

## ORIGINAL ARTICLE

## PERCEIVED STIGMA, FAMILY SUPPORT AND QUALITY OF LIFE AMONG CAREGIVERS OF FEMALE PATIENTS WITH SCHIZOPHRENIA DISORDER

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**Background:** Family caregivers of persons with schizophrenia experience high level of poor quality of life because, Schizophrenia is severe mental illness which leads long term decline in person overall functional competence, alters communication patterns in the family, leads to occupational difficulties, and puts a load on the family caregivers. This study was done to examine how stigma and quality of life correlate with each other, and to determine impact of family support on quality of life of schizophrenia patients. **Methods:** Purposive sampling technique served sample recruitment of 200 caregivers of female patients with schizophrenia and correlational research design was used to analyse data. Devaluation of Consumer Family Scale, Perceived Social Support from the Family Scale, and WHO Quality of Life Scale were used as tools for data collection. Descriptive statistics, Pearson product moment co-relational analysis and hierarchical regression analysis were practiced for data analysis. **Results:** Significant negative relationship was found between perceived stigma and quality of life sub scales (Physical, Psychological and Environmental). Significant positive correlation between familial support and Quality of Life sub scales (Physical, Psychological and Environmental) was found among caregivers of women with schizophrenia. No significant differences were found between males and females with reference of quality of life. **Conclusion:** Stigma and quality of life are negatively associated while family support is positively associated with quality of life. Perceived stigma and family support were significant predictors of Quality of Life.

**Keywords:** Perceived stigma, Family support, Quality of Life, Caregivers, Females with schizophrenia

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### INTRODUCTION

Family caregivers take the most important role in caregiving for people with mental illness. Family caretakers are relatives who give every day voluntary help to an individual requiring support for daily living assignments.<sup>1</sup> According to WHO 29 million people globally have schizophrenia, 20% show chronic illness, and 35% patients show mixed pattern of illness as they sometime remain stable and at other instance suffer from relapse. In Western countries 50% patients of schizophrenia live with families after discharge from institutes while in Asian countries 70% patients live under their family supervision. As they depend upon their families for their personal needs, that is why family faces financial burden, avoidance of own mental health, stress, depression and anxiety.<sup>2</sup>

Families of patients with schizophrenia experience severe tasks because of clinical heterogeneity and variety of signs and their intervention. The caregivers of schizophrenia patients face burden to deal with them as they spend money for their treatment and face extra financial burden. The other factors include the time they spend on their care and also face stigmatization from society.<sup>3</sup> When families face stigma, they get negative comments from society and feel guilty to have mentally ill family member(s). They feel

sorrow, fright, loneliness, and less social interaction.<sup>4</sup> The caregivers face psychological burden; a study conducted in Latino family caregivers shows 40% care givers are at risk of developing depression.<sup>5</sup> Caregivers of schizophrenia patients were compared with caregivers of other disease like Alzheimer, cancer and stroke in India. The results show that caregivers of schizophrenia disorder patients face sleep disturbance, body pain, headache, anxiety issues, low quality of life and depression.<sup>6</sup> A study in Mayo Hospital Lahore also revealed that caregivers face high level of burden psychologically and spend poor quality of life. The study highlights the need to consider caregivers' mental health as well.<sup>7</sup>

Family support plays an important role in life of schizophrenia patients and caregivers as family does extensive range of activities which reinforce positive familial social networks through social based programs and services.<sup>8</sup> Familial support is a help provided through other family affiliates to increase bodily and emotional relief for individuals exposed to worrying conditions.<sup>9</sup> Familial support permits the family to work efficiently and increases family's wellbeing. In an investigation most of participants who showed contentment on the quality of life were persons who had got moral support from the family.<sup>10</sup>

The family members face psychological issues and their quality of life is a person's individual experience of life in the perspective of personal value systems and culture to which they belong, compelling into account their aims, values, expectations, and interest.<sup>11</sup> Quality of life is deliberated as a sign of general happiness, including pleasure and contentment with life. Health-Related Quality of Life (HrQOL) is a narrow term that encompasses health components that are related to life satisfaction as well as the ability of self-caring, nursing, mobility and communication.<sup>12</sup>

The current study was done to see problematic factors which affect quality of life of caretakers of female schizophrenics, and to provide information and awareness to authorities and policy makers in both social and clinical fields.

