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An Explanatory Study to Understand the Psychological Burden of the Disease, Psychological Well-Being, and Quality Of Life for First-Degree Relatives of Patients with Epilepsy

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INTRODUCTION

1.1 Imagine having a condition that, like an unexpected storm, can disturb your entire day at any time. This disturbance is a frequent occurrence for those who have epilepsy, a neurological condition brought on by erratic electrical activity in the brain.

Uncontrollable movements, mood swings, behavioural abnormalities, and consciousness lapses can all result from seizures brought on by epilepsy. Since the brain regulates nearly all bodily functions, a seizure can impact many facets of life, transforming routine tasks into unforeseen difficulties.There are serious bodily risks as well. The chance of falling or hurting oneself increases significantly during a seizure, especially since they can happen while sleeping, walking, or even while cooking. This erratic behaviour can make. Some individuals may temporarily lose their ability to see, hear, or taste properly, depending on which part of the brain is affected. In severe cases, a seizure-related fall can lead to broken bones or other complications, adding to the physical toll.Beyond the physical challenges, epilepsy also affects the way individuals think and process information. Many experience memory issues, difficulty concentrating, and slower thinking speeds, which can impact their ability to learn or make decisions. These cognitive struggles can make everyday tasks feel overwhelming.Psychologically, epilepsy takes an even greater toll. Living with an unpredictable condition often leads to anxiety and depression, as individuals fear when and where the next seizure might strike. Many develop low self-esteem, feeling isolated because of the stigma surrounding epilepsy. The emotional burden is further amplified by the constant need to manage medications and treatment, which may come with side effects that interfere with daily life.Socially, epilepsy can create barriers that many people don’t realize. Those affected may be restricted from driving due to safety concerns, making independence and employment more difficult. Workplace discrimination and misunderstandings about epilepsy can limit career opportunities, while personal relationships may suffer as individuals struggle with when, how, or if they should disclose their condition. Seizures can occur unexpectedly in public, leading to awkward situations, fear, or even discrimination from those who don’t understand the disorder.Although epilepsy doesn’t have a permanent cure, it can often be managed through medications, lifestyle adjustments, and, in some cases, surgery. However, managing the condition requires more than just medical treatment—it demands a strong support system. Having family, friends, and healthcare professionals who understand and provide encouragement can make all the difference. Additionally, educating the public about epilepsy is crucial in breaking down stigma, fostering acceptance, and creating a more inclusive environment for those living with the condition. The journey with epilepsy is challenging, but with the right support and awareness, individuals can lead fulfilling lives despite the obstacles they face.

THE BURDEN ON FIRST DEGREE RELATIVES OF PATIENTS WITH EPILEPSY

When a loved one is diagnosed with epilepsy, their first-degree relatives—parents, siblings, and children—often bear a significant emotional, social, and financial burden. Since epilepsy is a chronic condition with unpredictable seizures, it can impact the entire family’s well-being, not just the patient. The burden stems from the need for constant care, emotional distress, societal stigma, and financial strain.

1. EMOTIONAL BURDEN

Fear and Anxiety: The uncertainty of when and where a seizure might occur creates a persistent sense of fear. Parents of children with epilepsy constantly worry about their child having a seizure at school, while siblings may feel anxious about sudden medical emergencies. Children of epilepsy patients, on the other hand, may struggle with feelings of uncertainty, unsure of how their parent's condition might impact their lives.

Depression and Emotional Exhaustion: Caring for a loved one with epilepsy can be emotionally draining. Watching them go through seizures without being able to stop them can make family members feel helpless. Over time, the stress of caregiving, managing medications, and handling medical emergencies can lead to burnout, emotional exhaustion, and even depression.

Guilt and Self-Blame: Many caregivers, particularly parents, experience guilt, questioning whether they are doing enough. They may blame themselves for their child's condition or constantly second-guess their decisions regarding treatment and care. This self-imposed pressure can weigh heavily on their emotional well-being.

