stigmatised[1]. UNAIDS defines HIV-related stigma and discrimination as: "... a 'process of devaluation' of people either living with or associated with HIV and AIDS ... Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Health care sector is perhaps the most conspicuous context for HIV/AIDS-related stigmatization, discrimination and denial. Fear of illness and fear of contagion is a common reaction among health workers, co-workers, and caregivers. Literature on care-giving shows that fear of contagion and fear of death have

clear negative effects on health care workers' attitudes toward and treatment of PLHA[2,3,4]. These attitudes range from mild disdain, through outright refusal to treat, to outright abuse of PLHA. Negative attitudes from health care staff generate anxiety and fear among PLHA. Understanding the various dimensions of HIV-related discrimination in health settings is the first step in successfully meeting this challenge.

Keeping in view the above facts, this study was planned to gain an insight into the situation of stigma and discrimination towards PLHA in health care sector in the Surat.

MATERIAL AND METHOD

This was qualitative cross sectional study conducted among 30 HIV positive person selected by purposive sampling. In depth interview facilitated by guideline (questionnaire)

Total 14 were selected from VCTC (Voluntary Counseling and Testing Centre) of Tertiary Care Hospital, Surat and another 16 from GSNP+ (Gujarat State Network of People Living with HIV/AIDS), Surat. In depth interview facilitated by guideline (questionnaire) were conducted in year 2005

Confirmed HIV positive persons who knew their positive status for more than 2 months were included in the study. Considering around 250-300 HIV positive persons at each of the places (VCTC and GSNP+), sample size of around 15 at each of the places with total 30 was considered enough for qualitative study of experience of stigma and discrimination in health care sector by PLHA at these 2 centres.

HIV positive persons were contacted during 9 am to 1 pm and 4 pm to 6 pm (timing of VCTC) at VCTC and during 9 am to 5 pm (clinic time) at GSNP+ counseling centre. After obtaining written informed consent, in depth interview was taken. Interview was recorded in tape recorder to facilitate the smooth flow of conversation and transcribed on paper same day.

Written informed consent was taken from each participant for participation in the study in their vernacular language (Guajarati, Hindi, English versions were used). For those who were not able to read, the information in the form was read in front of him/her in presence of his/her known (witness), and signature of witness was taken. Oral consent was taken for recording of interview. All the participants were informed in the consent form about withdrawal from participation at any stage of interview. As the study was a part of dissertation work of the first author, necessary approval had been taken from the institute (where work has been carried out) and concerned university by submission of study protocol before and full thesis after completion of study.

Data were audiotaped, transcribed, translated, coded and computerized for thematic analysis.

OBSERVATIONS

In this study, 30 PLHA knowing their positive status for more than two months were interviewed.

All the names mentioned in verbatim are not original ones.

Table 1: Age and Sex wise distribution of Study Participants

Age group (in years)	Sex		
	Male	Female	Total
20-24	03	03	06
25-29	06	04	10
30-34	04	Nil	04
35-39	04	02	06
40-44	03	Nil	03
45-49	01	Nil	01
Total	21	09	30
Mean	**31.9+6.9**	**27.9+4.6**	**30.7+6.5**

Table 2: Distribution as per important Social variables

Social variables	Persons (n=30)
Marital Status	
Married	20 (66.7)
Unmarried	06 (20.0)
Widow/Widower	02 (6.7)
Divorced	02 (6.7)
Education Status	
Illiterate	02 (6.7)
Primary	08 (26.7)
Higher secondary	17 (56.7)
Graduate & above	03 (10)

(Figures in parenthesis are percentages)

Table 3: Occupation of Study participants

Occupation	Persons (n=30)
Diamond worker	07 (23.3)
Textile worker	06 (20.0)
Housewife	05 (16.7)
Work at home (All are female)	03 (10.0)
Driver	02 (6.7)
Dying industry worker	02 (6.7)
Street Vendor	02 (6.7)
Plumber	01 (3.3)
Primary school teacher (Female)	01 (3.3)
Salesman	01 (3.3)

(Figures in parenthesis are percentages)

Experiences of Stigma and discrimination from Health care providers; other patients and relatives; and Harassment from Health care providers

About thirty seven percent (36.7%) respondents experienced stigma and/or discrimination from health care staff; mainly in government setup (72.7%) in the form of 'not being examined, not heard complaints properly by doctor', 'bad behaviour from person at case registry, drug dispensing window', 'try to avoid by interdepartmental referral' and 'changed the treatment modality'. In private setup (36.4%), it was mainly in the form of 'not providing treatment'. In charitable trust hospitals (18.2%) it was mainly in the form of 'health care providers not treating and caring properly'.

When asked for stigma and/or discrimination by other patients and relatives, majority (70%) were not aware of others behaviour. Only 10% respondents experienced such behaviour; mainly in the form of 'looking towards him in strange way' and 'adjacent patients have shifted their cots away, after knowing his/her status'. Harassment from health care staff was experienced by 13.3% respondents, both in public setup (75%) and by private providers (25%). Harassment was mainly in the form of talked very badly.