## MATERIAL AND METHODS

The current study used correlational research design to observe the relationship between perceived stigma, familial support and quality of life. The study was conducted after getting approval from Ethical Research Committee/Institutional Review Board. Sample size was determined through G-Power analysis keeping  $\alpha=0.05$ , with medium effect size 0.15. Purposive sampling technique was used to recruit the sample of 200 caregivers of female schizophrenics from Lahore, Pakistan. The participants of the study were assured about their confidentiality through a proper consent form and all ethical considerations were followed.

First degree relatives (parents, sibling, or offspring) and husbands were selected who were actively involved for at least 6 months in the care of 20–40 year old females diagnosed with schizophrenia (duration of illness 1 to 3 years) as per the DSM5 criteria. Data was collected from both private and public hospitals. Caregivers having history of chronic physical illness, drug abuse, and psychological symptom were excluded from the study. Also participants with incomplete forms or partially filled questionnaires were excluded from the study.

The data was collected from different hospitals in Lahore through a questionnaire translated in Urdu language. The Urdu versions of scales were completed through MAPI guidelines (Forward and backward translation).

Devaluation of Consumer Family Scale (DCFS), originally developed by Struening *et al*<sup>13</sup>, in 2001 was used. The items were analysed on 5-point Likert scale (1= strongly disagree, 5= strongly agree). The scale consisted of 7 items (Cronbach's  $\alpha$  reliability= 0.86). Perceived Social Support from the Family Scale (PSS-FA), developed by Procidano and Heller<sup>14</sup>. This scale has 20 items consisting of

declarative statements to which the individual answered 'Yes', 'No' or 'Do not know'. (Cronbach's  $\alpha$  reliability= 0.89). World Health Organization Quality of Life Scale (WHO-QOLS)<sup>15</sup>, developed by Naumann and Byrne was also used. This scale has 26 items. This tool used 5-point Likert scale (1= strongly agree, 5= strongly disagree). The Chronbach's  $\alpha$  reliability for this scale is 0.80. Data was analysed using SPSS-21.

## RESULTS

Demographic characteristics of participant were analysed using descriptive statistics. Majority (54.5%) of the participants were married, 62% were from nuclear family system, 41.5% had unpleasant home environment, and 44% participants were siblings of the patients. (Table-1).

Table-2 shows that perceived social supports has significant negative correlation with Perceived Stigmatization [ $r(200) = -0.16, p < 0.05$ ] and significant positive correlation with overall quality of life [ $r(200) = 0.33, p < 0.01$ ], and its subscales (physical, social and environmental). Findings also reveal that perceived stigmatization has significant negative relationship with Quality of Life [ $r(200) = -0.34, p < 0.01$ ].

Table-3 reveals that there is no significant difference between male and female on quality of life. Results reveal that first model was found to be highly significant predictor  $F(15, 184) = 2.81, p < 0.005, R^2 = 0.18$  and accounted for 18% of variance in quality of life. Second model also found to be highly significant predictor  $F(16, 183) = 4.54, p < 0.005, R^2 = 0.28$  and accounted for 28% of variance in quality of life. Third model was also found to be highly significant predictor  $F(17, 182) = 5.27, p < 0.005, R^2 = 0.33$  and accounted for 33% of variance in quality of life.

Hierarchical regression analysis for independent and dependent variables is tabulated in Table-4.

