

## Psychological Distress, Affiliate Stigma and Burnout in Caregivers of Patients with Schizophrenia

Ayesha Asghar<sup>1</sup> & Saima Majeed<sup>2</sup> & Farah Malik<sup>3</sup>

<sup>1,3</sup> Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan

<sup>2</sup> F C College: A Chartered University, Lahore, Pakistan

Correspondence: Ayesha Asghar, University of the Punjab, Lahore Pakistan.

Email: psychologistayesha@yahoo.com

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**Abstract:** The present study aimed to investigate the relationship between psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. It was hypothesized that there is likely to be a positive relationship between psychological distress, affiliate stigma and burnout and psychological distress and affiliate stigma are likely to predict burnout in caregivers of patients with schizophrenia. Differences for gender and caregiver's relationship were also examined. The sample consisted of ( $N=150$ ) caregivers including parents and spouse with age range 25 to 50 years ( $M = 41.28$ ,  $SD = 7.49$ ). Cross sectional correlational research design and purposive sampling technique was carried out to collect data from psychiatry units of four government hospitals. Measures for data collection were Kessler Psychological Distress Scale (Kessler, Andrews & Colpe, 2002), Affiliate Stigma Scale (Mak & Cheung, 2008) and Burnout Measure (Pines & Aronson, 2005). The results revealed a significant positive relationship between all the study variables. Results also indicated that psychological distress and affiliate stigma predict burnout. According to the results no significant gender differences were found in all the study variables. Parents and spouses were found to be significantly different on affiliate stigma. The findings of the present study are speculated to have sound implications in the clinical settings for planning interventions in order to reduce psychological distress, affiliate stigma and burnout in caregivers.

**Keywords:** Psychological Distress, Affiliate Stigma, Burnout, Caregivers of Patients with Schizophrenia

### 1. Introduction

Schizophrenia is a severe psychological disorder that disturbs numerous executive functions. Care of a person with schizophrenia involves multiple burdens, possibly leading to burnout (Astrom, 1991). Burnout can be defined and personally experienced as a state of physical, emotional and mental exhaustion caused by long-term taking part in situations that are emotionally demanding (Saliari et al., 2011). In many social circumstances, patients unable to perform functions properly due to this relatives feel sad and distressed. Frantic families feel pessimistic, start to live alone and withdrawal from the society in order to avoid stigmatization and discrimination (Mak & Cheung, 2008). Caregivers have to experience stigmatization because of their ill relatives which is termed as affiliate stigma. It is defined as

the stigma experienced by family members as a consequence of being associated with a stigmatized relative (Larson & Corrigan, 2008).

Stigmatized individuals frequently face discrimination, due to this discrimination they could not get opportunities in many domains including education, relationships with friends and relatives, marriage prospects and employment (Time to Change, 2008; Social Exclusion Unit, 2008; Time to Change, 2009). Many researches have been done on the symptoms of schizophrenia in order to check their impacts on burnout. The findings of every study were different. In different studies hallucinations, delusions, speech and disorganized behaviors were evaluated as positive while alogia, asociality, avolition and apathy were evaluated as negative symptoms. Some researchers said that predisposing factors to burnout are negative symptoms, while others suggested positive symptoms (Kate et al., 2013).

A few decades back, psychiatric hospitals and clinics were responsible for caring of patients with severe mental illness like schizophrenia. In the past, the functions which were performed by psychiatrists and psychologists, now-a-days these are performed by family members. Most of the caregivers experience psychological distress because of providing care to the patients from long duration. Psychological distress is a state of emotional suffering characterized by symptoms of anxiety (feeling tense and restlessness) and depression (sadness, pessimism and loss of interest) (Mirowsky & Ross, 2002). These progressions bring burden and negative changes in family's satisfaction from life. There is a research evidence to suggest that greater level of burden was experienced by those caregivers who were providing care to the patients for long duration (Sreeja et al., 2008). Caregivers and other relatives feel stressed because of having patient with schizophrenia (Martens & Addington, 2001). Therefore, caregiver's burden and their satisfaction from life has been documented increasingly because of their family member suffering from schizophrenia (Caqueo et al., 2009). Researchers found that higher level of burden was related to caregivers who have lower level of education, caregiver's abilities, patient contact, being a parent of patient, quality of life, as well as symptoms of the patients, total duration of illness, needs for hospital care, economic difficulty, patient's violence toward the caregivers, personality factors, male gender, age of onset of disease, lack of social support, unemployment and marital status (Zahid & Ohaen, 2013).

