Review Paper

Care Needs of Parents With Epileptic Children: A Systematic Review

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ABSTRACT

Background: Understanding the care needs of parents with epileptic children is crucial, as they experience unique challenges affecting their mental and physical health.

Objectives: This study aims to investigate the needs of parents caring for children with epilepsy.

Methods: This is a systematic review study. A search was conducted in databases such as PubMed, Web of Science, and Scopus for related articles published from 1975 to 2023, using keywords "epilepsy", "children", "parents", "caregivers", "care needs", and "unmet needs". The review followed the preferred reporting items for systematic reviews and meta-analysis (PRISMA) guidelines. Finally, 30 articles were selected for review after quality appraisal using the critical appraisal skills program (CASP) and strengthening the reporting of observational studies in epidemiology (STROBE) checklists.

Results: The care needs were identified as psychological, educational, supportive, economic, social, and unmet needs. Parents expressed their supportive, economic, and social needs to reduce the burden of caregiving; their educational needs to cope with epilepsy; their psychological needs to reduce stress and anxiety; and their unmet needs to reduce emotional distress.

Conclusions: To improve the health status of children with epilepsy, their parents' care needs should first be considered. The healthcare providers should provide health care services to the parents of epileptic children tailored to the identified needs.

Key Words:

Caregivers, Child, Epilepsy, Parent, Need

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Introduction

Childhood epilepsy is a severe and common neurological disorder with lasting complications that can affect all aspects of family life [1]. Approximately 0.6% of children aged 1 to 17 years have active epilepsy [2]. The prevalence of epilepsy among Iranian children varies across studies, with estimates ranging from 5 to 16.6 per 1000 people [3]. The results of studies also show that the diagnosis of childhood epilepsy can have a negative impact on children's school attendance and education, outdoor recreation, social activities, sleep, and quality of life [4-6]. On the other hand, children with epilepsy are more dependent on their parents' care to manage their condition due to their greater dependence on their family [7]. Therefore, the more parents participate in care programs for children with epilepsy, the more effective the disease control and the lower the severity and complications of the disease [8].

The results of the study by Okiah et al. [9] show that caregivers of children with epilepsy perceive caring for a child with epilepsy as stressful, and the dimensions identified in their study included psychological, social, economic, and physical stress [9]. Other studies have reported the problems experienced by parents of children with epilepsy, such as spending more time caring for their children at home, feeling helpless in caring for them during a seizure, experiencing psychological disturbances, emotional disturbances such as sadness, anger, depression, and anxiety, caregiving challenges such as family adjustment, physical strain, psychological stress, and time management, and financial problems such as unemployment and limited family income [10, 11]. On the other hand, parents' care needs are influenced by many factors, and they may experience various types of internal (emotional and behavioral) and external (interpersonal, financial, housing, and educational) psychosocial problems that interfere with parents' provision of effective care [12].

Therefore, considering the different care situations faced by parents, the care needs of parents vary from one parent to another [13]. On the other hand, chronically ill patients are completely dependent on their caregivers, parents lack the necessary skills to provide effective and quality care, and support resources for parents are limited [14, 15]. Therefore, understanding, recognizing, and planning for parents' care needs are among the priorities of care interventions, and the first step in meeting parents' care needs is to identify them [16] correctly. Because an extensive search for studies did not find a clear definition of the care needs of parents with epileptic children, the present review study was conducted to identify the care needs of parents with epileptic children.

Materials and Methods

This study is a systematic review conducted to investigate the care needs of parents with epileptic children in Hamadan City, Iran, in 2023, according to the (preferred reporting items for systematic reviews and meta-analysis [PRISMA]) guidelines. PRISMA is a set of evidence-based elements for reporting in systematic reviews and meta-analyses. It can be used as a basis for reporting on systematic reviews with objectives other than evaluating interventions (such as assessing causality, prevalence, diagnosis, or prognosis) [17].

A comprehensive search was performed in PubMed, Scopus, and Web of Science databases to select the relevant studies. The keywords used in the search included "epilepsy," "parents," "care needs," and "unmet needs." Articles published between 1975 and 2023 in Persian and English that were pertinent to the topic were considered (Table 1).

