HIV and Stigma

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Abstract

Stigma is mainly associated with diseases which are incurable and are perceived by the society as caused by the violation of societal norms. HIV/AIDS is an example of one such disease. HIV/AIDS related stigma is present at all levels: family, community and health services. This stigma prevents people from getting tests done, from disclosing their seropositivity and taking proper treatment, which in turn, increases the chances of infection and causes various mental health problems. Various programmes have been developed at the national and international levels to address the stigma and provide proper treatment to such individuals.

Introduction

Stigma is defined by Erving Goffman (1963) [1] as a "significantly discrediting" attribute possessed by a person with an "undesired difference". In recent times stigma came to be defined as a social process that involves recognizing and using "differences" between groups of people to create and legitimize social hierarchies and inequalities (Horizons 2002) [2]. Stigma has been associated with mainly those diseases which are incurable;, especially those that society perceives are caused by the violation of social norms like HIV/AIDS [3].

Two types of stigma are mainly spotted, namely, felt stigma and enacted stigma. Felt stigma is defined as anticipation of stigma and discrimination and internal sense of shame while enacted stigma is actual experience of stigma. Felt stigma is not present overtly, it refers to the fear of being treated differently and labeled by others. Enacted stigma is overt and visible, e.g., hesitating in shaking hands with an HIV-infected person or not letting HIV positive individual to work at their workplace.

HIV/AIDS-related stigma prevents people from seeking counseling and testing, disclosing about their seropositivity to others, taking adequate medical care as well as complying with medications [4]. The stigma also destroys social lives, leads to depression and other conditions that lowers mental health status, reduces support groups and income due to job loss [4]. HIV infection is often perceived by people, in general, as being associated with immoral acts of an individual which further enhances the complexities of stigma.

Stigma about HIV infection also varies in different sexuality, gender, race, cultures. For instance, HIV infection is related to sexuality as AIDS is mainly a sexually transmitted disease. Thus, it has reinforced pre-existing sexual stigma associated with sexually transmitted diseases.

The associated stigma for HIV positive people might become a source of chronic stressor and might also result in coping with problems, improper self-care, and disturbances in mental health [6]. They face discrimination in workplace, health-care, and housing-related settings [7]. These collectively contribute to stress and adjustment difficulties in persons with HIV infection [8-10]. Thus, understanding the effects of stigma and approaching the treatment from different perspectives is important in dealing with such people.

Stigma and Discrimination Confronted by PLHA

Family & Community

Family and community is the place where people live and spend most of their times. Thus, stigma at such places has a significant effect on people living with HIV/ AIDS (PLHA). In family setup, the form of discrimination reported mostly are separation of utensils, other family members' avoiding sharing food, or not allowing them to cook and denial of use of common areas like toilet, etc. [11]. Other studies have found that PLHA were denied rights in property, care and treatment resources [12-14].

The daughter-in-laws were often not allowed to live in their matrimonial homes, sometimes even when their HIV-positive husbands are alive. The women are even devoid of any rights in the husband's property after his death. It is also found that in some households, HIV positive women are not even allowed to reach to their children [12,14, 17]. Due to stigma and discrimination present in the community women even fear disclosing their HIV-positive status [18-20].

However, studies do report support for PLHA from families. It is reported that in most developing countries, people do get a supportive environment of care, management and treatment of illness. Pradhan et.al reported that the current attitude of the spouse/family was supportive for 58% of the sample in the study [21]. Similar finding was also observed in a study where 70% of the respondents were willing to care for their relatives with HIV/AIDS [22].

It has also been seen that once people disclose their HIV infection status, most of them have received support from their family members although gender discrimination could be seen in the care provided. Men were more privileged when it comes to be taken care by family than women. The female counterparts including daughters, wives and daughters-in-law experience higher levels of discrimination than men [14].Thus, in the study gender was observed to be a strong determinant for the type of response one may receive from the family.

Behaviour of families towards the HIV-infected individuals is seen to be affected, to some extent, by the community's attitude and perception towards HIV / AIDS. The family members will treat the PLHA with care, support if they know that the presence of a positive person in family will not result in isolation and banishment from the community.

The most common type of stigma present in the community is that of labelling and shaming [11,12,14]. In a study on Nigerian population, Dahlui M (2015) found that 50% of people agreed with the view that PLHA should be ashamed of themselves, this view was held more by men (60%) as compared to women (50%). In another community based study in Nicaragua approximately 86% participants echoed similar views. Around 54.2% of respondants in the Nicaragua study also believed that even individuals who work with PLHA should feel ashamed about themselves [23].

Other forms of discrimination also exist in community which are more extreme such as barring HIV-positive individuals from social functions;, expulsion of children of HIV-positive parents from schools;, prohibit social visits to homes;, physical isolation;, and denial of last rites and burial plot upon death [12,14].

