Original Article

Burden of depression and anxiety among caregivers of children having structural epilepsy

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Abstract

Context: Epilepsy is one of the most common chronic neurological disorders in childhood. Structural malformations of the cerebral cortex are an important cause of developmental disabilities and epilepsy; this leads to a significant amount of psychological burden on parents of such children. Despite being a common and debilitating neurological illness, there is a paucity of data on the burden of stress and depression in parents of such children. **Aims:** The objective was to find out the burden of these illnesses on caregivers of such children. **Settings and Design:** This was a hospital-based cross-sectional, questionnaire-based study conducted in the Department of Pediatrics (both inpatient and outpatient), PGIMS Rohtak, during the period of June–September 2023. Parents of children with structural epilepsy (age: 2–14 years) were study subjects. **Methods and Material:** A cross-sectional study involving parents of 100 children with structural epilepsy (aged 2–14 years) was conducted using Hamilton Depression Rating Scale (HDRS) and Hamilton Anxiety Rating Scale (HAM-A). **Statistical Analysis Used:** Data were recorded in Microsoft Office Excel. Statistical analysis was performed using Statistical Package for Social Sciences v22. Statistical significance was checked by *P* value (two-tailed) considering value < 0.05 as significant. **Results:** Higher levels of anxiety and depression were seen in parents of children having structural epilepsy. Relatively higher levels were seen in parents of such children who were receiving polytherapy (HDRS ($P = 0.002$); HAM-A (0.001)). **Conclusions:** This study shows a higher prevalence of anxiety and depression among caregivers of children having structural epilepsy. Parents of such children require extra support as they appear to be a population prone to illnesses that will hinder the proper care of children with structural epilepsy and their quality of life. This circle has to be broken for better upbringing and treatment compliance for such children. Preventive and therapeutic interventions need to be taken to reduce the burden of such psychiatric illness at the community level.

Keywords: Anxiety, depression, structural epilepsy

Introduction

Caring for a child with structural epilepsy extends beyond medical management. It encompasses a complex web of emotions, challenges, and responsibilities that can significantly impact caregivers. This neurological disorder, characterized by abnormalities in the brain's structure, presents a unique burden for both affected children and those dedicated to their well-being. This burden, often unseen and underestimated, transcends physical and financial aspects, deeply affecting caregivers' emotional well-being. Epilepsy is a common neurological disorder in children, with a higher incidence (3.4–3.9 per 1000) in developing countries compared to developed nations.[1-3] In children, roughly half of all epilepsy cases have a documented cause, and 28% of these are structural.[4]

Structural epilepsy is a subset of epilepsy characterized by identifiable abnormalities in the brain. These abnormalities can be congenital malformations or acquired conditions. The nature of structural epilepsy complicates caregiving as the underlying issues can impact seizure frequency and severity, treatment response, and overall prognosis. Brain damage can arise from abnormal cell growth, migration, or cortical tissue

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formation. Cortical developmental malformations (CDMs) are a common cause of epilepsy and motor/cognitive impairment in children. The European Brain Malformation Network (Neuro-MIG) recently proposed a new classification system for CDMs (2020), categorizing them based on abnormal cell death (apoptosis) into conditions such as primary microcephaly, brain overgrowth spectrum, and focal cortical abnormalities. In addition, the classification includes abnormal brain development (ectopia, anencephaly, subcortical heterotopia, cobblestone malformation, schizencephaly) and later developmental abnormalities (gyriencephaly, focal cortical dysplasia types I and III, polymicrogyria, secondary microcephaly).[5] Despite advancements in molecular and radiological methods, the etiology and treatment of many structural epilepsy causes remain unclear, often leading to a poor prognosis. Treatment typically involves long-term use of multiple antiepileptic drugs, adding further psychological stress to parents. Recent advancements, however, offer hope for the development of targeted treatments and improved medical and social care for affected children and their families.