Initially, duplicate articles were removed using EndNote software, version 18. Subsequently, the abstracts of the remaining articles were screened independently by two researchers to identify studies that met the inclusion and exclusion criteria. In the next step, the full texts of the selected articles were thoroughly reviewed, and those that fully aligned with the study's objectives were included in the final analysis.

Standard tools were employed to assess the included studies' quality and risk of bias. We used the critical appraisal skills program (CASP) checklist for qualitative studies to evaluate the methodological quality and potential biases. For quantitative studies, the strengthening the reporting of observational studies in epidemiology (STROBE) checklist was applied to assess the design and reporting quality [18].

Two researchers (Araash Khalili and Farshid Shamsaei) conducted evaluations independently, and in case of disagreement, a third researcher (Fatemeh Cheraghi) was consulted for final decision-making. This meticulous process for selecting and assessing the risk of bias in the studies ensured the credibility and quality of the systematic review findings, guaranteeing that only high-quality studies were included in the final analysis.

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Table 1. Search strategy [7]

International databases	Embase, PubMed, PsycINFO, Medline, CINAHL, Web of Knowledge, ASSIA, Web of Science, Scopus, Google Scholar
Iran databases	IranDoc, IranMedex, Magiran, SID, Google Scholar
Keywords	Epilepsy care needs, needs of career, barriers to epilepsy care, epilepsy care, caregiver needs, unmet needs, epilepsy needs, parent needs,
The concept of interest	Caregiver needs
Type of studies	Quantitative and qualitative
Search strategy	Parent* OR mother* OR father* OR family OR child* OR adolescent* OR teen* OR young people AND epileps* AND care* OR need* OR barriers* OR unmet needs* OR epilepsy care* OR caregiver need* OR caregiver needs* OR epilepsy need* epilepsy needs* OR parent needs* OR parent need* OR mother need* OR father need* OR child need* OR adolescent need*.

Journal of Pediatrics Review

Inclusion and exclusion criteria

The inclusion criteria for the study were the studies published between 1975 and 2023 in Persian and English, the full text's availability, and the presence of one or more keywords from the desired keywords in the article's title. The exclusion criterion for the study was the lack of access to the full text.

Results

A comprehensive review of articles identified 2702 articles. After removing duplicate studies, two researchers independently assessed whether there was bias in selection and whether studies lacked conceptual focus or were irrelevant to the research objective. Finally, 30 studies were included in the analysis (Table 2). The steps in the process are shown in Figure 1.

Based on the results of a systematic review of studies, the care needs of parents of children with epilepsy can be grouped into five dimensions: Psychological needs, educational needs, support needs, economic and social needs, and perceived needs in caring for a child with epilepsy.

Regarding the first dimension, psychological needs, the results of the systematic review show that certain types of seizures are associated with higher levels of psychological distress. For example, complex partial seizures are associated with higher levels of psychological problems, or children taking phenobarbital have more severe psychological problems than children taking other medications [44]. The side effects of antiepileptic drugs can also lead to psychological symptoms [45].

Regarding educational needs, parents' need for accurate information about the cause of their children's epilepsy diagnosis, the problems they face in obtaining information about their children's condition, access to diagnostic testing, general information about epilepsy, and not knowing about their children's future condition are considered educational needs [45-47].