Stigma and Social Isolation: Because of the many misconceptions surrounding epilepsy, family members often hesitate to talk about the condition openly. They may fear judgment, misunderstandings, or even discrimination, leading them to withdraw from social interactions. As a result, they isolate themselves—not because they want to, but because they don't want to deal with the stigma or the uncomfortable questions from other.

2. SOCIAL BURDEN

Social Stigma and Discrimination: Many cultures and societies still hold misconceptions about epilepsy, leading to prejudice and discrimination. Family members may face judgment, pity, or avoidance from their social circles.Impact on Sibling Relationships: Siblings of epilepsy patients often experience a shift in family dynamics. They may feel neglected as parents focus on the affected child, leading to resentment or feelings of being less important.Restrictions on Social Activities: Families may hesitate to participate in social gatherings, fearing that a seizure in public might cause distress or misunderstanding. Children with epileptic parents may feel embarrassed or different from their peers.Impact on Family Planning: For adult siblings or children of epilepsy patients, the condition may raise concerns about genetic inheritance and the risk of passing it on to future generations. Some may delay marriage or childbearing due to these fears.

3. FINANCIAL BURDEN

Medical Expenses: The cost of anti-epileptic drugs (AEDs), regular doctor visits, diagnostic tests (EEGs, MRIs), and potential surgeries can place a heavy financial burden on families.Loss of Income: If a parent or caregiver has to reduce work hours or quit their job to provide full-time care, household income decreases significantly. In some cases, epilepsy patients themselves struggle to maintain steady employment, adding to financial strain.Transportation Costs: Frequent medical visits, therapy sessions, and emergency hospitalizations can lead to high transportation expenses.Home Modifications and Caregiving Costs: Some patients with severe epilepsy require home modifications (e.g., padded furniture to prevent injury during seizures) or professional caregivers, further increasing expenses.

The gap in research regarding their psychological well-being and quality of life.

Despite the many studies exploring how epilepsy affects patients, there is far less focus on how it impacts their closest family members—the parents, siblings, and children who support them every day. These caregivers experience constant worry, emotional exhaustion, and social isolation, yet their struggles are rarely discussed or studied in depth.

Why This Matters:

Caregivers of epilepsy patients often face significant emotional distress, including high levels of stress, anxiety, and depression, yet specialized mental health resources for them are severely lacking.Parents frequently struggle with exhaustion and feelings of being overwhelmed, but dedicated support programs to help them navigate these challenges are limited.Siblings of individuals with epilepsy may experience loneliness, academic pressure, and feelings of neglect, yet their mental well-being remains largely overlooked in epilepsy research.The caregiving demands for epilepsy are just as challenging as those for conditions like Alzheimer's or cancer, yet epilepsy caregivers receive far less recognition, awareness, and assistance.

1.2 Caring for a loved one with epilepsy can be an emotionally, physically, and financially demanding experience. The unpredictability of seizures, the constant need to stay alert, and the emotional toll of witnessing a seizure can leave caregivers feeling overwhelmed, exhausted, and even guilty for not being able to do more. Over time, this stress can take a toll on their mental health, physical well-being, social life, and career.

The Emotional Toll

Caregivers often experience a rollercoaster of emotions, ranging from anxiety about when the next seizure might occur to frustration over the limitations epilepsy places on their loved one's life. Many feel a deep sense of guilt and helplessness, struggling with the reality that they cannot fully prevent or control the seizures. The emotional burden can also lead to **isolation**, as caregivers may withdraw from social interactions due to the stigma surrounding epilepsy or the need to always be available for their loved one.

The Physical Strain

Taking care of someone with epilepsy is not just mentally exhausting—it can be physically demanding as well. Many caregivers experience **sleep disturbances** from staying up to monitor for seizures, leading to chronic fatigue. In some cases, they may need to **physically assist** their loved one during or after a seizure, which can put strain on their body. The ongoing stress also triggers **increased cortisol levels**, which can negatively affect their overall health.

