



RESEARCH ARTICLE

EFFECT OF STIGMA IN THE LIVES OF HIV POSITIVE PEOPLE

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ABSTRACT

HIV/AIDS epidemic has been accompanied by stigma from its very beginning. To measure the existence of internal and external stigma 300 PLHIVs (People Living with HIV) were selected. Focus group discussions were conducted with 50 PLHIVs (25 males and 25 females). Analyzing the effects of HIV related stigma on the quality of PLHIV's life it was found that the level of stigma on the quality of PLHIV's life was high. The results related to existence of internal stigma among PLHIV's indicate that 100% of the respondents were anxious and depressed about their HIV positive status. 97% feared to disclose their status and 94% felt they would lose everything. A high percentage (88%) had suicidal tendencies. The qualitative data obtained in this study substantiate the stigmatizing and discriminatory experiences such as denial of house for rent, denial of admission for the children in schools, denial of property and marital conflicts in the life of PLHIV's and therefore the individual and their families need support from community to deal with stigma and discrimination. There is a need to chalk out anti-stigma activities with PLHIV's, their families and communities.

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INTRODUCTION

AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. The consequences of stigma and discrimination are wide-ranging: being shunned by family, peers and the wider community, poor treatment in healthcare and education settings, an erosion of rights, psychological damage, and a negative effect on the success of HIV testing and treatment. AIDS stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination, such as racism, stigma based on physical appearance and can be directed towards those involved in what are considered socially unacceptable activities such as prostitution or drug use. Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care. UN Secretary-General Ban Ki Moon (2008) says: "Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world."

Why is there stigma related to HIV/AIDS?

Fear of contagion coupled with negative, value-based assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS (Campbell, 2001). Factors that contribute to HIV/AIDS-related stigma include:

- HIV/AIDS is a life-threatening disease, and therefore people react to it in strong ways.
- HIV infection is associated with behaviors (such as homosexuality, drug addiction, prostitution or promiscuity) that are already stigmatized in many societies.
- Most people become infected with HIV through sex, which often carries moral baggage.
- There is a lot of inaccurate information about how HIV is transmitted, creating irrational behavior and misperceptions of personal risk.
- HIV infection is often thought to be the result of personal irresponsibility.
- Religious or moral beliefs lead some people to believe that being infected with HIV is the result of moral fault that deserves to be punished.
- The effects of antiretroviral therapy on people's physical appearance can result in forced disclosure and discrimination based on appearance.

The fact that HIV/AIDS is a disease with no cure also contributes to the stigma attached to it. From early in the AIDS epidemic a series of powerful images were used that reinforced and legitimized stigmatization. HIV/AIDS-related stigma is not a straightforward phenomenon as attitudes towards the epidemic and those affected vary massively. Religion, gender, sexuality, age and levels of AIDS education can all affect how somebody feels about HIV and AIDS.

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AIDS-related stigma is not static. It changes over time as infection levels, knowledge of the disease and treatment availability vary. "As HIV/AIDS becomes a disease that can be both prevented and treated, attitudes will change, and denial, stigma and discrimination will rapidly be reduced." (WHO, 2008). The epidemic of fear, stigmatization and discrimination complicates decisions about testing, disclosure of status, and ability to negotiate prevention behaviors, including use of family planning services. AIDS-related stigma has had a profound effect on the epidemic's course. The WHO (2008) cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose their HIV status or to take antiretroviral drugs. HIV the virus that causes AIDS is one of the most serious health and developmental challenges. More than 33.4 million people are currently living with HIV. In India 2.4 million people are living with HIV (NACO, 2011). Tamilnadu is one of the hardest hit states of India and is home to 2.4 lakh people living with HIV.

HIV-related stigma and discrimination occur in all settings, and manifest differently and in varying degrees. It denies an individual his/her dignity, respect and right to participate in the community activities. It may also lead to lack of self-confidence, loss of motivation, withdrawal from the society leading to isolation and quality of life. Because of stigma and discrimination individuals' do not get themselves tested for HIV and fear to disclose their HIV status and fail to access health care services available in the community. Stigma affects people living with HIV/AIDS themselves owing to the internalization of the stigma into their self-identity and self perception thereby affecting one's perceptions and interactions. Research indicate that people living with HIV/AIDS feel a sense of isolation, guilt and shame which is normally integrated into identity (Kalichman, 2004). Persons living with HIV are stigmatized throughout the world in varying degrees. PLHIVs (People Living with HIV) experience stigma in two forms – internal and external stigma. Due to internal stigma, PLHIVs isolate themselves from the community and they do not even access essential health care services. Due to external stigma, PLHIVs are rejected by their loved ones and their community, unfairly treated in the workplace and are denied access to health services. The present study made an attempt to bring out the effects of HIV related stigma on the lives of PLHIVs in Mumbai.

Objectives

- To elicit the effects of HIV related stigma on the quality of PLHIV's life.
- To measure the existence of internal stigma among PLHIV's.