Chien et al. (2007) in their research on perceived burden found that high level of perceived burden was associated with those relatives who had poor status of health, poorer functioning of family members, unemployment and lower social support. Number of family members and monthly income was positively related to the burden experienced by caregivers. Caregiver burden was highly predicted by social support, if the social support increased then burden experienced by caregivers decreased. Pakistani culture is a collectivistic culture where all family members have strong bonding and needs social support to remain happy and healthy. Psychological well-being of caregivers is essential to enhance their quality of life and ultimately improve quality of care given by them to their loved ones. The basic purpose underlying this research is to find out the relationship among psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. Care of a person with schizophrenia involves multiple burdens, possibly leading to burnout. Researches show that most of the caregivers are stigmatized in our society. They are depressed and they cannot look after them very well. Due to these factors they feel a psychological distress. Caregivers require resilience to overcome the burden of care,

and this requires health and life adaptation for themselves and their families. The present study is intended to find out the severity level of burnout in caregivers of patients with schizophrenia due to psychological distress and affiliate stigma. Schizophrenia is a very severe form of mental illness and caregivers face many difficulties in a society when they take care of them. People prejudice them when they participate in social activities and they cannot build a good relationship in the society. Sometimes, they do not come for their patient's treatment due to lack of awareness and stigma face by them. So, it needs to do work on this topic and examine related problems and difficulties that care givers facing in our society. So that solutions can be suggested. It will be a great obligation to do work in this regard to solve the difficulties and provide care givers and their patients a social acceptance in the society.

### **1.1 Objectives**

This research will aim to achieve the following objectives;

- To assess the level of psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia.
- To investigate the relationship between psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia.
- To assess whether psychological distress and affiliate stigma can predict burnout in caregivers of patients with schizophrenia.
- To examine gender differences in the level of psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia.

### **1.2 Hypotheses**

Following hypotheses were formulated to attain the above mentioned objectives;

- There is likely to be a significant relationship between psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia.
- Psychological distress and affiliate stigma are likely to predict burnout in caregivers of patients with schizophrenia.
- There is likely to be a significant gender difference in psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia.
- Spouse and parents of patients with schizophrenia are likely to be different in psychological distress, affiliate stigma and burnout.

## **2. Method**

### **2.1 Participants**

The sample comprised of 150 caregivers including equal number of parents & spouse ( $n=75$  men) and ( $n=75$  women), were recruited from Services Hospital Lahore, Punjab Institute of Mental Health, Jinnah Hospital Lahore and Mayo Hospital Lahore. Only parents and spouse whose patients suffer from schizophrenia were included. Relatives as a caregiver other than parents and spouse were excluded and if caregivers also diagnosed with any psychiatric illness were also excluded. The age range of the sample from 25-50 years ( $M = 41.28$ ,  $SD = 7.49$ ).

## 2.2 Research Design

Cross sectional correlational research design was used to find the relationship among psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia.

## 2.3 Sampling Technique

Purposive sampling technique was used to collect the data.

Table 1: Descriptive Statistics of Demographic Variables (N=150)

Characteristics	<i>M</i>	<i>SD</i>	<i>f</i>	%
Age (in Years)		41.28	7.49	
Gender				
Men			75	50
Women			75	50
Caregivers				
Parents			75	50
Spouse			75	50
Education				
Illiterate			53	35.3
Primary			27	18
Middle			18	12
Matric			26	17.3
Intermediate			8	5.3
Graduation			14	9.3
Masters			4	2.7
Occupation				
Govt. Employed			19	12.7
Private Employed			24	16
Self-Employed			42	28
Laborer			24	16
Unemployed			3	2