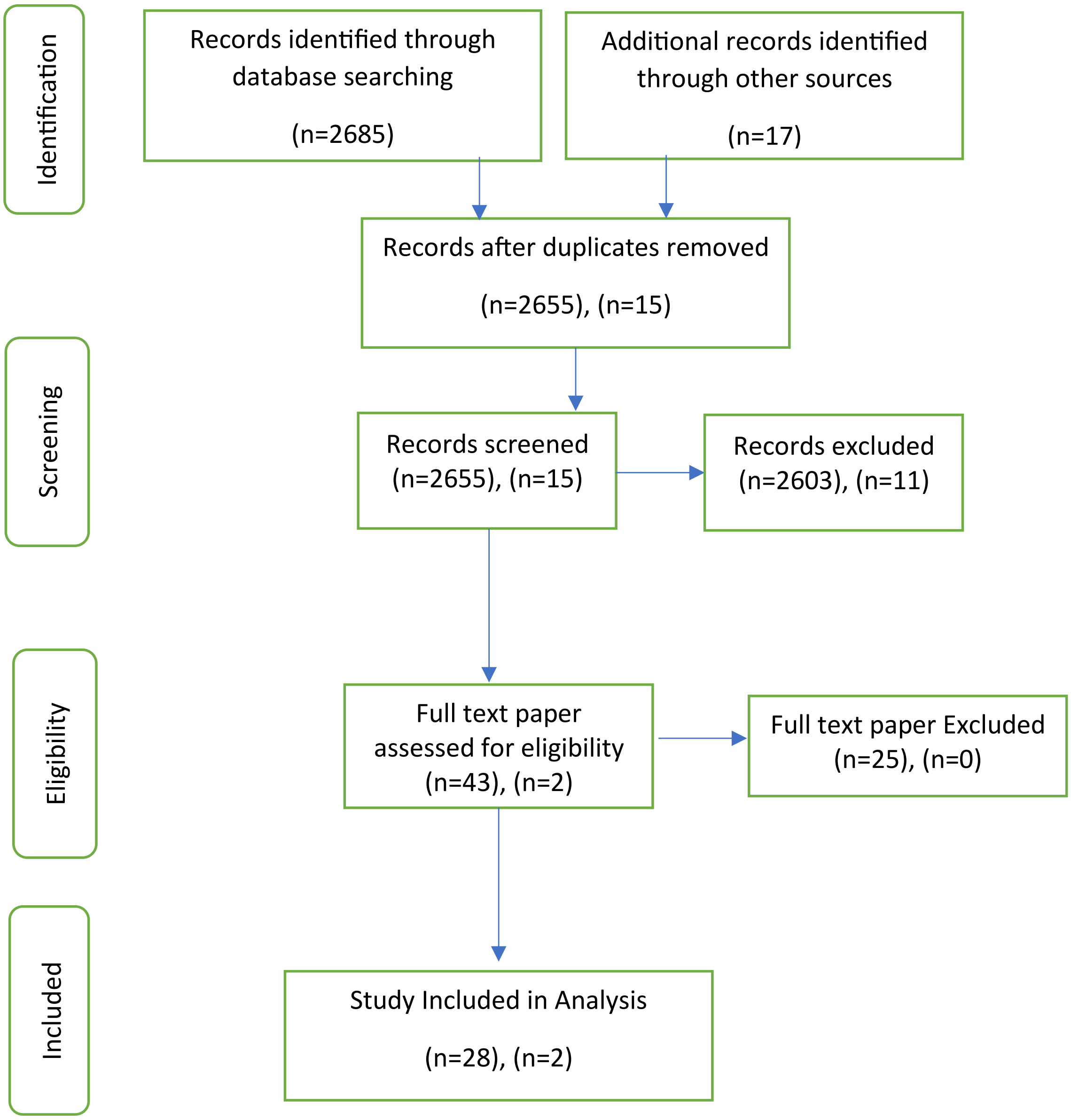
The third dimension is support needs. One of the most comprehensive areas common to all caregivers of children with epilepsy is support needs, which can be divided into seven domains: Practical, spiritual, social, psychological, informational, emotional, and physical. These dimensions help meet the patient's support needs in all areas during the illness [31, 48].

The fourth dimension is the economic and social needs. The most important need shared by all caregivers of children with epilepsy was the financial need to cover the costs of medications, doctor visits, and hospitalizations, as well as the disruption of parental social activities due to the challenges associated with caring for a child with epilepsy [49, 50].

Regarding the perceived needs during care, this dimension includes needs identified when caring for a child with epilepsy, such as handling seizures, medication management, seizure triggers and access to appropriate sources of information, knowledge of child nutrition and limited activity, and the need for professional life counseling [5].

