ORIGINAL RESEARCH A Mixed Study on the Health Education Needs of Caregivers for People Living with Epilepsy Undergoing Surgical Treatment and the Effects of a Health Education Program

Shuiying Zeng, Hui Liu, Xiaozhen Wen, Yujing Huang

Department of Neurosurgery, Ganzhou People's Hospital, Ganzhou, Jiangxi, 341000, People's Republic of China

Correspondence: Yujing Huang, Ganzhou People's Hospital, No. 17 hongqi Avenue, Zhanggong District, Ganzhou City, Jiangxi Province, 341000, People's Republic of China, Tel +86-0797-8083557, Email huangzhang202202@163.com

Objective: This study aims to understand and address the health education needs of family caregivers of people living with epilepsy, irrespective of the patient's age. It seeks to construct and implement a targeted health education program informed by empowerment education theory and evaluate its effectiveness.

Methods: Through semi-structured interviews, we explored the diverse health education needs of family caregivers of people with epilepsy, identifying key themes and constructing a responsive health education plan. The program's effectiveness was assessed through a quasi-experimental study. The control group received routine health education, while the intervention group participated in an empowerment-based education program in addition to the standard protocol. We evaluated changes in caregivers' disease management capabilities, knowledge about epilepsy, and quality of life at baseline, one month, and three months post-intervention using appropriate statistical analyses to confirm significance.

Results: Sixty-five family caregivers participated, with 32 in the intervention group and 33 in the control group. Guided by phenomenological research, four main themes were identified. Significant improvements in disease management, epilepsy knowledge, and quality of life were observed in the intervention group, exceeding those in the control group at both follow-up intervals (p < 0.05). **Conclusion:** An empowerment-based health education program significantly enhances caregivers' competencies across age groups in managing epilepsy, underscoring its effectiveness as an intervention model.

Keywords: epilepsy, caregiver, health education, empowered theory

Introduction

Epilepsy is a brain disorder characterized by a persistent tendency for epileptic seizures, with diverse neurological, cognitive, psychological, and social impacts.¹ The global incidence of epilepsy is approximately 61.4 per 100,000, with a lifetime prevalence of 7.60 per 1000.² Around 30% to 40% of individuals with epilepsy continue to experience seizures despite two years of first-line drug treatment, a condition known as drug-refractory epilepsy.³ Surgical intervention, an option for 10% to 50% of these patients, often yields significant benefits over medication alone by aiming to control seizures and preserve critical brain functions.⁴

Patients undergoing epilepsy surgery frequently lack the self-care skills necessary for independent living, increasing their reliance on caregivers.⁵ Caregivers, in turn, face significant challenges due to the unpredictable nature of seizure recurrence and their varied educational backgrounds, which often result in inadequate disease-related knowledge.^{6,7} This leads to diminished disease management capabilities, substantial psychological stress, and an increased care burden.^{8,9} Research highlights the extensive psychological, economic, and social impacts of epilepsy on patients and their caregivers, which exacerbate the caregivers' burden and may lead to further health deterioration for both parties.^{10,11} Other research confirms that prolonged, frequent, or severe epileptic seizures can lead to further brain damage and have a significant impact on the physical and mental health of the patient as well as their relatives, family, and society at large.

Educational interventions have been pivotal in lessening caregiver burdens, as demonstrated by Shore's¹² familybased educational program, which notably improved knowledge, attitudes, and caregiving skills while alleviating children's fear and anxiety about epilepsy.

The concept of empowerment, derived from the World Health Organization's definition of health promotion, is a cornerstone of our approach to caregiver education.¹³ Empowerment-based education helps caregivers gain control over their health by equipping them with necessary knowledge and skills, thereby encouraging proactive disease management and support-seeking behavior.^{14,15}

In this study, we apply empowered education theory to enhance the disease management abilities of caregivers, assessing its impact through indicators like knowledge levels, quality of life, and patient disease control.

