

Review Article

FACTORS ASSOCIATED WITH CAREGIVER BURDEN IN CAREGIVERS OF PATIENTS WITH SEIZURE DISORDERS

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ABSTRACT

Seizures are among the most prevalent neurological disorders in children and adults. Family caregivers often face a considerable burden in providing care. Given that caregiver burden is influenced by various factors, this review explores factors associated with caregiver burden among families of individuals with seizure disorders. This review was conducted by searching Elsevier, Scopus, ScienceDirect, Google Scholar, and PubMed for publications between 2014 and 2024. The initial search yielded 40 articles, and after applying inclusion and exclusion criteria, 13 studies were included in the final analysis. Caregiver burden is influenced by multiple factors, including caregiver-related characteristics such as age, gender, marital status, education level, weekly caregiving hours, number of caregivers in the household, resilience, anxiety, sleep quality, overall health, and financial and emotional family support. Patient-related factors include age, level of dependence, duration of illness, cognitive impairments, comorbidities, epilepsy type and severity, and polypharmacy. Caregiving-related factors also contribute, such as traditional values, health policies, availability of resources, caregiver training and safety, treatment adherence, follow-up processes, and duration of caregiving. The findings suggest that reducing caregiver burden can improve care quality. Implementing support services and financial assistance may improve outcomes. Addressing caregivers' psychological needs through education, counseling, and psychosocial interventions may further reduce caregiving challenges.

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INTRODUCTION

Seizures are neurological disorders caused by sudden and excessive electrical discharges in neurons and are the most common neurological condition in both children and adults. Due to their chronic nature and high prevalence, seizures have significant direct and indirect impacts on individuals' lives. Approximately 5–10% of people experience at least one seizure during their lifetime ^(1–3). Seizures are considered medical emergencies; in the United States and Europe, they account for approximately 1.2% of emergency department visits and 1.4% of hospital admissions, of which 24% are classified as first-time seizures ^(1–3). Each year, around 15,000 adults presenting with a first seizure seek care in healthcare facilities in the United States ^(4–5). Recurrent seizures, particularly those associated with epilepsy, are common, with 2–4% of individuals in developed countries experiencing at least one seizure during their lifetime ^(6–7). Epilepsy is a chronic, non-communicable neurological disorder affecting approximately 70 million people worldwide ⁽⁸⁾ and is the second most prevalent neurological disorder after stroke ⁽⁹⁾. Nearly 80% of individuals with epilepsy live in low- and middle-income countries, and their risk of premature death is up to three times higher than the general population ⁽¹⁰⁾. The impact of chronic and recurrent seizures extends beyond patients and significantly affects their families and caregivers ⁽¹¹⁾. Caregivers are individuals who provide ongoing support during illness or disability, helping patients manage and adapt to chronic conditions ⁽¹⁰⁾. Family caregivers are particularly vulnerable to high care burden ⁽¹³⁾. Caregiver burden is defined as the distress experienced as a result of providing care ⁽¹⁴⁾ and encompasses psychological, physical, and social challenges, which can lead to burnout, anxiety, depression, and other negative outcomes ⁽¹³⁾. Caregiver burden is a multidimensional and complex construct, reflecting the unique caregiving experiences of individuals with different backgrounds, resilience, and resources while coping with specific disease symptoms. Mental burden refers to the strain on caregivers' emotional, social, financial, physical, and spiritual well-being, while objective burden involves actual changes in daily life, social and occupational relationships, leisure activities, and physical health ⁽¹²⁾. Research indicates that caregiving is perceived differently across societies, and caregivers often face challenges in meeting patients' primary and secondary needs ⁽⁸⁾. Parents caring for a child with epilepsy remain constantly vigilant to meet the child's needs. The duration and intensity of caregiving not only impose a heavy burden on parents but also significantly affect their sleep quality ⁽⁴⁾. Studies have also shown that epilepsy impacts patients' quality of life (QOL) and, indirectly, the quality of care provided by their caregivers ⁽⁹⁾. Social stigma, fueled by insufficient knowledge and misconceptions, can lead to feelings of shame and discrimination, representing a major contributor to caregiver burden. Furthermore, societal prejudice and fear of seizures may result in patient isolation and difficulties in employment, education, and social participation ⁽¹⁸⁾. Understanding the factors that influence caregiver burden is essential for developing strategies and interventions to reduce it, thereby preserving caregivers' physical and mental health and improving the quality of care provided. This review aims to examine the factors associated with caregiver burden in caregivers and families of patients with seizure disorders.

METHODS

This study was conducted through a systematic search of articles in English- and Persian-language databases, including Elsevier, Scopus, ScienceDirect, Google Scholar, and PubMed. English keywords used in the search included: burden of care, epilepsy, seizure, caregivers, seizure disorders. Inclusion criteria were studies addressing factors related to caregiver burden in caregivers of patients with seizure disorders, full-text availability, publication in English, and publication between 2014 and 2022. Exclusion criteria included studies unrelated to the study objectives, articles published before 2014, articles in languages other than English or Persian, and studies available only as abstracts. The initial search yielded 40 articles. After screening based on inclusion and exclusion criteria, 13 studies were selected for analysis. Data were extracted and categorized using a researcher-developed checklist, which included article title and year, study design, sample size, research setting, participant characteristics (patients and caregivers), type of epilepsy, outcomes, and results. During data extraction, no interpretation was applied; original phrases used by the authors were retained. Validity and data analysis were performed independently by two groups of researchers. The results were then compared and confirmed collaboratively. In cases of disagreement, a senior researcher familiar with the study topic and objectives reviewed and adjudicated the findings.