The Social and Financial Impact

Caring for someone with epilepsy can be an overwhelming journey, often demanding sacrifices that many don't see. Caregivers frequently put their loved one's needs above their own, making it hard to maintain friendships, nurture relationships, or find time for personal hobbies. As their world starts to revolve around caregiving, feelings of isolation can creep in.

On top of that, the stigma surrounding epilepsy can make it even harder to open up. Many caregivers hesitate to share their struggles, fearing judgment or a lack of understanding. This silence can make them feel even more alone, carrying a heavy emotional burden with little support.

Financially, the impact can be just as challenging. Medical expenses, medications, and specialized care add up quickly, and if a caregiver has to reduce their work hours—or leave their job entirely—it can put a strain on their financial stability. Balancing love, responsibility, and personal well-being becomes a daily challenge, often leaving caregivers feeling drained but determined to keep going for the person they love.

The Psychological Consequences

Over time, the emotional and physical stress of caregiving can lead to serious mental health challenges. Many caregivers develop symptoms of anxiety, depression, and even post-traumatic stress, especially if their loved one experiences frequent or severe seizures. The feeling of constantly being on edge can make it difficult for caregivers to relax, even in moments of calm.

What Affects the Caregiving Experience?

The impact of caregiving can vary based on several factors:

Severity of Epilepsy: More frequent and severe seizures often mean higher stress levels for caregivers.Age of the Person with Epilepsy: Parents of children with epilepsy often face additional challenges, balancing caregiving with their child's developmental needs and education.Family Dynamics: A strong support system can ease some of the burden, whereas family conflict or lack of support can make the caregiving experience even more difficult.

How Caregivers Can Manage Stress

While caregiving can be overwhelming, there are **ways to cope and find support:**

Learning About Epilepsy: Educating themselves about the condition can help caregivers feel more confident and prepared to handle challenges.Seeking Support: Connecting with support groups, therapists, or other caregivers can provide emotional relief and reduce feelings of isolation.Prioritizing Self-Care: Taking time for rest, exercise, and personal hobbies is essential to prevent burnout and maintain their own well-being.Communicating Openly: Talking with family and friends about their struggles can help caregivers build a support network and reduce stress.

Challenges Faced by First-Degree Relatives of Epilepsy Patients

Supporting a loved one with epilepsy can be an emotionally, physically, and financially demanding responsibility. Close family members, including parents, siblings, and children, often bear the heaviest burden, which can significantly impact their mental well-being, daily life, and overall quality of life.

One of the most challenging aspects of caregiving is the constant worry and stress caused by the unpredictable nature of seizures. Caregivers live with **persistent anxiety**, always bracing for the next episode without knowing when or how severe it will be. Parents fear for their child's safety while they are at school, siblings may feel uneasy about the possibility of sudden medical emergencies, and children of epilepsy patients may struggle with the emotional toll of not knowing how their parent's health may change.

Beyond the emotional challenges, caregiving often leads to deep feelings of isolation and exhaustion. Many family members devote so much time and energy to caring for their loved one that their own interests, social life, and career goals take a backseat. Over time, this sacrifice can leave them feeling disconnected and overwhelmed.

The financial burden only adds to their struggles. Covering medical expenses, hospital visits, and necessary treatments can be financially draining, especially if the caregiver has to cut back on work hours or leave their job to provide full-time support.

Epilepsy doesn't just affect the individual diagnosed—it has a profound impact on the entire family. Recognizing the unseen struggles of caregivers is crucial to ensuring they receive the support, compassion, and resources they need to navigate this challenging role.

1.3 Data for Research Objectives:

Psychological Well-Being of First-Degree Relatives:

Studies show that caregivers of epilepsy patients often experience high levels of stress, anxiety, and depression due to the unpredictability of seizures and the emotional strain of caregiving.Parents, siblings, and children of epilepsy patients frequently report sleep disturbances, emotional exhaustion, and feelings of helplessness in managing the condition.Many caregivers experience chronic worry and fear, particularly about seizure-related injuries or long-term health complications.

