

## **SOCIAL STIGMA AND FAMILY SUPPORT AMONG HIV/AIDS PATIENTS: A PSYCHOLOGICAL ANALYSIS**

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### **ABSTRACT**

*Considering psychological health an eminent part of HIV/AIDS eradication, current study has investigated the role of perceived social support from family and perceived stigma in predicting psychological problems – depression, anxiety, and stress- among HIV/AIDS patients. To achieve the objective of the study quantitative cross-sectional research design was employed where data were collected through survey method. The sample was based upon HIV/AIDS patients and sample size was 200. Data were collected from the district headquarters hospital Sargodha through convenient sampling technique, keeping in view the ethical considerations pertaining to research. The instruments used were Depression Anxiety Stress Scale (DASS) for measuring the psychological problems, Perceived Discrimination Devaluation Scale (PDSS) for evaluating perceived stigma, and Perceived Family Support Scale (PFSS). The scales were pretested and the value of Cronbach alpha range between  $\alpha = .811$  to  $.915$  revealing that instruments used are internally consistent. The findings of the study revealed that perceived social support from the family has significant negative relationship with the psychological problems (depressive symptoms, anxiety, and stress symptoms) among the HIV/AIDS patients. Moreover, the depressive symptoms, anxiety, and stress symptoms were found to be high among the participants reporting increase level of perceived social stigma. Results also revealed that HIV/AIDS related social stigma increased fear of rejection, loneliness, and other psychological issues among the targeted population. The results highlighted that perceived social stigma mediated the relationship between the perceived family support and psychological problems, revealing the fact that it is eminent to prevent the HIV/AIDS related stigma.*

**Keywords:** Social Stigma, Family Support, Stress, Depression, Anxiety, Patients.

### **INTRODUCTION**

Pakistan has been struggling to control the pandemic not because of the medical reasons but for socio-psychological reasons (Ansari et al., 2013). A report published by EMRO (2017), indicated that Pakistan has contributed around 80% of the total AIDS cases with serious social and psychological adversities in the HIV/AIDS patients and their families. In Pakistan, 165,000 individuals are living with the HIV/AIDS. Among them only 24331 (14.7%) HIV-positive individuals are registered with the National AIDS Control Program (NACP) in accordance with statistics of June, 2019. The number of patients receiving antiretroviral therapy is 17149 (70.5%), after being registered to NACP. Among these 7182 (29.5%) did not attend the follow-up therapies for different reasons. Indigenously, lack of awareness, social support, and social stigma lies at the core of spread of the disease hampering the effectiveness of the intervention plans (Ahmed, Hashmi, & Khan, 2019). Alongside, little or no attention to the psychological problems further aggravate the situation in Pakistani context (Bashir, 2011; Santos et al., 2018). Thus, current study has emphasized on the relationship between the perceived social support, perceived social stigma, and psychological problems among the targeted population.

HIV/AIDS has progressed in adverse way and now it is recognized as a medical as well as social issue. HIV/AIDS patients have been subjected to social stigmatization by their colleagues, community, family and friends (Kalichman et al., 2009; Kontomanolis et al., 2017; Mahajan et al., 2008). HIV-related social stigma impose adverse impacts on the physical and psychological well-

being of the targeted population. Fear of social stigma refrain HIV/positive individuals to seek health care services and disclose their HIV status (Rueda et al., 2016; Wong et al. 2009). Social Stigmatization also prevents the effectiveness of the treatment plans associated with the disease under scrutiny (Ma & Loke, 2020). All these facts, aggravates the spread of HIV-virus. Social stigmatization related to HIV/AIDS is quite prevalent in Pakistan and is recognized as one of the main reason behind the spread of the disease (Hussain et al., 2018; Khan & Bilal, 2019). Thus, it is important to address the issue of social stigma related to HIV/AIDS for prolific results.

The adversities caused by HIV/AIDS could be buffered by means of increase social support. Family support is referred as the primary source of social support for the people living with the HIV/AIDS (Xu et al., 2017). AIDS patients with high level of perceived social support from the family tend to reduce the risks behavior associated with the disease, take medications regularly, prevents disease transmission, and are found to have positive outcomes of the treatment (Mi et al., 2020; Okonkwo, Larkan, & Galligan, 2016). Perceived social support from family have found to be inversely related with the negative impacts of the social stigmatization among the HIV-patients (Shrestha et al., 2019). Moreover, the physical and psychological outcomes enhance with the high perceived social support among the targeted population (Garrido-Hernansaiz et al., 2016). Keeping in view the significance of the perceived social support from the family, it has been investigated in relation to other study variables in indigenous context.