Method

Study Design

Initially, the researchers adopted qualitative, interpretive, and exploratory phenomenological methods to investigate the perceptions and needs regarding health education of epilepsy patients undergoing surgical treatment and their primary caregivers. Semi-structured interviews were conducted to collect qualitative data, which were then analyzed using the phenomenological approach proposed by Colaizzi. The content of the health education was tailored to the needs of the patients and caregivers, incorporating principles of empowerment education theory. Consequently, a health education program for caregivers of epilepsy patients was developed and implemented among hospitalized epilepsy patients and their caregivers to test its effectiveness.

Due to the constraints of the hospital environment and the inability to conduct true randomization, the study employed a quasi-experimental research method to assess the effectiveness of the empowered health education. Patients were divided into two groups based on their bed numbers. The control group received the hospital's existing health education processes, which included disease knowledge education, precautions during hospitalization, procedures for handling epileptic seizures, complications after surgical treatment for epilepsy, and medication knowledge for epilepsy patients. Nurses provided untargeted, nonsystematic health education during the patients' treatment based on individual patient circumstances. In contrast, patients and caregivers in the intervention group received systematic health education through the empowerment-based health education program designed by the researchers.

Participants

Participant Recruitment

From 2021 to 2022, patients diagnosed with epilepsy were selected as research subjects from the neurosurgery department of a tertiary hospital in China. For the qualitative interviews, purposive sampling was used, while convenience sampling was employed for the quasi-experimental study to test the effectiveness of the empowered health education.

Inclusion and Exclusion Criteria

The inclusion criteria for participants were as follows: Patients and their caregivers who met the diagnostic criteria. According to the 2017 definition by the International League Against Epilepsy (ILAE), epilepsy can be diagnosed if one of the following criteria is met: at least two unprovoked epileptic seizures occurring more than 24 hours apart; a single seizure with a high risk of recurrence (more than 60% over the next ten years, such as previous brain injury, significant abnormalities on EEG, neuroimaging abnormalities, or nocturnal seizures); diagnosed with an epilepsy syndrome. Caregivers are defined as family members with kinship who provide daily care and emotional support to the patient, live with the patient, spend the most time caring for the patient, and perform most care-related activities. Caregivers aged between 20 and 60 years old. Caregivers who are able to read texts and possess good communication skills. Voluntary participation and informed consent provided. The exclusion criteria were: Patients with malignant diseases, other systemic chronic diseases, or organic diseases. Patients or caregivers with severe illnesses, mental disorders, personality disorders, or intellectual disabilities who are unable to cooperate

with the survey or understand the questions. Any patient or caregiver previously diagnosed and treated for a mental illness was excluded from the study prior to its commencement.

Sample Size

The sample size for the qualitative interviews was based on the principle of data saturation. Data were considered saturated when no new themes or information emerged in subsequent interviews. For the part of the study testing the effectiveness of the educational program, the sample size was calculated based on a randomized controlled trial design. Based on the results of a preliminary experiment, with a mean difference of 2.5 and a standard deviation of 2.9, and setting a two-sided α =0.05 and a power of 1- β =0.90, the sample size ratio between the intervention and control groups was calculated as 1:1. Using R software, the required sample size was calculated to be 29 participants for each group. Considering a 10% dropout and refusal rate, at least 33 participants were needed for each group, totaling a minimum required sample size of 66 participants.

Interview Data Collection Procedure

Interview Preparation

The research team conducted a literature review to gather evidence related to the self-management of epilepsy patients and held two brainstorming sessions to develop the initial interview outline. Pre-interviews were then conducted with two caregivers of epilepsy patients who met the inclusion and exclusion criteria. Based on the results of these pre-interviews, the final interview outline was established. The interview outline can be found in Table 1.

