

## HIV/AIDS and Social Exclusion (Marginalisation) in Balrampur Dist. (U.P)

Tufel Akhtar<sup>1</sup>, Abdul Raffie Naik<sup>2</sup>

\*\*Tufel Akhtar, Abdul Raffie Naik

<sup>1, 2</sup> Research Scholar Department of Psychology, Aligarh Muslim University.

Email - abdulraffienaik@gmail.com

**Abstract:** HIV/AIDS is an acronym of “Acquired Immune Deficiency Syndrome” which is a fatal disease. HIV is spread primarily by unprotected sex (including anal & oral sex), contaminated transfusions, hypodermic, and from mother to child during pregnancy, delivery, or breastfeeding. Some bodily fluids, such as saliva and tears, do not transmit HIV. The first cases of AIDS were reported in the United States in 1981.

It has emerged as an unprecedented pandemic cutting across all boundaries – national and International, considering people of any Sex, Age, and Race. When people are diagnosed with HIV/AIDS, the family member, friend circle, relatives and society see them in a negative light. These factors have a lasting impact on the mental health of the patient. The present study looks at the reactions the people of Balrampur district, when diagnosed as being HIV positive, have faced. Twenty HIV/AIDS Patients being treated at an ART Centre in district hospital Balrampur at U.P were interviewed. The responses showed both positive and negative responses to the questions they were asked. This shows that HIV/AIDS people, face the discrimination badly, majority of the people were diagnosed as positive. However, the people also face mental health issues as well as physical issues.

Social exclusion of the people living with HIV/AIDS in Balrampur district showed a significant barrier to the quality of life of a person and the health of a person. Stigma is closely related to social exclusion. Balrampur sees the inflow labourers coming from different regions and diverse backgrounds, and there is an increasing movement of Balrampurites to other areas of India where they might indulge in high-risk behaviour. During late eighties, the HIV/AIDS pandemic saw its way into Balrampur. There are still many ways through which the disease spreads. For example, intravenous Drug Users (IDU), and Unprotected Sex (US) have been the major factors for the transmission of HIV in the Balrampur. Further, the majority of the people view the epidemic as a disease of people who do not follow the norms of the society. Many people refuse to be treated, as the diagnosis is associated with shame and disgust, and we could see the ignorance of people regarding this fatal disease.

**Key Words:** HIV/AIDS, Social Exclusion, Unprotected Sex, Balrampur.

### 1. INTRODUCTION:

AIDS is an acronym of “Acquired Immune Deficiency Syndrome” which is a fatal disease described variously as modern plague, modern scourge, devastating disease, insidious microbiological bomb. It has emerged as an unprecedented pandemic cutting across all boundaries international, socio-economic, age, race and gender. AIDS emerged as one of the most important public health issues of late twentieth and early twenty first centuries and, is now one of the leading causes of global morbidity and mortality (Wallace, 2014). AIDS is also considered a socio-cultural issue because when this epidemic emerged in 1981, it was perceived as a deadly disease that was transmissible from person to person, as well as closely associated with historically disenfranchised groups and culturally and historically taboos and issues such as sexual orientation, drug use, unethical sex, prostitution, commercial sex workers etc. it is a spectrum of conditions caused by infection with the human immunodeficiency virus (HIV).

HIV is spread primarily by unprotected sex (including anal and oral sex), contaminated transfusions, hypodermic, and from mother to child during pregnancy, delivery, or breastfeeding. Some bodily fluids, such as saliva and tears, do not transmit HIV. Methods of prevention include safe sex, programs, treating, and male circumcision. Disease in a baby can often be prevented by giving both the mother and child antiretroviral medication. There is no cure or vaccine; however, antiretroviral treatment can slow the course of the disease and may lead to a near-normal life expectancy. Treatment is recommended as soon as the diagnosis is made. Without treatment, the average survival time after infection is 11 years.

The first cases of AIDS were reported in the United States in 1981 (CDC, 2001). At that time, the average life expectancy for a person diagnosed with AIDS was 6 months (Satriano et al., 2005). Subsequent advances in treatment, particularly the use of combination antiretroviral therapy, have transformed HIV/AIDS into a chronic, manageable condition. A 35-year-old person diagnosed with HIV infection has an estimated life expectancy of 32 years, depending on nadir CD4 (Hogg et al., 2008). In the setting of these successes, however, patients with HIV infection still face many challenges.