Discussion

By correctly identifying the needs of parents, caregivers can help them adapt and provide safe and quality care to children with epilepsy [51]. The results of the present study show that the care needs of parents caring for a child with epilepsy may include psychological needs, educational needs, support needs, economic and social needs, and perceived needs while caring for



Journal of Pediatrics Review

Figure 1. PRISMA flow diagram for selecting studies on the care needs of parents with a child with epilepsy

a child with epilepsy. Okiah et al. [9] labeled caregiver needs as psychological, social, economic, and physical. The results of Bruno et al.'s [37] study indicate that the most important needs of caregivers include improving safety, clinical management, and self-management; and providing sedation. Carter et al. [1] also described caregivers' needs as emotional, psychological, and social concerns while caring for a child.

Yu et al. [5] described the needs of caregivers with epilepsy as information needs, unmet needs, general seizure management needs, medication management, seizure triggers, access to appropriate information sources, nutritional awareness, and urgent need for professional life counseling. Kaddumukasa et al. [21] described the needs of caregivers with epilepsy as limited knowledge about epilepsy, lack of medication adherence, caregiving burden, lack of family support, and poor access to health care. The Jones et al. [47] study also shows that parents often have difficulty seeing a neurologist. Parents are satisfied with the initial information they received about seizures and their treatment. The researchers pointed out that epilepsy and the resulting neurological problems can limit family activities and increase financial burden. Woodgate et al. [42] also noted that parents of children with complex care needs did not receive the services and support they needed to help their children.

Table 2. Implicit items, examples, and keywords related to the concept of care need

Row	Title	Authors, Year, Country	Hidden Meanings in the Author's Words	Example	Keywords Related to the Concept
1	An exploratory study on psychosocial needs and impacts of pediatric epilepsy on caregivers	Kumar et al. 2021, India [19]	A child with epilepsy needs more care, time, and attention, which can lead to dissatisfaction in the family.	Caring for a child with epilepsy creates a financial burden due to the cost of medications, medical care, and other special needs.	The burden of care due to epilepsy can cost the family.
2	Anxiety among caregivers of children with epilepsy from western	Yang et al. 2019, China [20]	The young age of the child, poor financial situation, and fear of recurrent seizures are some of the issues that require attention.	Health workers should pay more attention to younger caregivers who have a poor financial situation and parents with a high fear of seizures.	Perceived support needs of caregivers when caring for a child with epilepsy
3	Barriers to epilepsy care in central Uganda, a qualitative interview and focus group study involving PLWE and their caregivers	Kaddumukasa et al. 2019, Uganda [21]	It is critical to address the lack of awareness, inadequate or incorrect knowledge, fears, poor access, mental disorders, and adherence to evidence-based treatments in patients with epilepsy.	Participants reported that financial constraints in meeting their basic needs and receiving medication were the greatest stressors in their lives, and they reported that these were barriers to managing their epilepsy.	The care and treatment needs associated with epilepsy are the main source of parental stress.
4	Burden and perceptions associated with epilepsy: Caregivers' perspectives	Singh, 2015, India [22]	There is a need for a comprehensive healthcare system that focuses on mental health education and support group formation for all caregivers to reduce the anxiety and burden associated with this condition.	The burden of caring for a person with epilepsy can translate into losing a job or becoming unable to work, a decrease in family income, a burden of care giving on the family that further decreases wages, and high drug costs.	Support is needed to reduce the burden of care due to illness.
5	Burden of seizure clusters on patients with epilepsy and caregivers	Penovich et al. 2017, USA [23]	Educate people on how to manage epilepsy and the availability of life-saving treatments to reduce the potential burden of the disease.	Patients and caregivers should request and use management strategies from their physicians.	The need for education on the management of epilepsy to reduce the burden associated with the disease
6	Caregivers of school children with epilepsy: Findings of a phenomenological study	Roberts & Whiting, 2011, Canada [24]	A teacher who has experience working with children with epilepsy can help reduce some of the challenges for parents.	One of the families decided to homeschool their child to ensure their medical needs were met during the school year.	The need to ensure that the child is well outside the home
7	Caregiving in pediatric epilepsy: Results of focus groups and implications for research and practice	Smith et al. 2014, The USA [25]	The parents' concern for continuous care of their child with epilepsy to enable him to lead a normal life is understandable.	Caregivers of children with epilepsy agreed that supportive measures are necessary to help their children lead normal lives.	The need for support to gain confidence in a normal life for a child with epilepsy
8	Concerns and needs of children with epilepsy and their parents	McNELIS et al. 2007, The USA [26]	Basic information about the disease and medical and social support in overcoming the challenges of caring for a child with epilepsy is helpful for both parents and children.	Parents reported a great need for information and support and a reduction in fear of unlikely events such as brain damage and death.	The need for medical and social support to overcome the challenges of caring for a child with epilepsy
9	Effects of family-centered empowerment intervention on stress, anxiety, and depression among family caregivers of patients with epilepsy	Etemadifar, 2018. Iran [27]	Access to appropriate resources, such as information, is essential for improving the quality of care and enhancing self-management skills to strengthen the self-efficacy of caregivers of children with epilepsy.	While caring for the patient, the family must adequately understand the disease. In addition to caring for the patient, the medical and therapeutic staff also have the task of helping the family members increase their hope and confidence.	The need for support and training to improve the care and self-efficacy of caregivers of children with epilepsy
10	Epilepsy is associated with unmet health care needs compared to the general population despite higher health resource utilization—A Canadian population-based study.	Reid, 2012, Canada [28]	Consultation with a specialist, regular medical consultation, and consideration of unmet health needs are among the essential needs of parents of a child with epilepsy.	Suffering from epilepsy has increased the need to consult a specialist, seek regular medical attention, go to the hospital, and have unmet health needs.	Unmet needs related to the care of a child with epilepsy