Interview Implementation

Semi-structured face-to-face interviews were conducted at a time and place agreed upon by both parties to collect data. It is recommended that the interviews be held in a quiet and secluded area, such as a garden beneath the building. The process involved two interviewers; one conducted in-depth interviews based on the interview outline, while the other was responsible for taking notes, recording necessary details, and asking follow-up questions as needed. To establish trust and effective communication between interviewers and participants, the interviewer began with some general questions. Subsequently, open-ended questions based on the interview outline were posed, utilizing probing techniques (eg, asking for details, examples, and relevant insights) to gather rich data. Each interview lasted approximately 30 minutes. All interviews were recorded, and significant details noted; participants' subtle facial expressions, vocal tones, body movements, and emotions were also recorded during the interviews. To ensure anonymity, interviews were conducted privately, and participants were assigned random numbers. Data collection ceased after the 13th interview as no new information emerged, indicating data saturation had been reached.

Main Problem	Follow Up Questions		
How do you care for someone with epilepsy?	Do you think there is anything that is not done properly in caring for patients with epilepsy?		
	What do you think are the reasons for these imperfections?		
	What kind of help would you like?		
Where do you usually obtain relevant health knowledge about	Do you think the relevant health knowledge you have acquired in the past is		
caring for patients with epilepsy?	enough for you to carry out caring behaviors?		
	Have you received health education from medical staff? How do you feel?		
Do you think health education is necessary for you and your patients? Why?	If you were asked to participate in a health education course, what kind of content and methods would you like?		
	If you were asked to take a health education course, what knowledge or abilities		
	would you most want to gain?		
	In your opinion, how to best evaluate the effectiveness of health education?		

Table I The Interview Outlines

Interview Data Analysis

The processes of data collection and data analysis were conducted simultaneously. All semi-structured interviews were anonymized and transcribed verbatim in Chinese. To protect participant confidentiality, names and other personal identifiers were removed. One researcher conducted the transcriptions, while another assessed the accuracy of the transcribed texts.

In the first phase, two researchers independently read through the full transcripts to familiarize themselves with the data. In the second phase, all interview data were coded using NVivo 12 plus, and significant statements were extracted. In the third phase, based on a theoretical framework, researchers developed general meanings of meaningful statements until a consensus was reached between them. In the fourth phase, the researchers organized the meanings of these statements into thematic clusters to form a prototype of the themes.

In the fifth phase, researchers developed detailed descriptions and refuted each earlier theme by incorporating three to four typical statements. In the sixth phase, similar themes and descriptions were compiled and compared with each other to extract common ideas, forming emerging themes. These emerging themes were then organized into main themes and subthemes to describe caregivers' perceptions of health education for epilepsy patients.

In the final seventh phase, all themes were discussed among the research team and revised as necessary. The validity of the resulting analysis was later reconfirmed by the research participants.

Development of Health Education Curriculum

Drawing on earlier literature reviews and the results of qualitative interviews, an empowered health education intervention plan was established through discussions with an expert panel, considering the characteristics of empowerment education and the feasibility of the intervention. During the patients' hospitalization, a total of six sessions were arranged for the caregivers. The intervention was delivered in a one-on-one format using the empowerment approach. The curriculum was structured around the five steps of empowerment-based education: introducing the course, establishing problems, expressing emotions, setting goals, formulating plans, and evaluating effects. These sessions were conducted either at the patient's bedside or in a meeting room.

Evaluation of the Intervention

The study conducted three follow-up assessments: before the intervention, one month after the intervention, and three months after the intervention, to evaluate its effects. The Family Management Measure (FaMM) was used to assess the situations encountered by caregivers during patient care. This scale primarily evaluates the family's response to the disease, caregiving methods, and the impact of the disease on daily life in families of children with chronic conditions. For the purposes of this study, three subscales of the FaMM were used: Disease-Related Worries (10 items), Disease Management Difficulty (14 items), and Disease Management Ability (12 items). The FaMM uses a 5-point Likert scale, where a higher total score on the Disease-Related Worries subscale indicates a higher level of parental concern about the disease. A higher total score on the Disease Management Difficulty subscale suggests that disease care is more challenging. A higher score on the Disease Management Ability subscale indicates that the disease is easier to manage. In addition, a custom-designed health education effectiveness assessment form was used to evaluate caregivers' mastery of disease-related care knowledge. This survey consists of 10 questions: ability to state the diagnostic name, explain symptoms and signs during an episode, describe main treatment measures, identify situations requiring timely medical attention, name the main medications, list necessary tests, discuss potential issues during treatment, outline preparations needed before treatment, highlight daily life precautions for patients, and identify helpful resources. The questionnaire has a total score of 100 points, with 10 points per question. Caregivers score 0 points if unable to answer a question, 5 points for partially answering, and 10 points for fully answering a question. The Quality of Life Measurement Scale is an internationally recognized scale developed by the World Health Organization (WHO). It consists of 6 domains and 24 aspects that cover various aspects of quality of life. Additionally, it includes 4 questions that assess overall quality of life, resulting in a total of 100 questions. In this study, the aim is to evaluate the impact of empowerment-based education on the quality of life of family caregivers of patients with epilepsy. The quality of life of family caregivers is used as the evaluation index. However, due to the large number of items in the scale and the potential time constraints faced by participants, a shortened version of the quality of life measurement scale will be utilized for assessment purposes.