## **2. SIGNIFICANCE OF THE STUDY:**

This kind of research will be an important psychological domain to work upon. It will help the researcher to deal with different psychological issues among people living with HIV/AIDS. Exhaustively work is supposed to be done on the constructs like quality of life and mental health among people, living with HIV/AIDS.

The present study tries to understand the problems faced by the people living with HIV/AIDS in Balrampur District.

## **3. OBJECTIVES:**

The study will be conducted with the following objectives:

- The present study looks at the reactions the people of Balrampur, when diagnosed as being HIV positive, have faced.
- To understand the circumstances through which people living with HIV/AIDS are passing through.

## **4. METHODOLOGY**

This study is undertaken in a qualitative approach to make an attempt for understanding the mental set of people regarding the HIV/AIDS patients of Balrampur District (U.P).

### **4.1 Population:**

The population for the present study consists of people living with HIV/AIDS in Balrampur District.

### **4.2 Sampling technique:**

The samples were taken from Balrampur District Hospital by the purposive sampling technique. The researcher had chosen the sample among HIV/AIDS patients who are coming to ARTC Balrampur District Hospital. The researcher collected data from 20 samples.

### **4.3 Sources of the data:**

For the study, only primary data was used. The data required for the study was collected using self-constructed questionnaire.

### **4.4 Procedure:**

The patients were welcomed and rapport was established. The researcher gave brief information about the purpose of the study and informed consent had been taken from them. Each participant was reminded that their participation was voluntary, and that their responses would remain anonymous and reported only in aggregate form. After completing the questionnaires, participants were debriefed and were thanked for their participation.

## **5. RESULTS AND DISCUSSION:**

Stigmatization of the people having HIV/AIDS (PLWHA) can posture a significant intimidation to quality life and health of a person. Stigma is associated to the social exclusion that could be regarded as a means of describing the unfair responses arising out of the process of stigmatisation. Possible reasons for the stigmatisation of PLWHA might be the negatively allied with the disease and the dearth of information about the disease. (Fabianova, 2011). Other reasons could be the common masses interpretation about the disease as infecting the people who have diverged from the social norms and doing irregular activities like homosexuals, drug users or people having multiple heterosexual partners (Habib & Rahman, 2010). It has been regarded as a method that has brought about in excluding the stigmatized from routine social processes.

### **Reading HIV/AIDS and Exclusion in Balrampur:**

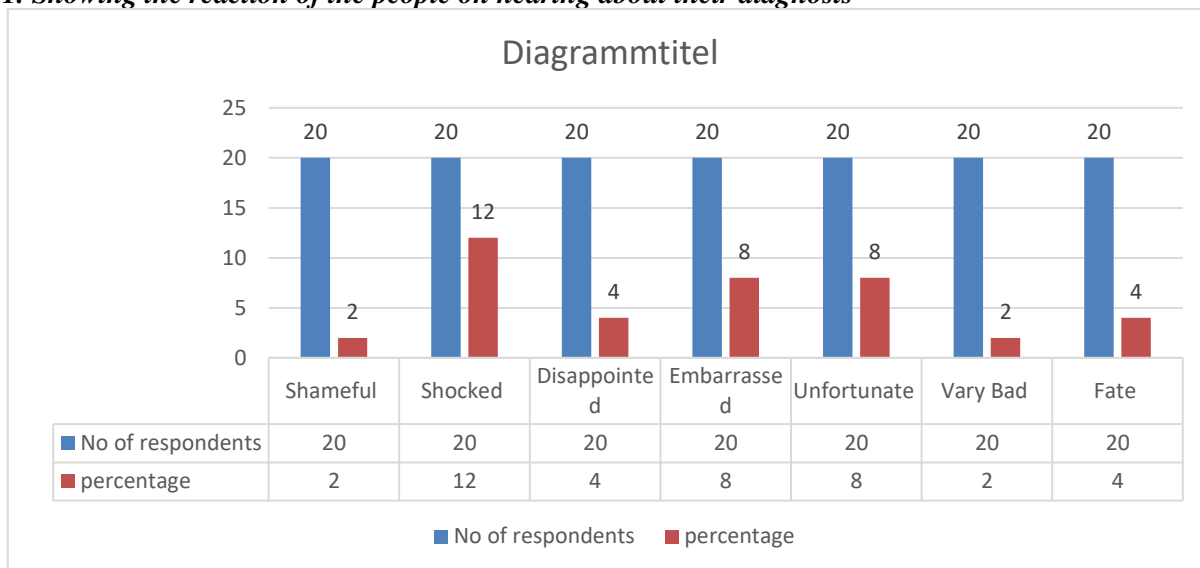
In Balrampur it has been more than two decades since HIV/AIDS cases had been found, first case was reported in 1986, fortunately, the number of HIV positive patients is still very less (Around 240 according to ART cell Balrampur Report till June 2014).