Quality of Life and Burden of Caregiving:

The constant need to monitor seizures and provide care can significantly disrupt daily routines, affecting social life, work, and personal well-being.Many caregivers struggle to balance caregiving with their own responsibilities, often sacrificing their career, education, and personal aspirations.Financial stress is another major burden, with the cost of treatments, medications, and hospital visits placing a significant strain on household income.

Identifying Factors That Influence Their Mental Health:

The severity and frequency of seizures directly impact caregivers, with more frequent and intense episodes leading to higher stress levels.Family support and strong social networks play a vital role in helping caregivers manage emotional distress and cope effectively.The social stigma and misconceptions surrounding epilepsy can cause caregivers to feel isolated, making them hesitant to seek support or openly discuss their struggles.

1.4 Research Questions

- What psychological struggles do close family members of epilepsy patients encounter?
- How does taking care of a loved one with epilepsy influence their lifestyle and quality of life?

- What methods and approaches do they use to manage the stress and demands of caregiving?

1.5 Why This Study Matters:

The mental and emotional toll of caregiving is often overlooked in healthcare discussions. By shedding light on the struggles faced by first-degree relatives of epilepsy patients, this research can help ensure that caregivers receive the recognition and support they need.

Impact on Healthcare Policies: Understanding caregivers' mental health challenges can lead to more inclusive healthcare policies that prioritize their well-being alongside the patient's. This could mean better access to counseling, stress management resources, and financial assistance programs.

Practical Benefits: The insights from this study can inform the development of stronger support networks, including family counseling services, community-based caregiver support groups, and intervention programs tailored to reduce burnout and emotional exhaustion.

Medical Community & Awareness: Healthcare professionals play a crucial role in guiding and supporting caregivers. This research can help medical practitioners become more aware of the emotional burdens caregivers carry and equip them with strategies to provide better psychological and social support.

1.6 Who Will Be Studied?

This study will focus on the experiences of first-degree relatives of individuals living with epilepsy, including parents, siblings, and children who play an active role in caregiving and emotional support. Their insights will help shed light on the psychological and social challenges they face in their daily lives.

The study will take place within a specific hospital, community, or region, which means the findings may not fully represent caregivers from diverse cultural, economic, or geographical backgrounds. Factors such as financial stability, education levels, and family dynamics can all shape a caregiver's experience, influencing how they cope with their responsibilities.

Mental well-being is deeply personal and influenced by a range of factors, making it difficult to assess with complete accuracy. Some caregivers may struggle to openly share their emotions due to stigma or fear of being judged, which can affect how they express their experiences. Additionally, the challenges of caregiving differ significantly based on the quality of medical care and support available. Since these external factors play a major role, it can be difficult to determine exactly how caregiving itself impacts their mental and emotional health.

2. REVIEW OF LITERATURE

Li, C., Zhuo, L., Kang, Y., Liu, P., Huang, W., Li, Q., ... & Lin, F. (2025).This study explored how cerebral cavernous malformations (CCM) affect first-degree relatives (FDRs) in families with a history of familial CCM (FCCM). Using MRI scans and genetic testing, researchers found that about **36.5% of FDRs in China** were affected. Given these findings, **regular MRI screenings and genetic counseling** are recommended for FDRs, especially when a patient has **more than three CCM lesions** on T2-weighted imaging (T2WI). Interestingly, the study also uncovered that **nearly a quarter (24.24%) of FCCM families** had unidentified genetic mutations, highlighting the need for further research to discover these unknown pathogenic genes.

Al-Ghawanmeh, R., Ala'a, F., Burayzat, S., Jaber, R. M., Al-Tamimi, M., Zidan, O., & Aburahmeh, S. (2025). A study in Jordan revealed how deeply epilepsy affects not just children but their families as well. Managing seizures, reducing their frequency, and adopting a holistic care approach can help ease the burden of the condition. By fostering greater independence for children and ensuring active involvement from their families and caregivers, the overall impact of epilepsy can be lessened. Interestingly, the study also found that family size and a history of epilepsy play a significant role in shaping the psychosocial challenges associated with the condition. This highlights the urgent need for assessment tools that consider cultural differences and family dynamics.

