

HIV Related Stigma and Discrimination among People Living with HIV/AIDS in Ernakulam District: A Qualitative Study

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Abstract

Introduction: Human immunodeficiency virus (HIV)-related stigma refers to the negative beliefs, feelings, and attitudes, while discrimination is the unfair and unjust treatment of people living with HIV/acquired immunodeficiency syndrome (PLHA). Their manifestations are context-specific and have varied impacts. **Objectives:** (1) To determine the different contexts in which PLHA face stigma and discrimination. (2) To study the impact of stigma and discrimination on the health of the PLHA. **Methodology:** A qualitative study was conducted among PLHA at the office of the network for positives. Fourteen key informant interviews were conducted on PLHA and the peer counselors to determine the contexts in which they faced stigma and discrimination. To understand its impact on health, two Focus Group Discussions were carried out separately for male and female PLHA. The data were collected using a semi-structured interview guide and were audio recorded. They were then transcribed, manually coded, thematically analyzed, and triangulated. **Results:** The themes that arose showed that stigma and discrimination were context-specific and were experienced in different levels such as an individual, family, community, health-care system, and media. They experienced violence in addition to the loss of shelter and economic support. Stigma and discrimination was found to have a negative impact on the health of the PLHA. It was a major hindrance to health-care utilization resulting in worsening of health conditions and indirectly contributed to the spread of diseases. **Conclusion:** PLHA experience different forms of stigma and discrimination which have an adverse impact on their health. Behavior change communication initiatives for the community are required.

Keywords: Discrimination, human immunodeficiency virus/acquired immunodeficiency syndrome, people living with human immunodeficiency virus/acquired immunodeficiency syndrome, stigma

INTRODUCTION

Human immunodeficiency virus (HIV)-related stigma refers to the negative beliefs, feelings, and attitudes toward people living with HIV/acquired immunodeficiency syndrome (PLHA), while HIV-related discrimination refers to the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status.^[1] According to the WHO, fear of stigma and discrimination is the main reason which prevents people from getting tested, disclosing their HIV status, and adhering to antiretroviral therapy. Both stigma and discrimination are context-specific and have varied impacts on health.^[2] Hence, the objective of this study was to determine the different contexts in which PLHA face stigma and/or discrimination and also to analyze its impact on the health of the PLHA.

METHODOLOGY

This qualitative study was conducted as a part of a larger study

and was carried out after obtaining the institutional ethical committee clearance. It was conducted at the district office of the network for positives. This study setting was purposively selected since PLHA in Ernakulam district routinely visited the office for collecting their nutrition supplements and also for attending the peer counseling sessions. Using convenience sampling, PLHA and peer counselors who were willing to participate in this study were included. The data were collected till saturation was reached. Informed verbal consent was obtained for participation in the study as well as for voice recording the interviews.

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A total of 14 key informant interviews (KIIs) were conducted on PLHA and the peer counselors to determine the contexts in which they faced stigma and discrimination. It was then followed by two focus group discussions (FGDs) which were carried out separately for male and female PLHA to understand the impact of stigma and discrimination on health. The KIIs and FGD guides consisted of a list of predetermined open-ended questions based on the extensive formative research. Probing questions were also asked to explore further. These questions were pilot tested on two of the PLHA to ensure that the questions were clear, relevant, and understood by the participants. The interviews were conducted in the local language (Malayalam) and were audio recorded. Each interview lasted for 30–45 min and it was translated into English and was transcribed. The transcripts were then coded manually line by line to identify emerging themes and subthemes that were further categorized into different categories by the researcher, and data triangulation was carried out.

RESULTS

The age of the study participants ranged from 28 to 40 years. There were three peer counselors who participated in the study and rest of the participants were PLHA who were attendees at the network. Of the 14 KII participants, 8 were females and 6 were males. There were 11 females and 7 males in each of the FGDs. Among the female participants interviewed, they were educated up to higher secondary or less, while the male participants were educated up to high school or less. Majority of them were occupied in unskilled jobs, were either married or separated, and were the Hindus by religion.

Different contexts in which people living with human immunodeficiency virus/acquired immunodeficiency syndrome face stigma and discrimination

The study identified five different contexts in which the PLHA faced stigma and/or discrimination and they were at the individual, family, community, health-care system, and by the media.

“HIV/acquired immunodeficiency syndrome (AIDS) is a life-threatening disease with no cure and people are afraid of contracting it.”

–29-year-old female PLHA

At the individual level, fear was identified to be one of the predisposing factors for stigma and discrimination. Fear has always existed around HIV infection since it is a disease with no permanent cure and sexual transmission of the disease being a subject of taboo. It is often considered that being infected with HIV occurs as a result of a moral default. The fear among the HIV infected/affected often leads to a vicious cycle of silence leading to ignorance, which, in turn, leads to misconceptions and fear. This prevents people from utilizing the health-care services, thereby worsening the situation, as stated by one of the peer counselors. This was agreed by all the study participants.

“Fear of stigma and discrimination often leads to silence resulting in ignorance, which in turn leads to fear.”

–35-year-old male peer counselor

Felt stigma is the feeling that individuals harbor about their HIV-positive condition and the likely reactions of others toward their HIV-positive state, while enacted stigma refers to actual experiences of stigmatization and/or discrimination faced by the HIV-positives. It was observed that when compared to males, females were found to be more prone to felt and enacted forms of stigma in the community. This was due to the fact that women were often the first to be diagnosed in the family mostly at the time of antenatal care and their status would be revealed to all other family members. Children too suffered as they were separated from their families. As stated below:

“I was the first to be tested positive during my antenatal check-up. So everybody felt I brought the disease into the family. My in laws treat me badly. They never showed any discrimination towards their son. However they have totally isolated me. Children were taken away from me, in fear of them becoming HIV orphans.”