One of the reason for this less number could be that people do not report the disease because of the disgrace and infamy that is attached with the disease. Since Balrampur is living with the virus, the fact, which cannot be over ruled, but it has not immersed the dist. much as it does as per its characteristic features. There are two main trepidations regarding the breakout of HIV/AIDS virus in Balrampur; one is to find out the reasons about the breakout of HIV/AIDS and how it spread in Balrampur and the other main and important concern is to find out answer of the question why HIV could not make its possibilities influential in the area. It raises certain questions like as, why there is a little number of HIV patients, even when the circumstances like illiteracy, unawareness and backwardness are in favour of transmissions and spreads? This paper, along with the focus on the above concerns and question, will

explain the magnitude of stigma and exclusion specifically in Balrampur; it is based on primary data by conducting field study and a self-constructed questionnaire based on the nature of the HIV/AIDS pandemic was formulated. Separate questionnaire is framed, specially meant to measure the social and exclusionary aspects of the disease. Different dimensions of exclusion are put into course and data were analysed, processed and explained through different measures like tables, charts and graphs.

**Reaction of respondents diagnosed as HIV positive.**

*Figure 1. Showing the reaction of the people on hearing about their diagnosis*

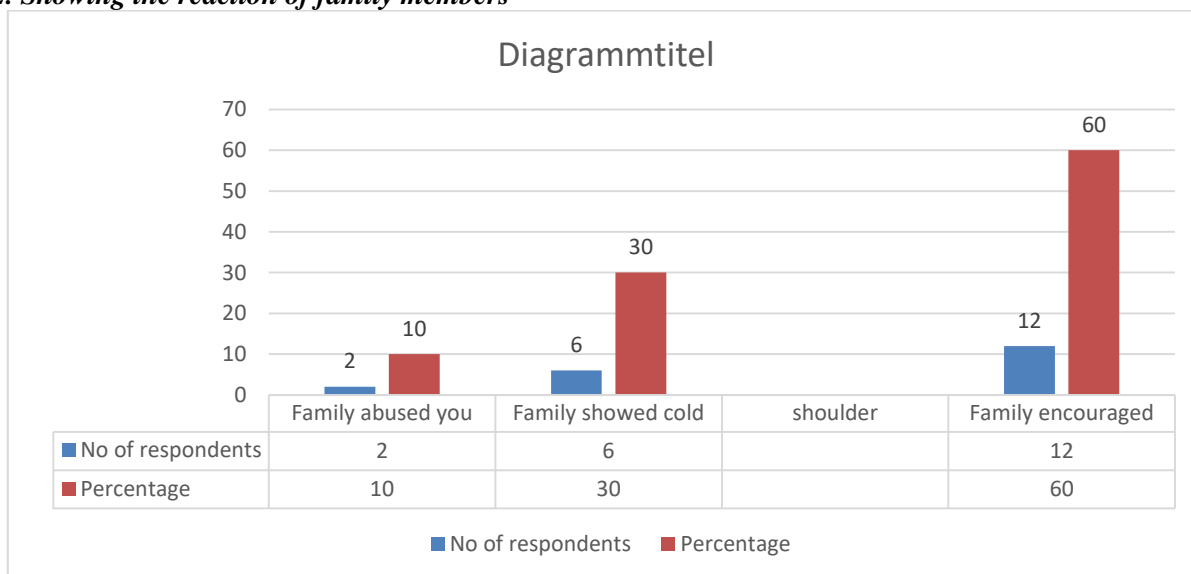


Source: ART Centre

The above graph defines the sample size of total twenty respondents. The respondents were asked about how they felt the first instance they heard about their status of being diagnosed as HIV positive. All were questioned that how they felt at the first instance when heard of their HIV positive status. 2 out of 20 respondents said they felt ashamed when they came to know of their status. The maximum 12 replied that they were shocked. 4 respondents were disappointed, 8 said it was unfortunate and 8 were feeling embarrassed. 2 of total said it was very bad and 4 have advocated it to fate.