HIV/AIDS results in considerable psychological problems along with physical complications (Tesfaye & Bune, 2014). Depression and anxiety disorders the most prevalent psychological burdens borne by the HIV/AIDS patients (Unnikrishnan, Jagannath, Ramapuram, Achappa, & Madi, 2012; Charles et al., 2012; Pappin, Wouters, & Booysen, 2012). The pain of physical ailment increases many folds because of psychological problems making progress near to impossible an inducing hopelessness (Chandra, Desai, & Ranjan, 2005). Psychological problems have a direct positive relationship with the HIV/AIDS progression as revealed by many of the international studies (Parhami et al., 2013; Treisman & Angelino, 2007). In Pakistan, ample work has been done on the physical pains that HIV-positive individuals are facing. But, psychological issues pertaining to the disease have acquire less attention, comparatively (Hafeez, 2018). Not more than 1% of the health budget is invested on mental health issues in developing countries such as Pakistan (Vitoria, Vella, & Ford, 2013). Identified as a less explore research area, current study has reflected upon the relationship between HIV/AIDS and psychological problems among the people living with the HIV virus.

## **REVIEW OF LITERATURE**

### **Perceived Social Stigma**

Stigmatization is strongly associated with the HIV patients, a process that discredits and devalue them that results in social inequality and stress at the individual level (Hamra, Ross, Karuri, Orrs, & D'Agostino, 2005; Herek, 1999; Kontomanolis, Michalopoulos, Gkasdaris, & Fasoulakis, 2017; Thomas et al., 2005). A study conducted in Thailand revealed that the HIV patients are often isolated and this fear of isolation result in delay in access to care (Vanlandingham, Im-em, & Saengtienchai, 2005). People living with this disease were considered as outcasts and untouchable (Adewuya et al., 2009). In many cases, they were not allowed to attend any social gatherings (Lee, Kochman & Sikkema, 2002). Studies have supported the notion that miseries of the HIV patients increase many folds because of the stigmatization (Kontomanolis, Michalopoulos, Gkasdaris, & Fasoulakis, 2017; Olapegba, 2010). Emphasizing on the issue of stigmatization empirical researches have highlighted that it is not only the community that discriminates the HIV positive but also the caregivers and physicians (Doka, Danjin, & Dongs, 2017). Many of the HIV/AIDS patients have reported fierce emotional rejection as a result of stigmatization (Kumar et al., 2017). Despite of the grave impacts of stigmatization on the HIV patients, it is less explored in indigenous context. HIV turns out be a complete trauma for the people living with it, killing them physically and psychologically.

Empirical studies have indicated that actual experience of social stigma among the HIV/AIDS individuals is far less than those who have perceived the stigma. It was found that among the people living with HIV/AIDS only 26% of the individuals have experiences actual stigma. Contrarily, perceived social stigma or fear of stigmatization was found to be 97% (Thomas et al., 2005). Comparatively, perceived social stigma have a high potential to negatively affect the quality of life of

HIV/AIDS patients. Moreover, the environment adversities were also found to escalate more sharply due to perceived social stigma rather than the actual stigma (Nthomang et al., 2009). Perceived social stigma has also been associated with low self-esteem and confidence among the HIV/AIDS infected individuals (Trani et al., 2020). Additionally, perceived social stigma diminishes the determination to live among the people living with the HIV/AIDS epidemic. This relationship is less evident in those who have actually experienced stigmatization (Campbell & Deacon, 2006.). Keeping in view these facts, current study has emphasized on the perceived social stigma in relation to HIV/AIDS. It is important to address the adversities that are caused by stigmatization in HIV patients who are already suffering the worse. The negative impacts of the perceived social stigma associated with HIV/AIDS can be buffered with the social support from family.