Housewife	38	25.3
Marital Status		
Married	114	76
Divorced	11	7.3
Separated	10	6.7
Widow	15	10
Family System		
Nuclear	94	62.7
Joint	56	37.3
Regional Affiliation		
Rural	38	25.3
Urban	112	74.7
Patient's Age (in years)	34.27	10.21
Patient's Gender		
Men	85	56.7
Women	65	43.3
Patient's Education		
Illiterate	17	11.3
Primary	29	19.3
Middle	24	16
Matric	45	30
Intermediate	21	14
Graduation	10	6.7
Masters	4	2.7
Marital Status		
Unmarried	103	68.7
Married	43	28.7
Divorced	3	2

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Widow		1	0.7
Duration of Illness (in years)	3.09	2.69	
Duration of Treatment (in years)	1.91	1.37	

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## 2.4 Assessment Measures

For assessment, Kessler Psychological Distress Scale, Affiliate Stigma Scale and Burnout Measure were used.

### 2.4.1 Kessler Psychological Distress Scale (Kessler, Andrews & Colpe, 2002)

This scale was used to assess psychological distress in caregivers. The Urdu Version of this tool was used in the current study. It consists of 10 items. The response scale was five point Likert scale which ranges from none of the time=1 to all of the time=5. The higher the score, the greater the level of psychological distress. It was pleasing to note that alpha level of the scale was much higher for the present study ( $\alpha = .98$ ).

### 2.4.2 Affiliate Stigma Scale (Mak & Cheung, 2008)

After seeking permission from the author, this scale was translated in Urdu Language. It consists of 22 items. In which 4 point Likert scale was used which ranges from strongly disagree=1 to strongly agree=4. The higher the score, the greater the level of affiliate stigma. The alpha level for current study was reported as ( $\alpha = .94$ ) for affect subscale of affiliate stigma, ( $\alpha = .93$ ) for behaviour subscale of affiliate stigma and ( $\alpha = .53$ ) for cognitive subscale of affiliate stigma.

### 2.4.3 Burnout Measure (short version) (Pines & Aronson, 2005)

After seeking permission from the author, this scale was translated in Urdu Language. It consists of 10 items. In which 7 point Likert scale was used which ranges from never=1 to everyday=7. The higher the score, the greater the level of burnout. The reliability of the scale for current study was reported as ( $\alpha = .98$ ).

## 2.5 Procedure

After seeking formal permission from hospital authorities, caregivers of patients with schizophrenia were approached. Rationale of the study was explained to the caregivers and their written consent was sought. Individual assessments of those willing to participate were carried out at the premises of the hospitals and it took approximately 40-45 minutes to assess each caregiver. All ethical consideration of research and data collection was important part of the whole procedure.

### 3. Results

The results of the present research are presented for psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. The data was analyzed in five steps. The data analytic strategy began with reliability analysis using Cronbach's Alpha for scales and subscales. In the second step, descriptive statistics of study variables were computed. In the third step, Pearson Product Moment correlation was computed to assess the relationship among study variables that included psychological distress, affiliate stigma and burnout and demographic variables. In the next step, Hierarchical Regression analysis was conducted in order to find out predictors of burnout. In the last step, Independent Sample t-test was conducted to examine group differences. Descriptive analysis was done to assess mean, standard deviation, minimum, maximum scores and reliability of the study variables.

Table 2: Psychometric Properties of the Major Study Variables (N=150)

Variables	<i>k</i>	<i>M</i>	<i>SD</i>	<i>Range</i>		<i>a</i>
				<i>Potential</i>	<i>Actual</i>	
Psychological Distress	10	32.77	6.26	10-50	18-47	.98
Affiliate Stigma	22	65.29	8.76	22-88	25-88	.98
Affect	7	20.75	2.57	7-28	13-28	.94
Behavior	8	23.71	3.17	8-32	14-32	.93
Cognition	7	20.81	3.75	7-28	12-28	.53
Burnout	10	45.13	10.24	10-70	17-61	.98

Table 2 shows mean, standard deviation, actual and potential range of scores and reliability coefficients of psychological distress, subscales of affiliate stigma and burnout in caregivers of patients with schizophrenia. Results revealed excellent internal reliability of all the study variables. It was hypothesized that there is likely to be a significant relationship between psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. To test the first hypothesis Pearson Product Moment correlation was conducted.

