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PA AP	CSILIENCE IN THE PRIMARY CAREGIVERS OF TIENTS WITH SCHIZOPHRENIA, BIPOLAR FECTIVE DISORDER AND ALCOHOL EPENDENCE SYNDROME	<b>KEY WORDS:</b> Caregiver, Resilience, Schizophrenia, Bipolar disorder, Alcohol	
Dr. Pranavi Reddy Gunamgari	Postgraduate, Department of Psychiatry, Gov Nizamabad.	vernment Medical College,	
Dr. Rajendhar Soorineedu	Asst. Professor, Department of Psychiatry, Go Nizamabad.	vernment Medical College,	
Dr. Raja shekar	Asst. Professor, Department of Psychiatry, Go	vernment Medical College,	

Reballi **Dr. Siva Prasad** Professor and HOD, Department of Psychiatry, Government Medical College, Nizamabad. \*Corresponding Author Kasimahanti\*

Caregivers who possess resilience are better able to manage and overcome adversity that comes with caring for a family member diagnosed with major mental illnesses like Schizophrenia, Bipolar Affective Disorder and Alcohol Dependence Syndrome. Family plays a key role in the care of patients with mental illnesses especially in India owing to the tradition of interdependence and the lack of sufficient mental health facilities making it important to understand the resilience of the caregiver in caring for the mentally ill. Aim: The aim of the present study is to study the resilience in primary caregivers of patients with Schizophrenia, Bipolar Affective Disorder and Alcohol dependence syndrome. Methods: The crosssectional comparative study included 90 primary caregivers of patients, 30 from each group. The diagnoses of the patients were confirmed with the MINI screen scale. A semi-structured interview was used to obtain demographic data and resilience in the caregivers was measured using the Connor Davidson Resilience Scale. Results: Resilience was found to be higher in males, mostly children of the patients hailing from higher income groups and carers with shared burden. Caregivers of the patients with schizophrenia were found to have higher resilience than those of the other 2 groups. Conclusion: Gender, age, socioeconomic status, family support and diagnosis were all factors found to be influencing resilience in a caregiver.

#### INTRODUCTION

ABSTRACT

In psychiatry, duration and the severity of disability inflicted define major mental illnesses. These illnesses range from disorders with psychosis like schizoaffective disorder and schizophrenia to other disorders like major depression and bipolar disorder. Most often, the patient is discharged after achieving remission to live with the family, in the community.

Nizamabad.

In the Indian context, families play an important role in the care of patients with mental illnesses, following their discharge. The traditional Indian joint family which follows the principles of collectivism, has proved itself to be an excellent resource for the care of the mentally ill<sup>(1)</sup>

This creates a need for us to examine the attributes that promote better resilience in caregivers.

#### Resilience

In psychiatry, resilience is defined as one's capacity to recover from severe trauma and stress. It is a quality of some individuals who manage to fully recover despite suffering significant traumatic conditions of extreme deprivation, serious threat, and major stress. Resilience reflects successful psychosocial adjustment and is considered an essential component of mental health<sup>(2)</sup>. Research over the years has identified that members of the family who possess indicators of resilience such as acceptance, hardiness, hope, mastery, self-efficacy, sense of coherence, and resourcefulness are better able to manage and overcome adversity associated with caring for a family member diagnosed with a mental illness<sup>(3)</sup>.

Caregiver is the person responsible for meeting the psychological and physical needs of the patient. Psychiatric patients need their activities supervised and assistance in activities of daily living. This often places a major burden on their caregivers, thereby placing the caregiver at a great risk

of mental and physical health problems. The term "caregiver burden" is used to describe the physical, emotional and financial toll of providing  $care^{(4)}$ .

Schizophrenia is a complex, chronic mental health disorder characterised by an array of symptoms, including delusions, hallucinations, disorganized speech or behavior, and impaired cognitive ability. The early onset of the disease, along with its chronic course, make it a disabling disorder for many patients and their families<sup>(5,6</sup>

Bipolar affective disorder is a chronic and complex disorder of mood that is characterised by a combination of manic, hypomanic and depressive episodes, with substantial subsyndromal symptoms that commonly present between major mood episodes. It is one of the top causes of worldwide disability<sup>(7)</sup>.