Parental stress and depression can significantly impact a child's quality of life and behavior. Anxiety and depression arise from perceived threats and the inability to predict or control outcomes. When these symptoms become debilitating, daily functioning is impaired. Parents of children with structural epilepsy are particularly susceptible to anxiety and depression due to uncertainties about their child's illness, concerns about future finances and health, and the unpredictable nature of seizures, which often lead to embarrassing and dangerous situations. Structural epilepsy carries a social stigma for both families and children. Compared to healthy children, those with structural epilepsy face potential discrimination as being less intelligent and "social," leading to limited opportunities for education, employment, and marriage in the future.[6] An intact family environment is likely one of the most critical factors for maximizing a child's rehabilitation, particularly for those with structural epilepsy. It is crucial to recognize the importance of family support.[7] The physical and mental health of parents significantly impacts the quality of life for children with structural epilepsy.[8] Families with a child suffering from a chronic illness like structural epilepsy experience a significant burden of care, requiring increased demands and role reorganization. In addition, each parent's response to and understanding of their own mental health can affect the parent-child relationship and the child's overall functioning. Parents need better support systems to help them cope with the challenges they face at different stages of their child's illness. This support should include problem-solving resources, information access, and financial and practical assistance. Studies have shown that parents of children with epilepsy experience psychological distress. Having a child with structural epilepsy not only strains parents emotionally but also restricts their daily lives, impacting their quality of life.[9-11] While research has explored the effects of childhood epilepsy on parental mental health, there is a lack of a systematic analysis specifically addressing how structural epilepsy in children affects parental quality of life.

This study aimed to evaluate the burden of depression and anxiety among caregivers of children with structural epilepsy by using standardized scales: Hamilton Depression Rating Scale (HDRS) and Hamilton Anxiety Rating Scale (HAM-A).

Subjects and Methods

This was a hospital-based, cross-sectional, questionnaire-based study conducted in the Department of Pediatrics (both inpatient and outpatient), PGIMS Rohtak, during the period of June–September 2023. Parents of children with structural epilepsy (aged 2–14 years) were the study subjects. The sample size was calculated to be 100 subjects at an alpha error of 0.05 and 80% power for the study purpose.

Prior approval from the institutional ethical committee on human subjects was obtained before commencing the work.

Subjects were divided into two groups. Group A consisted of 50 children with structural epilepsy and their parents. Group B consisted of 50 age and sex-matched controls, which were normal children and their parents.

Parents asked to participate in the study were briefed about the study, and a written information sheet describing the disease and study procedure along with a written consent sheet for participation was distributed. Parent information sheets and informed consent forms were made available in local and English languages. Exclusion criteria included parents having children with moderate or severe mental retardation, progressive central nervous system disease, and diseases of other systems besides structural epilepsy. Semi-structured interviews were conducted. Both parents were interviewed and evaluated separately. Parents were then administered HDRS and HAM-A scores.

Data were recorded in Microsoft Office Excel. Statistical analysis was performed using the Statistical Package for Social Sciences (SPSS) v22. Statistical significance was checked by *P* value (two-tailed) with a value of <0.05 considered significant.

Results

A total of 100 subjects were analyzed for the burden of anxiety and depression.

The study sample (parents) were in the age group of 32 years and below to 38 years and above, with a mean age of 35.3 years in group A and 37.8 in group B. Regarding the parents between the two groups, there was a trend to statistical significance between the two groups regarding parent occupation, where 34 parents were unemployed in the epileptic children group in contrast to 19 parents unemployed in the control group. This may reflect the effect of childhood structural epilepsy

on the function of the parents [Table 1]. The data also reveals a significant disparity in parental education level between groups A and B (*P* value = 0.001). Group B had a considerably higher proportion of individuals with parents who have higher education (44%) compared to group A (14%). This suggests that parental educational background might be a contributing factor that differentiates the two groups, but more data would be needed to determine the cause-and-effect relationship as groups themselves are formed in a way that affects parental education levels of parents with structural epilepsy versus normal parents.

Parents in group A were found to have higher HAM-A scores (mean = 13.67 (1.668)) than group B (mean = 2.33 (1.647)) (*P* = 0.001) [Table 2].

Parents in group A were found to have higher HDRS Scores (mean = 14.38 (2.456)) than group B (mean = 2.53 (1.737)) (*P* = 0.001) [Table 2].

Polytherapy refers to the use of two or more medications in treatment. The specific decision and plan for polytherapy were taken by the consultant in charge after a thorough assessment of the patient's condition such as the severity of symptoms, underlying conditions, and potential for medication interactions. After carefully accessing the potential risks and benefits, the patient was initiated on polytherapy. Parents of children receiving polytherapy were found to have higher HAM-A scores (mean = 17.27 (3.36)) than those who were not receiving polytherapy (mean = 14.65 (2.27)) (*P* = 0.001). Parents of children receiving polytherapy were found to have higher HDRS scores (mean = 16.35 (2.433)) than those who were not receiving polytherapy (mean = 14.05 (2.3)) (*P* = 0.002) [Table 3]. While it may seem contradictory that the group receiving polytherapy has higher average scores for both depression and anxiety, it is important to consider that these scores reflect the severity of the conditions before treatment. Typically, we prescribe polytherapy for more complex cases.