**Response of family members**

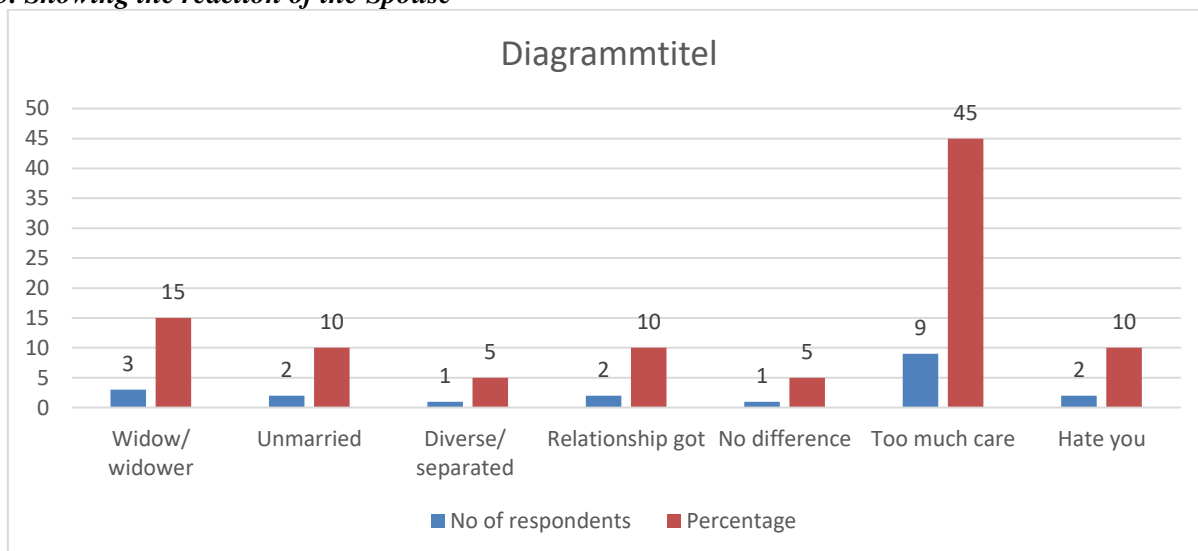
*Figure2. Showing the reaction of family members*



The graph displays some interesting facts related to strength of stigma in terms of Balrampur. It shows quite well that 60% of respondents say that they have been encouraged and taken care of since they were tested HIV positive. 30% said that some of the family members started to show a cold shoulder, as they are afraid of what will happen if they are exposed to a person diagnosed as being HIV positive. The very least 10% of the people replied in affirmative when asked if they were abused sometimes being HIV positive.

**Effect on marital relationship**

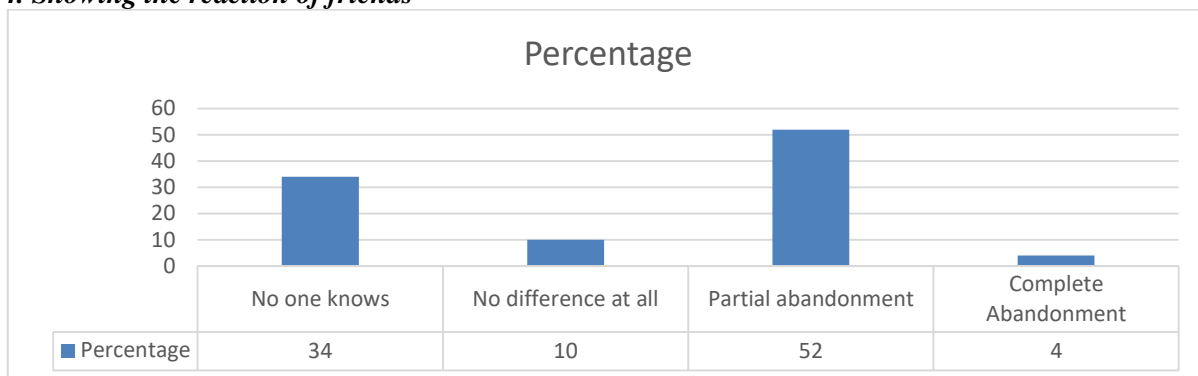
Figure3. Showing the reaction of the Spouse



The graph clearly defines the reaction of spouse when getting to know the HIV status of his/her spouse. 15% of respondents are already widow or widower and 10% of all are unmarried. The remaining has many different things to say. The majority of 45% says that their spouses started to take much care of them. Although 10% says, their husband/wife started to dislike him/her and the 5% says that there was no difference in relationship at all. 10% says that relationship was deteriorated and 5% people's marriages saw the drastic outcome in the form of divorce or separation.

