

Parental stress, coping mechanisms and predictors of parental stress among parents of children with epilepsy

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Abstract

Objectives: To investigate the parental stress and coping mechanisms in parents of children with epilepsy (CWE) and to determine the predictors of parental stress. **Methods:** Parents of CWE (n=323) were evaluated for parental stress (PS) with a modified Abidin's parental stress index short-form scale (PSI-SF) and the coping mechanisms by modified ways of coping of Folkman and Lazarus. PS was defined by calculating 90 percentile values of the PSI total score. **Results:** A significantly higher mean parental stress index total and parenting distress subscale score was observed in females than in males. The percentage of PS was 10.52% among the parents of CWE. Distancing was the dominant coping mechanism used by the parents of CWE. Type of family, seizures, duration of illness, number of drugs used, seizure-related injuries, neighbour know child taking antiepileptic drugs and seeking social support were found to be the significant predictors of parental stress in the combined group. Seeking social support was found to be the common predictor for PS in both sexes, whereas duration of illness and number of drugs used were specific to females only.

Conclusions: Interventions need to be designed to improve the mental health and information seeking among the parents of CWE to reduce parental stress and to improve the quality of life of the caregiver and the cared.

Keywords: Parental stress, coping mechanisms, children with epilepsy

INTRODUCTION

Epilepsy is a chronic neurological disease characterised by the predisposition to provoke seizures and has cognitive, neurobiological, psychological and social consequences of seizure recurrence.¹ The prevalence (6.38/1000 people) and incidence (61.4/100,000 person-years) of epilepsy in world populations were reported with a higher magnitude in low-middle than in high-income countries.¹ Around the globe, 4 to 8 cases of epilepsy per 1000 children were observed.² In Kashmiri children, the reported prevalence rate of epilepsy was 3.74 in males and 3.13 in females/ 1000.³ Due to the financial limitations and cultural attitudes, children with epilepsy (CWE) are cared for by the parents.⁴ Parenting in children with special needs accompanied by personal difficulties leads to the stress among the

parents due to mismatch between the commitments and internal resources of parents.^{5,6}

Higher scores of parental stress index (PSI) were observed in caregivers of patients with chronic illness⁷, CWE^{8,9} than the parents of healthy children.¹⁰ Parental stress (PS) can cause marital discord, child abuse, neglect and decreased adherence to medication among CWE.⁶ Due to the PS, parents adopt coping strategies that help the health care workers investigate the needs of CWE and their families.¹¹ Within the country, the cultural value systems and social practices vary between different regions.¹² Most of the studies on PS and coping behaviours of parents of CWE were done in other countries.^{8,13} A few studies conducted on the parents of CWE in India focused on psychosocial problems¹², stigma, stress¹⁴ knowledge, attitudes^{15,16} and perceptions¹⁷ but not on the predictors of PS and coping mechanisms. Studies

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on the predictors of PS and coping behaviours may lead to the development of evidence-based interventions to understand the needs, to reduce the stress, and to support and improve the quality of life of CWE and their family members.^{6,18} In this study, an attempt was made to evaluate PS, coping mechanisms and the predictors of PS among parents of CWE.

METHODS

A Study among the parents of children with disabilities in India using Abidin's parental stress index short-form scale (PSI-SF) showed a PSI total mean score of 170.5 ± 20 .⁶ Assuming $\alpha=0.05$, $\beta=0.20$, hypothetical mean values of 167.37, the estimated sample size was 323. In this study, 323 participants were recruited.

The questionnaire and methodology for this study were approved by the Human Research Ethics Committee of the (IEC No. 149) of Sri Venkateswara Institute of Medical Sciences (SVIMS), Tirupati. Informed consent was obtained from all the individual participants.

This is an observational study carried out using purposive sampling technique. Participants were caregivers of CWE attending outpatient department of Neurology, SVIMS, Tirupati, Andhra Pradesh. The purpose and objectives of the study were explained to the participants, and those who fulfilled the inclusion and exclusion criteria and consented in writing were recruited.