Thus the fear, ignorance and denial associated with HIV/AIDS lead to stigma and discrimination, which in different ways cast an adverse effect on an HIV-positive individual's daily life and create a hidden epidemic of HIV/AIDS.

There is fear of transmission from infected persons present in the community and visible signs enhance such stigma and discrimination [12]. There is enacted stigma present in the community wherein PLHA are neglected, isolated, verbally abused. The individuals are not allowed to participate in Mahila Mandals, Panchayats and they are also refused house for renting. The marriage of their sibling is affected once people came to know that they are infected with HIV/AIDS. Some other studies also provide evidence for reactions like ostracism, differential treatment at death, and discrimination in schools towards children of PLHA [14,26]. The children of PLHA are not allowed to play with other children or enter anganwadi centres and are also debarred from public amenities.

Gender

The lack of education and patriarchal system puts women in a submissive position. As a result, women have lesser control over their own bodies and lack negotiating skills for their protection [27-29] which is reflected in the manner family and society deals with a HIV-positive woman.

Although discrimination exists for both the genders, women were found to face more discrimination as compared to the men by Bharat et at. (2001)–a finding that is also reported by Greeff et al. (2008) [14, 15]. The study found that Malawian and South African women reported more incidents of stigma than men. Studies observed that family oriented, cultural beliefs of India too contribute in greater acceptance and support for HIV positive men as compared to women [16].

Being HIV positive, women are blamed and named in various ways. Often married women are blamed for bringing the disease to the family. Often due to the existing social hierarchal system, it was observed in several antenatal clinics that women were blamed for bringing the infection into the family, especially, when they are tested HIV positive before their husbands [30].

In majority of cases, men would accuse the women for being unfaithful partners and blame them for bringing the disease [31]. A study on the management of HIV sero-discordant couples in Ibadan, Nigeria, reported that out of 1,000 couples who participated in the study , 30% responded that they would not allow their sons to continue in a marital relationship if their partner is tested positive for HIV infection and sons are not HIV positive [32].

Women are also blamed by the in-laws for the wrong behaviour of their husbands. They are also accused of not being able to control their husbands resulting in such misery to the family. Married women are also denied their rights in their matrimonial homes. They are not allowed to stay in the home and sometimes they are not also allowed access to their children. After the death of their husband, they are forced to leave and are denied any right in the husband's property [12,14]. In a study by Paxton et al.(2005), it was found that approximately 10% of HIV-positive women were forced for abortion. Sometimes women are also forced to have sexual relations with an HIV-positive husband.

Workplace

It has been seen that while HIV infection is not readily transmitted in the majority of workplace settings, still the supposed risk of transmission has been used by numerous employers to terminate or refuse employment. Thus, people fearing social isolation and loss of job often restrain from disclosing their HIV/AIDS status at their workplace. The major reason for hiding their HIV/AIDS status is fear of job loss. Besides this apprehension, PLHAs also fear facing unfair practices when they are hired at a lesser pay, biased promotion policies, discrimination in work allocation and denial of benefits like loan, insurance or health benefits [26].

These findings reiterate the discrimination faced by HIV-positive individual in various situations. For instance, in a study on HIV/AIDS related stigma and discrimination against PLHA in Nigeria, 40% of the participants responded that teachers who are infected by HIV should not be allowed to teach even if they are not sick [22]. This has also been supported by Oyediran et.al. (2005) who found that about two-third the Nigerian population were in agreement that colleagues who are found to be HIV positive should not be allowed to work further [33]. In another study on unemployment, participants who lost their jobs in past 12 months 50% of them attributed their job loss to their HIV sero-status [34].

Apart from these practices by the employers, the attitude of the co-workers also influences their decision for status disclosure. Many HIV-positive people report of experiencing discrimination in the form of isolation, non-sharing of food by co-workers and non-sharing of the same glass for drinking water etc. More than one-third of the respondents in the study by Porter (1993) refused to dine and work with HIV-positive people [35]. Colleagues avoid sitting close to HIV-positive individuals and sometimes even showed hostile behaviour towards them. Most of the employees with HIV/AIDS reported in various studies reported discriminatory behaviour from their supervisors and colleagues in the form of social isolation and ridicule [36, 37].

Often co-workers pressurize the employer to terminate the duties of HIV-positive workers. Frequently, due to lack of knowledge regarding HIV infection other people feel anxious because they feel that they will also be highly at risk of being infected by working with a seropositive person.

