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Original Research Article

CAREGIVER BURDEN, PSYCHOLOGICAL DISTRESS, AND QUALITY OF LIFE AMONG PRIMARY CAREGIVERS OF CHILDREN WITH EPILEPSY: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Childhood epilepsy is a chronic neurological disorder requiring long-term treatment, seizure monitoring, healthcare utilization, and substantial family involvement. These demands may adversely affect the quality of life (QOL) and psychological well-being of primary caregivers. This study assessed caregiver burden, perceived stress, anxiety, depressive symptoms, and QOL among primary caregivers of children with epilepsy and examined their demographic and clinical correlates.

Materials and Methods: A hospital-based cross-sectional study was conducted among 150 primary caregivers of children with epilepsy attending the Departments of Pediatrics and Psychiatry at a tertiary care hospital. Caregivers aged 18–60 years who had lived with the child and participated in caregiving for at least 6 months were recruited using purposive sampling. Data were collected using a semistructured questionnaire, the WHOQOL-BREF, 22-item Zarit Burden Interview, 10-item Perceived Stress Scale, Hamilton Anxiety Rating Scale (HAM-A), and Beck Depression Inventory-II (BDI-II). Associations between demographic and clinical characteristics and caregiver outcomes were assessed using appropriate statistical tests. Pearson's correlation analysis was used to examine relationships between QOL and psychological variables. Statistical significance was set at $p < 0.05$.

Results: Women constituted 69.0% of the caregivers, and parents accounted for 80.0%. Moderate-to-severe caregiver burden was present in 57.4% of participants, while 55.3% reported poor QOL. High perceived stress was observed in 54.7%, severe depressive symptoms in 63.3%, and moderate-to-severe anxiety symptoms in 50.7%. Caregiver burden was significantly associated with age, sex, socioeconomic status, educational status, age at seizure onset, and duration of illness. Perceived stress was significantly associated with age, sex, and caregiver relationship. Depressive symptoms were associated with age, caregiver relationship, socioeconomic status, duration of illness, and history of hospitalization. Anxiety symptoms were associated with sex, caregiver relationship, socioeconomic status, family type, and age at seizure onset. QOL was significantly associated with caregiver sex and the number of hospitalizations. Significant correlations were observed between QOL and caregiver burden, perceived stress, anxiety, and depressive symptoms.

Conclusion: Primary caregivers of children with epilepsy experienced substantial caregiving burden and psychological distress, accompanied by impaired QOL. Routine assessment of caregiver well-being, along with psychoeducation, counselling, psychosocial support, and appropriate mental health referral, should be considered as integral components of comprehensive pediatric epilepsy care.

Keywords: Childhood epilepsy, caregiver burden, quality of life, perceived stress, anxiety, depression.