Row	Title	Authors, Year, Country	Hidden Meanings in the Author's Words	Example	Keywords Related to the Concept
11	Evaluation of care burden and caregiving preparedness in caregivers of patients with epilepsy: A sample in eastern Turkey	Turan et al. 2021, Turkey [29]	The Turkish Language Institute defines the concept of care as follows: "The act of caring, the effort made to make something progress well or stay well, or the task of taking care of one's needs, such as feeding and dressing."	Assessing caregivers' readiness is very important because they are responsible for caring for the patient. Caregivers also have their own needs, which may differ from the patients'.	Trying to solve the challenges to get out of the normal situation.
12	Exploring the needs and challenges of parents and their children in childhood epilepsy care: A qualitative study	Wo et al. 2018, Malaysia [30]	Parents' main concerns include the side effects of antiepileptic drugs, knowledge of epilepsy, the child's future, the child's self-esteem, or anxiety.	Parents indicated a need for epilepsy awareness, continuity of care, and a parent support group.	The concerns that arise for caregivers when caring for a child with epilepsy.
13	Unmet supportive care needs among informal caregivers of patients with cancer: Opportunities and challenges in informing the development of interventions	Lambert, 2017, Canada [31]	Care needs include comprehensive cancer care, emotional and psychological care, impact and daily activities, relationships, information, and spirituality.	Assessing unmet needs can help develop interventions and prioritize resources to address key service gaps.	Support needs related to the responsibility of caring for a child with epilepsy.
14	Validation of the needs assessment of family caregivers-cancer scale in an Asian population	Yang et al. 2020, The USA [32]	Psychological, social, medical, and financial difficulties in the care of the patient.	In cancer care, family caregivers have needs in different dimensions, such as psychological, social, medical, and financial.	Needs during the care of a child with epilepsy
15	Measuring the needs of family caregivers of people with dementia	Bangerter et al. 2017, The USA [33]	Acute unmet need occurs when a need is identified, and it is subsequently determined that current services, supports, or other resources are not meeting it.	Caregivers' needs are often complex and have different priorities. They are influenced by both their resources and the demands of the stage of illness.	Unfulfilled and beyond the ability of caregivers to care for a child with epilepsy.
16	Families' experiences of living with pediatric epilepsy: A qualitative systematic review	Harden et al. 2016, The UK [4]	Experiences such as frustration, worry, stress, personal growth, and gaining experience caring for a child with epilepsy.	Some parents consider their experience of caring for their child as part of their 'personal growth' and take pride in having acquired the necessary knowledge and skills.	Self-knowledge needs and personality development in the care of a child with epilepsy
17	Knowledge, attitudes, and practices of caregivers of children with epilepsy in Sudan	El-Amin et al. 2021, Sudan [34]	The daily care of children with epilepsy requires the necessary knowledge of the caregivers.	Family caregivers need epilepsy care education programs to bridge the gaps and reduce anxiety caused by the disease.	Need to raise awareness of the care of a child with epilepsy to lead a normal life
18	Lived experiences of caregivers of persons with epilepsy attending an epilepsy clinic at a tertiary hospital, eastern Uganda: A phenomenological approach	Okiah et al. 2022, Uganda [9]	Services and programs targeting patients with epilepsy should take into account the burden that caregivers have in managing epilepsy.	Caregivers of children with epilepsy experience a heavy emotional, physical, and economic burden due to the nature, chronicity, disability, and anxiety associated with epilepsy.	Support needs related to the care of a child with epilepsy.
19	Parents/caregivers' fears and concerns about their child's epilepsy: A scoping review	Carter et al. 2022, The UK [1]	Emotional, psychological, and social concerns in the care of a child with epilepsy	A 'program' validates and addresses the common fears and anxieties of caregivers, and it can also provide a new perspective on epilepsy in children. This may reduce parents' or caregivers' emotional, psychological, and social concerns.	Reduce emotional, psychological, and social concerns when caring for a child with epilepsy
20	Prevalence and Associated Factors of Mental Distress among Caregivers of Patients with Epilepsy in Ethiopia	Seid et al. 2018, Ethiopia [35]	Social, emotional, behavioral, and financial challenges of caring for a child with epilepsy	Caregiving is often a very stressful task that presents caregivers with social, emotional, behavioral, and financial challenges. This makes them vulnerable to mental health problems such as depression and anxiety, as well as physical ailments.	Support needs related to the care of a child with epilepsy