**Reaction of friends**

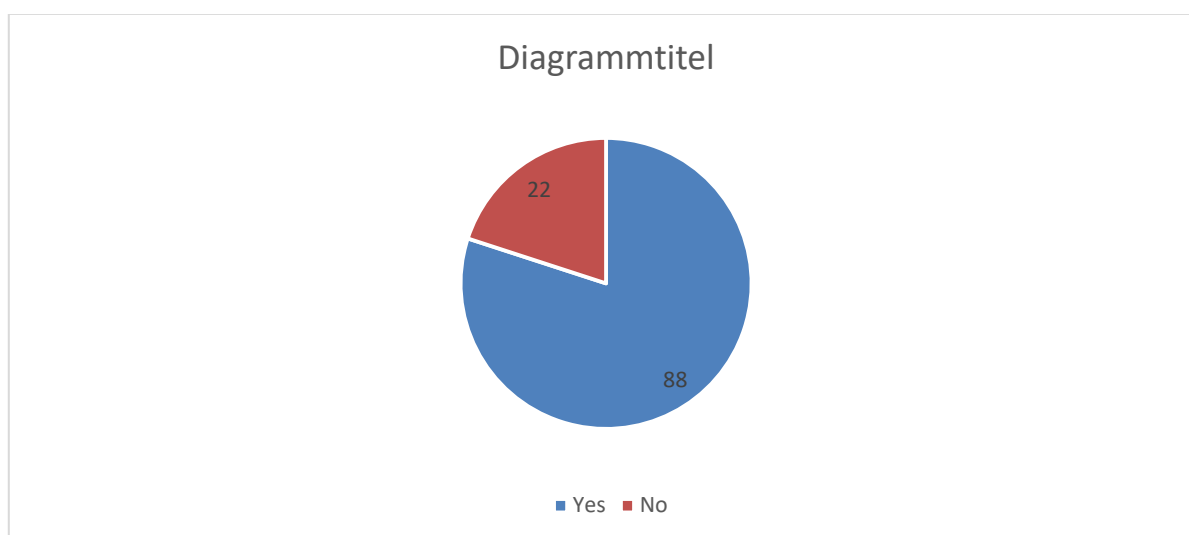
Figure 4. Showing the reaction of friends



The above graph shows the identification of the fact of stigma which is attached to HIV and AIDS. The close friends may get detached after their friends have been declared HIV positive. 52% of the respondents experienced the partial abandonment from their close mates and friends. The major reason for this may be the fear of transmission of HIV. The friends will continue to love and take care of their HIV positive friends but at the same time they keep themselves at back foot when need to come closer. The 10% say that was not a prominent change in such relationships as in before and after. A very less 4% say that they experienced complete abandonment from their friends. There is one more important thing to identify here that 34% of HIV positive persons are still hiding their HIV status to their close and intimate friends. The bar charts show a much-expected numbers as most of the people in Balrampur believe that people diagnosed as HIV positive are just like others who suffer other diseases like diabetes, blood pressure, cancer etc. but this can be somewhat on humanitarian grounds. Most of the people seem to have no complaints with the HIV positive persons but they surely seem to part from such people as well, taking their own health statuses in to considerations. Some of the respondents say the people take this epidemic otherwise and incorrect. They seemingly put a bad tag on it and hence People living with HIV/AIDS do suffer by the same. Only a small number of people say that people, on knowing their status, make bitter faces and show resentment towards them. Here it is further to note that most of respondents have kept their health status secret even from the close relatives. Such people mostly experience self-stigma.

**Reaching health centres and difficulties thereof**

Figure 5. Showing discrimination faced in Hospitals.