RESULTS

All of the reviewed articles were published in either English or Persian. In terms of study design, the majority were analytical (44%) and descriptive (28%), with the remainder employing other methodologies. Regarding the research settings, most studies were conducted in the United States (33%) and various Asian countries, including China (24.5%), Saudi Arabia (14.5%), Malaysia (11%), Nepal (9%), Iran and Turkey (7%), and Israel (4%). The study populations primarily consisted of caregivers, parents, and family members of patients with seizure disorders and epilepsy. The most frequently used assessment tools included the Zarit Caregiver Burden Interview (ZBI) (43%), the SF-36 Quality of Life Questionnaire (15%), the Quality of Life in Epilepsy Inventory (QOLIE-31) (13%), the Patient Assessment of Care Questionnaire (PAC) (11%), the Family Resilience Assessment Scale – Caregiver version (FRAS-C) (8%), the Stigma Scale (6%), the Pittsburgh Sleep Quality Index (PSQI) (3%), and the Hamilton Anxiety and Depression Scale (HAMILTON) (1%).

Zarit Caregiver Burden Interview (ZBI): Developed by Zarit and colleagues in 1980, this questionnaire contains 22 items assessing personal, social, emotional, and financial burdens. Each item is rated on a 5-point Likert scale from 0 (never) to 4 (almost always). Total scores range from 0 to 88, with higher scores indicating greater caregiver burden. ^(5,2)

SF-36 Quality of Life Questionnaire: The SF-36 consists of 36 items across eight subscales: physical functioning (PF, 10 items), role limitations due to physical health (RP, 4 items), role limitations due to emotional problems (RE, 3 items), energy/fatigue (EF, 4 items), emotional

well-being (EW, 5 items), social functioning (SF, 2 items), pain (P, 3 items), and general health (GH, 5 items). Two summary scores, physical health and mental health, are derived from these subscales. Lower scores indicate poorer quality of life. ⁽²⁶⁾

QOLIE-31 Epilepsy Quality of Life Questionnaire: The QOLIE-31-P includes 31 items and is a standardized tool for assessing quality of life in patients aged 18 years and older with epilepsy. It evaluates seven dimensions: seizure worry, emotional well-being, energy/fatigue, cognitive functioning, medication effects, social functioning, and overall quality of life. Domain scores are calculated according to the scoring manual, ranging from 0 to 100, with higher scores reflecting better quality of life. The overall score is obtained by weighting and summing the individual subscale scores. ⁽¹⁾

Patient Assessment of Care (PAC): The PAC questionnaire includes 65 items across three dimensions: physical (24 items), communicative (13 items), and psychosocial (28 items), based on the validated research by Wandelt and Agar (1974). Responses are rated on a 5-point Likert scale (0 = not at all, 1 = rarely, 2 = sometimes, 3 = often, 4 = always). Total scores range from 0 to 260, with higher scores indicating better quality of care. ⁽²¹⁾

Family Resilience Assessment Scale (FRAS): Developed by Sixbey in 2005 based on Walsh's family resilience model, this scale measures family resilience across six subscales: family communication and problem-solving, economic and social resources, maintaining a positive outlook, family connectedness, spirituality, and meaning-making in the face of adversity. The FRAS-C consists of 66 items rated on a 4-point Likert scale (1 = strongly disagree to 4 = strongly agree), with one open-ended question allowing participants to add additional information. Total scores range from 66 to 204, with higher scores indicating higher family resilience. ⁽²¹⁾

Stigma Scale: Developed by Jacoby in 1992, this scale evaluates perceived stigma in patients with epilepsy. Patients report their perception of negative attitudes from others due to their condition. Scores range from 0 (no stigma) to 1–6 (mild social stigma) and 7–9 (severe social stigma). ^(1,11,9)

Sleep Quality Scale (PSQI):

The Pittsburgh Sleep Quality Index (PSQI) includes 19 items rated on a 4-point Likert scale (0–3) to assess sleep quality. It evaluates seven domains: subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction. Scores range up to 21, with higher scores indicating poorer sleep quality ^(10, 11).

Hamilton Anxiety and Depression Scale (HAMILTON):

The Hamilton scale is a clinical tool for assessing depression. It consists of 21 items that measure behavioral, physical, and cognitive symptoms. Seventeen of these items are most commonly used, while the remaining four provide additional clinical information. Total scores allow classification of depression severity ⁽¹³⁾.

The results regarding the prevalence of caregiver burden among family caregivers showed that most caregivers experienced a certain level of burden ranging from mild to severe. Specifically, the frequency of caregiver burden scores was 42 in Shah S's study ⁽¹³⁾, 29.93 in Siew-Tim Lai's

study⁽¹⁶⁾, 22.16 in Qingqing Ma's study⁽²¹⁾, and 20 in Karakis's study⁽⁵⁾. In C. Oliveira's study⁽¹¹⁾, caregiver burden was reported to be mild to moderate.

Based on the results obtained from the studies, factors associated with caregiver burden among caregivers of patients with seizure disorders were categorized into three groups: patient-related factors, caregiver-related factors, and care-related factors, as described below.

Patient-related factors: Based on the reviewed studies, factors affecting caregiver burden were categorized into three groups: patient-related factors, caregiver-related factors, and care-related factors.