Statistical Analysis

IBM SPSS 26.0 was used to conduct all the statistical analyses. For continuous data, depending on their distribution, either the mean, standard deviation, or interquartile range (IQR) was used to summarize the data. If the data were not normally distributed, the median was utilized. Results for categorical data were often presented using counts (N) and percentages (%). Patient follow-up data were analyzed using repeated measures analysis of variance. For continuous variables, the Student's *t*-test was used to compare differences between the two groups, while the chi-square test was utilized to check for statistical differences between groups for categorical data. In this study, a p-value of less than 0.05 was considered statistically significant.

Ethics

This study was approved by the Institutional Ethics Committee. All participants agreed to have their statements in the interviews quoted anonymously in manuscripts that might be published. Each participants informed and agreed to participate in this research and signed an informed consent form.

Result

Using the phenomenological research paradigm, we conducted semi-structured interviews to investigate the health education needs of caregivers of patients with epilepsy. Ultimately, 13 participants were included in our study. Using Colaizzi's seven-step method, we identified four themes and 12 sub-themes, as shown in Figure 1. The four themes were: the current state of care for patients with epilepsy, obtaining health-related knowledge regarding the care of patients with



Figure 1 Interview themes and subthemes on health education needs of caregivers of patients with epilepsy.



Figure 2 Flowchart of authorized health education for caregivers of patients with epilepsy.

epilepsy, the health education needs of epilepsy patient caregivers, and health education methods for caregivers of epilepsy patients. We have provided relevant quotes related to specific topics in <u>Appendix 1</u>. After analyzing the health education needs of primary caregivers of patients with epilepsy and considering the theory of empowered education, our team developed an empowered health education course aimed at improving patient outcomes. The course comprises six sessions: Course Introduction, Problem Clarification, Emotion Expression, Goal Setting, Plan Making, and Results Evaluation. A detailed outline of the teaching process can be found in Figure 2.

We evaluated the effectiveness of our health education intervention by including a total of 61 patients, with 32 in the control group and 29 in the intervention group. Table 2 presents the demographics data of epilepsy patient caregivers and epilepsy patients in both groups enrolled in the study. Figure 3 showcases the changes observed in disease management

	Total (n = 61)	Group		t/χ²	Р
		Control (n = 32)	Intervention (n = 29)		
Caregiver age, Mean ± SD				0.753 ^a	0.454
	36.90 ± 4.46	37.31 ± 4.06	36.45 ± 4.89		
Relationship with patients, n (%)				0.808 ^b	0.668
Father	(18.03)	7 (21.88)	4 (13.80)		
Mother	41 (67.21)	21 (65.63)	20 (68.97)		
Other	9 (14.75)	4 (12.50)	5 (17.24)		
Education level, n (%)				1.213 ^b	0.750
Primary school	7 (11.48)	4 (12.50)	3 (10.34)		
Junior high school	21 (34.43)	(34.38)	10 (34.48)		
Senior high school	24 (39.34)	(34.38)	13 (44.83)		
Bachelor degree and above	9 (14.75)	6 (18.75)	3 (10.34)		
Family place of residence, n (%)				0.547 ^b	0.459
Urban	37 (60.66)	18 (56.25)	19 (65.52)		
Rural	24 (39.34)	14 (43.75)	10 (34.48)		
Daily care time, n (%)				1.958 ^b	0.376
4–8h	7 (11.48)	3 (9.38)	4 (13.79)		
8–12h	(18.04)	4 (12.50)	7 (21.14)		
≥226412h	43 (70.49)	25 (78.13)	18 (62.07)		

 Table 2 Demographic Profile of Caregivers and Patients with Epilepsy

(Continued)

Table 2 (Continued).