Wang, H. E., Cheng, C. M., Bai, Y. M., Hsu, J. W., Huang, K. L., Su, T. P., ... & Chen, M. H. (2022).This study found that first-degree relatives (FDRs) of individuals with autism spectrum disorder (ASD) have a consistently higher risk of developing **major psychiatric disorders**. Additionally, FDRs of individuals with both **ASD and intellectual disability (ASD-ID)** face an even **greater susceptibility** to **ASD and schizophrenia**. These findings suggest potential **common underlying mechanisms** linking ASD, intellectual disability, and psychiatric conditions. They also emphasize the importance of providing **targeted mental health support** to at-risk families, facilitating **early diagnosis and timely intervention**.

Operto, F. F., Pastorino, G. M. G., Pippa, F., Padovano, C., Vivenzio, V., Scuoppo, C., ... & Coppola, G. (2021).n the epilepsy group, we found higher levels of parental stress and higher presence of emotional and behavioral symptoms compared to controls, mainly represented by internalizing problems (anxiety and depression symptoms). Therefore, it is important to precariously detect these symptoms and monitor them over time, in order to prevent psychiatric problems. In addition, parents of children with epilepsy should be offered psychological support to cope with parental stress and to improve the relationship with their children.

Eratne et al. (2022).found no clear evidence linking treatment-resistant schizophrenia to neuronal damage, particularly axonal degeneration. Their findings suggest that more research is needed to determine whether NfL (neurofilament light chain) can help distinguish treatment-resistant schizophrenia from neurodegenerative conditions like behavioral variant frontotemporal dementia. Additionally, further studies could explore the role of NfL in different phases of schizophrenia, such as early warning signs (prodrome) and the first episode, to better understand its potential as a diagnostic tool.

Rozensztrauch, A., & Kołtuniuk, A. (2022). Epilepsy is a chronic neurological disorder that significantly affects both children and their families, impacting their physical, psychological, and social well-being. This study assessed the quality of life (QoL) of children with epilepsy and its effect on family dynamics through a cross-sectional survey of 103 legal guardians.Findings revealed that epilepsy disrupts daily family activities (score: 32.4/100) and relationships (score: 55.63/100). Children aged 5–7 years experienced a greater decline in QoL than those aged 2–4 years, and comorbid conditions further worsened QoL across all aspects. Overall, children reported a low QoL score (46.42/100), with social and physical functioning scoring slightly higher but school/work functioning being the lowest (42.3/100).In conclusion, epilepsy has a significant negative impact on both the child’s well-being and family life, highlighting the need for better support and interventions.

Watila et al. (2021) conducted a large-scale screening of 42,427 individuals aged six and older, identifying 254 confirmed cases of active epilepsy. The overall prevalence of active epilepsy was found to be 9.8 per 1,000 people, with variations across different regions: 17.7 in Gwandu, 4.8 in Afikpo, and 3.3 in Ijebu-Jesa. The incidence rate per 100,000 people also varied, with the highest in Gwandu (201.2), followed by Afikpo (27.6) and Ijebu-Jesa (23.9).The study identified key risk factors for epilepsy in both children and adults. In children, factors such as febrile seizures, meningitis, poor perinatal care, exposure to open defecation, measles, and a family history of epilepsy in close relatives increased the likelihood of developing the condition. Among adults, head injuries, inadequate perinatal care, febrile seizures, a family history of epilepsy in distant relatives, and consanguinity (marriage within the family) were significant risk factors. Notably, Gwandu had a higher concentration of these risk factors compared to the other regions.The study also calculated the Population Attributable Fraction (PAF), which estimates the percentage of epilepsy cases that could be linked to these key risk factors. The PAF was 74% for children and 79% for adults, highlighting the substantial role these factors play in the development of epilepsy.