Age: Younger children require more intensive care, and seizures in early childhood can result in neurological, skeletal, or developmental impairments, increasing caregiver responsibilities. Both young children and older adults, due to biological vulnerabilities and cognitive limitations, require higher levels of attention and care^(6, 24, 31).

Education Level: Higher education in patients is associated with better self-care skills, greater independence, and reduced reliance on caregivers, leading to lower caregiver burden^(1, 7).

Insurance Status: Access to healthcare services often incurs ongoing costs for diagnostics, treatment, and medications. Patients without insurance place financial pressure on their families, which increases caregiver stress and burden^(6, 12).

Living Environment: Unsafe home conditions and lack of supportive resources reduce patient independence and increase the risk of accidents such as falls, which further increase dependency on caregivers. Families in rural or underserved areas experience higher caregiver burden due to limited access to healthcare^(5, 8, 14, 27).

Severity and Duration of Disease (Duration, Seizure Frequency): Frequent or severe seizures increase patient dependence and the need for continuous care. Uncontrolled or unpredictable seizures create crises for patients and families, leading to physical and emotional fatigue. Recurrent seizures may also extend hospitalization and create additional psychological and financial stress^(5, 11, 18, 26).

Type of Treatment (Monotherapy vs. Polytherapy): Patients on multiple anti-seizure medications often experience more severe or less controlled seizures, which increases caregiver workload. Treatment complexity and drug resistance contribute to higher caregiver burden^(11, 26).

Financial Support: Inadequate financial assistance, particularly for adult and elderly patients, increases dependence on family members and imposes financial strain, which contributes to higher caregiver burden^(12, 23, 25).

Employment: Many patients work to meet financial or social needs. Fear of stigma or discrimination may prevent them from disclosing epilepsy at work. However, self-employment or home-based work can improve financial independence, reduce social isolation, boost confidence, and decrease caregiver burden. High unemployment rates among patients with epilepsy increase family financial and caregiving pressures^(8, 9, 11).

Comorbidities: The presence of additional chronic conditions increases care demands due to the unique needs of each condition, thereby elevating caregiver burden^(6, 25).

Physical Functioning: Lower physical functioning, especially in older patients, increases dependency and caregiver workload. Impairments in performing daily activities heighten caregiver involvement⁽⁶⁾. Some studies show that regular physical activity may reduce seizure frequency in children. Deep breathing during exercise lowers CO₂ levels, decreasing seizure occurrence. Exercise also reduces stress, improves mood, enhances concentration, and supports seizure control, which can reduce caregiver burden^(11, 18, 33).

Cognitive and Mental Functioning: Research indicates that cognitive impairments in elderly patients and children lead to decreased functional capacity and quality of life, increased disability and vulnerability, reduced independence, and greater reliance on caregivers, which in turn raises caregiver burden^(6, 7). In children, care needs also significantly affect parental burden: the higher the child's care requirements, the more stress and responsibility parents experience over time. Children with lower cognitive abilities often require assistance with basic tasks such as eating, sleeping, and toileting. In these cases, parents must not only manage other household responsibilities but also devote substantial time to fulfilling the child's essential needs^(7, 24).

Self-Care: Patients' perception of family support can encourage greater participation in self-care activities, which can help reduce caregiver burden⁽³²⁾. Self-management interventions for individuals with epilepsy have been shown to improve awareness, enhance confidence in managing disease-related stressors, improve seizure control, and increase overall quality of life⁽²⁵⁾.

Based on the results obtained from the review of the conducted studies, the caregiver-related characteristics associated with caregiver burden are as follows:

Age: Older caregivers of adult or elderly patients tend to experience higher burden, likely due to their own declining physical abilities and potential chronic health conditions⁽²³⁾. Conversely, younger parents of children with seizure disorders report higher caregiving stress, possibly due to limited experience and financial challenges, which hinder their ability to cope with the child's needs^(7, 31).

Number of Caregivers: Long-term and continuous caregiving, especially when provided alone without support from other family members or formal caregivers, results in physical and psychological fatigue over time, increasing caregiver burden^(6, 16).

Gender: Caring for children with seizure disorders is especially stressful for mothers, creating significant emotional strain. Research consistently shows that maternal caregiver burden is high, as women often provide care for both children and spouses, increasing overall caregiving demands^(5, 24, 26).

Marital Status and Number of Children: Married caregivers generally report higher burden than single caregivers, as they must balance caregiving with parenting, household management, and social obligations^(5, 12). Families with more children face increased social and financial demands, which further heightens parental burden in caring for a child with a seizure disorder⁽⁷⁾.

Education Level: Limited education or literacy reduces caregivers' access to online and virtual health resources and diminishes their ability to effectively utilize healthcare and educational tools. Caregivers with higher education levels tend to apply more coping strategies and experience lower burden ^(2, 18).

Economic Status: Covering patient care costs represents a major source of stress. Alongside regular personal and household expenses, caregivers may need to reduce work hours or quit their jobs to provide care, which further increases stress and caregiving burden ^(12, 24).

Employment Status: Employed caregivers generally report higher burden compared to non-employed caregivers, as they must manage multiple roles at home and work, leading to role conflict and additional stress ^(11, 15).

Employment status: The caregiving burden is more on caregiver employees than nonemployees ⁽¹⁵⁾. Having numerous roles and responsibilities in the family and job leads to conflict and, as a result, more pressure on this group ⁽¹¹⁾.