### **Perceived Social Support from Family**

Family plays a crucial role in enhancing the health of its ill members by offering them care and support for preventing disease. In reference to HIV/AIDS, family support lies at the core to prevent the transmission of disease, educating individuals, and endorsing behaviors that reduce the risks related to HIV/AIDS among those living with it (Amiya et al., 2014). In accordance to American Psychological Association, family is the de facto caretaker for the individuals living with HIV/AIDS (Badahdah, 2016). Richter et al., (2009) states that HIV/AIDS is a family disease as without support from the family effectiveness of prevention could not be prolific. UNAIDS has also emphasized on the role of family in controlling the adversities of HIV/AIDS (Mohanani & Kamath, 2009; Webster, 2019). Recent researches on HIV/AIDS have revealed that best intervention and prevention strategies were those that have involved the couples and family centered approaches. Such interventions enhanced the positive outcomes of HIV/AIDS treatment and care (Myer et al., 2014).

Social support from the family lies at the core of productive psychosocial management (Modabbernia, Ashrafi, Malekzadeh, & Poustchi, 2013). Research indicated that perceived family support enhances the mental state of individuals suffering through the HIV/AIDS (Caress, Luker, Chalmers, & Salmon, 2009; Vermaas, 2010). As part of a family, HIV/individuals expect aid, assistance, and support from their family and on fulfillment of their expectations their subjective-well-being enhances to a significant extent (Pinquart & Sorensen, 2000; Thomas, 2010). Moreover, perceived family support is recognized as a protective factor that enhances the psychological well-being by mitigating the psychological problems pertaining to the disease (Asante, 2012; Gonzalez et al., 2004). Keeping in view these facts, it is evident that perceived family support is significantly positively related with the effective treatment and improved quality of life of people living with HIV/AIDS patients. Thus, requires attention from the researchers and policy makers.

### **Psychological Problems**

Psychological problems related to HIV/AIDS patients include emotional, cognitive, behavioral, and vegetative problems. HIV/AIDS positive individuals show persistent crying and sadness revealing their emotional disturbance (Singer & Thames, 2016). Cognitively, they are found to be more pessimistic and well-equipped with negative beliefs about their life and health. Moreover, recurrent thoughts of death, suicide ideations, and guilt is also quite evident leading them to serious psychological problems that mainly includes depression disorder. Apart from this, their psychological problems are reflected in their behavior as well. They are found to have low level of motivation towards the treatment and medication and towards life activities (American Psychiatric Association, 2012a). In many cases of HIV/AIDS, patients suffer from disturbed sleep, menstruation, bowel function, improper bladder activities, and eating patterns (Koen, Uys, Niehaus, & Emsley, 2007). As a result, they struggle to maintain their life that leads social retardation, sense of worthlessness, lower self-esteem, and demoralization (Basavaraj, Navya, & Rashmi, 2010). Thus, it can be stated that psychological problems must require as much attention as the medical complications among the HIV/AIDS individuals.

Of the many psychological problems diagnosed in HIV/AIDS patients the most prevalent were depression, anxiety disorders, and stress (Pence, Miller, Whetten, Eron, & Gaynes, 2006; Remien et al., 2019). An empirical study has revealed that the prevalence rate of stress related psychological problems is 72%, for anxiety disorders it is 70%, and for depression it is 55%, among the HIV/AIDS patients. These psychological problems are found to be prevalent in symptomatic and

asymptomatic patients of HIV/AIDS (LeRoy & Barnes, 2005; Rizwan & Irshad, 2012). For these reasons, current study will emphasize on the prevalence of the aforementioned psychological problems among the HIV/AIDS patients in Pakistan.

### **Purpose of the Study**

The HIV epidemic in Pakistan has turned out to be more grave as compare to other Asian countries. It has moved from low prevalence to concentrated epidemic in a short period of time (WHO, 2016). The potential reasons behind this were found to be escalated perceived social stigma associated with the disease, negligence of family members, and unaddressed psychological problems (Malcolm et al., 1998; Sun, Zhang, & Fu, 2007; Vanable, Carey, Blair, & Littlewood, 2006). These aspects tend to refrain the people living with HIV/AIDS to adhere with their treatment plans (Malcolm et al., 1998). Keeping in view these facts, current study would evaluate the extent to which people living with HIV/AIDS face perceived social stigmatization and how it is related to psychological problems that they face. Moreover, the buffering effect of perceived social support from the family would also be explored which seem to be gap in literature in indigenous context. Also, the psychological problems that remains unaddressed by the intervention plans in Pakistan would also be brought in limelight. In this vein, a more effective and practical intervention plans could be formulated that would specifically focus on the adversities that the indigenous population living with HIV/AIDS are facing.

