

# PERCEIVED STIGMA SOCIAL SUPPORT AND PSYCHOLOGICAL WELL BEING IN HIV PATIENTS

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#### **ABSTRACT**

#### **OBJECTIVE**

To investigate the relationship between perceived stigma, social support and psychological well-being in HIV patients.

#### STUDY DESIGN

Co relational research design

# PLACE AND DURATION OF THE STUDYHIV

positive patients from two hospitals situated in the city of Lahore were selected in year 2015.

# **SUBJECTS AND METHODS**

Sample comprised of N=148 HIV positive patients with age ranged from 25 to 50 years. Perceived stigma was assessed through HIV/AIDS Stigma Scale. Social support was measured through Multidimensional Social Support Scale and psychological well-being was assessed through The Warwick-Edinburgh Mental Well-being Scale (WEMWBS).

## **RESULTS**

Results of the study showed that Perceived stigma (verbal abuse, social isolation, negative self-perception and fear of contagion) had a negative relationship with social support (significant others, family and friend) and psychological well-being. Moderation through Hierarchal regression analysis revealed that education was a predictor of psychological well-being. Perceived stigma (fear of contagion and negative self-perception) negatively predicted while social support (friend, family and significant others) positively predicted psychological well-being in HIV patients. Interaction was found between perceived stigma (fear of contagion) and social support (friends).

## CONCLUSION

Perceived social support has found to buffer the bad effect of stigma related to HIV.

## **KEY WORDS**

Perceived Stigma, Social Support, Psychological Well-Being.

## INTRODUCTION

HIV Human Immuno-Deficiency Virus is a public health issue worldwide. HIV prevalence is reported to be 0.8% globally with majority of these people living in low income countries including Pakistan¹. The term stigma indicates that the person stigmatized is of lesser value². HIV infection duration may intensify trauma symptoms and deteriorate social support. Perceived available social support may act as a buffer against HIV-related trauma symptoms³. HIV is a condition that is mostly stigmatized and consequently affects one's physical health and psychological well-being⁴.

Stigma associated with HIV/AIDS refers to prejudice, ignoring, slurring, and discrimination directed at persons who have AIDS /HIV, and also the groups and societies with whom they are related. Discrimination occurs in HIV patients and is seen in form of biased and unfair behavior of people due to actual or apparent HIV position<sup>5</sup>. Individuals with HIV can be a victim of hatred, gossips and verbal abuse in the society. The consequences can also involve life-threatening deprivation, refusal and desertion<sup>6</sup>. Therefore, individuals with HIV have a dire need of social support to cope effectively. Social support refers to various types of aid and support provided by members of one's social network. Social support is the process of interaction or communication in relationships which increase survival, self-worth, belonging and capability through actual or perceived exchange of physical or psychosocial resources7. Social support is a network of family, friends, neighbors and community member that is accessible in times of necessity to give emotional, physical and financial help'. Social support is the verbal and nonverbal interaction among receivers and suppliers that declines the indecision about state, the self, and the other or the relationship, and increases awareness of individual's control in one's life experience<sup>2</sup>.

Psychological well-being is a state characterized by health, happiness and prosperity. Well-being is a dynamic notion that contains personal, emotional, societal and psychological extents along with health connected deeds8. Wellbeing is equal to happiness and meaning in life9. Stigma and its accompanying negative consequences are source of stress which intensify anxiety and the feelings of helplessness and hopelessness that frequently accompany the course of HIV-related illness. Researches have showed that HIV stigma can have negative effect on the willingness to disclose one's status and on receiving and requesting social support. There is an inter-relationship among humiliation, confession and emotional functioning; findings revealed that as the level of observed stigma increases the level of disclosure and psychological well-being reduces 10. Psychological well-being and social support are interrelated. People who have high social support have less chances of getting depressed due to their illness. Social support provided by family members, spouse, friends, colleagues, or community members creates a buffering effect for HIV patients9. It results in an improved well-being and improved quality of life of the patients. The delivery of

# Journal of Pakistan Psychiatric Society

social support will allow patients with HIV to manage well with their illness, which might lead to a sense of gratification, contentment and confidence. This might similarly lead to the decline in humiliation and discernment to HIV, and it may also boost an exposed argument about HIV and provide free exposé of HIV position. Social support encourages social inclusion and enhances psychological well-being of patients with HIV<sup>11</sup>.