INTRODUCTION

Epilepsy is a chronic neurological disorder characterized by recurrent unprovoked seizures and represents an important cause of morbidity and functional impairment during childhood.[1] Recurrent seizures, long-term antiepileptic medication, frequent medical consultations, and the need for continuous supervision can adversely affect a child's physical, cognitive, behavioral, educational, and social development. However, the consequences of childhood epilepsy extend beyond the affected child and substantially influence the well-being and functioning of family members, particularly those who assume primary caregiving responsibilities.[2,3] Primary caregivers, most commonly parents, are responsible for medication administration, seizure monitoring, supervision, hospital visits, adherence to treatment, and provision of emotional and practical support.[4] In some families, grandparents or other relatives may also undertake major caregiving responsibilities.[5] The unpredictable nature of seizures, fear of injury, prolonged treatment requirements, repeated hospitalizations, concerns regarding treatment effectiveness, and uncertainty about the child's future can impose considerable physical, emotional, social, and financial strain on caregivers. These challenges may contribute to caregiver burden, which is a multidimensional experience encompassing emotional distress, physical exhaustion, social restrictions, and financial difficulties.[6] Caregiver burden may vary according to several disease- and family-related factors, including seizure frequency, severity of epilepsy, age at seizure onset, duration of illness, treatment requirements, hospitalization, socioeconomic status, and availability of family and social support.[7] In addition, caregivers may experience persistent psychological stress, anxiety, and depressive symptoms while attempting to manage the child's condition and meet routine family responsibilities.[8] Prolonged psychological distress may interfere with coping abilities, interpersonal relationships, and caregiving capacity and may subsequently affect the overall quality of life (QOL) of both the caregiver and the child.[9] Families of children with epilepsy may also face additional psychosocial challenges.[10] Fear of seizures occurring in public, concerns about the child's education and future employment, uncertainty regarding marriage and independent living, and misconceptions about epilepsy may contribute to social isolation and emotional distress.[11] Epilepsy-related stigma can further restrict social participation and discourage families from seeking appropriate medical and psychosocial support.[12] Consequently, caregiver well-being should not be considered separately from the clinical management of childhood epilepsy, as caregiver health and coping capacity are closely linked to treatment adherence, supervision, and the child's long-term care.[13] Assessment of caregiver well-being is therefore an important component of comprehensive pediatric epilepsy management. Although several studies have examined individual aspects of caregiver burden, psychological distress, or QOL, comparatively limited evidence is available from Indian tertiary-care settings examining these domains collectively among primary caregivers of children with epilepsy.[14] Understanding the demographic and clinical factors associated with caregiver outcomes may help clinicians identify caregivers at increased risk of psychological difficulties and provide timely supportive interventions. The present study was undertaken to assess caregiver burden, perceived stress, anxiety, depressive symptoms, and QOL among primary caregivers of children with epilepsy and to examine the association of these outcomes with relevant demographic and clinical characteristics. The study also evaluated the relationships between caregiver QOL and psychological factors, with the aim of highlighting the need for integrated psychosocial support as part of routine pediatric epilepsy care.

MATERIALS AND METHODS

Study Design and Setting

A hospital-based cross-sectional study was conducted in the Departments of Pediatrics and Psychiatry at a tertiary care hospital in Tamil Nadu, India, over a period of six months. The study was designed to assess caregiver burden, perceived stress, anxiety, depressive symptoms, and quality of life (QOL) among primary caregivers of children with epilepsy and to examine their association with relevant demographic and clinical characteristics.

Study Population and Participants

The study population comprised primary caregivers of children diagnosed with epilepsy according to the 2017 criteria of the International League Against Epilepsy (ILAE). Eligible caregivers were aged 18–60 years and had been living with the child and actively participating in caregiving for at least six months. The child was required to have a documented history of epilepsy for more than one year and to be attending regular follow-up. Caregivers were excluded if the child had a comorbid psychiatric disorder, cerebral palsy, or another chronic neurological illness that could independently influence caregiver burden or psychological well-being. Caregivers with a known psychiatric disorder or a chronic debilitating medical condition were also excluded.

Sampling and Sample Size

Purposive sampling was employed to recruit eligible participants during the study period. A total of 150 primary caregivers who fulfilled the predefined eligibility criteria were included in the study.

Data Collection and Study Instruments

Data were collected using a pretested semistructured questionnaire administered through face-to-face

interviews. The questionnaire was translated into the local language to facilitate comprehension and ensure accurate responses. The following domains and standardized instruments were used:

1. Sociodemographic and clinical characteristics: Information regarding caregiver age, sex, relationship to the child, educational status, socioeconomic status, family type, and relevant clinical characteristics of the child was collected. Socioeconomic status was assessed using the Modified Kuppuswamy Socioeconomic Scale (2021).[15]
2. Quality of life: Caregiver QOL was assessed using the World Health Organization Quality of Life-BREF (WHOQOL-BREF), which evaluates QOL across physical, psychological, social, and environmental domains.[16]
3. Caregiver burden: The 22-item Zarit Burden Interview (ZBI) was used to assess the perceived burden associated with caregiving. The instrument evaluates the extent to which caregiving responsibilities affect the caregiver's emotional, social, and personal well-being.
4. Perceived stress: Perceived stress was assessed using the 10-item Perceived Stress Scale (PSS-10), which measures the degree to which individuals perceive situations in their lives as stressful.
5. Anxiety: Anxiety symptoms were assessed using the Hamilton Anxiety Rating Scale (HAM-A).
6. Depressive symptoms: Depressive symptoms were evaluated using the Beck Depression Inventory-II (BDI-II).