**Table-1: Demographic characteristics of the subjects (n=200)**

Variables	Frequency	Percentages (%)
<b>Marital Status</b>		
Single	91	45.5
Married	109	54.5
<b>Family System</b>		
Nuclear	124	62
Joint	76	38
<b>Home Environment</b>		
Unpleasant	83	41.5
Pleasant	50	25
Satisfactory	67	33.5
<b>Relationship with Patients</b>		
Parents	43	21.5
Husband	43	21.5
Siblings	28	14
Children	26	13

**Table-2: Descriptive statistics and inter correlations, for study variables (n=200)**

Variables	Mean±SD	1	2	3	4	5	6
1. PSS	11.94±4.26	-					
2. DCFs	19.60±3.17	-0.162*	-				
3. QOL	79.47±12.82	0.332**	-0.344**	-			
4. Physical QOL	21.67±3.69	0.256**	-0.326**	0.785**	-		
5. Psychological QOL	18.61±3.54	0.193**	-0.238**	0.758**	0.498**	-	
6. Environmental QAL	23.66±5.03	0.311**	-0.307**	0.872**	0.566**	0.500**	-

\*\*p<0.01 (2-tailed); \*p< 0.05, PSS= Perceived Social Support Scale; DCFs=Devaluation of Consumer Family Scale, QOL= Quality of Life Scale

**Table-3: Comparison of quality of life between males and females**

QoL	n	Mean±SD	t	p	95% CI	
					LL	UL
Male	86	78.99±12.35	-0.461	0.646	-4.46	2.77
Female	114	79.83±13.20				

QoL= quality of life, CI= confidence interval, LL= lower limit, UL= upper limit

**Table-4: Hierarchal regression analysis for independent and dependent variables (n=200)**

Predictors	Quality of Life of Caregivers	
	ΔR <sup>2</sup>	B
Step 1	0.12*	
Age		0.26*
Family System		0.18***
Relationship with Patient		0.29**
Step 2	0.22***	
Perceived Stigmatization		0.29***
Step 3	0.26***	
Family Support		0.22***
Total R <sup>2</sup>	33%	

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001

a. Dependent Variable: Quality Of Life

b. Predictors in the Models: Perceived Stigma, Family Support, Age, Family System, Relationship with Patient

## DISCUSSION

Family caregivers face burden due to dealing with schizophrenia patients. The current study focuses the factor of stigma and highlights how family caregivers of mentally ill people face the society reaction. The present study examines how stigma and quality of life correlate with each other and their impact on quality of life of caregivers.

The current study shows high level of stigma among the caregivers which seems consistent with work from India<sup>16</sup>. Perceived social support has negative correlation with perceived stigmatization which is consistent with a previous study from China<sup>17</sup> where people with care giving for long time showed more stigma compared to people with short period of time.

The current work shows that social support is negatively correlated with quality of life and also with subscales including physical, environmental and social factors it shows consistent results with another study from India which concluded that people who care for schizophrenia patients show poor quality of life.<sup>18</sup> On the other hand people who care for mentally ill patients and have less social support show lower quality of life consistent with research conducted in

China<sup>17</sup>. Caregivers who had poor family support were five times more likely to have perceived stigma compared to those with strong social support. The current study also shows that social support is a predictor of quality of life among caregivers of schizophrenia patients.

Sharma *et al*<sup>19</sup> observed that stigma is high among the caregivers of patients with schizophrenia. The research revealed that female caregivers show more stress as compared to males. Females face more burdens compared to males while dealing with mentally ill patients.<sup>19</sup> The current study shows no major differences in quality of life among males and females.

## CONCLUSION & RECOMMENDATIONS

Stigma and quality of life (Sub scales: Physical, Psychological & Environmental) are negatively associated while family support is positively associated with quality of life. Perceived stigma and family support was significant predictors of quality of life. There were no significant differences among male and female caregivers with reference of quality of life. Further work with indigenously developed questionnaires and a larger sample size will help in better understanding of the problem.

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