In India, among an estimated 62.5 million alcohol users, there are 10.6 million dependent alcohol users<sup>(8)</sup>. The spouses and children continue to be the "forgotten victims" of such persons with alcohol dependence.

#### Aim of the Study

To study the resilience among the primary caregivers of patients with Schizophrenia, Bipolar Affective Disorder and Alcohol Dependence Syndrome.

## METHODS AND MATERIALS

Study Design: This study is designed as a comparative crosssectional study. The data was collected from the Outpatient unit of government Medical College Nizamabad after obtaining approval by the institutional ethics committee.

Study Period: The study was carried out between January 2021 to August 2022 for 18 months.

Study Population: For collection of the sample, a convenient sampling method was used. 30 caregivers of patients with

Schizophrenia, 30 caregivers of patients with Bipolar Affective Disorder and 30 caregivers of patients with Alcohol Dependence Syndrome, i.e. a total of 90 caregivers were assessed during the study period. They were assessed for resilience using appropriate scales and compared on various parameters.

**Statistical Method:** The following scales were used to obtain the data:

- 1. MINI International Neuropsychiatric Interview (M.I.N.I PLUS 5.0)
- 2. Connor Davidson Resilience Scale (CD-RISC)

The data was charted and analyzed using SPSS version 23. The mean scores were calculated and compared using the unpaired t test.

# MINI International Neuropsychiatric Interview (M.I.N.I PLUS 5.0):

It is a structured diagnostic interview compatible with DSM-IV criteria designed for clinical practice and research in psychiatric and tertiary care settings. The interview was considered comprehensive enough to cover all patient symptoms and the patient's views of the tool were positive.

The interview has questions to screen for and make diagnosis of 26 psychiatric disorders: psychotic, mood, anxiety, somatoform, substance use, panic, phobia, obsessive compulsive disorders and so on<sup>(19)</sup>

## Connor Davidson Resilience Scale (CD RISC)

The Connor Davidson Resilience Scale (CD-RISC) consists of 25 items, which are evaluated on a five-point Likert scale ranging from 0-4: not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all of the time (4) - these ratings result in a number between 0–100, and higher scores indicate higher resilience<sup>(10)</sup>.

The rating scale consisted of questions related to the following qualities:

- 1. Personal competence, high standards, and tenacity
- 2. Trust in one's instincts, tolerance of negative affect, and strengthening effects of stress
- $3. \ \ \, {\rm Positive\,acceptance\,of\,change\,and\,secure\,relationships}$
- 4. Control
- 5. Spiritual influences

## RESULTS

Demographic data and Resilience scores were obtained from 90 caregivers belonging to all three groups.

It was found that the female caregivers (n = 51/90) were outnumbered by males(n = 39/90). by nearly 14%. The mean age was found to be 44.9 with a large number of caregivers in the 5th (25.6%) and 6th (28.9%) decades of life. Among the 4 groups of caregivers, Spouses (n = 34/90, 37.8%), Parents (n = 36/90, 40%), Children (n = 8/90, 8.9%), Siblings (n = 12/90,13.3%), parents were highest in number, constituting a major chunk (78%) along with spouses. Majority of the sample was from Lower Middle SE status (n = 38/90, 42.2%), followed by Upper lower SE status (n = 29/90, 32.2%), Upper middle SE status (n = 13/90, 14.4%) and Lower SE status (n = 10/90, 11.1%)

For more than half of the patients, the burden of care is shared by more than one person (n=49/90, 54.4%), while people with single caregiver (n=41/90) form 45.6% of the sample.