All instruments were administered according to their respective standard scoring procedures. The assessment was conducted in a private setting to facilitate confidentiality and encourage participants to provide accurate responses.

Study Procedure

Potentially eligible caregivers attending the pediatric and psychiatric services were screened according to the inclusion and exclusion criteria. The purpose and procedures of the study were explained to eligible participants, and written informed consent was obtained before enrolment. Participants were then interviewed individually using the pretested semistructured questionnaire and standardized assessment instruments. Relevant clinical information regarding the child was obtained from the caregiver and available medical records. Confidentiality and privacy were maintained throughout the data collection process.

Statistical Analysis

Data were entered, coded, and analyzed using IBM SPSS Statistics version 23.0 (IBM Co., Armonk, NY, USA). Categorical variables were expressed as frequencies and percentages, while continuous variables were summarized using means and standard deviations. The chi-square test was used to assess associations between categorical variables. The independent-samples *t* test was used for comparison of means between two groups, while one-way analysis of variance (ANOVA) was used for comparisons involving more than two groups. Pearson's correlation coefficient was used to assess the relationships between QOL and psychological variables, including caregiver burden, perceived stress, anxiety, and depressive symptoms. Appropriate statistical tests were selected based on the type and distribution of the variables. A two-sided *p* value of <0.05 was considered statistically significant.

Ethical Considerations

The study was conducted after obtaining approval from the Institutional Ethics Committee of the study institution. Written informed consent was obtained from all participants before their enrolment. Participants were informed about the purpose and procedures of the study and their voluntary participation. Confidentiality and anonymity of the collected information were maintained throughout the study, and the data were used solely for research purposes.

RESULTS

A total of 150 primary caregivers of children with epilepsy were included in the study. The demographic characteristics of the caregivers are presented in Table 1. The largest proportion of caregivers belonged to the 21–30-year age group (52, 34.7%), followed by those aged 41–50 years (48, 32.0%) and 31–40 years (35, 23.3%). Fifteen caregivers (10.0%) were aged >50 years. Women constituted the majority of caregivers (104, 69.0%), whereas 46 (31.0%) were men. Regarding educational status, 73 (48.7%) caregivers were graduates, 62 (41.3%) had completed middle school, and 15 (10.0%) had completed high school. Most caregivers belonged to the middle socioeconomic group (88, 58.7%), followed by the upper (54, 36.0%) and lower (8, 5.3%) socioeconomic groups. A majority lived in nuclear families (90, 60.0%), while 60 (40.0%) belonged to joint families. Parents represented the predominant caregiver relationship (120, 80.0%), followed by grandparents (20, 13.3%) and other caregivers (10, 6.7%).

Table 1: Demographic Characteristics of Primary Caregivers

Variable	Category	n (%)
Age (years)	21–30	52 (34.7)
	31–40	35 (23.3)
	41–50	48 (32.0)
	>50	15 (10.0)

Sex	Male	46 (31.0)
	Female	104 (69.0)
Education	Graduate	73 (48.7)
	High school	15 (10.0)
	Middle school	62 (41.3)
Socioeconomic status	Upper	54 (36.0)
	Middle	88 (58.7)
	Lower	8 (5.3)
Family type	Nuclear	90 (60.0)
	Joint	60 (40.0)
Caregiver relationship	Parent	120 (80.0)
	Grandparent	20 (13.3)
	Other	10 (6.7)