General Health: Poor physical or mental health reduces caregivers' capacity to provide care. Many experience fatigue, depression, helplessness, and burnout, increasing their vulnerability to chronic conditions and significantly heightening caregiver burden ^(6, 15, 25).

Quality of Life: Higher caregiver burden negatively impacts the quality of care provided, which in turn reduces the patient's quality of life. Worsening patient condition can create a feedback loop that further increases caregiver burden and may lead to gradual burnout. The quality of life of patients is closely linked to that of their caregivers; as caregiver well-being declines, patient well-being diminishes correspondingly ^(15, 16).

Social Stigma: Social stigma is a significant concern for individuals with epilepsy, often discouraging them from seeking treatment and generating feelings of shame and hopelessness. Over time, this may lead to social withdrawal and isolation, depriving patients of personal, social, and civic rights ⁽²⁹⁾. Family caregivers are also vulnerable to stigma, as they may internalize negative societal attitudes toward epilepsy, resulting in psychological effects such as fear, anxiety, and depression ⁽⁹⁾. Numerous studies have confirmed a direct link between caregiver burden and social stigma associated with the disease ^(8, 14).

Self-Efficacy: Self-efficacy refers to an individual's sense of empowerment, predisposing factors, and essential skills required for effective self-management ⁽²⁸⁾. Higher self-efficacy has been shown to facilitate positive behavioral changes, improve adherence to treatment, enhance physical and mental health outcomes for patients, and consequently reduce caregiver burden ⁽²⁷⁾.

Nationality and Citizenship: In developing countries, limited healthcare and caregiving resources, combined with insufficient government funding, contribute to more severe disease outcomes and complications ⁽¹⁸⁾. Conversely, cultural norms, societal welfare, and well-structured educational and healthcare systems are associated with higher quality family care for both patients and caregivers ⁽¹¹⁾.

Social Support: Perceived social support from the community plays a vital role in mitigating caregiver burden. Higher perceived support correlates with lower caregiving stress ⁽³⁴⁾. Conversely, the absence of social care systems, weak integration with caregivers, small social networks, and low levels of social support are linked to increased caregiver burden ⁽⁶⁾.

Family Resilience: Family resilience positively influences caregiver burden ⁽¹⁰⁾. Resilient families provide caregivers with coping strategies, effective communication skills, emotional regulation, and self-confidence ⁽⁸⁾. This resilience enhances the positive aspects of caregiving while reducing negative emotional responses ⁽²¹⁾.

Awareness and Knowledge of Disease and Care: Informal caregivers require sufficient knowledge about the disease to prepare for their caregiving role and provide high-quality care. A lack of awareness and skills increases the difficulty of caregiving and contributes to higher caregiver burden ⁽¹⁹⁾. Polypharmacy can also lead to drug interactions, missed doses, or intentional discontinuation of antiepileptic medications due to side effects or fatigue from long-term use ⁽³⁰⁾. These challenges often result from inadequate training and knowledge among caregivers and patients ⁽²⁶⁾.

Coping Skills: Effective coping strategies are essential under stressful conditions. Proper coping mechanisms enable patients and caregivers to manage stress and avoid physical and psychological harm ⁽³⁰⁾. Coping strategies consist of cognitive and behavioral efforts aimed at interpreting and managing stressful situations, reducing associated distress ⁽²⁸⁾.

Spiritual Health and Beliefs: Adherence to religious beliefs and spiritual practices significantly supports individuals in coping with stress and challenges ⁽²³⁾. Spirituality improves mental health, enhances physical well-being, and strengthens resilience. For parents and caregivers of children with seizures, spirituality serves as a source of comfort and hope, aiding acceptance of the disease and potential losses ^(6, 32).

Personal and Moral Attributes of Caregivers (Care Ethics): Family caregivers dedicate considerable time to patient care, which affects their personal lives and the quality of care provided. Personal attributes such as patience, trust, love, respect, conscientiousness, and religious beliefs motivate caregivers, even under fatigue, heavy workloads, and limited resources ⁽³⁷⁾. Empathy, responsibility, pride in caregiving, commitment to quality care, and personal challenges influence caregiving behavior. Emphasizing ethical caregiving practices can help reduce caregiver burden ⁽³⁶⁾.

Anxiety and Depression: Anxiety and depression are common emotional responses to caregiving stress. These emotions negatively impact caregivers' feelings, thoughts, perceptions, behaviors, and overall functioning, hindering effective caregiving and adaptation, which ultimately increases caregiver burden ⁽¹⁸⁾.

Compassion Fatigue: Compassion fatigue arises when caregivers' efforts to help others are overwhelmed by patients' suffering, leading to emotional exhaustion. It manifests as anger, inefficiency, anxiety, and depression due to an inability to cope with stress ⁽⁶⁾. Compassion fatigue may result in depression, insomnia, reduced empathy, high tension, guilt, helplessness,

decreased motivation, and an inability to provide care, thereby threatening caregivers' physical and mental health and increasing caregiver burden ^(11, 35).

Sleep Quality and Insomnia: Poor sleep quality is directly associated with increased caregiver burden, particularly among caregivers of children with epilepsy ^(12, 24). Reduced sleep quality, especially in mothers, adversely affects both the quantity and quality of care provided ^(11, 12, 24).