Table 3: Relationship between Demographic Variables, Psychological Distress, Affiliate Stigma and Burnout (N=150)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Age (in years)	-	-.32***	.02	-.27***	.46***	.11	.35***	.18*	.31***	.25**	.22**	.11	.33***
2. Gender		-	-.11	.06	.40	-.39***	-.07	.03	.12	.04	.03	-.05	.12
3. Family System			-	-.06	-.01	-.06	.03	-.03	.11	.17*	.17*	.09	.13
4. Regional Affiliation				-	-.27***	-.02	-.23***	-.13	-.11	-.09	-.09	-.03	-.11
5. Patient's Age (in years)					-	-.11	.14	.16	.15	.04	-.02	-.07	.19*
6. Patient's Gender						-	-.18*	-.09	-.13	.00	-.03	-.07	-.14
7. Duration of Illness (in years)							-	.70***	.31***	.27***	.30***	.15	.28***
8. Duration of Treatment (in years)								-	.19*	.18*	.18*	.09	.17*
9. Psychological Distress									-	.73***	.76***	.51***	.91***
10. Affiliate Stigma (Affect)										-	.95***	.70***	.77***
11. Affiliate Stigma (Behavior)											-	.71***	.78***
12. Affiliate Stigma (Cognition)												-	.53***
13. Burnout													-

Note. Gender: 0= men, 1= women; Family System: 0= nuclear, 1= joint; Regional Affiliation: 0= rural, 1= urban.

$p < .10$ . \* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Table 3.2 reveals that age of the caregiver had a significant positive relationship with psychological distress, two subscales of affiliate stigma (affect and behavior) and burnout. No significant relationship was found between age and third subscale of affiliate stigma (cognition). Gender of the caregiver, regional affiliation, gender of patient and duration of illness had no significant relationship with all the study variables. Family system had a significant positive relationship with affect and behavior subscales of affiliate stigma. It had no significant relationship with remaining scales and subscale of affiliate stigma. Significant positive relationship was found between age of the patient and burnout, which means that as age of the patient increases, the level of burnout in caregiver also increases. Age of the patient had no relationship with remaining study variables. Duration of illness had a highly significant positive relationship with all the study variables except the cognition subscale of affiliate stigma. Duration of treatment also had a significant positive relationship with all the study variables except the cognition subscale of affiliate stigma. Psychological distress had a significant positive relationship with all the subscales of affiliate stigma and burnout. All the subscales of affiliate stigma had a significant positive relationship with one another and with burnout, which indicates that as the affiliate stigma increases, the level of burnout also rises. Further, it was hypothesized that psychological distress and affiliate stigma are likely to predict burnout in caregivers of patients with schizophrenia. To test the second hypothesis hierarchical regression analysis was carried out.



Table 4: Hierarchical Regression Analysis of Psychological Distress and Affiliate Stigma as Predictors of Burnout (N=150)

Variables	Burnout	
	$\Delta R^2$	<i>B</i>
Step 1	.14***	
Control Variables <sup>a</sup>		
Step 2	.69***	
Psychological Distress		.90***
Step 3	.02***	
Affiliate Stigma (Affect)		.22*
Affiliate Stigma (Behavior)		.03
Affiliate Stigma (Cognition)		-.01
Total $R^2$	.85***	

Note. <sup>a</sup>Control variables included caregiver's age, patient's age, duration of illness and duration of treatment

$P < .10$ . \* $p < .05$ . \*\*\* $p < .001$ .

The overall model was significant, it explained 85% variances in burnout  $F(8, 141) = 103.68$ ,  $p > .001$ . Age of the caregiver was significant positive predictor of burnout. Psychological distress was found to be a significant positive predictor of burnout. Affect subscale of affiliate stigma was also a significant positive predictor of burnout. Burnout was not predicted by remaining two subscales of affiliate stigma.

Moreover, it was hypothesized that there is likely to be a significant gender difference in psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. To test the third hypothesis independent sample t-test was carried out.