–32-year-old female PLHA

In the community, PLHA felt that their actions and movements were constantly under scrutiny and that they had no freedom at all. PLHA were not invited to be a part of any social functions. They experienced verbal and nonverbal violence in addition to the loss of shelter and economic support, often forcing them to lead a life of isolation. This was a common experience for most of the study participants.

“If the house owner comes to know that I am positive, he will ask me to vacate immediately. Once my employers get a clue that I am positive, they will start acting differently, indirectly persuading me to leave the job quickly and silently.”

–39-year-old male PLHA

The PLHA faced discrimination by the health-care system too. They felt that doctors and nurses were avoiding treating them and they had to constantly change doctors or shift to other hospitals. They felt that stigma was expressed in silent ways, making them uncomfortable that they were forced to use health-care services far away from home secretly. As one participant stated:

“They constantly kept shifting me from one ward to the other. Doctor’s too kept changing. In the name of shared confidentiality, they kept telling everybody about my HIV status. I no longer go to the hospitals nearby; I travel to the next district for extracting my tooth. I tell the doctor if you want to wear double gloves, please go ahead and do it.”

–40-year-old male PLHA

In all spheres of their daily life, PLHA are faced with a lot of challenges and they have to constantly fight for their rights. However, to fight for their rights, they would have to reveal their HIV status in public. Most participants stated that due to fear of revealing their status, they were finding it difficult to find a leader for their peer network group since most of them

shun away from doing so and they quietly suffer the stigma and discrimination. As stated by a participant:

“For gaining one’s own rights, we will have to protest in the open and thereby reveal our status to others. So, most often we end up keeping quiet and suffer silently”

–30-year-old male PLHA

Media’s portrayal of HIV as a life-threatening disease being transmitted mainly through the sexual route with no cure instills fear in the minds of the people.

“Media portrays specific groups of PLHIV as guilty (e.g., commercial sex workers or injection drug users) while others like infants and children as innocent victims.”

–32-year-old female PLHA

Subtle ways of victimization and false portraying of PLHA in media were found to create fear among the general population leading to stigma toward the HIV infected/affected.

Impact of stigma and discrimination on the health of the people living with human immunodeficiency virus/acquired immunodeficiency syndrome

Stigma and discrimination was found to have a negative impact on the health of the PLHA. It was a major hindrance to health-care utilization resulting in worsening of health conditions and indirectly contributing to the spread of diseases.

“I fear that the doctors and nurses would discriminate me, so I delay going to the hospital until I am very sick. Even if go to the doctor for treatment, I will have to discontinue it midway, because others will get to know my status.”

–39-year-old female PLHA

It was observed that participants would either practice self-medication or totally avoid or delay or discontinue utilizing health-care services fearing stigma and discrimination at the health-care centers. Lack of bystanders at the hospital was also a factor for not utilizing the health services, as stated by one participant:

“I am delaying my surgery, since none of my friends or relatives are willing to be bystanders.”

–40-year-old male PLHA

The participants fear so much about stigma and discrimination that some even resorted to alternative system of medicine or totally stopped taking any forms of medication. This resulted in worsening their health condition and spreading infectious diseases such as tuberculosis.

“There are other forms of medicine other than allopathy that promises to make me well.”

–39-year-old male PLHA

“We all fear stigma and discrimination from people around us, so we keep quiet about it. So I think it leads to spread of diseases like TB etc.”

–32-year-old female PLHA

Therefore, the study observed that PLHA experienced different forms of stigma and discrimination which have an adverse impact on their utilization of health-care services.

DISCUSSION

The study identified fear to be a major determinant for stigma and discrimination. The fear surrounding HIV existed from the beginning of the epidemic in the early 1980s when very little was known about it and the fear still continues to persist even now.^[3] The stigma and discrimination which occur as a result of it is often directed toward the key affected populations such as men who sex with men, intravenous drug abusers, and sex workers simply because others disapprove of their behaviors.^[4] These key affected people belong to the marginalized sections of the society which prevent them from utilizing the services that protect them from HIV.^[5] Half of all new HIV infections worldwide are among people belonging to key affected populations.^[6] In our study, it was observed that stigma and discrimination was directed toward anyone who was believed/suspected to be infected or affected with HIV irrespective of whether they belonged to the key population.

According to the WHO, fear of stigma and discrimination is the main reason why people are reluctant to get tested, disclose their HIV status, and take antiretroviral drugs.^[7] A study conducted by Sayles *et al.* revealed that participants who reported high levels of stigma were over four times more likely to have poor access to care.^[8] This could contribute to an increase in the global HIV epidemic and increase in the number of AIDS-related deaths. Furthermore, unwillingness to screen for HIV, fearing stigma would mean that more people are diagnosed late, when the disease would have progressed to AIDS making treatment less effective and increasing the likelihood of transmitting HIV to others, and even resulting in early death.^[9] Our study too clearly confirmed these findings, and the lack of confidentiality among health-care workers worsened the situation. Studies have shown that 34% of PLHA in India reported breaches of confidentiality by health workers.^[10]

CONCLUSION

PLHA experienced different forms of stigma and/or discrimination mainly in five different contexts such as the individual, family, community, health-care system, and by the media. It was found that stigma and discrimination had a negative impact on the health status of the people since it delayed/discontinued/prevented them from utilizing the available health-care services, leading to further worsening of their health situation. As studies in the past have suggested, there is an urgent need for creating holistic awareness through different mass media.^[11] Thus, behavior change communication has become the need of the hour for combating the HIV/AIDS epidemic.

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Conflicts of interest

There are no conflicts of interest.

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