Discussion

Caring for a child with epilepsy, especially when it involves structural abnormalities in the brain, can be emotionally and physically demanding for parents and caregivers. The index study found higher levels of anxiety and depression symptoms among parents of children with neurological structural disorders compared to other forms of epilepsy. These findings align with previous research by Scherer *et al.*,[12] Chouhan *et al.*,[13] and Dave D. *et al.*,[14] who reported similar results in parents caring for children with intellectual disabilities and neurological disorders. In addition, studies by Chandorkar *et al.*[15] and Shabo *et al.*[16] support these findings.

The unpredictable nature of seizures in structural epilepsy is a significant contributor to caregiver stress and anxiety. The constant concern for a child's safety during seizures and the potential for complications or long-term consequences can lead to chronic emotional distress. Furthermore, the daily responsibilities associated with caring for a child with structural epilepsy can be overwhelming. Medication management, medical appointments, and constant vigilance disrupt routines and contribute to feelings of exhaustion and frustration. Balancing these demands with work, personal relationships, and other aspects of life intensifies the risk of depression. The financial burden of caring for a child with structural epilepsy is another significant stressor. Medical treatments, medications, and specialized care can create financial strain and anxiety about the family's economic stability. Navigating the healthcare system to access necessary resources and support services further adds to the burden. Social isolation is another common theme. The demands of caregiving can limit social activities and opportunities to connect with others who understand the unique challenges faced by the caregivers of children with structural epilepsy. The lack of a strong support network can exacerbate feelings of loneliness and contribute to depression.

Addressing the burden of depression and anxiety among caregivers is crucial for the well-being of both caregivers and children. Healthcare professionals should proactively assess and address the mental health of caregivers, offering support and resources to manage the emotional challenges they face. Educational programs and support groups focused on mental health can provide caregivers with coping strategies, stress management techniques, and opportunities for mutual support.

Table 1: Baseline characteristics between Group A and Group B

	Group A (*n*=50)	Group B (*n*=50)	*P*
Age (Mean)	35.3±6.2	37.8±4.5	0.378
Gender			0.001*
Male	19 (38%)	37 (74%)	
Female	31 (62%)	13 (26%)	
Occupation			0.001*
Not working	34 (68%)	19 (38%)	
Working	16 (32%)	31 (62%)	
Parental education			0.001*
Primary	32 (64%)	20 (40%)	
Secondary	11 (22%)	8 (16%)	
Higher	7 (14%)	22 (44%)	

Table 2: Comparision of HDRS and HAM-A scores between Group A and Group B

	Group A Mean (SD)	Group B Mean (SD)	*P*
HDRS	14.38 (2.456)	2.53 (1.737)	0.001
HAM-A	13.67 (1.668)	2.33 (1.647)	0.001

Table 3: Sub-comparision of HDRS and HAM-A scores in Group A in those receiving polytherapy and those not receiving polytherapy

Parents of Children in Group A	Receiving Polytherapy	Not Receiving Polytherapy	*P*
HDRS	16.35 (2.433)	14.05 (2.3)	0.002
HAM-A	17.27 (3.36)	14.65 (2.27)	0.001

The index study acknowledges some limitations. The open recruitment approach limited control over disease distribution and participant demographics. The majority of participants were mothers with lower education levels, potentially introducing selection bias as lower education is associated with higher anxiety and depression. In addition, the cross-sectional design precludes establishing causal relationships between caregiving challenges and mental health outcomes. Further research is needed to understand the trajectory of anxiety and depression over time in this population.

Conclusion

Parents of children with structural epilepsy experience higher rates of anxiety and depression compared to control groups. This highlights the need for greater support for parents of children with structural epilepsy as they are a population at increased risk for mental health concerns. These conditions may hinder their ability to provide appropriate care for their children. In conclusion, the burden of anxiety and depression among caregivers of children with structural epilepsy is a complex issue requiring attention from healthcare professionals, policymakers, and the community at large. Recognizing and addressing the unique challenges faced by these caregivers is crucial for a more holistic approach to caring for children with structural epilepsy. By supporting the mental health of those who play a vital role in their lives, we can ultimately contribute to better overall outcomes for the children themselves.

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Conflicts of interest

There are no conflicts of interest.

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