The clinical characteristics of the children with epilepsy are presented in Table 2. Seizure onset occurred before 2 years of age in 72 children (48.0%), between 3 and 10 years in 65 (43.3%), and after 10 years in 13 (8.7%). Regarding duration of illness, 50 children (33.3%) had epilepsy for <5 years, 56 (37.3%) had an illness duration of 5–10 years, and 44 (29.3%) had epilepsy for >10 years. Generalized tonic-clonic seizures (GTCS) were the predominant seizure type, occurring in 111 children (74.0%), followed by absence seizures in 32 (21.3%) and complex partial seizures (CPS) in 7 (4.7%). Most children were receiving two antiepileptic drugs (90, 60.0%), while 43 (28.7%) were receiving three drugs and 17 (11.3%) were receiving one drug. More than five hospitalizations were reported in 121 children (80.7%), compared with 29 (19.3%) who had fewer than five hospitalizations.

Table 2: Clinical Characteristics of Children with Epilepsy

Variable	Category	n (%)
Age at seizure onset	<2 years	72 (48.0)
	3–10 years	65 (43.3)
	>10 years	13 (8.7)
Duration of illness	<5 years	50 (33.3)
	5–10 years	56 (37.3)
	>10 years	44 (29.3)
Type of seizure	GTCS	111 (74.0)
	Absence	32 (21.3)
	CPS	7 (4.7)
Number of AEDs	1	17 (11.3)
	2	90 (60.0)
	3	43 (28.7)
Hospitalizations	<5	29 (19.3)
	>5	121 (80.7)

**AEDs, antiepileptic drugs; CPS, complex partial seizures; GTCS, generalized tonic-clonic seizures.*

The distribution of caregiver burden, QOL, perceived stress, depression, and anxiety is shown in Table 3. Of the 150 caregivers, 26 (17.3%) reported no burden, 38 (25.3%) had mild burden, 55 (36.7%) had moderate burden, and 31 (20.7%) had severe burden. Thus, 86 caregivers (57.4%) experienced moderate-to-severe caregiver burden. With respect to QOL, 83 caregivers (55.3%) reported poor QOL, while 60 (40.0%) had moderate QOL and only 7 (4.7%) reported normal QOL. Regarding perceived stress, 12 caregivers (8.0%) reported low stress, 56 (37.3%) reported moderate stress, and 82 (54.7%) reported high stress. Depressive symptoms were severe in 95 caregivers (63.3%), while 31 (20.7%) had moderate and 24 (16.0%) had mild depressive symptoms. Anxiety symptoms were mild in 74 (49.3%), moderate in 52 (34.7%), and severe in 24 (16.0%). Overall, 76 caregivers (50.7%) experienced moderate-to-severe anxiety.

Table 3: Distribution of Caregiver Outcomes

Outcome	Category	n (%)
Caregiver burden	No burden	26 (17.3)
	Mild	38 (25.3)
	Moderate	55 (36.7)
	Severe	31 (20.7)
Quality of life	Poor	83 (55.3)
	Moderate	60 (40.0)
	Normal	7 (4.7)
Perceived stress	Low	12 (8.0)
	Moderate	56 (37.3)
	High	82 (54.7)
Depression	Mild	24 (16.0)
	Moderate	31 (20.7)

	Severe	95 (63.3)
Anxiety	Mild	74 (49.3)
	Moderate	52 (34.7)
	Severe	24 (16.0)

The factors associated with QOL, caregiver burden, perceived stress, depression, and anxiety are summarized in Table 4. QOL was significantly associated with caregiver sex ($p = 0.007$) and the number of hospitalizations ($p = 0.034$). Caregiver burden was significantly associated with age ($p < 0.001$), sex ($p < 0.001$), socioeconomic status ($p = 0.004$), education ($p < 0.001$), age at seizure onset ($p < 0.001$), and duration of illness ($p < 0.001$). Perceived stress showed significant associations with caregiver age ($p < 0.001$), sex ($p = 0.038$), and caregiver relationship ($p = 0.017$). Depression was significantly associated with age ($p = 0.003$), caregiver relationship ($p < 0.001$), socioeconomic status ($p = 0.029$), and duration of illness ($p = 0.022$). Anxiety was significantly associated with sex ($p = 0.001$), caregiver relationship ($p = 0.047$), socioeconomic status ($p < 0.001$), family type ($p = 0.046$), and age at seizure onset ($p = 0.009$).