Inclusion criteria: Father or mother caring CWE aged 6-15 years with >2 unprovoked seizures, speaking the Telugu language and willing to participate in the study were included.

Exclusion criteria: Parents of CWE suffering from hypertension and type 2 diabetes and CWE diagnosed with meningitis and mental retardation were excluded from the study. The data on the demographic variables of both caregivers and the cared were obtained using a semi-structured questionnaire. Variables in the questionnaire were selected based on earlier studies.¹⁹⁻²² Data on PS were collected with a modified Abidin²³ scale and coping mechanism by modified ways of coping of Folkman and Lazarus.²⁴ The details of validity, reliability, description of the scales and the definition of PS are as follows:

Validity, reliability and description of the scales: The content validity of the modified tools was determined by experts in nursing, epileptology, psychology and psychiatry. The suggested

modifications were carried out as per the experts' instructions. All tools were translated into the Telugu language and back-translated into English by bilingual experts, and their concurrence was obtained. The correlation between Telugu and English versions of PSI was 0.88 and ways of coping was 0.88. Before initiating the study, a pilot study was done, and the reliability across items and time was calculated employing Cronbach's alpha and intercorrelation coefficients.

Description of the tools

Modified Parental Stress Index Short Form (PSI-SF or PSI-3): This instrument developed by Abidin²³ was modified to investigate PS among parents of CWE. The modified scale contained 24 items grouped into three domains: PD, parent-child dysfunctional interaction (PCDI) and difficult child (DC), each containing eight items. Parents of CWE were asked to rate their responses on the five-point Likert scale of 1 to 5 (strongly disagree-1, disagree-2, not sure-3, agree-4 and strongly agree-5). The scores obtained for each item were summed to obtain the final score in each subscale, and the total score was calculated by summing the three subscale scores. The score in each subscale ranged from 8 to 40, and the total score from 24 to 120. The higher the score, the greater the parental stress. PSI total score ≥ 90 percentile is considered a clinically significant level of PS in the study. The calculated 90-percentile score for PSI total was 96. The higher the score, the greater the level of PS. The Cronbach's alpha and intercorrelation coefficient values obtained for total and subscales are given in Table 3.

Ways of coping: The coping responses of the participants were evaluated using the modified revised ways of coping (WOC) tool developed by Folkman & Lazarus.²⁴ The modified tool contained 32 items, eight subscales each representing 4 items and rated on a four-point Likert scale (0 - not used, 1- used somewhat, 2- used quite a bit and 3 - used a great deal). The items in each subscale were summed to get a final score. The scores in each subscale ranged from 4 to 16. The total score was obtained by summing the three subscale scores. The total score ranged from 32 to 128. The greater the score, the higher the usage of that coping strategy. The respective Cronbach's alpha and intercorrelation coefficients for the total and each subscale were calculated and presented in Table 3.

Statistical analyses

After collecting the data, the raw data were entered into an Excel spreadsheet, and the statistical analyses were carried out using SPSS software version 22. Quantitative data are presented as mean and standard deviation, and categorical qualitative data as numbers and percentages. The significance of the mean difference was evaluated with an independent 't' test. The association of qualitative categorical variables with quantitative variables was investigated using multivariate analysis of variance (MANOVA) and one-way

analysis of variance (one-way ANOVA). The association of variables with predictor (parental stress index) was examined with backward regression analyses.

RESULTS

The socioeconomic characteristics of caregivers are provided in Table 1, and CWE in Table 2.