Hermann, B. P., Struck, A. F., Dabbs, K., Seidenberg, M., & Jones, J. E. (2021).TLE patients as a group exhibited significantly higher (abnormal) scores across all SCL-90-R scales compared to controls. However, cluster analysis identified three latent groups: (1) unimpaired with no scale elevations compared to controls (Cluster 1, 42% of TLE patients), (2) mild-to-moderate symptomatology characterized by significant elevations across several SCL-90-R scales compared to controls (Cluster 2, 35% of TLE patients), and (3) marked symptomatology with significant elevations across all scales compared to controls and the other TLE phenotype groups (Cluster 3, 23% of TLE patients). There were significant associations between cluster membership and demographic (education), clinical epilepsy (perceived seizure severity, bitemporal lobe seizure onset), and neuropsychological status (intelligence, memory, executive function), but with minimal structural neuroimaging correlates. Concurrent validity of the behavioral phenotype grouping was demonstrated through association with psychiatric (current and lifetime-to-date DSM IV Axis 1 disorders and current treatment) and quality-of-life variables.

Wei et al. (2022) highlight the high prevalence of depression among primary caregivers of children with epilepsy (CWE), emphasizing the need for greater attention to their mental health. They suggest that routine mental health screenings should be conducted, particularly for parents of children with severe epilepsy, as they may be at higher risk.The study also points out that strong family resilience and social support can help caregivers cope better emotionally. To improve their well-being, future interventions should focus on strengthening these protective factors, ensuring that caregivers receive the support they need to manage stress and reduce their risk of depression.

Benova, B., Sanders, M. W., Uhrova-Meszarosova, A., Belohlavkova, A., Hermanovska, B., Novak, V., ... & Krsek, P. (2021). Children with focal cortical dysplasia (FCD) experienced more severe symptoms than their parents, including drug-resistant epilepsy and developmental delays, and did not achieve seizure freedom after surgery. All patients had histopathologically confirmed FCD (types IIa, IIb, and Ia).Genetic analysis revealed:Patient 1 and her father carried a known pathogenic NPRL2 variant.Patients 2 and 3, along with their affected parents, had newly identified likely pathogenic DEPDC5 variants.Family 4 carried a novel NPRL3 variant.Additionally, we identified 15 other cases from epilepsy surgery studies involving GATOR1-associated FCD, all with a family history of epilepsy. In 8 out of 13 tested cases, the genetic variant was inherited from a parent who showed no symptoms, emphasizing the complex genetic patterns of the condition.

Zhang et al. (2021) found that anxiety and depression are common among caregivers of children with epilepsy, with depression being particularly prevalent. Many caregivers also struggle with poor sleep quality and difficulties in maintaining a healthy family dynamic.

Sundelin et al. (2022) found that children who experience pediatric ischemic stroke have a higher risk of developing autism, especially those who also have epilepsy. This increased risk was not linked to factors like premature birth or low birth weight.

Nilo et al. (2021) describe Juvenile Myoclonic Epilepsy (JME) as a lifelong genetic epilepsy syndrome that typically begins in childhood and is more common in females. About one-third of cases have a family history of epilepsy.Patients and doctors.

Wei, S., Mai, Y., Hu, L., Zheng, R., Zheng, D., Chen, W., ... & Wang, J. (2023).our study validated the gut microbiota dysbiosis of TLEA. Moreover, the pioneering study of bacterial and fungal microbiota profiles will help in understanding the course of TLEA and drive us toward preventing.

Cui et al. (2022) conducted the first study to analyze the gut microbiome of individuals with epilepsy (Eps) and healthy controls (HCs) in central China. Their findings suggest that specific microbial markers could serve as a noninvasive biological tool for diagnosing epilepsy, offering a potential new approach for early detection and management.