Since local literature is scarce upon the interaction of these variables, present study was designed to investigate the relationship between perceived stigma, social support and psychological well-being in HIV patients.

## **SUBJECTS AND METHODS**

## **Participants**

The sample consisted of 148 HIV positive patients with age ranged from 25 to 50 years. Sample was enrolled from hospitals located in the city of Lahore. These hospitals included Services Hospital and Jinnah Hospital. Demographic information including age, gender, education, and occupation were recorded. HIV positive patients who were currently under treatment and were taking antiretroviral therapy (ART) were included. Those taking medication for any severe psychiatric disorder like depression or anxiety were not included because their psychological well-being was already affected due to these psychiatric disorders. Patients who had not disclosed their HIV positive status to their family and friends were not included in the study.

## Measures

#### The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)<sup>12</sup>

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) was used to assess psychological well-being of HIV patients. The Questionnaire comprises of 14 positively worded item designed to assess psychological well-being on a 1–5 response scale (1= none of the time, 2= rarely, 3= some of the time 4= often and 5 = All of the time). The score on this scale range from 14-70. The reliability of the scale is  $\alpha=.83$ . The Warwick-Edinburgh Mental Well-being (WEMWBS) Urdu version scale was used for this study after taking the permission from author 12.

# HIV/AIDS Stigma Scale - PLWA (HASI-P)13

HIV/AIDS Stigma consisted of 33 items and had five factors: (i) Verbal Abuse (8items items) had reliability 0.88 (ii) Negative Self-Perception (5items) had alpha reliability 0.91 (iii) Healthcare Neglect (6items), had alpha reliability 0.83, (iv) Social Isolation (6items) had alpha reliability 0.89(v) Fear of Contagion (6 items) had alpha reliability. This scale has 4-point likert scale (0 = Never, 1 = once or twice, 3 = several time and 4 = Most of the time). The total alpha reliability of this scale was .86. Total score is obtained by the sum of all responses. Higher scores indicate higher levels of perceived stigma. The permission has been taken from the original author for the use of scale. The scale was translated in Urdu with the permission of the author.13

# Multidimensional Social support scale 14

The Multidimensional Social support scale is 12 item scale assessed the perception of emotional, informational, structural social support form family, friends and significant others. The scale offers 7- point response range from very strongly disagree (1) to very strongly agree (7). Total score is obtained by the sum of all responses. Higher scores indicate higher levels of perceived support. The test retest reliability coefficient was .85. The Urdu version of Multidimensional Social support scale was used for this study with the permission of original author and also from the author who translated this scale in Urdu version<sup>14</sup>.

#### **Procedure**

The formalities for approval of research project were fulfilled duly. The scale translation was done following the MAPI guidelines. A pilot study was carried out to assess the reliability of the translated scales. The participants were recruited from O.P.Ds of public sector hospitals in Lahore, Pakistan. The formal ethical considerations were maintained while administration of assessment measures. The response rate was 83 %.

#### **RESULTS**

The sample comprised of n= 148 participants with an age range from 25-50 years (M= 33.14, S.D= 9.25). 73% of the HIV infected  $participants\,were\,males\,and\,among\,them\,65\%\,were\,uneducated\,and$ 71% of them were currently working. 89% males and 90% females were married and reported living in a joint family system (88% males and 95% females). 55% males and 58% females were from an urban background. 72% of males reported having an average monthly income of 10,000 PKR. The overall mean age at diagnosis of HIV for the study participants was 30. 16 years (S.D= 9.72). Reliability coefficient of the perceived stigma (verbal abuse, negative selfperception, healthcare neglect, social Isolation, fear of contagion), multidimensional social support (Significant others, family and friends) and psychological well-being Scale. All study variables had good reliability i.e. .92, .72, .84, .86, .89, .92, .94, .92, .97 and .94 respectively, except health care neglect that is .55. When the covariates (education and family background) entered as control variable to assess the predictive significance on psychological wellbeing 76% variance came in the overall model that is  $\Delta F$  (2, 144) = 5.93, p<.01.