Row	Title	Authors, Year, Country	Hidden Meanings in the Author's Words	Example	Keywords Related to the Concept
21	Psychosocial care needs of the parents having children with epilepsy	Rajalakshmi, 2014, India [36]	The need for necessary knowledge for the management of epilepsy in children	Most parents indicated they needed information about interacting with their children.	Need for awareness to manage epilepsy
22	Seizure detection at home: Do devices on the market match the needs of people living with epilepsy and their caregivers?	Bruno et al. 2020, The UK [37]	To meet the needs of caregivers of people with epilepsy and ensure improvement in their quality of life, future efforts should focus on demonstrating the validity and usefulness of data collected in daily life.	Studies have shown that the main needs of caregivers are the following: a) Improvement in safety, b) Improvement in clinical and self-management, and c) Reassurance.	It is necessary to increase safety, improve clinical management, and ensure the future state of the disease of a child with epilepsy.
23	Continuing Psychosocial Care Needs in Children with New-Onset Epilepsy and Their Parents	Shore et al. 2009, The USA [38]	Psychosocial care needs that can negatively impact family life.	Children with epilepsy and their parents have many psychosocial care needs. These include worries and fears and the need for information and support.	Support needs related to the care of a child with epilepsy.
24	Stressors of Caregivers of School-Age Children with Epilepsy and Use of Community Resources	Saburi, 2011, Zimbabwe [39]	The need for support and information to reduce parents' stress and enable them better to address the emotional needs of their child with epilepsy	The greatest need of caregivers is support and information, which can be helpful in counseling. In this way, they can better respond to the emotional needs of their children.	Need for support to meet the emotional needs of a child with epilepsy.
25	The experiences of caregivers of children with epilepsy: A meta-synthesis of qualitative research studies	Yu et al. 2022, China [5]	Unfulfilled care requests are a significant emotional burden for the parents.	Parents have a very high care burden and psychological stress, and their care needs are not met.	The unmet needs associated with caring for a child with epilepsy can put emotional strain on parents.
26	The information needs of careers of adults diagnosed with epilepsy	Kendall et al. 2004, The UK [40]	The need for parents to receive the necessary knowledge and information in an understandable form to take care of a child with epilepsy is one of the needs of parents.	Caregivers' needs are unknown when caring for a child with epilepsy.	Perceived needs of parents in caring for a child with epilepsy
27	The information needs of parents of children with early-onset epilepsy: A systematic review	Nevin, 2020, Australia [41]	The special need to know the diseases associated with epilepsy and how parents can emotionally support a child with epilepsy	Parents reported a clear need for understandable, realistic, and targeted information. They emphasized a particular need for content on comorbidities and emotional support.	Parents' information needs for appropriate management of children's epilepsy disorder
28	The needs and problems in epilepsy caregiving: A qualitative exploration	Lua et al. 2015, Malaysia [10]	The need for caring, psychological, and financial support in the care of a child with epilepsy.	Respondents expressed a desire for more support from their family members and experts regarding physical (relief from caregiving), psychological, and financial aspects.	Support needs related to the care of a child with epilepsy.
29	Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs	Woodgate, 2015, Canada [24]	More support and resources are needed to care for children with complex care needs.	Parents of children with complex care needs lack the services and support they need to help their children.	Unmet needs related to the care of a child with epilepsy
30	Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers	Deeken et al. 2003, The USA [43]	Needs are "problems related to health status and problems related to health care quality, insofar as either may trigger the need for further professional care."	Care needs are only those for which the caregiver requires the assistance of professional healthcare providers.	Motivational needs of caregivers when caring for a child with epilepsy to improve health status and quality of care