A 38-year-old Sundaram originally belong to Andhra Pradesh and having HIV since 6 years, explained his experience of harassment while seeking medical care in public hospital, "*Han aek tha vo medicine dene vala, bole kitana din aata hai, kayam ke liye dava, dava. Jaldi marata nahi hai. Mere munh par bola, mere saamane. Meine bola dactar ko bol dunga andar jaa ke, tu kya baat kar raha hai, hein. Tere ko rog lagaga to aese hi bolega kya. Fir vo chup ho gaya.*" *{Yes, one drug dispenser said to me, coming here for many days; forever medicines, medicines. Not even get died early. He spoke like this, in front of me, on my face. I have said that, I will tell this to doctor, what you are speaking. If you will get the disease, then also you speak like this. Then he became silent.}*

Experiences about High charges in private sector and Change of treatment modality and behaviour after knowing HIV positive status

On asking about 'any time charged extra for treatment', 13.3% respondents had replied that, they were charged extra by private practitioners. Change of treatment modality from invasive to oral was observed by 13.3% respondents, mainly in public setup (75%) and by private practitioners (50%). It was mainly in the form of not giving injectables and IV drips. According to 20% respondents, behaviour of staff including doctor was changed after knowing his/her status; private practitioners (66.7%) and public setup (33.3%).

A 23-year-old Shakila narrated her experience of changed behaviour of staff of charitable trust hospital, after knowing her status: "*First, when I was admitted, their (staff including doctor) behaviour was good, but when result of my HIV test came, their behaviour changed. I was not able to believe that, I was in the same hospital. Everything was changed.*"

Experiences regarding Extra precautions being taking by staff; Confidentiality maintenance; and Preference of setup for seeking treatment

About 44% respondents have observed at least once that, staff was taking extra precautions while treating or caring them, which they did not generally practicing with other patients; proportions were same in public as well as private setup. On asking whether this type of extra precautions can lead to disclosure of your status, 33% respondents said 'yes'. According to 20% respondents, confidentiality of their HIV positive status was not maintained (at least once), while seeking medical care. Most of (66.7%) these incidents happened in public setup.

On asking the preferred setup for medical care, 90% replied public setup and only 10% preferred private setup. Main reasons mentioned for preferring public setup were 'free treatment' (85.2%), 'good treatment' (40.7%) and 'good counselling-VCTC' (14.8%). While, reasons for preferring private setup were 'immediate treatment' (60%), 'status disclosed in public setup' (20%) and 'fewer queues' (20%).

Asking on breach of confidentiality, a 40-year-old Rameshbhai said, "*Doctor asks me about my illness in front of other patients; due to that, other patients and their relatives will obviously make out my status.*"

Experiences of PLHA regarding Hiding their status while seeking medical care; and Avoid to visit doctor/hospital for their illness

Due to fear of stigma and/or discrimination from health care staff, 26.7% respondents were hiding their status while seeking medical care and 16.7% were avoiding doctor/hospital, and taking the drugs over counter for minor illnesses.

A 23-year-old Seema said, "*Private ma doctor saari dava nahi aape, ae karan thi hun janavati nathi.*" *{In private, I am not informing my status due to fear that, doctor will not provide good treatment.}*

DISCUSSION

Health sector is one of the main settings where HIV-positive individuals and those perceived to be infected experience stigma and discrimination[5,6]. Studies show that HIV-related stigma in this context is pernicious, and that it's physical and mental health consequences to patients can be damaging[7-11]. There are many ways in which HIV-related stigma manifests in health care settings.

Current study revealed that stigma and /or discrimination towards PLHA do exist in health care sector both in public and private. In public sector, these were principally in the form of no proper history taking and examination; dreadful behaviour at case registry and drug dispensing window; avoiding PLHA by interdepartmental referral; not maintaining confidentiality of PLHA's HIV positive status; changing treatment modality from invasive to oral; and even verbal harassment. In private setup, the major forms were denial for treatment and charging high for medical care. Practice of taking extra precautions while treating PLHA was observed equally in both public and private sector.

Studies have reported practices including denying treatment, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines to PLHA[12,13].

In a study conducted by UNAIDS in Mumbai and Bangalore, total 47 doctors, 3 Nurses and 44 PLHA were interviewed[14]. The observations of the study were: most of the PLHA alleged widespread harassment when they tried to access health services; in some hospitals patients for surgery once tested HIV-positive, prior decision about surgery was reversed on the grounds that it might not be of much use to the patient; none of the hospitals included in the study followed universal precautions for all patients in managing patient care, and when precautions like double gloving and masks suddenly began to be used for a patient on the ward, the effect was dramatic both for the patient concerned and for other people in the ward; some of those PLHA who were unable to conceal their sero-positive status were avoiding to visit doctors or hospitals or delaying treatment.