Table 4: Factors Associated with Quality of Life, Caregiver Burden, Perceived Stress, Depression, and Anxiety Among Primary Caregivers

Variable	QOL	Caregiver burden	Perceived stress	Depression	Anxiety
Age	—	<0.001	<0.001	0.003	—
Sex	0.007	<0.001	0.038	—	0.001
Caregiver relationship	—	—	0.017	<0.001	0.047
Socioeconomic status	—	0.004	—	0.029	<0.001
Education	—	<0.001	—	—	—
Family type	—	—	—	—	0.046
Age at seizure onset	—	<0.001	—	—	0.009
Duration of illness	—	<0.001	—	0.022	—
Number of hospitalizations	0.034	—	—	—	—

Correlation analysis demonstrated significant inverse relationships between QOL and all four psychological variables (Table 5; Figure 1). QOL was negatively correlated with caregiver burden ($r = −0.306$, $p < 0.001$), indicating that greater caregiver burden was associated with poorer QOL. A strong negative correlation was observed between QOL and perceived stress ($r = −0.836$, $p < 0.001$), representing the strongest correlation identified in the study. QOL was also negatively correlated with anxiety ($r = −0.345$, $p < 0.001$) and depressive symptoms ($r = −0.300$, $p = 0.005$). Figure 1 illustrates the inverse relationships between caregiver QOL and caregiver burden, perceived stress, anxiety, and depression. The strongest inverse relationship was observed between QOL and perceived stress ($r = −0.836$, $p < 0.001$). Significant negative correlations were also observed between QOL and anxiety ($r = −0.345$, $p < 0.001$), caregiver burden ($r = −0.306$, $p < 0.001$), and depression ($r = −0.300$, $p = 0.005$). These findings indicate that increasing psychological distress and caregiving burden were associated with progressively poorer QOL among primary caregivers of children with epilepsy.

Table 5: Correlation between Quality of Life and Psychological Variables

Variables compared	Correlation coefficient (r)	*p* value	Interpretation
QOL vs. caregiver burden	−0.306	<0.001	Negative
QOL vs. perceived stress	−0.836	<0.001	Strong negative
QOL vs. anxiety	−0.345	<0.001	Negative
QOL vs. depression	−0.300	0.005	Negative