Bivariate correlations analysis was used to find out the relationship between perceived stigma (verbal abuse, negative self-perception, healthcare neglect, social isolation and fear of contagion) social support (significant others, friend and family) and psychological wellbeing. There is a positive relationship of perceived stigma (verbal abuse) with negative self-perception, r = .71\*\*, p < .01, social isolation, r = .60\*\*, p<.01, and fear of contagion, r = .74\*\*, p<.01 and negative relationship with social support (friends, family significant others), r = -.54\*\*, p<.01, r = -.52\*\*, p < .01, r = -.52\*\*, p<.01 and psychological well-being r = -.77\*\*, p < .01. Results showed that negative self-perception had positive relationship with perceived stigma (social isolation and fear of contagion) r = .63\*\*, p < .01, r =.64\*\*, p<.01 and negative relationship with social support (friend, family significant others) r = -.51\*\*\*, p<.01, r = -.54\*\*\*, p<.01, r = -.57\*\*\*, p<.01 and psychological well-being r=-.62\*\*, p<.01. There is a positive relationship of healthcare neglect with social support (friend), r=.26\*, p<.01. A positive relationship of social isolation with fear of contagion r=.65\*\*, p<.01, and negative relationship with social support (friend, family significant others) r=-.59\*\*, p<.01, r=-.60\*\*, p<.01, r=-.55\*\*, p<.01 and psychological well-being r=-.67\*\*,

# Journal of Pakistan Psychiatric Society

patients with HIV even when the level of observed stigma increases, talking with significant others like family members and friends helps to reduce feelings of distress and associated anxiety<sup>10</sup>. Social support is likely to prevent in negative appraisal of stress and people with high social support tend to reappraise the stress in a positive manner. Social resources act as buffers for stress associated with illness<sup>11</sup>. So it can be safely concluded that patients with HIV who have social support of significant others have greater wellbeing even in face of stigma. Our findings are in line with earlier findings in which researchers have documented protective and positive effects of social support in case of stress <sup>5, 7, 11, 15, 19</sup>. The findings of our study strengthen the buffering hypothesis 11; protecting patients with HIV from potential harmful effects of stigma.

# LIMITATIONS AND SUGGESTIONS

The sample was not representative of the financially well-off class as participants were only recruited from 2 hospitals, which makes the population quite restricted, not allowing diversity of social classes, prevalent within our society. The assessment measures were administered in the hospital setting and external factors like noise and other distractions cannot be ruled out. Since participants did not have sufficient privacy during the assessment as some of them were accompanied by family members, response bias is likely to exist. This is a correlational study that limits our ability to form conclusions regarding the causal associations between HIV stigma and psychological wellbeing.

#### **IMPLICATIONS**

Social support from significant others has a considerable association with psychological well-being. Health psychologists and physicians can psycho-educate and counsel HIV clients and their families about the importance and buffering effects of social support. The findings obtained in this study need to be confirmed in future prospective studies. Examining the multiple processes that link social support to wellbeing may shed light on the extent to which various dimensions of social relationships serve as health-protective resources. This information, in turn, could aid in designing interventions that utilize social resources to promote successful psychological resilience in patients with HIV/AIDS.

# CONCLUSION

Besides improving medical and psychological health care facilities, work needs to be done at reducing stigma, discrimination and bias towards people with HIV. General public needs to be educated to restructure their stereotype thinking about the stigma associated with HIV/AIDS.

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p<.01 was found. There is a negative relationship of fear of contagion with social support (friends, family, significant others) r=-.68\*\*, p<.01, r=-.67\*\*, p<.01, r=-.52\*\*, p<.01 and psychological well-being r=-.79\*\*, p<.01. There is a positive relationship of social support (friends, family and significant others) with psychological well-being r=.63\*\*, p<.01, r=.68\*\*, p<.01, r=.64\*\*, p<.01.