The higher proportion of caregivers of CWE was in the age group of 25 - 35 years, mothers, Hindus, secondary school educated, labourers, had a monthly income of Rs.5-10,000, married, had

Table 1: Characteristics of caregiver (n=323)

Variable	No. and percent
Age (Years)	
25-35	186 (57.58)
36-45	127 (39.31)
46-55	10 (3.09)
Gender	
Male	141 (43.65)
Female	182 (56.34)
Religion	
Hindu	286 (88.54)
Muslim	25 (7.73)
Christian	12 (3.71)
Education of mother	
Bachelor degree and above	40 (21.97)
Higher secondary school	40 (21.97)
Secondary school	67 (36.81)
Primary school	25 (13.73)
Illiterate	10 (5.49)
Education of father	
Bachelor degree and above	16 (11.34)
Higher secondary school	22 (15.60)
Secondary school	68 (48.22)
Primary school	12 (8.51)
Illiterate	23 (16.31)
Occupation of mother	
Government	1 (0.54)
Private	20 (10.98)
Business	2 (1.09)
Agriculture	7 (3.84)
Labourer	65 (35.71)
Home maker	87 (47.80)
Occupation of father	
Government	7 (4.96)
Private	18 (12.76)
Business	22 (15.60)
Agriculture	33 (23.40)
Labourer	61 (43.26)

Variable	No. and percent
Family income per month (Indian Rupee)	
>25000	32 (9.90)
20001-25000	4 (1.23)
15001-20000	17 (5.26)
10001-15000	82 (25.38)
5000-10000	188 (58.20)
Marital status	
Married	297 (91.95)
Divorced	13 (4.02)
Widowed	13 (4.02)
No of children	
One	47 (14.55)
Two	216 (66.87)
Three	51 (15.78)
More than three	9 (2.78)
Type of family*	
Nuclear Family	270 (83.59)
Joint Family	52 (16.09)
Extended Family	1 (0.30)
Family size	
Small	209 (64.70)
Large	114 (35.29)
Residence	
Urban	67 (20.74)
Semi urban	69 (21.36)
Rural	187 (57.89)
Feels difficult in administering drugs	
Yes	69 (21.36)
No	254 (78.63)

*Nuclear family: a couple and their unmarried children; Joint family: sibling, their spouses and their dependent children; Extended family: combination of two or more nuclear families, extending the parent-child relationships.

Table 2: Characteristics of children with epilepsy (n=323)

Variable	No. and percent	Variable	No. and percent
Age (Years)		Types of seizures	
6-10	142 (43.96)	Simple partial	61 (18.9)
11-15	181 (56.03)	Generalized tonic clonic	195 (60.4)
Gender		Complex partial	67 (20.74)
Male	195 (60.37)	Duration of illness (Years)	
Female	128 (39.62)	0-5	220 (67.90)
Religion		6-11	78 (24.14)
Hindu	286 (88.54)	11-15	25 (7.73)
Muslim	25 (7.73)	Duration of treatment (Years)	
Christian	12 (3.71)	0-5	241 (74.40)
Order of birth		6-11	64 (19.8)
1	173 (53.56)	11-15	18 (5.60)
2	125 (38.69)	Total no. of seizures	
3	23 (7.12)	2-10	153 (47.36)
4	2 (0.61)	11-20	110 (34.05)
Education		21-30	16 (4.95)
Primary	160 (49.53)	31-40	13 (4.02)
Secondary	163 (50.46)	≥41	31 (9.59)
Age of onset (Years)		Seizure free time (Years)	
0-5	139 (43.03)	0-5	298 (92.26)
6-10	139 (43.03)	6-10	21 (6.50)
11-15	45 (13.93)	11-15	4 (1.23)
Seizure frequency		Seizure related injuries	
Daily	75 (23.21)	Yes	34 (10.52)
Weekly	62 (19.19)	No	289 (89.47)
Monthly	70 (21.67)	Hospitalization due to injuries	
Two monthly	9 (2.78)	Yes	107 (33.12)
Three monthly	20 (6.19)	No	216 (66.87)
Six monthly	28 (8.66)	Relatives know child is taking antiseizure medications	
One per year	59 (18.26)	Yes	283 (87.61)
Duration of attack (in minutes)		No	40 (12.38)
<1	89 (27.55)	Teachers know child is taking antiseizure medications	
1	209 (64.70)	Yes	274 (84.82)
2	24 (7.43)	No	49 (15.17)
4	1(0.30)	Neighbours know child is taking antiseizure medication	
Time of attack		Yes	277 (85.75)
Day	179 (55.41)	No	46 (14.24)
Night	118 (36.53)		
Day and night	26 (8.04)		
Onset of seizures with fever			
Yes	109 (33.43)		
No	217 (66.56)		
No. of drugs taken			
1	194 (60.06)		
2	101 (31.26)		
≥3	28 (8.66)		