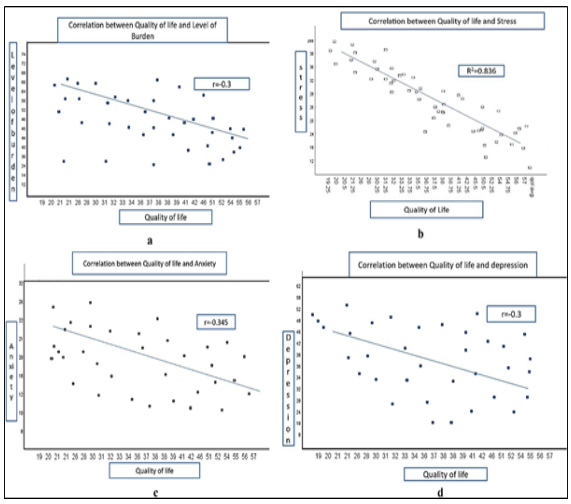

Figure 1: Correlation between QOL and psychological variables

DISCUSSION

The present cross-sectional study evaluated caregiver burden, quality of life (QOL), perceived stress, anxiety, and depressive symptoms among 150 primary caregivers of children with epilepsy in a tertiary-care setting in Tamil Nadu. The findings demonstrate a substantial psychosocial burden among caregivers, with 57.4% experiencing moderate-to-severe caregiver burden, 55.3% reporting poor QOL, 54.7% reporting high perceived stress, 63.3% reporting severe depressive symptoms, and 50.7% experiencing moderate-to-severe anxiety. These findings support the concept that childhood epilepsy affects not only the child but also the psychological, social, and functional well-being of the entire family. Epilepsy is a chronic neurological disorder affecting approximately 50 million people worldwide, with nearly 80% of affected individuals living in low- and middle-income countries, where families frequently provide the majority of long-term care.[17] In the present study, women constituted the majority of caregivers (69.0%), and parents accounted for 80.0% of the caregiving population. This predominance of women, particularly mothers, is consistent with the traditional distribution of caregiving responsibilities within families. A systematic review of QOL among parents of children with epilepsy reported that mothers generally had poorer QOL than fathers and that parental QOL was influenced substantially by psychosocial factors.[18] The predominance of parental caregivers in our study is also consistent with evidence from India indicating that individuals with epilepsy are predominantly cared for by family members, with caregivers responsible for medication administration, seizure safety, emergency management, and hospital attendance.[19] The clinical characteristics of the children in our study suggest a considerable long-term caregiving requirement. Nearly half of the children (48.0%) had seizure onset before 2 years of age, 37.3% had an illness duration of 5–10 years, and 29.3% had epilepsy for more than 10 years. Generalized tonic-clonic seizures were the predominant seizure type (74.0%), while 60.0% of children were receiving two antiepileptic drugs and 28.7% were receiving three drugs. Furthermore, 80.7% had experienced more than five hospitalizations. These findings indicate that many caregivers were exposed to prolonged disease management, complex treatment schedules, and repeated healthcare utilization. Previous Indian research has similarly demonstrated that longer duration of epilepsy, frequent or recent seizures, polytherapy, developmental problems, and hospitalization are associated with poorer QOL in children with epilepsy.[20] Such clinical complexity may indirectly increase caregiver responsibilities and contribute to psychological distress. A major finding of the present study was the high prevalence of caregiver burden. Moderate-to-severe burden was identified in 57.4% of caregivers, comprising 36.7% with moderate burden and 20.7% with severe burden. This finding is consistent with the broader literature demonstrating that epilepsy-related caregiving can adversely affect physical health, mental health, family functioning, social life, and financial well-being.[21] A systematic synthesis of qualitative studies involving caregivers of children with epilepsy identified heavy caregiving burden, disease-related challenges, inadequate social support, and difficulties in adaptation as major recurring themes.[22] Therefore, caregiver burden should not be interpreted solely as the number of tasks performed for the child but as a multidimensional response to the continuing physical, emotional, social, and financial demands of epilepsy.

In our study, caregiver burden was significantly associated with age, sex, socioeconomic status, education, age at seizure onset, and duration of illness. These findings suggest that caregiver burden is influenced by both caregiver-related and disease-related factors. Lower socioeconomic circumstances may increase financial stress related to medication, transportation, investigations, hospital visits, and loss of employment or productivity. Lower educational attainment may also limit access to reliable health information and affect confidence in seizure management. Importantly, duration of illness and age at seizure onset were significantly associated with burden, suggesting that prolonged exposure to caregiving demands may contribute to cumulative stress. The Indian literature emphasizes that caregiver distress is influenced by multiple interacting factors, including seizure-related characteristics, caregiver characteristics, psychosocial factors, family support, and cultural attitudes.[21] The present study also demonstrated substantial impairment in caregiver QOL, with 55.3% reporting poor QOL and only 4.7% reporting normal QOL. This finding is consistent with a systematic review of 15 studies, which concluded that parents of children with epilepsy generally have

poorer QOL than healthy controls or population norms. The review further reported that poorer parental QOL was consistently associated with anxiety, depressive symptoms, socioeconomic disadvantage, and poorer child QOL.[18] Our finding therefore reinforces the importance of assessing caregiver QOL as an independent outcome rather than focusing exclusively on seizure control.