### **Objectives**

Following are the main objectives of the study:

- To investigate the relationship between perceived social stigma and psychological problems among the HIV/AIDS patients.
- To investigate the role of perceived social support from the family in dealing with the psychological problems and perceived social stigma among the HIV/AIDS patients.

### **Hypothesis**

Following are the main hypothesis to be tested to achieve the objectives of the study:

1. There is a positive relationship between perceived social stigma and psychological problems (stress, anxiety, and depression).
2. Perceived Family support would negatively correlate with perceived social stigma in HIV/Aids patients.
3. Perceived Family support would negatively correlate with psychological problems in HIV/Aids patients
4. Perceived Social stigma acts as a mediator between perceived family support and psychological problems.

### **THE DATA AND METHODS**

For this study, a quantitative cross-sectional research design was employed. A survey method technique was opted to conduct the study. A sample of 200 HIV/AIDS patients was sampled through convenient sampling technique from district headquarters hospital Sargodha. The measurement scales were used including Demographic Sheet, Depression Anxiety Stress Scale (DASS), Perceived Discrimination Devaluation Scale (PDSS), and Perceived Family Support Scale (PFSS). It was pretested before the final data collection and the value of Alpha was ranging from .811 to .915. Further, statistical analysis including Cronbach Alpha and Split-Half reliability coefficients test and an OLS multiple linear regression analysis had been employed to test the hypotheses and draw conclusions using Statistical Package for Social Sciences (SPSS). Likewise, the study findings were elaborated the developing settings of the area.

### Operational Definition of Each Variable

**Perceived social stigma.** In the current study, the operational definition of perceived social stigma has been drawn from Goffman theory of stigmatization while emphasizing on the micro and meso- level effects social stigma on the HIV/AIDS patients. By adopting the psychological and sociological approach perceived social stigma has been defined as *a type of stigma in which a person internalizes the beliefs that the society hold prejudice against them and devalue them for their human differences as a result of which they have to face discrimination and status loss* (Clair, Daniel, & Lamont, 2016; Corrigan & Rao, 2012).

**Perceived family support.** Study has taken into account the extent to which an individual considers his/her family members supportive and offering hand in dealing with the disease, rather than taking into account the actual support that the family members would have been offering. In this vein, perceived social support has been defined as how people living with HIV/AIDS perceive their immediate family members as sources available providing them with material, psychological, and overall support to cope with the adversities associated with HIV/AIDS (Siedlecki, Salthouse, Oishi, & Jeswani, 2014).

**Psychological problems.** The study has emphasized on the severe as well as mild psychological symptoms that people living with HIV/AIDS would have been dealing with. Unlike previous studies, current study has remained open in addressing the psychological issues that the targeted population has been facing. The emphasizes has not been limited to the patients who were clinically diagnosed with mental disorders. In this context, Psychological problems have been defined as *“a board concept that incorporates both more severe psychological symptoms and less serious mental strains that could negatively impact an individual’s emotional regulation, cognition, or behavior leading to impairment in social, individuals, occupation, and other areas of functioning”* (Granlund et al., 2021).

### RESULTS

This section provides the results and discussion. It consists of descriptive statistics and an OLS multiple regression analysis along with standard errors and parameter estimates.

Table 1 reveals that internal consistency of the measures used in the study are high as indicated by their alpha coefficients. The reliability coefficients show good reliability indices for both the scales that are PPSS and PFSS. Moreover, the mean score of the participants on PPSS was 29.90 ( $SD = 11.28$ ) indicating that majority of the participants scored low on the scale. Whereas, for PFSS the average scores are found to be 80.62 ( $SD = 12.49$ ) indicating that perceived family support was fairly good for most of the participants in the study. Additionally, values of the standard deviation indicate that dispersion of the scores around the mean is low for the PPSS as compared to PFSS. Furthermore, the value of skewness and kurtosis is also in acceptable range indicating that data is normally distributed. Similarly, the results also reveal the descriptive statistics and internal consistency of the three measures that are depression, anxiety, and stress that reflect the presence of psychological problems in the sample of the study. Results reveals that reliability coefficients for all the three measures are good ranging between .81 to .91. Table 2 depict that the mean score is higher for the stress symptoms ( $M= 19.20$ ,  $SD= 7.19$ ) as compared to depression ( $M= 16.77$ ,  $SD= 9.30$ ) and anxiety ( $M= 17.13$ ,  $SD= 7.15$ ). Moreover, dispersion of the scores is highest for the depression scale. Additionally, the values of skewness and kurtosis are within range that is -2 to +2 indicating that data is normally distributed.