Care-Related Factors: Care-related factors, often underexplored in research, include hours spent caregiving, caregiving methods, frequency of care, assistance with daily activities, uncertainty regarding care needs, and limited opportunities for social engagement. Long-term and continuous caregiving without sufficient support leads to physical and mental fatigue, ultimately increasing caregiver burden over time ^(5, 6, 26).

DISCUSSION

This study investigated factors associated with caregiver burden among caregivers of patients with seizure disorders through a comprehensive literature review. The findings indicate that caregiver burden is highly prevalent in this population, with most studies reporting levels ranging from mild to very severe ⁽¹⁾. Variations in caregiver burden may be influenced by the type of epilepsy, treatment and disease management, social factors, the level of support from caregiving systems, as well as individual characteristics of caregivers, families, and patients. Increased caregiving demands can lead to negative outcomes, including reduced quality of care and lower quality of life for the patient ^(5, 6).

Research findings indicate that women constitute the majority of family caregivers and are typically the primary caregivers ⁽²⁴⁾. Mothers, in particular, assume the central role in caring for ill family members, especially children, and are therefore more exposed to caregiving-related stress. They must often manage multiple professional, social, and familial responsibilities simultaneously while providing care for their ill child ⁽⁷⁾. Additionally, cultural and social norms that regard caregiving as primarily a female role reinforce women's dominant participation in home caregiving ⁽⁶⁾.

In this study, factors associated with caregiver burden among caregivers of patients with seizure disorders were examined through a literature review. The findings show that caregiver burden among these families is highly prevalent, with most caregivers experiencing varying levels of burden ranging from mild to severe ⁽⁵⁾. Differences in experienced burden may be related to disease severity, social factors, the level of support from caregiving systems, and individual characteristics of both caregivers and patients ⁽⁶⁾. Previous studies emphasize that mothers, as primary caregivers, are key to maintaining family cohesion and emotional stability. Because women naturally assume caregiving responsibilities for their children, they are more vulnerable to caregiving-related stress, making the use of effective coping strategies essential for reducing burden and improving adaptation to the child's illness.

Research by Alibakhshi, Karakas, and Siew-Tim demonstrates that a higher number of caregivers is associated with lower caregiving and psychological burden on each caregiver ^(7, 5, 16).

Studies by Karakas and Shah indicate that married caregivers experience higher burden compared to single caregivers, likely due to multiple family roles and responsibilities toward spouses, children, and extended family ^(5, 13).

Age is another important factor influencing caregiver burden. According to Sabzalipour and Ge, older caregivers tend to experience higher burden ^(6, 23). Aging caregivers may face physical limitations and chronic health conditions, and reduced physical activity can increase psychological vulnerability. Social isolation resulting from dedicating extensive time to caregiving can further exacerbate stress among older caregivers.

Employment status also affects caregiver burden. Siew-Tim reports that employed caregivers experience higher burden due to the combined responsibilities at work and home, increasing overall stress ⁽¹⁶⁾.

Economic status is another key factor. Oliveira shows that low family income and poor financial conditions are strongly associated with higher caregiver burden ⁽¹¹⁾. Financial strain, including the costs of patient care, is a major source of stress, sometimes forcing caregivers to reduce work hours, leave employment, or take on additional jobs, all of which increase caregiving burden.

Finally, general health significantly impacts caregiver burden. Shah demonstrates that caregivers with chronic illnesses or poor general health experience higher burden ⁽¹³⁾. Such caregivers often feel fatigued, incapable, and overwhelmed, leading to increased depression, helplessness, burnout, and susceptibility to chronic physical and psychological conditions, which further intensifies caregiving-related stress.

According to the study by Jabbari Nejad ⁽²⁶⁾, caregivers with lower educational levels experience higher caregiver burden. This may be due to insufficient knowledge and understanding of the disease and the patient's care needs, as well as limited ability to utilize available information resources. Lack of awareness increases psychological stress among caregivers, thereby intensifying their burden.

Studies by T. Berg et al. ⁽¹⁶⁾ and Aboozadeh et al. ⁽³⁸⁾ showed that social support is an important factor influencing caregiver burden. In some studies, informal caregivers have been referred to as "hidden patients" because they often face insufficient knowledge and skills, limited assistance from healthcare providers, lack of social support, additional stress related to disease progression, patient disability, and increasingly complex and long-term care needs. Supporting informal caregivers is therefore essential, as it benefits both caregivers and patients ⁽³⁸⁾.

A significant factor affecting caregiver burden is the lack of knowledge, awareness, and skills required for patient care. Berg et al. ⁽¹⁷⁾ demonstrated that educational and supportive programs can effectively reduce caregiver burden. By teaching caregivers how to provide home care and equipping them with problem-focused coping strategies, they can perform their roles effectively, adapt to responsibilities, and manage lifestyle changes resulting from patient care, ultimately reducing their burden.

Recent advances in communication technology have increased interest in using virtual platforms and social networks for caregiver education. With proper training and support, caregivers can maintain their well-being while fulfilling their caregiving responsibilities ⁽⁶⁾. Both in-person and remote training improve self-efficacy, health outcomes, and positive attitudes toward caregiving tasks. Internet-based tools, due to their accessibility, low cost, and convenience, have become a preferred method for obtaining health information. Non-face-to-

face educational methods, combined with counseling and support, can help reduce stress and caregiver burden ⁽³⁰⁾.