## Table 1: Mean Resilience Scores Of The Study Population

	(n=90)	Mean Resilience	P value
		scores	
Sex:			0.05
Male	39 (43.3%)	66.28	
Female	51 (56.7%)	61.20	
		•	

Relationship			
with the patient:			
Spouse	34 (37.8%)	66.18	
Parent	36 (40.0%)	59.47	
Child	8 (8.9%)	68.00	
Sibling	12 (13.3%)	64.25	
Socioeconomic			0.001
status:			
Lower	10 (11.1%)	49.80	
Upper Lower	29 (32.2%)	65.41	
Lower middle	38 (42.2%)	63.16	
Upper middle	13 (14.4%)	70.08	
Shared Burden:			0.04
Yes	49 (54.4%)	66.70	
No	41 (45.6%)	61.32	

**Mean Resilience Scores:** It was noticed that the Mean resilience score in male caregivers (n=39,66.28), was greater than the females (n=51,61.2) and is found to be statistically significant (p value=0.05).

The majority of the caregivers in the current study were either the Spouse (n=34/90) or a Parent (n=36/90) with resilience scores 66.18 and 59.47 respectively. However, the mean resilience score in the children (n=8/90, 68) was surprisingly the highest.

The mean Resilience score is highest in the Upper middle SE strata (70.8) and nearly the same in the Lower middle (63.16) and Upper lower (65.16) groups. The mean resilience score was the lowest in the Lower SE strata (49.8). The difference showed a high statistical significance of (p value=0.001)

Caregivers who could share the burden (66.7) of care of the patient had a higher resilience score than the ones who didn't (61.32). This difference was also statistically significant (p value=0.04)

# Table 2: Comparison Of Resilience Of Caregivers Across AllThe Diagnostic Groups

	N	Mean	SD	95% Confidence Interval for Mean		ANOV A
				Lower Bound	Upper Bound	
Schizo-	30	69.67	11.167	65.50	73.84	6.65
phrenia						
BPAD	30	61.30	11.768	56.91	65.69	
ADS	30	59.23	12.235	54.66	63.80	
Total	90	63.40	12.455	60.79	66.01	

The findings showed the mean resilience score in the caregivers of patients with schizophrenia (69.67) was highest followed by caregivers of patients with BPAD (61.3) and then caregivers of patients with Alcohol dependence (59.23).

## DISCUSSION

India is a country with a huge percentage of rural and uneducated population. The age-old stigma around mental illnesses and lack of education among caregivers also contribute to the illness going either unnoticed or under noticed for long periods of time. Major mental illnesses cause significant behavioral problems, social embarrassment and shame to the family and friends. Hence, it requires a great deal of patience and compassion on the part of the caregiver in the process of caregiving.

Although there are many studies on caregivers' burden, there are a few studies in India on caregivers' resilience. This study was conducted as an attempt to address this issue and fill the gap.

The current comparative study was designed to examine the resilience in the primary caregivers of people with Schizophrenia, Bipolar affective disorder and Alcohol dependence syndrome and compare the resilience across all three groups.

Female caregivers (n= 51) were more in number than their male counterparts(n=39). It was also found that more than 50% of the caregivers in their fifth and sixth decades of life. These findings are consistent with the findings by Rameshwar S Manhas et. $al^{(11)}$  and another study by Fernandes JB  $^{(12)}$ 

Most often the caregiver was a parent or a spouse together constituting nearly 78% of the sample obtained, while the child or sibling caregiver groups contributed a mere 22% to the sample. This finding is in concurrence with studies done by Rameswar Manhas et al<sup>(11)</sup> and with Ramanujam Vaishnavi et al

Considering the sample is derived from a government establishment, the majority of the caregivers (54.4%) were from the Upper lower (n =29/90, 32.2%) and Lower middle (n=38/90, 42.2%) SE groups. These findings bear an overall similarity to the caregiver profiles from Vaishnavi et al<sup>(13)</sup>.

The Mean resilience score in males is 66.28 which was higher than females 61.2. It was statistically significant (p value= 0.05) . This finding is consistent with Manhas et  $al^{(11)}$ .

The majority of the caregivers were either a parent or a spouse. However it is interesting to note that the mean resilience score in the children (68) was found to be the highest. This is consistent with the findings by Camille Hall<sup>(14)</sup>.