two children, were members of nuclear family, residing in rural areas, had small family and reported no difficulty in administering the drugs to their children.

The majority of the CWE was 11-5 years old, male, first child, secondary schoolers, had the age onset of epilepsy between 0-5 years, had generalised tonic-clonic seizures, had daily seizures of 1-minute duration mostly in the daytime, were taking one drug, had a total of 2-0 seizures, was seizure free for 0-5 years, had fewer seizure-related injuries and hospitalizations and the history of taking antiepileptic drugs was known to the neighbours, teachers and relatives.

The mean and standard deviation of subscales, total score of PSI and revised ways of coping are presented in Table 3. Higher mean scores in parental distress and lower mean scores in difficult child subscales of PSI were found. A higher mean in distancing and a lower mean in escape avoidance coping mechanisms of revised ways of coping were found. To know whether sex differences exist in total and subscales of PSI and WOC, we have compared the mean of both sexes, and the significance values are given in Table 3. Mean parental distress ($p=0.009$) and PSI total score ($p=0.033$) were significantly higher in females than males.

Table 3: Descriptive statistics of total and subscales of the tools and sex differences

Variable	Mean ± S. D	Cronbach alpha	Intraclass correlation coefficient	Male (n=141)	Female (n=182)	Significance
Parental Stress Index (PSI)						
Parenting distress	60.42 ± 17.81	0.803	0.90	57.48 ± 16.96	62.69 ± 18.17	0.009
Parent child dysfunctional interaction	57.86 ± 16.83	0.781		57.12 ± 17.33	58.43 ± 16.46	0.489
Difficult child	15.56 ± 4.57	0.803		15.47 ± 4.62	15.63 ± 4.55	0.743
PSI total score	70.76 ± 18.28	0.907		68.31 ± 17.64	72.67 ± 18.59	0.033
Ways of coping (WOC)						
Confronting	35.95 ± 15.46	0.537	0.88	35.85 ± 14.51	36.02 ± 16.20	0.925
Distancing	45.53 ± 14.98	0.427		44.81 ± 15.18	46.08 ± 14.85	0.450
Self-control	35.35 ± 15.47	0.489		35.37 ± 15.55	35.33 ± 15.45	0.984
Seeking social support	43.69 ± 15.91	0.674		43.48 ± 15.52	43.85 ± 16.25	0.837
Accepting responsibility	30.88 ± 16.69	0.148		30.80 ± 15.91	30.94 ± 17.32	0.943
Escape avoidance	30.84 ± 18.34	0.744		29.16 ± 17.75	32.14 ± 18.73	0.148
Planful problem solving	40.88 ± 15.92	0.787		41.79 ± 15.97	40.17 ± 15.89	0.365
Positive reappraisal	37.51 ± 13.88	0.324		36.43 ± 14.44	38.35 ± 13.41	0.218
WOC total score	47.99 ± 11.79	0.826		47.51 ± 11.46	48.37 ± 12.05	0.515

The effect of demographic, social, and clinical variables on total and subscales of PSI and WOC was analyzed using MANOVA. As the total number of variables was 35, showing the effect of demographic, social and clinical variables on

PSI and WOC components was not the aim of the study. Therefore, those variables that showed a statistically significant relationship with total and subscales of PSI and WOC are shown in Tables 4 and 5. The variables such as religion,

Table 4: Effect of demographic, social and clinical variables on total and subscales of parental stress index analyzed by two-way multivariate analysis of variance