Education was only predictor of psychological well-being while family background did not predict psychological well-being. In step 2 the effect of social support (significant others, family and friend) on psychological well-being was seen. After controlling the effect of covariates, 47% variance came in the overall model that is  $\Delta F$  (3,141) = 50.59, p<.01. Results showed that social support (significant others, friends and family) all predict psychological well-being. In step 3

 Table 1

 Differences between mothers and fathers on various dimensions of stress scale.

Predictors	Psychological well being	
	$\Delta R^2$	В
Step 1	.07**	
Education		.27**
Family background		.13
Step 2	.47***	
Family		.22**
Friend		.33***
Significant others		.39***
Step 3	.10***	
Verbal Abuse		.13
Negative self-perception		13
Health care neglect		05
Social isolation		.01
Fear of contagion		22*
Step 4	.05	
Verbal Abuse x Significant others		.14
Verbal Abuse x Family		03
Verbal Abuse x Friend		.12
Negative self-perception x		04
Significant others		
Negative self-perception x Family		.16
Negative self-perception x Friend		09
Healthcare Neglect x Significant		13
others		
Healthcare Neglect x Family		40
Healthcare Neglect x Friend		41
Social isolation x Significant		12
others		
Social isolation x Family		03
Social isolation x Friend		.21
Fear of contagion x Significant		24**
others		
Fear of contagion x Family		28
Fear of contagion x Friend		27
Total R <sup>2</sup>		.71*

perceived stigma (verbal abuse, negative self-perception, healthcare neglect social isolation and fear of contagion) explained 10% variance  $\Delta F$  (8, 136) = 8.01, p<.01and only perceived stigma (fear of contagion) predicted well-being negatively. In the final block, when interaction term of Perceived stigma and Social support were added, the observed variance was 50%, F (15, 121) = 1.74, p < 0.05, so interaction between perceived stigma (fear of contagion) and social support (significant others) were found.

The interaction plot explained that at high level of moderator a relationship between perceived stigma (fear of contagion) and psychological well-being exists  $B = -.752 \ p = 0.00$ . It means the patients who had more social support from significant other have less fear of contagion and have high psychological well-being. At a low level of moderator the nature of relationship between perceived stigma (fear of contagion) and psychological well-being was found  $B = -0.9^{***}, \ p = 0.00$ , it means that when social support from significant others is low then fear of contagion is high and psychological well-being is low.

#### DISCUSSION

(discussion is too small, please elaborate your results and compare them with previous findings)

Results of the current study confirm that education has positive relationship with wellbeing. Educated patients with HIV had greater psychological wellbeing. Education has found to have a positive association with wellbeing6. Research endorses that educated patients were better off at taking care of their physical and mental health needs compared with the uneducated ones<sup>4</sup>.

In our study social support was found to have a main positive effect when (fear of contagion was not entered into the model). Fear of contagion had a negative main effect when effect of social support was significant. Social support of friends, family and significant others appear to have a positive influence on one's psychological well-being 11. Patients who had more social support from significant other had less fear of contagion and reported greater psychological well-being. Results of our study highlight the grim societal bias and discrimination towards people with HIV<sup>15</sup>, and reveals that social support<sup>16</sup> tends to have a considerable buffering effect on psychological wellbeing. Perceived social support has found to buffer the ill effect of disease and stigma<sup>17</sup>.

In our study high social support from (significant others) even when fear of contagion is high does not affect wellbeing; it remains fairly stable. Literature highlights that people with lack of social support, suffering from medical illnesses tend to feel more distressed during the course of their illness and ongoing medical treatment<sup>10</sup>. Results of our study reveal that low social support from (significant others) when fear of contagion is high decreases wellbeing Research endorses that people with HIV tend to have greater psychological wellbeing if they have social support from family, friends and significant others<sup>18</sup>. Patients diagnosed with HIV tend to have associated features of depression, usually when they are unable to share their misery and experiences related to stigma; with significant others <sup>19</sup>. Perceived social support tends to reduce the feelings of discrimination and bias created in patients with HIV and helps to improve their psychological health<sup>19</sup>. Research validates that in