A study in Tanzania documented a wide range of discriminatory and stigmatizing practices, and categorized them broadly into neglect, differential treatment, denial of care, testing and disclosing HIV status without consent, and verbal abuse/gossip[15].

Similarly, a study in Ethiopia found that common forms of stigma in health facilities were designating patients as HIV positive on charts or in wards, gossiping about patients' status, verbally harassing patients, avoiding and isolating HIV-positive patients, and referring patients for HIV testing without counselling[16].

Patankar et al. also documented experience of discrimination in health care setting by one-fourth subjects in their study in Mumbai[17].

Rehana Khalil et al. in their study at Karachi, Pakistan reported that a large majority (89%) of the respondents perceived their experience with health care providers as discouraging or unsatisfactory and 35% of the participants reported negative experiences due to their positive HIV status[18].

A qualitative study in Iran found that almost all the respondents had experienced stigma and discrimination by their healthcare provider[19].

PLHA have been found to react to stigma and discrimination by avoiding seeking healthcare[7,12,19,20], turning to alternative medicine[12] and in some cases even feeling violent and vengeful[7,19]. Therefore, they find non-disclosure as the best option to avoid the stigma and discrimination[21].

In a current study; due to fear of stigma and/or discrimination from health care staff, many of the participants prefer to hide their HIV positive status while seeking medical care and to avoid doctor/hospital by taking over the counter drugs for minor illnesses.

Likewise, researchers in Botswana and Jamaica found that stigma leads many people to seek testing and treatment services late in the progression of their disease, often beyond the stage of optimal drug intervention[22,23].

Determinants for stigma and discrimination towards PLHA are probably the misbelieves about routes of transmission of HIV/AIDS among health care providers mainly the paramedical staff; believe casual contacts as modes of transmission like touching, coughing etc.; lack of proper knowledge that HIV can be transmitted by other than sexual route; prejudice for certain groups in society e.g. female sex workers, truck drivers, migrant workers and for persons with high risk behaviour, lack of proper knowledge that "with routine universal precautions there is no threat"; and fear of acquiring HIV infection among health care providers.

Studies in Nigeria, Mexico, Ethiopia and Tanzania[6, 24-29] have found high levels of fear of contagion among health workers.

In India, a study of hospital workers found that those who expressed greater agreement with stigmatizing statements about people living with HIV and hospital discriminatory practices were more likely to have incorrect knowledge about HIV transmission[30].

In Nigeria, results of a study among nurses and laboratory technicians showed that 35% felt that HIV-positive people deserved being infected as punishment for their "sexual misbehaviours"[26]. Similarly in Mexico, three-quarters of health providers surveyed thought people with HIV bore responsibility for having HIV[29].

CONCLUSION

Present study concluding that various forms of stigma and discrimination do exist in health care sector towards PLHA. These are in the form of asking embarrassing questions, breach of confidentiality, refusal to treat/admit and referral to other place (mainly to government hospitals) by private practitioners, refusal for surgery/delivery/special procedures, isolation in the ward, extra use of protective measures, change of treatment modality, delays in treatment, charging high for the treatment by private practitioners and charitable trust hospitals, not giving proper attention, not examining properly, neglect the patient and stigmatized behaviour from adjacent indoor patients.

With its potentially devastating consequences on care-seeking behaviour, stigma represents a major "cost" for both individuals and public health. Both experienced and perceived stigma and discrimination are associated with reduced utilization of prevention services, including programmes to prevent mother to child transmission, HIV testing and counseling, and accessing care and treatment.

RECOMMENDATIONS

Reducing stigma in health facilities

At the individual level, increasing awareness among health workers of what stigma is and the benefits of reducing it is critical. Health workers' fears and misconceptions about HIV transmission must also be addressed. Training programmes at regular intervals are needed to provide health workers with complete information about how HIV is and is not transmitted and how practicing universal precautions can allay their fears. It is important for health care workers to disassociate persons living with HIV from the behaviors considered improper or immoral by sensitizing them towards PLHA.

HIV training and knowledge might not have direct impact on providers' discriminatory behaviour at work, but they can inversely influence providers' general prejudicial attitudes toward PLWHA; also, HIV training is likely to help providers identify institutional policy and procedure support. These positive changes can in turn contribute to a willingness to work with PLWHA.

The findings showed that the more institutional support providers were perceived to have, the less discrimination intent they would exhibit at work toward PLWHA. In the physical environment, programmes need to ensure that health workers have the information, supplies and equipment necessary to practice universal precautions and prevent occupational transmission of HIV. This includes gloves for invasive procedures, sharps containers, adequate water and soap or disinfectant for hand-washing and post-exposure prophylaxis in case of work-related, potential exposure to HIV.

Health facilities need to enact policies that protect the safety and health of patients, as well as health workers, to prevent discrimination against people living with HIV.

Legal support provided by government can reduce the stigma and discrimination towards PLHA in health care sector.

Increasing access to treatment and care resources may function to lower HIV stigma.

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