Depression and anxiety are additional factors associated with caregiver burden. Shah ⁽¹³⁾ and T. Berg ⁽¹⁷⁾ reported that caregivers experiencing depression and anxiety have higher levels of burden. Providing long-term care for patients with chronic illnesses increases the risk of physical and mental health problems among caregivers. Studies by Oliveira ⁽¹¹⁾ and Zhang ⁽¹⁰⁾ show that family caregivers of patients with seizures experience significant psychological distress, including stress, anxiety, and depression. Increased caregiving demands may lead to inadequate patient care, family grief and isolation, and disruption of family relationships.

Qing Q et al. ⁽²¹⁾ found that caregiver burden is inversely related to resilience; caregivers with higher resilience experience lower burden. Some caregivers with high burden do not experience depression because protective factors, such as resilience, enhance their ability to adapt effectively to stress and adversity. Kenis-Coskun et al. ⁽³⁹⁾ also reported that resilience plays a key role in mitigating the negative effects of caregiver burden, with more resilient caregivers experiencing lower levels of burden.

King-Stephens et al. ⁽¹⁵⁾ demonstrated that caregivers' quality of life is linked to caregiver burden. Poor physical and mental health, insufficient social and financial support, and weak social relationships with family and friends—all dimensions of quality of life—can increase caregiver burden.

Some studies indicate that older patient age increases caregiver burden. Age-related physiological changes, including musculoskeletal, cognitive, and functional decline, reduce independence and increase reliance on caregivers ⁽⁵⁾. Similarly, in infants and young children, immature nervous and cognitive systems increase dependency, resulting in higher caregiver burden ⁽²⁴⁾.

Lower educational levels in patients are also associated with higher caregiver burden ^(21, 25). Patients with limited education often have less knowledge, fewer skills, and lower self-efficacy for self-care, making them more dependent on caregivers.

Financial factors further influence caregiver burden.

Karakas ⁽⁵⁾ found that insufficient financial support for patients increases caregiver burden. Lack of financial resources reduces patient independence, increases family dependency, and imposes additional costs, creating stress for caregivers.

Siew-Tim ⁽¹⁶⁾ reported that patients without insurance coverage increase caregiver burden due to the financial strain placed on the family.

Patient dependency is another major factor.

Karakas ⁽⁵⁾ found that higher patient dependency correlates with increased caregiver burden, leading to caregiver fatigue, disruption of family and social roles, and reduced personal time. Sabzalipour ⁽⁶⁾ indicated that elderly patients with multiple chronic conditions and specific disease types increase caregiver burden, as each condition has unique care needs that require additional attention, further raising caregiving demands.

Aboozadeh ⁽³⁸⁾ found that lower physical functioning in patients is associated with higher caregiver burden. Declines in functional ability increase patient dependency for daily activities, intensifying caregiver burden. Cognitive impairments in patients similarly increase caregiver burden by reducing independence, increasing vulnerability, and creating greater reliance on caregivers.

According to the study by Jabbari Nejad ⁽²⁶⁾, inadequate living conditions are associated with higher caregiver burden. This can be explained by the fact that the interior design of patients' homes does not match their needs and conditions, safety measures are often neglected, and necessary amenities are lacking. These factors reduce patient independence and increase the risk of accidents, such as falls, along with their associated consequences.

The results of the study by Berg, A. ⁽¹⁷⁾ indicated that caregivers who spend more time caring for a patient experience a higher caregiver burden. This can be explained by the fact that long-term and continuous caregiving, especially when performed alone without the support of other family members or formal caregivers, can lead to physical and psychological fatigue and burnout over time, ultimately increasing the caregiver burden.

Caregiver burden among caregivers and families of patients with seizure disorders is influenced by multiple factors, including caregiver characteristics, patient-related factors, and care-related conditions. Therefore, it is essential to strengthen and provide comprehensive support, counseling, and educational services. Medical teams should incorporate these factors into their supportive programs to effectively reduce caregiver burden. Based on the literature review, the following strategies are recommended to alleviate caregiver burden in this population: educating caregivers and enhancing their knowledge and awareness through traditional and digital campaigns, as well as remote care initiatives; promoting public awareness; identifying and assessing caregivers' physical and psychological needs; providing counseling sessions and targeted psychosocial interventions through the establishment of support centers and active participation in caregiver support groups; creating a comprehensive care system in which caregivers are recognized as collaborative partners, thereby facilitating better medical follow-up and improving patient care; monitoring caregivers' general health and screening for anxiety, depression, and other health issues; strengthening positive coping skills and encouraging engagement in social activities to maintain and enhance mental well-being; optimizing patients' living environments in terms of physical, safety, and welfare standards; and organizing resources while providing financial and medical assistance to vulnerable and low-income families through governmental and private charitable organizations.