F value	Significance	Partial Eta2
PSI total		
<i>Religion</i>		
3.853	0.022	0.024
<i>Feeling difficulty in administering drugs</i>		
5.226	0.006	0.032
<i>Duration of illness</i>		
6.601	0.002	0.040
<i>Seizure related injuries</i>		
8.287	0.004	0.025
<i>Number of drugs taken per day</i>		
6.325	0.000	0.057
Parenting distress		
<i>Gender</i>		
4.589	0.033	0.014
<i>Type of family</i>		
4.765	0.009	0.030
<i>Child age</i>		
4.056	0.045	0.013
<i>Seizure type</i>		
3.092	0.047	0.020
<i>Time of seizure attack</i>		
3.820	0.023	0.027
Difficult child		
<i>Residence</i>		
4.181	0.016	0.026
<i>Type of family</i>		
2.919	0.056	0.019
<i>Educational status of child</i>		
4.037	0.019	0.026
Parent child dysfunctional interaction		
<i>Educational status of the father</i>		
3.007	0.019	0.043
<i>Seizure related injuries</i>		
4.786	0.029	0.015

Table 5: Effect of demographic, social and clinical variables on domains of coping scales analyzed by two-way multivariate analysis of variance

F value	Significance	Partial Eta2
Accepting responsibility		
<i>Family income</i>		
3.084	0.016	0.040
<i>Number of children</i>		
2.763	0.042	0.027
<i>Time of seizure attack</i>		
3.294	0.039	0.023
Confronting		
<i>Number of children</i>		
4.388	0.005	0.043
<i>Time of seizure attack</i>		
3.117	0.046	0.022
Self-controlling		
<i>Residence</i>		
4.273	0.015	0.027
Escape avoidance		
<i>Type of family</i>		
3.624	0.028	0.023
Seeking social support		
<i>Total number of seizure attack</i>		
3.740	0.006	0.048
<i>Age of the child</i>		
3.951	0.048	0.012
Planful problem solving		
<i>Seizure type</i>		
3.128	0.045	0.020
<i>Seizure free time</i>		
4.284	0.015	0.027
<i>Positive reappraisal</i>		
4.848	0.008	0.031

feeling difficulty in administering drugs, duration of illness, seizure-related injuries, and number of drugs used showed significant effects on PSI total, contributing 2.4%-5.7% of variation as shown by partial Eta.² Variables such as gender, child age, family type, seizure type and time of seizure attack on PD (1.3-3%); residence, type of family and educational status of the child on DC (1.9-2.6%) and education of the father and seizure-related injuries on PCDI (1.5-4.3%) showed a significant effect, contributing a minimal variation.

Analyses of two-way MANOVA on the effect of variables on the subscales of coping as follows: family income, number of children and time of seizure attack on accepting the responsibility (2.3-4%); the number of children and time of seizure attack on confronting (2.2-4.3%); residence on social support (2.7%); type of family on escape avoidance (2.3%); child age and total number of seizure attack on seeking social support (1.2-4.8%); seizure type and seizure free time (2-2.7%) on planful problem solving, and seizure type on

positive reappraisal (1.3%) showed significant variation.

Predictors identified for PS are furnished in Table 6. In the combined group, type of family, seizure type, duration of illness, number of drugs used, seizure-related injuries, neighbour knowing the child is taking antiepileptic drugs, and seeking social support (SSS) were the predictors for PS contributing 16.2% variation in the dependent variables as shown by the adjusted R². In both sexes, SSS was the common predictor for PS, whereas duration of illness and number of drugs used were specific to the females only. SSS contributed a 5.6% variation in PS in males, whereas variables enlisted under females contributed a 19.7% variation in the dependent variable.

DISCUSSION

In the Indian context, both parents may not be present when their children are taken for the consultation at the hospital due to socio-economic and cultural reasons such as work obligations, different work hours or responsibilities, transportation issues, the traditional role of a mother taking children to the hospitals, single parent families, and busy hospitals. Therefore, in this study, we included either of the parents as caregivers. The majority of caregivers (56.34%)

in this study were female. This may be due to a higher percentage of females being homemakers (47.80%) followed by separated (4.02%) and widowed (4.02%), who constitute around 56% of caregivers who may have spare time to attend to and fulfil the medical needs of their children.