**Table 1**  
**Descriptive Statistics, Cronbach Alpha and Split-Half Reliability Coefficients Test (n=200)**

Scales	k	A	M	SD	Skewness	Kurtosis	Range	
							Potential	Actual
PPSS	12	.91	29.90	11.28	.17	-.66	12-72	12-66
PFSS	30	.88	80.62	12.49	-.41	.26	30-120	46-108
<i>Note.</i> PPSS = Perceived Public Stigma Scale; PFSS = Perceived Family Support Scale								
Depression	14	.91	16.77	9.30	.24	-1.06	0-42	1-42

Anxiety	14	.83	17.13	7.15	.12	-.85	0-42	1-34
Stress	14	.81	19.20	7.19	.25	-.66	0-42	6-38

*Note.* DASS = Depression, Anxiety, Stress Scale

Table 2 shows the possible mediation of perceived social stigma for the effect of perceived family support on depression. There is a significant total effect ( $\beta = -.53, p = .00$ ), and a significant direct effect ( $\beta = -.43, p = .00$ ) of perceived family support on depression. Mediation of perceived social stigma in the model was observed with a significant indirect effect ( $\beta = -.09, CI = -.16, -.04$ ). Similarly, the results also indicate the possible mediation of perceived social stigma for the effect of perceived family support on anxiety. There is a significant total effect ( $\beta = -.39, p = .00$ ), and a significant direct effect ( $\beta = -.35, p = .00$ ) of perceived family support on anxiety. Mediation of perceived social stigma in the model was observed with a significant indirect effect ( $\beta = -.04, CI = -.09, -.005$ ). Further, statistical analysis also depicts the possible mediation of perceived social stigma for the effect of perceived family support on stress. There is a significant total effect ( $\beta = -.41, p = .00$ ), and a significant direct effect ( $\beta = -.34, p = .00$ ) of perceived family support on stress. Mediation of perceived social stigma in the model was observed with a significant indirect effect ( $\beta = -.07, CI = -.12, -.04$ ).

**Table 2**  
***An OLS Multiple Linear Regression Analysis for Mediation by perceived social stigma for the relation between perceived family support (N = 200)***

Variables	Depression			
	Model 1		Model 2	
	$\beta$		95% CI	
Perceived family support	-.47**	-.43**	-.57	-.36
Perceived social stigma (M)		.19**	-.01	.07
R <sup>2</sup>	.26	.54		
$\Delta R^2$		.28		
F	70.19	117.69		
$\Delta F$		47.5		
Constant	67.29**	45.86**	37.49	54.23
Anxiety				
Perceived family support	-.47**	-.35**	-.42	-.28
Perceived social stigma (M)		.09**	.01	.16
R <sup>2</sup>	.26	.48		
$\Delta R^2$		.22		
F	70.19	91.73		
$\Delta F$		21.54		
Constant	67.29**	42.71**	35.85	49.57
Stress				
Perceived family support	-.47**	-.34**	-.40	-.28
Perceived social stigma (M)		.16**	.09	.23
R <sup>2</sup>	.26	.56		
$\Delta R^2$		.30		
F	70.19	128.41		
$\Delta F$		58.22		
Constant	67.29**	41.82**	35.50	48.13

## DISCUSSION

In order to test the proposed hypothesis of the study, researcher has employed quantitative research technique where data was collected through questionnaire based survey technique. It is widely used research technique in the academic settings offering valid and reliable results. Researcher has preferred this method as the study is cross-sectional in nature and it has to be completed in a fixed time frame and in limited resources and quantitative research design requires less resources and time, comparatively. The results acquired from a quantitative study are also found to be more objective, comparatively. (Park & Park, 2016). Moreover, the survey technique has assisted the researcher to collect large data in short time (Ponto, 2015). The core purpose of the study was to investigate the given phenomenon rather to explore that further validates the selection of the quantitative research method.