The fear of image getting tarred, sense of low esteem, being called by names in workplace, often makes PLHAs to apprehend that they would be thought of as people of low character. Hence, they stop going to work, take voluntary retirement or they refrain from declaring their HIV positive status till medical/physical signs start showing up. All these lead to problems in compliance of treatment. Stigma and discrimination often force HIV-positive people to switch jobs frequently. At times, taking up jobs that are less paying, or jobs that are less demanding due to their physical capacities or the working conditions might be such that it would expose them to things that hamper their health and make them ill, as recorded in a case study. The case study published in “India: HIV and AIDS-related Discrimination, Stigmatization and Denial” by S. Bharat (2001) reported the problems faced by the workers in transport department. While working in buses, they often use to fall sick. So they have to request for lighter jobs in place of their current workplace.

Many organization do not have defined policies or guidelines for HIV-positive workers. Thus, they are unable to deal with the discrimination faced by HIV-positive people. Since no special benefits are provided to HIV-positive employees most of them find it difficult to stick to their treatment regime. This also affected the precautionary measures taken up by them as the special safety measures might make other co-workers curious.

However, very few companies in developing countries seem to have developed policies to deal with fear, stigma and discrimination in the workplace, and some had also defined the responsibilities of employers towards workers with HIV/AIDS [26]. A process has been initiated for facing the HIV/AIDS in organizations by the name of Industrial Response to AIDS (IRTA) still there are very few takers for these steps [38].

Health Services

Health-care facilities have been reported by various studies as the place where HIV-positives experience discrimination the most. [12,14, 39]. HIV-positive individuals feel that presence of special secluded wards or units propagate stigmatization and people who visit such places are subjected to discrimination by others.

Individuals reported discrimination in the the form of denial of admission or treatment services. The government hospitals and private clinics blame each other for negligence of patients on learning about their HIV-positive status. It is often reported by patients that they are offered treatment services at a higher cost and predefined conditions or clauses. Also, if the positive status of an individual is found out during treatment of some other ailment, the patients are then subsequently denied further treatment. Often HIV/AIDS status is not disclosed to the patient instead they are referred to some other medical facility. If, at all, they are provided medical care, they are kept in separate wards, their movement is restricted and sometimes their beds are categorized as “AIDS patient” etc.

HIV-positive patients often experience poor quality of treatment and segregation in hospital wards [40]. It has been seen in two sites (Bangalore and Mumbai) of S Bharat (2001) study that in India pregnant women and people who come for surgery were denied treatment facilities by hospital when their HIV infection test results came out to be positive.

Various studies report the discriminatory practices carried by health care facilities in the form of denying help to HIV-positive pregnant females during delivery, delay in treatment or asking for additional payment for health services [14,17,41]. Kurien et al. (2007) in their study reported similar discrimination faced by PLHA; The study found that 20% of doctors denied treatment to PLHA, 24% isolated HIV-positive people for care from others and 13% doctors changed treatment or postponed it.

Another major issue concerning testing of HIV infection is to take consent for testing and maintain confidentiality of the result. It has been learned during the S. Bharat (2001) study that in most of the cases pre and post-test counselling is not done and in some cases, it was mandatory for people coming in for surgery and for pregnant women to take up HIV/AIDS test. Paxton et al. (2005) found that 52% of positive respondents were told about the HIV test before beginning the test and approximately similar percentage of participants were counselled when they were given their HIV test results. The studies by Mahendra et al (2007) and Pisal (2007) found that health care staff do not consider taking consent of the patient before testing for HIV as important [39, 43]. A National AIDS Research Institute-Yale University (USA) study conducted in Maharashtra, India, observed that most of the healthcare providers associated patient's HIV infection to immoral conduct of the individual. They also reported presence of fear of touching HIV/AIDS patients. The study also found that healthcare service providers also indulge in malpractices of testing the individual without his or her consent as well as disclosure of his/her HIV sero-status on open charts [44].

Recently, however, Indian courts have started looking into matters of refusal of treatment to HIV-positive patients. In November 2002, the Delhi High Court issued notices to both the Union Government and the Delhi Government seeking their replies on the refusal of several city hospitals to treat an HIV-positive person. Notices were also issued to several hospitals where the person with HIV infection was refused treatment and denied admission.

Discrimination due to HIV infection related stigma is also observed in the way the dead body of an HIV-positive person is treated. In majority of cases, hospital staff refuse to touch the body. It is also reported that often the dead body is wrapped in plastic sheets and even accessing a transport for a dead body is a difficult task for the family members. Respondents of the study conducted by socio-economic impact of HIV/AIDS (2006) by Pradhan et.al reported problems in cremation of the body in form of non-cooperation by the staff at cremation ground or by the community [21].

Stigma Measurement

Scales were developed mostly for research purposes which mostly looked into the attitude of respondents pertaining to areas of negative and hostile feelings towards people with HIV infection, attribution of HIV-AIDS to vulnerable groups, avoidance intention or social distancing, and support for punitive actions and denial of rights. Responses were obtained on 3 or 4 point scale (No/ Yes/ Maybe/ Don't Know). However, earlier tests lacked standardisation and their reliability and validity scales were not known.