Parental stress

In the present study, 10.52% of caregivers had PS. To the best of our knowledge, we are the first to use a modified PSI-short form scale to evaluate the PS among parents of CWE in the Indian context. No normative data on PSI in Indian populations are available for comparison and to determine clinically significant parental stress in the present study. The present study is a descriptive observational epidemiological study, and therefore, the control group is not included. In the absence of a control group and normative data, determining a cut-off value for significant parental stress using 90 percentiles of PSI total among parents of CWE is a clinically relevant, statistically normalization process and follows the practices used in psychological research to identify parents who may benefit from intervention.

In the present study, a significant association between religion, difficulty in administering the drugs, duration of illness, seizure-related injuries, and the number of drugs used with PS was found

Table 6: Predictors of parental stress analysed by backward multiple regression

Variable	Standardized Beta Coefficient, 95% CI	Significance	Adjusted R ²
Combined			
Type of family	0.136(0.019-0.162)	0.014	0.162
Seizure type	0.135(0.015-0.117)	0.012	
Duration of illness	0.254(0.062-0.186)	0.000	
Number of drugs taking	0.156(0.019-0.126)	0.008	
Seizure related injuries	-0.107(-0.214—0.001)	0.048	
Neighbour know child is taking antiepileptic drugs	0.106(0.001-0.186)	0.048	
Seeking social support	-0.163(-0.005—0.001)	0.003	
Male			
Seeking social support	-0.220(-0.436 to -0.063)	0.09	0.056
Female			
Duration of illness	0.194(1.649-9.319)	0.005	0.197
Number of drugs taking	0.228(2.250-9.510)	0.002	
Seeking social support	-0.278(-0.468 to -0.164)	0.000	

CI: Confidence interval

Table 7: One way analysis results of PSI total and parental distress by gender

Variable	Male (Mean ± S. D)	Female (Mean ± S. D)	F	Significance
PSI total	68.31 ± 17.64	72.67 ± 18.59	4.561	0.033
Parental distress	57.48 ± 16.96	62.69 ± 18.17	6.900	0.009

S.D: Standard deviation

in the analyses of MANOVA. In one-way ANOVA analyses, gender showed significant differences in PSI total ($F = 4.561$, $p = 0.033$) and parental distress subscale score ($F = 6.900$, $p = 0.009$) (Table 7). Significantly higher mean PSI total and parental distress subscale scores in female than male caregivers in the present study may be due to the involvement of females in caregiving responsibilities, greater expectations on women to be primary caregivers, hormonal fluctuations, expectation to excel in work and family responsibilities, higher emotional investment when faced with parenting challenges and less social support for parental duties.

In an earlier study, a significant association of PS with intractable seizures, illness-related child behaviour problems²⁵, seizure severity, learning disabilities, and seizure frequency²² was observed. Other studies found no association of PS with seizure frequency²², sex, age, maternal education level, duration of epilepsy, family history of psychiatric disorders, seizure type, seizure frequency, and antiseizure medications.¹⁰

Coping mechanism

A distancing coping mechanism is an emotionally focused coping mechanism that is attempted either to reduce emotion or to manage emotional distress.²⁶ The use of this coping mechanism may be due to parenting activities such as meeting dietary, behavioural, educational, repeated hospitalizations and medication challenges, feeling of a loss of a perfect child, and thinking of the differences in their children against normal children.¹⁴

Predictors of parental stress

A meta-analysis reported that parents of children with chronic conditions show small to moderate general stress and stress relating to parent-child interaction. Stress levels were found to differ with the duration of illness.²⁷ In the present study, one-way ANOVA analysis showed increased scores of PSI total with an increased duration of illness ($p < 0.01$) (Table 8). Increased duration of illness increases the risk of refractory epilepsy, aphasia, mood disorders, attention problems, and non-attentional learning disabilities among CWE.²⁸ The presence of conditions above, years of caring, conflict with partners, life restrictions, dissatisfaction while interacting with children, and their perceptions of their children's self-regulatory abilities in comparison to the normal children may be causing increased PS among the parents of CWE.