METHODS

To measure the existence of internal and external stigma 300 PLHIVs were selected. Various qualitative research methods such as focus group discussions and case study were adopted to gather necessary data. Focus group discussions were conducted with 50 PLHIVs (25 males and 25 females). Case study highlights the in depth situation of the PLHIVs, therefore ten PLHIVs were interviewed and gathered needed information with their permission.

RESULTS

Stigma is long known to have negative impacts particularly among those individuals who have life changing and devastating illnesses. In particular, the phenomenon is characteristic of people with HIV/AIDS illness. Apart from being subjected to life-altering changes in their daily activities, people living with HIV/AIDS also have to contend with the painful actions of others who often hold that these people should be further discriminated for their stereotypical deviant behavior. There are various forms of discrimination and stigma faced by people living with HIV/AIDS. These further result in the reduction

of the overall quality of life and well-being. Analyzing the effects of HIV related stigma on the quality of PLHIV's life it was found that ninety four percent of respondents mentioned about the feelings of rejection. Ninety two per cent PLHIVs conversed about the guilty feeling of being a PLHIV. Ninety four percent of selected PLHIVs mentioned that they were emotionally affected due to the discriminatory activities of their own family members. Ninety percent of children of PLHIV parents experienced discriminatory practices in the school regardless of their HIV status. The results show a very high level of stigma on the quality of PLHIV's life.

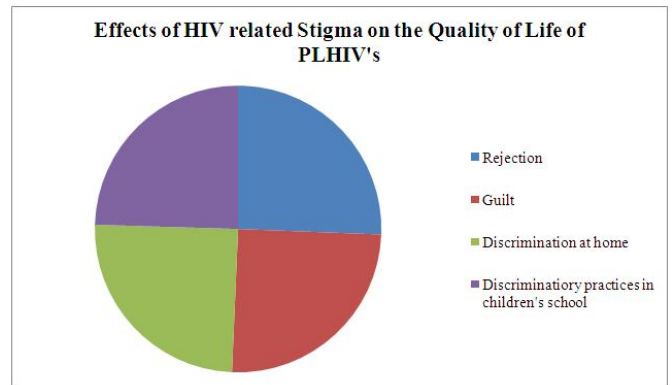


Fig. 1. Effect of HIV related Stigma on the Quality of life of PLHIV's.

The results related to existence of internal stigma among PLHIV's indicate that 100% of the respondents were anxious and depressed about their HIV positive status. 97% feared to disclose their status and 94% felt they would lose everything. A high percentage (88%) had suicidal tendencies. PLHIV's internalized stigma is found to be a barrier in availing the facilities provided by the government and community which in turn increase their vulnerability. Figure 2. depicts existence of internal stigma among PLHIV's.

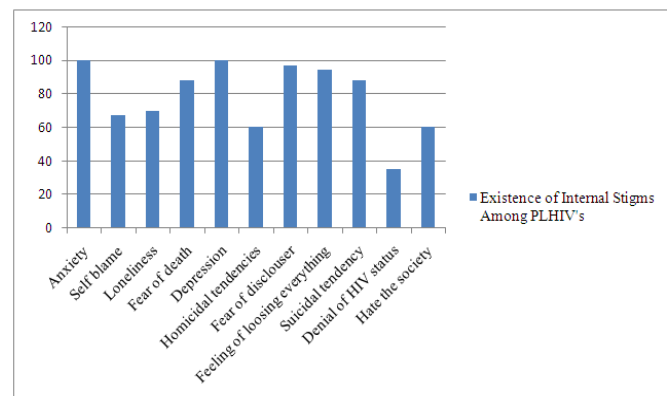


Fig. 2. Existence of internal stigma among PLHIV's.

Conclusion

Stigma and discrimination are negative social processes that provide a feeling of protection to the powerful while maximizing the load on people who are victimized in the process. The qualitative data obtained in this study substantiate the stigmatizing and discriminatory experiences such as denial of house for rent, denial of admission for the children in schools, denial of property and marital conflicts. PLHIV's and their families need support from community to deal with stigma and discrimination. Stigma has serious impact across various outcomes including self perception, motivation, group identification, social interaction, self-esteem, task performance and well-being. Individuals belonging to a stigmatized group are in most cases devalued, excluded or ignored. The results related to existence of internal stigma among PLHIV's indicate that a majority of respondents were anxious and depressed about their HIV positive

status, feared to disclose their status and felt they would lose everything. A high percentage had suicidal tendencies. Keeping the results in mind therefore there is a need to chalk out anti-stigma activities with PLHIV's, their families and communities. Combating stigma and discrimination against people who are affected by HIV/AIDS is vital to preventing and controlling the global epidemic. Education which gives correct information on HIV/AIDS can play an important role in reducing HIV related stigma. It is generally seen that stigma is the result of low knowledge about HIV therefore implementing systematic education and anti-stigma interventions with peer educators and community leaders can help PLHIV's and their families in dealing with their HIV status, reducing stigma and improve the quality of their life.

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