Table 1. Reviewed Studies on Factors Associated with Caregiver Burden

No.	Article Title	Author /Year	Country	Setting/ Study (Country)	Study Type	Sample Size	Sample Characteristics (Patient / Caregiver / Type of Epilepsy)	Study Results and Overall Conclusion
1	Family Resilience and Mental Responses to Caring for Children with Epilepsy	Qingqing Ma, Zeping Yan, 2021 (21)	China	Cross-sectional study	173 parents of children with epilepsy	Participants were recruited from the pediatric neurology department of a Three-A hospital in Shandong Province via convenience sampling. Included children were diagnosed with epileptic encephalopathy by physicians, and one parent per child was selected. Of the 173 parents who completed the questionnaire, 96 (55.5%) were female (mean age 36.08, SD 5.75) and 77 (44.5%) male (mean age 36.56, SD 5.60). Children included 106 boys (61.3%) and 67 girls (38.7%).	Modified Chinese CZBI questionnaire, based on Family Resilience Assessment Scale (FRAS-C) and Positive Aspects of Caregiving (PAC), plus demographic information	Study Results: Mean total CZBI score = 22.16 (SD 14.26), mean PAC score = 40.05 (SD 11.09). Total FRAS-C score positively correlated with PAC score ($r = 0.368$, $p < 0.001$) but negatively with CZBI score. Conclusion: Family resilience can enhance positive caregiving aspects and reduce negative emotions in parents of children with epilepsy.
2	Caregiver Burden in Adults with Epilepsy in Asian Families	Siew-Tim Lai, Wan-Yen Tan, 2019 (16)	China	Cross-sectional study	111 caregivers of adult patients with epilepsy	Caregivers included parents (55%) and nurses, mostly female (72.1%) and Chinese (59.5%). 51.4% of parents were unemployed and 46.0% had a university degree. Patients were adults over 18; epilepsy type not	ZBI (Caregiver Burden Inventory), IEQoL (Quality of Life), DASS-21 (Psychological Distress), FAD (Family Functioning), MSPSS (Perceived Social	Results: Seizure frequency and dependency were significant ($F(185)=11.37$, $P<0.001$). Family functioning was a significant predictive factor ($\beta=0.299$,

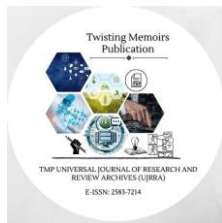
						specified.	Support), and demographic/ clinical questionnaires	p<0.001). ZBI scores correlated positively with depression (r=0.549), anxiety (r=0.599), and stress (r=0.576), and negatively with IEQoL (r=-0.653). Conclusion: Caregiver burden is significantly influenced by family functioning, social support, and number of caregivers, beyond demographic and clinical differences.
3	Effectiveness of Psychoeducational Program on Burden of Caregivers of Children with Epilepsy	Pei Lin Lua, Nor Khaira Wahida, 2015 (12)	Malaysia	Qualitative	15 family members of patients with epilepsy	Participants were Malaysian Muslim family caregivers, aged 19–66 years. Mostly female (53%), married (67%), and with secondary education or equivalent (73%). Patients were mainly adults, single, residing in Malaysia. Epilepsy type not specified.	Semi-structured group interviews analyzed using NVivo software	Conclusion: Five main caregiver concern factors were identified: caregiver support, emotional disturbances, caregiving challenges, financial problems, and positive aspects of caregiving. Emotional disturbances and suppressed feelings were most discussed, significantly affecting caregiving quality.
4	Perceived Burden and Related Factors in Adult Chinese Patients with	Binmi Tang, Yaqian Fu, 2022 (14)	China	Cross-sectional	143 adult patients with epilepsy	Patients were residents of Hunan, aged ≥18, capable of reading/writing, without	Demographic/ clinical questionnaire, SPB, SPBS, KSSE (Shame in Epilepsy),	Conclusion: High shame index and low quality of life were observed.

	Epilepsy					psychiatric disorders like schizophrenia or cancer. Mostly female, single, rural, and polypharmacy users. Caregivers included family members, nurses, and healthcare staff.	QOLIE-31 (Quality of Life)	SPBS correlated positively with KSSE ($r=0.510$) and negatively with QOLIE-31 ($r=-0.506$). Disease burden increases shame and reduces quality of life.
5	Caregiver Burden and Depression among Caregivers of Patients with Epilepsy	Shah S, Sah C, Shahi A, KC R, 2019 (13)	Nepal	Descriptive cross-sectional	100 caregivers of adult epilepsy patients	Caregivers were mostly employed, female, married, and included parents and siblings of patients. Patients mostly female, adult, and unemployed. Epilepsy type not specified.	Semi-structured interview, ZBI, Hamilton Depression Rating Scale (HAM-D)	Results: 42% of caregivers reported high ZBI scores; 50% reported moderate depression. High caregiver burden significantly correlated with caregiver age ($p=0.018$) and caregiver-patient relationship ($p=0.023$). Conclusion: Caregivers experience high burden associated with depression.
6	Factors Associated with Caregiver Burden in Adults with Epilepsy in a Middle-Income Country	Mariana C. Oliveira, Alan Marciehi ma, 2022 (11)	Brazil	Cross-sectional	44 caregivers of PWE	Caregivers mostly single (93.63%), low-income (63.63%), adults, low educational level. Patients had childhood-onset drug-resistant epilepsy (65.9%), mostly on polytherapy (75%).	ZBI, demographic questionnaire, STAI-X (anxiety/depression), PSQI (sleep), Stigma scale	Results: Mild-to-moderate caregiver burden. Factors associated with higher burden: age of epilepsy onset, caregiver education, need for daily assistance, anxiety, fatigue, and poor sleep quality. Conclusion: Caregivers require special attention regarding mental health