The inverse association of seeking social support with PS in the present study suggests lower seeking of social support (SSS) among parents of CWE while interacting with children, which may be responsible for PS. SSS is a problem-focused coping strategy aimed at problem solving by changing the source of stress.²⁶ SSS is done for either advice/assistance/information or to seek moral support/sympathy or understanding.²⁹

Increased scores of total PSI total in an extended and joint family, when compared to the nuclear families, may be due to the lack of resources for the parents to perform their parental role or their perception of failure to regulate the behaviour of children in an extended and joint family. Ten percent of CWE had seizure-related

Table 8: One-way analysis results of PSI total by duration of illness and number of drugs taken

Duration of illness			F	Significance
0-5 years (Mean ± S. D)	6-10 years (Mean ± S. D)	11-15 years (Mean ± S. D)		
68.92 ± 17.32	72.17 ± 18.88	82.56 ± 20.56	6.777	0.001
Number of drugs			F	Significance
One drug	Two drugs	Three and above		
67.89 ± 17.62	73.00 ± 18.17	82.57 ± 17.93	9.451	0.000

S.D: Standard deviation

injuries in the present study. Epilepsy seizure-related injuries present as a serious condition to the parents and often create a fear of losing their child among them. It was observed that monitoring every aspect of the life of CWE increases the burden of care on the parents, which may cause parental stress.³⁰

A higher mean PSI total score in complex partial seizures when compared to the generalized tonic-clonic and simple partial seizures was observed in the present study. Complex partial seizures impair the consciousness of the CWE³¹, and this, along with uncertainty and burden of care, may be responsible for PS among the parents of CWE in the present study. In a recent study, seizure type was not associated with PSI scores.¹⁰ Neighbour knowledge of children taking antiepileptic drugs was found to be significantly associated with PS. This may be due to the worry of parents about the judgment of neighbours, invasion of privacy, unsolicited advice, the uncertainty of reaction, differential treatment of their child, and apprehension of misunderstanding from neighbours.

Increased PSI total with increased number of drug use was observed in one-way ANOVA ($p < 0.01$) (Table 8) in the present study. An increased number of drugs involves increased expenditure on drugs, more time needed for parental care, and convincing the children to take poly pills besides restrictions in their daily activities, which might have increased PS in the parents of CWE.

In sex-wise analysis, duration of illness and number of drug use were found to be the specific predictors for PS in females in the present study. Longer duration of illness of child causes chronic fatigue, burnout, emotional distress, high emotional investment coupled with sustained caregiving efforts, compromised personal time, convincing child for medication adherence, managing side effects, financial strain, isolation, and uncertainty can contribute to PS among female caregivers.

The availability of limited studies on PS among parents of CWE using PSI-SF, the presence of the PSI tool in multiple forms (long and short), and its use in different study designs (case-control and experimental) limited us to compare with other studies. This is a single-centre study, and generalizing the findings of the present study for all populations requires multicentric studies. Risk factors of PS need to be established in longitudinal studies. As this study is an observational study, the control group is not included. The non-availability

of normative data on PSI in Indian populations is one of the limitations. The inclusion of a control group might have helped to determine the cut-off value for significant parental stress, which we are planning in future studies. However, we have used 90 percentile values of PSI total of caregivers of CWE to determine parental stress.

In conclusion, in this study, 10% of caregivers had PS. The results of the present study suggested that PS is influenced by sex. Females were found to have higher PS than males. Interventions need to be targeted to females to improve the mental health among them, and information seeking needs to be increased among the caregivers of both sexes of CWE to reduce PS.

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