Table 5: Independent Sample t-test for Gender Differences on Psychological Distress, Affiliate Stigma and Burnout (N=150)

Variables	Men	Women	<i>t</i> (148)	<i>p</i>	95% CI		Cohen's <i>d</i>
	( <i>n</i> =75)	( <i>n</i> =75)			<i>LL</i>	<i>UL</i>	
Psychological Distress	32.01(6.59)	33.53(5.85)	-1.49	.13	-3.53	.49	0.23
Affiliate Stigma	65.25(9.61)	65.33(7.88)	-.06	.96	-2.92	2.76	0.009
Affect	20.64(2.70)	20.87(2.44)	-.54	.59	-1.06	.60	0.09
Behavior	23.63(3.36)	23.82(2.99)	-.39	.70	.52	-1.23	0.06
Cognition	20.99(4.62)	20.64(2.64)	.56	.57	-.87	1.56	0.09
Burnout	43.87(10.66)	46.39(9.72)	-1.51	.13	-5.81	.77	0.25

Note. CI= confidence interval; *LL*= lower limit; *UL*= upper limit.

Table 5 shows that no significant gender differences in caregivers on psychological distress, affiliate stigma and burnout. Further, it was hypothesized that spouse and parents of patients with schizophrenia are likely to be different in psychological distress, affiliate stigma and burnout. To test the fourth hypothesis independent sample t-test was conducted.

Table 6: Independent Sample t-test for differences between Spouse and Parents of Patients with Schizophrenia on Psychological Distress, Affiliate Stigma and Burnout (N=150)

Variables	Parents (n=75)	Spouse (n=75)	t (148)	p	95% CI		Cohen's d
	M (SD)	M (SD)			LL	UL	
Psychological Distress	33.43(6.15)	32.12(6.33)	1.28	.20	-.71	3.32	0.21
Affiliate Stigma	66.87(9.36)	65.33(7.88)	2.23	.03	.36	5.94	0.37
Affect	21.11(2.69)	20.40(2.41)	1.70	.09	-.12	1.53	0.28
Behavior	24.31(3.33)	23.15(2.90)	2.27	.03	.15	2.17	0.37
Cognition	21.45(4.49)	20.17(2.72)	2.11	.04	.08	2.48	0.34
Burnout	45.64(10.08)	44.61(10.47)	.61	.54	-2.29	4.43	0.10

Note. CI = confidence interval; LL = lower limit; UL = upper limit.

Table 6 shows that parents and spouse were significantly different on affiliate stigma. Moreover, significant differences were found on two subscales of affiliate stigma i.e. behavior  $t(148) = 2.27$ ,  $p = .03$  and cognition  $t(148) = 2.11$ ,  $p = .04$ . Mean difference of two groups revealed that parents were found to experience higher level of behavior and cognitive affiliate stigma as compared to spouse.

#### 4. Discussion

The present research was conducted to explore the relationship among psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. Findings revealed that there was highly significant positive relationship among all the study variables. Wang, Bonita and Fang (2010) conducted a research on the association between social stigma and psychological distress among stigmatized individuals. The results indicated that social stigma was positively related to psychological distress. Their findings were consistent with the present study. Similarly, Zou et al., (2016) also conducted a research on the relationship among psychological distress, burnout and resilience among Chinese nurses. The results of the study indicated that psychological distress and burnout was negatively related to resilience; whereas, psychological distress was positively related to burnout in caregivers.

Likewise, Shah, Wadoo and Lato (2010) conducted a research on the relationship between psychological distress and demographic variables in carers of people with severe mental illness. The findings of the study indicated that psychological distress is related to the age, gender, lack of social support, cultural and ethnic affiliation, stressors of the disorder and coping style used by the caregiver in order to cope with the distress. So, the findings of their study also support the outcome of the present research. In the same way, Ong, Ibrahim and Wahab (2016) conducted a research on perceived stigma, psychological distress and coping among relatives of patients with severe psychological illness i.e.

schizophrenia. The results of the study indicated that psychological distress was positively related to courtesy stigma. So, their findings were consistent with the outcome of current study.