								and overall well-being.
7	Relationship between Sleep Quality, Caregiver Burden, and Individual Resilience in Parents of Children with Epilepsy	Kevin Zhang, Dongyu Sang, 2022 (10)	China	Descriptive cross-sectional	173 parents of children with epilepsy	Primary caregivers were parents, aged >20, residing in China. Children hospitalized in Shandong pediatric neurology from 2018–2022. Epilepsy type not specified.	ZBI, demographic questionnaire, PSQI, CD-RISC-10 (resilience)	Results: Individual resilience negatively correlated with caregiver burden and sleep quality ($p < 0.1$, $r = -0.215$). Caregiver burden and sleep quality were moderately negatively correlated. Conclusion: Higher individual resilience reduces caregiver burden and improves sleep quality.
8	Dependent Stigma and Caregiver Burden in Refractory Epilepsy	Meg Dalena, Rose Flareski, Barbara Hansen, 2018 (9)	USA	Cross-sectional	30 primary caregivers /family members of patients with refractory epilepsy	Participants from Alabama, aged >18. Caregivers with intellectual disability or major depression were excluded. Patients were children and adults with refractory epilepsy confirmed via EEG/VECG, with >4 years of seizure history and antiepileptic treatment.	CADI (Caregiver Difficulty Index, 30 items), PCA (Perceived Stigma, 60 items)	Results: Study examined the relationship between dependent stigma and caregiver burden, and differences between caring for children vs. adults. Conclusion: Caregivers experienced dependent stigma when caregiver burden increased significantly.
9	Dependent Stigma and Caregiver Burden in Parents of Children with Epilepsy	Jing Yanan Wang, Jing Hua Ye, 2024 (8)	China	Cross-sectional	194 parents of children with epilepsy	Children aged 0–18 (93 aged 0–8, 101 aged 9–18), 52.58% male, 47.42% female. Epilepsy diagnosed by neurologists at Guangdong Children's Hospital. Primary	ZBI, demographic questionnaire, Mack-Chung Chinese Stigma Scale (22 items, 4 domains: emotional, behavioral, cognitive)	Results: Average dependent stigma score = 2.50 ± 0.47 ; highest in emotional domain (2.50 ± 0.52). Conclusion: In rural areas, traditional

						caregivers: 78.35% mothers, 21.65% fathers. No chronic/high- risk illnesses in caregivers.		culture, limited education, and insufficient medical resources increase seizure frequency, dependent stigma, and social isolation in parents.
10	Determinants of Caregiver Burden in Patients with Epilepsy	Yu Anil Karakis, Andrew J. Cole, 2024 (5)	USA	Cross- sectional	126 PWE (Patients with Epilepsy)	Patients from Massachusetts undergoing video telemetry EEG, mean age 32, mostly male, half married, average 4 seizures/month. Types: temporal lobe epilepsy, idiopathic generalized epilepsy (IGE), TLE.	Demographic and epilepsy info, Beck Anxiety/Depre ssion Inventory, QOLIE-31, SF-36	Results: ZBI scores indicated moderate caregiver burden. Physical component score = 54, mental = 45. Higher AED use and lower neuropsych scores observed. Conclusion: Moderate caregiver burden negatively affects quality of life and psychosocial adaptation. Higher seizure severity and later onset reduce psychosocial adaptation.
11	Caregiver Burden and Related Factors in Adults with Epilepsy	Yeni Panel Kobra, Asil Kavchlu, Zeliha Tulak, 2024 (1)	Turkey	Descriptiv e cross- sectional	107 patients with seizures and 107 primary caregivers	Primary caregivers: parents/siblings, mean age 47, mostly female, primary/seconda ry education (72.9%). Patients male, >18, seizure onset >14.1 years. Epilepsy: focal and generalized seizures.	Demographic questionnaire, ZBI, HADST (Hospital Anxiety and Depression), QOLIE-31, Stigma Scale, MOCA (cognition)	Results: Moderate caregiver burden associated with AED count, cognitive functioning, patient QoL, and education. Later onset and higher education linked to higher stigma, anxiety/depres sion, and

								lower QoL (especially cognitive/mental).
12	Correlation of Caregiver Burden among Bedouin Muslim Mothers of Children with Epilepsy	Talia Schurer, E. Delstrin, 2022 (27)	Israel	Descriptive cross-sectional	50 Bedouin Muslim mothers of children with epilepsy	Mothers ≥ 18 , mean age 33, children < 18 , both genders. Most children on > 3 medications. Epilepsy type not specified.	General Self-Efficacy, MSPSS (Perceived Social Support), Demographic Questionnaire, ZBI	Results: Moderate caregiver burden (24/48). Burden negatively correlated with self-efficacy, social support, and residence; positively with number of medications. Conclusion: Self-efficacy acts as a protective factor, positively affecting stress, psychological well-being, and caregiving management.
13	Determinants of Caregiver Burden in Caregivers of Veterans with PTE after PTBI	Roksana Jabbari Nejad, Shira Cohen Zemiri, Jordan Grafman, 2020 (26)	USA	Interview and Questionnaire	31 spouses of veterans with post-traumatic epilepsy	Veterans with PTE after penetrating traumatic brain injury, caregivers were spouses volunteering for interviews	Modified researcher questionnaire: VHIS (Caregiver Distress), ZBI, IQCODE (Cognitive Decline), SF-36v2, MCS, NPI, demographic questionnaire, general QoL, AFQT (cognitive skills)	Results: PTE can impose caregiver burden even 50 years post-injury. Increased patient age and duration of care associated with caregiver distress due to cognitive decline, apathy, and physical role limitations. Caregiver age, low education, weekly care hours, number of caregivers, family support, attitude toward epilepsy, patient unemployment



								t, income, and residence all affect caregiver burden.
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Author contributions

All authors have contributed equally and substantially.

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There is no need of ethical statement.

Conflict of Interest

The authors declare that there is no conflict of interest.

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