The study sample was divided into 5 socioeconomic groups and the mean resilience score was highest in the Upper lower SE status (65.41). This finding is also consistent with the studies by Vaishnavi et al<sup>(13)</sup> and Goit BK et al<sup>(15)</sup>.

There is statistically significant difference (p value= 0.04) between the mean resilience score of caregivers with shared burden (66.7%) and those without shared burden (61.32%)

# **Resilience in Caregivers of People with Schizophrenia** (Group 1)

From the sample obtained, the resilience score for caregivers of people with schizophrenia (n =30) was found to be highest with a mean resilience score of 69.67. This score is almost consistent with the findings of Jain et al<sup>(16)</sup>.

# **Resilience In Caregivers Of People With Bipolar Affective Disorder**(Group 2)

The mean resilience score in caregivers of people with BPAD (n=30) was 61.3. This observations is nearly consistent with findings of Jain A et al<sup>(16)</sup> and Rameshwar Manhas et al<sup>(11)</sup>

# **Resilience In Caregivers Of People With Alcohol Depen**dence Syndrome (Group 3)

The mean resilience score in the caregivers of people with Alcohol dependence syndrome (n=30) was found to be 59.23. This was consistent with the findings by Jjohnson PR<sup>(17)</sup> et al

# Comparison of Mean Resilience across the 3 diagnostic groups

The mean resilience scores in Group 1 is 69.67, while Group 2 and Group 3 were lower than those in Group 1, with values of 61.3 and 59.23 respectively.

- 1. To compare the mean resilience scores of caregivers of patients with Schizophrenia (69.67) and Bipolar affective disorder (61.3.), ANOVA was applied and the p value obtained was 0.06, implying no statistically significant difference between these two caregroups. This finding is consistent with the study by S Jain<sup>(18)</sup> (p=0.14)
- 2. Comparison of mean resilience scores of caregivers of patients with Bipolar affective disorder (61.3) and Alcohol dependence syndromes (59.23) was made after ANOVA and the p value obtained was 0.50, which was not statistically significant.
- 3. Comparison of the mean resilience scores among caregivers of patients with Schizophrenia (69.67) and

Alcohol dependence syndrome (59.23) by applying ANOVA and t test revealed a p value of 0.001, revealed a highly significant difference. This significantly low mean resilience score of this group can be attributed to the impact of alcohol consumption on the interpersonal relation of the patient with the caregiver and the caregivers' assumption that the substance dependence is self imposed and exhausting their finances.

# CONCLUSION

Caregiver resilience is an important aspect to be assessed and addressed, and the comparison of caregiver resilience between major psychiatric illnesses has often been understudied.

There was a statistically significant difference between the resilience score of caregivers of patients with Schizophrenia and Alcohol Dependence syndrome. Males were found to have significantly better resilience than females. Caregivers who were children of the patients were more resilient with higher scores. This is possibly related to their younger age with better education. Caregivers from the Lower SE strata had the lowest resilience scores. Sharing the burden of care of the patient showed better resilience among the caregivers.

## Acknowledgements

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#### Limitations

- The size of the sample (90) was small. 1.
- 2. The population was hospital based and limited to one tertiary care setting (specific geographical area) and not representative of the community.
- 3. The study was cross-sectional with no intervention or followup.

# **Future Directions**

- 1. A longitudinal study with a larger sample may help better assess the association between the diagnosis and caregiver resilience.
- Comparison of resilience in the caregiver of a patient 2. before and after treatment can provide better insight on the need for treatment at an early stage of the illness.
- 3. Education and a wider promotion of awareness about mental illnesses may help the caregivers better understand the nature of illness and the need for treatment.
- 4. In mental health institutions, a holistic family-centred approach should be encouraged.
- 5. The primary caregivers must be assessed periodically for any mental health complaints.
- 6. Support groups exclusive to caregivers can be incorporated into the health care delivery system.
- 7. Although Alcohol Dependence syndrome is not as severe as Schizophrenia or Bipolar affective disorder, the lowest resilience score among the caregivers indicates the need for more supportive interventions in this group.

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