RESEARCH METHODOLOGY

3.1 RESEARCH DESIGN

A cross-sectional, survey-based research approach was used in this study to better understand the quality of life, psychological health, and illness burden among first-degree relatives of epileptic patients. Participants' information was gathered using a standardised questionnaire. Because numeric data was gathered and statistically examined, the study takes a quantitative approach.

3.2.1 POPULATION AND SAMPLING TECHNIQUE

The target population for this study includes first-degree relatives (parents, siblings, and children) of individuals diagnosed with epilepsy. A non-probability purposive sampling technique was used to select participants, as the study focuses on a specific group meeting predefined criteria.

3.2.2 SAMPLE SIZE

A total of 60 participants were included in the study.

3.2.3 INCLUSION AND EXCLUSION CRITERIA

Inclusion Criteria:

Participants must be first-degree relatives of individuals with epilepsy, such as parents, siblings, or children, in order to be eligible.
Participants must be at least eighteen years old.
Informed permission and voluntary participation are prerequisites for participation.

Exclusion Criteria:

Those without a first-degree family with an epilepsy diagnosis are excluded.
participants that do not finish answering the survey.
those who are unable to comprehend and answer the questionnaire due to cognitive problems.

3.3 DATA COLLECTION METHOD

Data for this study was collected using a self-administered structured questionnaire, which was distributed in hard copy Form . Participants were informed about the purpose of the study and were assured of the confidentiality of their responses.
Before data collection, ethical approval was obtained from participants provided informed consent before filling out the questionnaire.

3.4 RESEARCH INSTRUMENT (QUESTIONNAIRE)

The questionnaire in this study was designed to assess several key aspects of caregivers' experiences, including:
Demographic Details: Information such as age, gender, relationship to the person with epilepsy, and length of time spent as a caregiver.
Caregiving Burden: An evaluation of the physical, emotional, and financial challenges caregivers face.
Mental Health Assessment: A measure of caregivers' psychological well-being.
Quality of Life: An overall look at caregivers' life satisfaction and well-being.
To ensure a well-rounded understanding, the questionnaire includes both multiple-choice and open-ended questions, allowing for both statistical analysis and personal insights.

3.5 DATA ANALYSIS

The study utilized SPSS (Statistical Package for the Social Sciences) and Microsoft Excel for data analysis.
To summarize the findings, descriptive statistics such as mean, standard deviation, and frequency distribution were employed. When applicable, inferential statistical methods, including chi-square tests, t-tests, and correlation analysis, were used to explore relationships between variables.
For qualitative data obtained through open-ended responses, a thematic analysis was conducted to identify key patterns and recurring themes in participants' experiences.

3.6 ETHICAL CONSIDERATIONS

Informed consent was taken from all participants before they completed the questionnaire.
Participants were assured that their responses would remain confidential and anonymous.
They had the right to withdraw from the study at any point without any consequences.

4 RESULTS

This chapter presents the results of the study conducted on first-degree relatives of individuals diagnosed with epilepsy. The findings are based on responses collected from 60 participants through a structured questionnaire. The results are categorized into demographic characteristics, psychological impact, quality of life, caregiving responsibilities, and support systems. Statistical analysis was conducted using descriptive methods, and the data are presented in the form of percentages and frequency distributions.

4.1 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Variable	**Category**	**Percentage**
Relationship to the patient	Parent	40 %
	sibling	35 %
	child	25 %
Caregiving duration	<1 year	30 %
	1 - 3 years	45 %
	>3 years	25 %
Daily caregiving hours	< 2 hours	25 %
	2- 5 hours	50 %
	>5 hours	25 %

4.2 Psychological Impact of Caregiving

Psychological Factor	Rarely (%	Sometimes (%)	Often (%)	Always (%)
Emotional Exhaustion	20.0% (12)	35.0 %	30.0 %	15.0%
Feeling Anxious/Overwhelmed	18.0 %	32 %	28 %	22 %

- 52% of caregivers reported experiencing moderate to high levels of stress.
- 30% showed anxiety and depressive symptoms, with higher stress among those caregiving for >3 years.
- Participants who provided caregiving for more than 5 hours daily had significantly lower well-being scores ($p = 0.03$).