Kokurcan et al. (2015) conducted a research on relatives of patients with schizophrenia in order to measure burnout and to determine the relationship among burnout profile of caregivers, socio-demographic variables, symptomology and perceived social support. The results of the study showed that negative symptoms of the patients and perceived social support of the relatives were positively related to burnout profile of the caregivers. Burnout is determined by lower perceived social support. So, their findings also support the outcome of current research. Akintola, Hlengwa and Dagied (2013) conducted a research in order to find out predictors of perceived stress and burnout. The results of the research showed that predictors of stress were age of caregiver and number of patients under their care. The predictors of burnout were lack of social support and stigmatization was faced by the caregivers. The findings of their study were consistent with the outcome of the present research. Similarly, Chien et al. (2007) conducted a research on relatives of patients with severe mental illness in order to examine the perceived burden and burnout in them. The results of the study indicated that caregiver burden and burnout was highly predicted by lack of social support and age of caregiver. So, their findings also support the outcome of the current research.

It was also hypothesized that there was likely to be a significant gender difference in psychological distress, affiliate stigma and burnout in caregivers of patients with schizophrenia. But the findings of the current study showed no significant gender differences in psychological distress, affiliate stigma and burnout in caregivers. Likewise, Sreeja et al. (2008) conducted a research on caregivers of patients with neurological illness i.e. epilepsy and mental illness i.e. schizophrenia in order to examine differences between level of burden experienced by them. The results of the study indicated that greater level of burden was experienced by those caregivers who were providing care to the patients for long duration. The areas in which caregivers of patients with neurological and mental illness experienced were finance, patient care, emotional and physical burden, occupation and family relations. In both groups of caregivers no significant gender differences were found on the level/intensity of burden. The findings of their study were consistent with the outcome of the present research.

Likewise, Khan, Kausar, Khalid, and Farooq (2015) conducted a research on the level of discrimination and stigma experienced by people diagnosed with mental illness and their caregivers in order to examine gender differences. The results of the study revealed that considerably high level of associated stigma and discrimination was experienced by both men and women. However, women experienced significantly higher level of associated stigma especially when they had discrimination and social withdrawal than men. The findings of their study were not consistent with the outcome of present research. Similarly, Sharma, Chakrabarti and Grover (2016) conducted a research to examine gender differences in the level of psychological distress among relatives of patients with severe mental illness. The results of the study revealed that greater level of psychological distress, caregiver burden and psychological and physical strains were experienced by women when they were providing care to the patients than men; whereas, other studies did not find any difference in the level of psychological distress among caregivers. So, no conclusive results can be given to gender differences.

It was also hypothesized in the present study that spouse and parents of patients with schizophrenia are likely to be different in psychological distress, affiliate stigma and burnout because these psychological phenomena are determined by the relationship with the patients.

Similarly, Yin et al. (2014) conducted a research on experiences of stigma and discrimination among caregivers of persons with schizophrenia in order to investigate differences in parents and spouse. The results of the study indicated that parents as a caregiver experience greater stigma than spouse. The findings of their study were consistent with the outcome of the present research. Likewise, Zisman et al., (2013) conducted a research to measure the internalized stigma of parents of persons with a serious mental illness. The results of the study indicated that parents as a caregiver experience greater stigma than any other relative. The findings of their study were consistent with the outcome of the present research.

#### **4.1 Conclusions**

On the bases of obtained findings, it was concluded that there was highly significant positive relationship among all the study variables. It was concluded that age and gender of the caregiver, psychological distress and affect subscale of affiliate stigma were positive predictors of burnout. No significant gender differences were found on psychological distress, affiliate stigma and burnout in caregivers. Parents and spouses were scored differently on affiliate stigma. Also, no significant differences were found on psychological distress, and burnout.

#### **4.2 Implications**

The findings of the present research could be helpful to develop insight in any society about the critical issue of stigmatization. These findings could also be helpful for the caregivers to manage their own psychological distress and burnout so that they could provide care to their patients in a better way. It will also be helpful to enhance the importance of the quality of life of patients and caregivers, and take positive steps to handle patients more effectively.

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