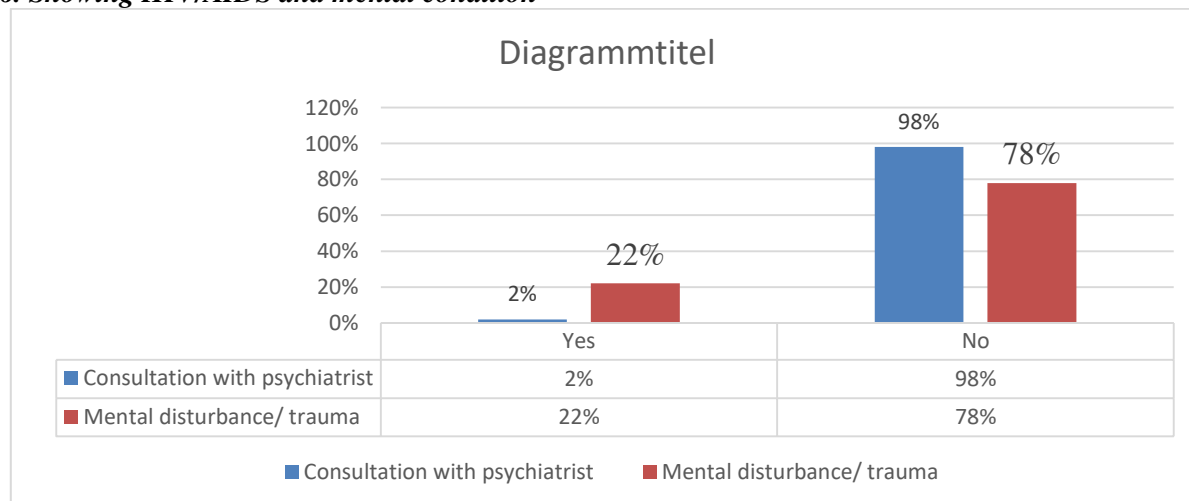


The pie chart shows that the intensity of care and treatment by the medical faculty. 88 % of the respondents admit that they do not face any complications from the medical faculty while availing the medical facilities. About 22 % somehow were not happy with the facilities for the reason they are supposed to visit the ART centre Balrampur each month to get a month's long medication course. There are some very poor who cannot afford even the bus fare. For such reasons they seemed unhappy with the medical administration and government policies. The medical staffs along with the patients feel the necessity for more ART centres in Balrampur

**Impact of disease (HIV/AIDS) on mental state**

HIV seems to have an impact on human beings. The disease alters the course of life of people by creating uncertainty, disturbance, imbalance and chaos to life. During the interview, people stated that they felt broken and started crying. Most of the people also stated that the disease felt like a 'death-sentence'.

*Figure 6. Showing HIV/AIDS and mental condition*



The respondents were asked two questions. One was if the patient felt any kind of mental disturbance or trauma of any sort. 78 percent of respondents replied in the affirmative and twenty-two percent of them replied in the negative. This shows that HIV has an impact on the mental condition of the person. The second question asked was whether they had consulted a psychiatrist ever. Only two percent of the people said yes and the rest ninety-eight percent of people said no for this question. This shows that people do not feel the need to go to a psychiatrist or are unaware about the benefits of going to a psychiatrist.

**6. CONCLUSION:**

Balrampur sees the invasion of labourers coming from different regions and diverse backgrounds, and there is an accumulative movement of Balrampurites to other areas of India where they might pander in high-risk behaviour (Mir, Sofi, Ahmad, Dar, Ahmad & Siddeque, 2010). During late eighties, the HIV/AIDS pandemic saw its way into Balrampur. There are many ways responsible for the spreading of this disease. For example, intravenous Drug Users (IDU), and Unprotected Sex (US) have always been the key factors for the transmission of HIV in the valley. Further, the majority of the people look the epidemic as a disease of people who do not follow the norms of the society. Many



people reject to be treated as the disease is associated with shame and disgust and the people are ignorant about this fatal disease.

## 7. LIMITATION OF STUDY:

In the current research, the small number of sample size is the first limitation, and due to the lack of diversity the findings cannot be generalized to all over the state. However, this study provides insight about the mind-set of people and their attitude towards the people living with HIV/AIDS. Second, collecting data, the researcher found that participants were not so open to respond. Third, since it is a self-report measure, the respondents might not express their real perception, attitude, and experiences fully.

## 8. RECOMMENDATIONS:

- More awareness should be given to the people so that they get knowledge about the disease.
- Policies by Govt. should be improved which can introduce new programs at primary as well as secondary level of education.
- Importance should be given to counselling which also will help people to understand stigmatization and other problems like marginalising etc.
- More and more research should be done on this field.

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