Caregiver QOL was significantly associated with caregiver sex and the number of hospitalizations in the present study. The association with sex is consistent with previous evidence indicating poorer QOL among mothers compared with fathers.[18] The association between hospitalization and QOL may reflect the cumulative impact of recurrent acute-care requirements, travel, treatment costs, disruption of family routines, and anxiety surrounding seizure recurrence. Previous Indian research has similarly reported that hospitalization is associated with poorer QOL among children with epilepsy,[20] suggesting that repeated healthcare utilization may affect both the child and caregiver. Perceived stress was another prominent finding, with 54.7% of caregivers reporting high stress. Stress was significantly associated with caregiver age, sex, and caregiver relationship. The high prevalence of stress may reflect the unpredictable nature of seizures and the continuous need for supervision and preparedness. A recent study of caregivers of children with epilepsy demonstrated that parental stress is influenced not only by seizure-related variables but also by cognitive, behavioral, and treatment-related factors, highlighting the importance of addressing the broader caregiving environment.[24] These observations suggest that seizure control alone may not adequately address caregiver distress and that comprehensive assessment should also consider treatment complexity, behavioral difficulties, developmental concerns, and family functioning. Depressive symptoms were particularly prominent in our study, with 63.3% of caregivers classified as having severe depressive symptoms. Depression was significantly associated with caregiver age, caregiver relationship, socioeconomic status, and duration of illness. The high proportion observed in the present study is clinically important because persistent depressive symptoms may impair coping, motivation, treatment adherence, and the caregiver's ability to provide sustained support to the child. Previous systematic evidence has shown that poorer parental QOL is consistently associated with greater depressive and anxiety symptoms.[18] However, direct comparison of prevalence rates between studies should be undertaken cautiously because different studies have used different instruments, scoring thresholds, sample characteristics, and clinical settings. Anxiety symptoms were also common, with 50.7% of caregivers having moderate-to-severe anxiety. Anxiety was significantly associated with sex, caregiver relationship, socioeconomic status, family type, and age at seizure onset. The unpredictable occurrence of seizures may generate persistent fear regarding injury, emergency situations, school participation, and the child's long-term future. Qualitative evidence indicates that caregivers of children with epilepsy commonly experience concerns related to diagnosis, future uncertainty, changes in their own lives, social restrictions, and inadequate support.[6] The present findings are therefore consistent with the broader understanding that caregiver anxiety is closely related to both the clinical unpredictability of epilepsy and the psychosocial consequences of chronic caregiving.

The relationship between caregiver QOL and psychological distress was particularly noteworthy. Significant inverse correlations were observed between QOL and caregiver burden ($r = -0.306$, $p < 0.001$), perceived stress ($r = -0.836$, $p < 0.001$), anxiety ($r = -0.345$, $p < 0.001$), and depression ($r = -0.300$, $p = 0.005$). The strongest relationship was between QOL and perceived stress. This finding indicates that caregivers experiencing greater psychological stress tend to report substantially poorer QOL. The direction of these associations is consistent with the systematic review literature showing that parental QOL is strongly related to psychosocial factors, particularly anxiety and depression.[18] However, because this was a cross-sectional study, these correlations should not be interpreted as evidence of causality. Poor QOL may contribute to psychological distress, while psychological distress may simultaneously reduce QOL, suggesting a potentially bidirectional relationship. The high level of caregiver distress observed in this study is particularly relevant in the Indian context. A review of caregiver distress in India identified significant caregiver burden and reported that caregiving may negatively affect physical and mental health, family functioning, and financial status.[21] The same review highlighted the limited number of well-designed Indian studies and emphasized the importance of culture-specific factors in understanding caregiver experiences. In addition, an Indian study from Western Tamil Nadu demonstrated that caregivers of children with epilepsy may have specific educational needs related to seizure recognition, seizure first aid, misconceptions, and treatment-related practices.[19] These findings support the need for culturally appropriate caregiver education rather than relying exclusively on conventional medical management. The findings have important implications for clinical practice. Routine pediatric epilepsy care should incorporate brief screening for caregiver burden, stress, anxiety, depressive symptoms, and QOL. Caregivers with significant psychological difficulties should receive appropriate counselling and, when indicated, referral to mental health professionals. Psychoeducation should include seizure first aid, medication adherence, recognition of seizure triggers, management of emergencies, clarification of misconceptions, and realistic