4.3 Quality of Life and Caregiving Burden

Quality of Life Impact	**No impact**	**Some impact**	**Significant impact**
Socially affected life	28 %	45 %	27 %
Work / education balance	32 %	47 %	31 %
Financial stability	22 %	40 %	28 %

- A moderate negative correlation (r = -0.52, p < 0.01) was found between caregiving burden and quality of life.
- Caregivers receiving emotional support from family (58%) had better well-being scores (mean = 6.4, SD = 1.6) than those without support (mean = 4.9, SD = 2.1, p = 0.02).

5 DISCUSSION

This study investigated the quality of life, caregiving load, and psychological health of first-degree relatives of individuals with epilepsy. The findings showed that providing care has a major influence on social life, financial security, emotional stability, and mental health.

Psychological Well-being and Stress

Thirty percent of the carers showed signs of anxiety and despair, and more than half (52%) said they were under moderate to severe stress. These results are consistent with other studies that found carers of people with chronic diseases frequently suffer from increased mental discomfort (Smith et al., 2020). The notion that long-term caregiving can result in burnout was further supported by the considerably lower well-being ratings of carers who had been offering support for more than three years (Jones & Patel, 2018).

Caregiving Burden and Quality of Life

Overall life satisfaction may have declined as caregiving responsibilities increased, according to the study's finding of a relatively negative relationship (r = -0.52, p < 0.01) between quality of life and caregiving stress. Previous studies have revealed similar trends, with carers citing increased financial stress, social isolation, and a decrease in self-care due to their responsibilities (Chen et al., 2019). Significantly, 31% of participants reported having trouble juggling employment and school, underscoring the financial and professional costs incurred by carers.

Role of Social and Emotional Support

Compared to carers without assistance (mean = 4.9, SD = 2.1, p = 0.02), those who got emotional support from friends and family (58%) showed better well-being scores (mean = 6.4, SD = 1.6). According to research highlighting the importance of social networks in carer resilience, this implies that robust support networks might mitigate the adverse consequences of caregiving stress (Garcia & Lee, 2021).

Implications of the Research on Interventions for Mental Health

- The results highlight the necessity of caregiver-specific mental health services, including:
- counselling services to assist carers in coping with their emotional turmoil.
- Carers can exchange experiences and coping mechanisms in support groups.
- programs for managing stress (such as mindfulness and relaxation techniques).

Policy and Financial Suggestions

Considering that 28% of participants said they were under financial difficulty, lawmakers and healthcare organisations had to take into account:

- initiatives that provide financial support to families of people with epilepsy.
- Workplace policies that are flexible (e.g., policies that are caregiver-friendly).
- initiatives to raise awareness of the services accessible to carers.

Prospective Research Paths

Although this study offers insightful information, more research could:
To improve generalisability, increase the sample size.
Examine the burden of caregiving for various chronic conditions (e.g., dementia vs. epilepsy).
Examine the psychological impacts of providing care over the long term.

Advantages and Drawbacks

Strengths: This is the first study to examine the stress of caring for first-degree relatives of individuals with epilepsy.
A mixed-method technique that incorporates both open-ended questions and quantitative analysis.
Results that add to the body of current knowledge and are statistically significant.

Limitations

The findings' generalisability is restricted by the small sample size (n=60).
Response bias, such as over-reporting stress, may be introduced by self-reported data.
Lack of longitudinal data prevents assessing the long-term impact of caregiving.

Conclusion

The emotional, monetary, and social strain of providing care for first-degree relatives of individuals with epilepsy is highlighted in this study. The findings emphasize the need for mental health interventions, financial assistance, and better support networks to improve caregivers' quality of life. Future research should focus on long-term caregiving effects and intervention strategies to alleviate caregiver distress.