Journal of Pediatrics Review

Zhang et al. [52] described the problems of caregivers of children with epilepsy as anxiety and depression, poor sleep quality, and poor family functioning. Nevin et al. [41] reported that parents need understandable, realistic, and targeted information. The authors suggested that unmet information needs were associated with higher stress levels, poorer psychosocial outcomes, and lower satisfaction with health care services. The results of the Hussain et al. [49] study show that depression and anger, disrupted social life, disturbed mental health, and numerous economic problems such as medication costs, medical fees, and hospitalization costs are among caregivers of children with epilepsy. In their study, Seid et al. [35] reported that caregiving is often a very stressful task and presents social, emotional, behavioral, and financial challenges for caregivers, making them vulnerable to mental health problems, such as depression, anxiety, and physical problems.

On the other hand, the results of the Smith et al. (2014) study show that caregivers of children with epilepsy share a common concern that they need supportive interventions to help their children live a normal life. In a study by McNELIS et al. [26], parents report a greater need for information and support and a lower concern about unlikely events such as brain injury and death. The study's results by Wu et al. [30] also show that parents need to know about epilepsy, continuity of care, and a support group for parents. The study's results by Lua et al. [10] show that caregivers need more support from family members and their experts regarding physical (caregiving), psychological, and financial aspects [10].

Conclusion

The complex psychological, educational, supportive, economic, social, and parental perceived needs of caring for a child with epilepsy can place a burden on parents. Therefore, it is necessary for systems providing services to children with epilepsy to consider the needs of their caregivers to improve caregiver skills and facilitate the caregiving process. This study may provide a context for a more detailed understanding of the needs of caregiving parents of a child with epilepsy.

Study limitations

The current limitation of this study was the lack of access to full-text copies of some of the required articles. To solve this limitation, an attempt was made to use academic institutions such as the University Central Library, which had permission to access some of the pages as much as possible.

Ethical Considerations

Compliance with ethical guidelines

This study was approved by the Ethics Committee of Hamadan University of Medical Sciences, Hamadan, Iran (Code: IR.UMSHA. REC.1402.165). The researcher made every effort to publish the results of her research, whether negative or positive, honestly, accurately, and completely, and to consider all ethical principles when conducting the study

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Authors contributions

Conceptualization and writing the original draft: Arash Khalili; Methodology: Alireza Soltanian; Data collection: Arash Khalili and Afshin Fayyazi; Data analysis: Alireza Soltanian; Investigation: Fatemeh Cheraghi; Supervision, review and editing: Farshid Shamsaei and Fatemeh Cheraghi.

Conflicts of interest

The authors declared no conflict of interest.

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