information regarding prognosis. Family-based interventions may also be beneficial because caregivers require support not only from healthcare professionals but also from family and community networks. Evidence from qualitative synthesis emphasizes the importance of multidimensional social support in helping caregivers adapt to childhood epilepsy.[22] The present study has several strengths. It included a relatively substantial sample of 150 caregivers and simultaneously assessed multiple dimensions of caregiver well-being using standardized instruments. The inclusion of caregivers attending both pediatric and psychiatric services allowed assessment of psychological outcomes in a clinically relevant tertiary-care population. The study also examined both caregiver-related and child-related factors and evaluated the interrelationship between QOL and psychological variables. However, several limitations should be considered. First, the cross-sectional design prevents determination of temporal or causal relationships between epilepsy-related factors, caregiver burden, psychological distress, and QOL. Second, purposive sampling from a single tertiary-care hospital may limit the generalizability of the findings to caregivers attending primary-care facilities or other geographic regions. Third, the study relied primarily on self-reported psychological measures, which may be influenced by response and reporting biases. Fourth, detailed variables such as seizure frequency, seizure-free duration, drug resistance, developmental status, behavioral problems, social support, sleep quality, and caregiver coping strategies were not comprehensively evaluated. Future multicenter longitudinal studies incorporating these variables would provide a more comprehensive understanding of caregiver distress and help identify caregivers at greatest risk.

Limitations

The present study has several limitations. First, the cross-sectional design limits the ability to establish temporal or causal relationships between epilepsy-related clinical factors, caregiver burden, psychological distress, and quality of life. Second, the study was conducted in a single tertiary-care hospital in Tamil Nadu, and therefore the findings may not be generalizable to caregivers attending primary-care facilities, other hospitals, or different geographic and socioeconomic settings. Third, purposive sampling was used, which may have introduced selection bias and limited the representativeness of the study population. Fourth, psychological outcomes were assessed using self-report and interviewer-administered standardized scales, which may be influenced by recall, reporting, or social desirability bias. The study did not include a clinical psychiatric diagnostic interview to confirm depressive or anxiety disorders. Fifth, although several clinical characteristics of epilepsy were assessed, potentially important factors such as seizure frequency, seizure-free duration, drug-resistant epilepsy, medication adverse effects, developmental and behavioral problems, sleep disturbances, caregiver social support, coping strategies, and family functioning were not comprehensively evaluated. These factors may independently influence caregiver burden and psychological well-being. Finally, the study included caregivers who had been involved in caregiving for at least six months and whose children had epilepsy for more than one year; therefore, the findings may not reflect the experiences of caregivers during the initial period following epilepsy diagnosis. Future multicenter, longitudinal studies with larger representative samples and comprehensive assessment of clinical, psychosocial, and family-related factors are recommended to better understand the long-term impact of childhood epilepsy on caregivers.

CONCLUSION

The present study demonstrates that primary caregivers of children with epilepsy experience substantial caregiver burden, psychological distress, and impaired QOL. More than half of the caregivers had moderate-to-severe burden, poor QOL, high perceived stress, or moderate-to-severe anxiety, while severe depressive symptoms were particularly common. Caregiver demographic characteristics, socioeconomic factors, family relationships, age at seizure onset, duration of illness, and hospitalization were significantly associated with different caregiver outcomes. The strong inverse relationship between perceived stress and QOL emphasizes the importance of addressing caregiver psychological well-being alongside seizure management. Pediatric epilepsy services should therefore adopt a family-centered approach incorporating routine caregiver screening, psychoeducation, counselling, psychosocial support, and timely mental health referral.

Availability of Data

The datasets generated and/or analyzed during the present study are available from the corresponding author on reasonable request, subject to institutional ethical and confidentiality requirements.

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Authors' Contributions

All authors contributed equally to the conception and design of the study, data collection, analysis and interpretation of data, drafting and critical revision of the manuscript, and approval of the final version for publication. All authors agree to be accountable for all aspects of the work.

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