Descriptive statistics of the study revealed that all the measures used in the study were having good reliability with alpha coefficient ranging between .81 to .91. As a rule of thumb alpha coefficient greater than .80 and less than 0.95 indicates good reliability as indicated by Ursachi, Horodnic, & Zait, (2015). Thus, the measures used for statistically approved. Additionally, the values of skewness and kurtosis indicated that the data is normally distributed as their value were in the acceptable range that is -2 to +2 as indicated by Kallner and Theodorsson, (2020). However, data were positively skewed for all the variables except for the PFSS which was negatively skewed indicating that the data was skewed to the left. Moreover, there were negative value of kurtosis for PPSS, depression, anxiety, and stress that reveals flatter distribution of the data for the variables. Whereas, PFSS was positively skewed indicating peaked distribution of the data (Field, 2005).

Multiple linear regression analysis was conducted to evaluate if perceived social stigma mediates the relationship between perceived family support and psychological problems. Results revealed that perceived social stigma significantly mediated the relationship between perceived family support and the psychological problems. There was a direct relationship between the perceived social support from the family and the psychological problems that includes depression, anxiety, and stress. The independent and dependent variables were inversely related that in with increase in perceived family support psychological problems significantly decreased (Lindsey, Joe, & Nebbitt, 2010). But, with increase in perceived social stigma the relationship weakened as it has negatively affected the effectiveness of the perceived family support. Findings of the study were supported by the past studies revealing that there is a direct impact of perceived social stigma on the relationship between the perceived family support and psychological problems (Gohain & Halliday, 2014). Perceived social stigma potentially decreases the positive impact of perceived family support in reducing the psychological problem (Shrestha et al., 2019).

With increase in perceived social stigmatization the perceived family support decreases because of fear of being infected, and shame and guilt associated with the disease. Family prefer to keep distance from the member of the family living with HIV/AIDS to assure that they are no more connected with the infected and thus, the discriminated attitude should not be extended to them. Consequently, individual feels more isolated, helpless, and hopeless that potentially increase the psychological problems causing emotional, cognitive, and behavioral dysfunction (Garrido-Hernansaiz, Heylen, Bharat, Ramakrishna, & Ekstrand, 2016). Another possible justification for the decrease in perceived social support with increase in perceived social stigmatization is that as people with HIV-positive progress to AIDS the symptoms associated with the disease become more repulsive and disruptive that potentially increase the difficulties for the family. Moreover, the adversity in symptoms make the disease more evident that further increase the chances of stigmatization (Herek, 1999; Jones, 1984). Thus, Hypothesis 8 has been confirmed by the results of the study and supported by the past literature.

On the whole from the results of the study, it has been deduced that the psychological problems require as much attention as the physical problems among the targeted population. Moreover, considering the negative impacts of perceived social stigmatization proper awareness are required that could inculcate in the targeted population that social stigma is a menace and major threat to the lives of HIV/AIDS individuals. Family support need to be promoted among the targeted population as it has positive impact on their physical and mental health.

## CONCLUSION

The overall conclusion that we reached based on the study findings revealed that perceived social support has significant positive relationship with the psychological problems among the HIV/AIDS patients. The depressive symptoms, anxiety, and stress symptoms were found to be high among the participants reporting increase level of perceived social stigma. HIV/AIDS related social stigma increase fear of rejection, loneliness, guilt, shame, irrational thoughts, reduced social support, and negative attitude from the community with irrational judgment on moral and religious grounds. Similarly, potentially increased the psychological problems among the HIV/AIDS. The study findings pointed out that perceived social stigma mediated the relationship between the perceived family support and psychological problems, revealing the fact that it is eminent to prevent the HIV/AIDS related stigma.

#### **Limitation of the Study**

This research is based on quantitative approach and does not include qualitative methodology or data.

#### **Future Implications**

This research will become the part of existing body of literature and may be used to create awareness to minimize social stigma. Further, research may be conducted using mixed method approach on the similar settings.

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