Validity and reliability of measures of HIV/ AIDS stigma are important to make sure the effectiveness of prevention and treatment program. Standardized measures of stigma can help trace stigma burden across varied regions and over time [45-47]. Such measures can help trace how stigma is affecting the treatment and testing procedures. Further they can help in development of programmes which aim for stigma reduction as per different cultures and populations [46].

Keeping this in mind, various efforts were made to measure HIV/AIDS stigma with a view to understand stigma in a better way than only as attitude[11, 29, 48, 49]. All the scales were based on prior qualitative research in various setups. One such significant scale was developed by Zelaya et al. (2008). It was a 24-item stigma assessment scale based on a male sample of unknown HIV infection status from the wine shops in Chennai. The scale focused on measuring perceived stigma. The strength of the scale was that it was completely standardised with psychometric properties. Thus, the final scale measured four major domains: "fear of transmission and disease, association with shame and blame, personal support of discriminatory actions towards people living with HIV infection, perceived community support for discriminatory actions or policies towards HIV-infected people, and perceived community support of discriminatory actions or policies towards HIV-infected people". These domains were assessed using 24 items. Since the scale was based on a low-income group which are comparatively high HIV-risk men, the scale might not apply to the general population.

The scale developed by Mahendra et al. (2007) during a stigma intervention project in three Delhi hospitals, traced the stigma of AIDS among the health workers in hospitals. It aimed to measure fear of contamination and moralistic attitudes with 21 items. Other than the above mentioned areas, it also assessed the dimensions of human rights and health management practices as aspects of discrimination within health settings, thus, proving to be an important tool for assessment of stigma among health practitioners.

To assess four different stigma forms, Steward et al (2008) developed four new and separate tools which assessed enacted, felt, internalised and vicarious stigma each with acceptable reliability 0.92, 0.94, 0.83 & 0.88 respectively. These scales took in to consideration the cultural and context-specific aspects of stigma which could be useful for future research work with HIV-positive individuals.

Enacted stigma could be assessed using the questionnaire developed by Paxton et al. (2005). It measures discrimination with respect to denial of human rights of the HIV-positive individuals as described in the Universal Declaration of Human Rights (right to health, privacy, security, freedom from degrading treatment, marry and found a family, employment, education and right to self-determination and association). The questionnaire thus developed measures discrimination in five areas–health sector, family, community, employment and education. This tool is applicable for measuring discrimination in

Asia at institutional and structural level. However, the drawback of the instrument is that it lacks in psychometric properties and needs testing on subsets of PLHA.

An indirect approach was taken up by Green et al. (2007) to assess stigma in the cultural context of care giving in India. The method used was observation, to record the relationship of the attendants of positive patients with their visitors. The study found that absence of caregivers was an indicator of strained relationships. A major setback of this method was lack of standardization and it was limited in scope as it assessed only the married population.

Another significant test which is applicable to the Indian culture is Implicit Association Test (IAT) developed by NARI, Pune in collaboration with Yale University, USA. It is a self-administered test assessing the thoughts and unconscious feelings of health care providers that are present during treatment of patient with HIV infection [44]. The test traces stigma associated with HIV/AIDS being a sexually transmitted disease and a fatal disease.[44, 50].

Intervention for Stigma and Discrimination Related to HIV/AIDS

Stigma and discrimination are the results of lack of awareness about the illness at the social and individual levels. Thus, various programs and policies are made across various countries to address the issues of acceptance and respect for PLHA at various levels. Policies address the issues both at individual and community level. Most of them target stigma by focusing on providing comprehensive care, support and treatment to eligible PLHA. They also aim to target stigma and discrimination through greater involvement of PLHA. Policies look into maintaining confidentiality of HIV/AIDS status of the individuals and condemn unauthorised disclosure of their HIV positive status. The policies also take care that HIV infected individuals are not discriminated against due to their seropositive status. Efforts towards raising public awareness are also being made, so that it facilitate acceptance, empathy and respect for PLHAs in the community, at the workplace and at places providing health services and various other services.

Conclusion

Stigma related to HIV/AIDS pose a great threat for the proper implementation of prevention and treatment programs. Existing stigma restrains the individuals from disclosing their status or getting tested for HIV infection which further aggravates the spread of infection. Not taking proper treatment because of the fear of getting noticed and looked down upon is a major concern for health services. Fear of facing loss of job and negative attitude from the family members and society too makes the individual pull himself into exile. In spite of various initiatives taken up by various authorities to mainstream the individuals who have been marginalized, prevalent stigma continues to play the spoil sport. Stigma and discrimination prevalent in the society presents a big challenge for programs associated with prevention and rehabilitation of people living with HIV/AIDS.

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