	Total (n = 61)	Group		t/χ²	Р
		Control	Intervention (n = 29)		
		(n = 32)			
Employment situation, n (%)				0.733 ^b	0.693
On the job	22 (36.07)	12 (37.50)	10 (34.48)		
Part-time job	6 (9.84)	4 (12.50)	2 (6.90)		
Unemployed	33 (54.10)	16 (50.00)	20 (58.62)		
Monthly household income, CNY, n (%)				0.504 ^b	0.927
>3000	21 (34.43)	10 (31.25)	(37.93)		
3000–5000	18 (29.51)	10 (31.25)	8 (27.59)		
5001–7000	13 (21.31)	7 (21.88)	6 (20.69)		
≥7000	9 (14.75)	5 (15.63)	4 (13.79)		
Patient's age, year, Mean ± SD				5.737 ^b	0.057
≤6	15 (24.59)	7 (21.87)	8 (27.59)		
7–18	34 (55.74)	15 (46.88)	19 (65.52)		
≥18	12 (19.67)	10 (31.25)	2 (6.90)		
Patient's gender, n (%)				1.600 ^b	0.206
Male	37 (60.66)	17 (53.13)	20 (68.97)		
Female	24 (39.34)	15 (46.88)	9 (31.03)		
Epilepsy type, n (%)			. ,	4.010 ^b	0.135
Focal seizure	46 (75.41)	21 (65.63)	25 (86.21)		
Generalized seizure	10 (16.39)	8 (25.00)	2 (6.90)		
Others	5 (8.20)	3 (9.38)	2 (6.90)		
Number of attacks in the past 3 months, n (%)			. ,	0.689 ^b	0.708
I–3	23 (37.70)	11 (34.38)	12 (41.38)		
4–10	32 (52.46)	17 (53.13)	15 (51.72)		
>10	6 (9.84)	4 (12.50)	2 (6.90)		
The duration of each seizure, n (%)	, , ,	. /		1.552 ^b	0.670
≤Imin	11 (18.03)	6 (18.75)	5 (17.24)		
I–3min	38 (62.30)	18 (56.25)	20 (68.97)		
3–5min	8 (13.11)	5 (15.63)	3 (10.34)		
>5min	4 (6.56)	3 (9.38)	I (3.45)		

Notes: ^a Independent sample t test; ^b Chi-square test.

situation, disease-related knowledge, and quality of life scores among family caregivers of epilepsy patients in the control and intervention groups. In terms of disease management ability, family caregivers of epilepsy patients in the intervention group exhibited a greater reduction in disease management difficulty scores over time as compared to the control group. Additionally, the disease management ability scores of family caregivers of children with epilepsy were higher in the intervention group than in the control group. These differences were statistically significant one month and three months post-intervention (p<0.05). In terms of disease-related knowledge, scores were higher among family caregivers of epilepsy patients in the intervention group than in the control group. Furthermore, we observed a significant improvement in the quality of life of the intervention group (p<0.05).

Discussion

This study underscores the complexities faced by patients with refractory epilepsy and their caregivers, especially when dealing with surgical treatment. Utilizing interviews and empowerment education theory, we developed a tailored curriculum designed to meet the specific needs of patients and caregivers. The objective was to empower them to manage epilepsy effectively, equipping them with necessary tools and resources for post-surgical success. Our qualitative research reveals that caregivers' perceptions of health education methods and needs vary significantly. They express



Figure 3 Effect of health education intervention empowering caregivers of patients with epilepsy. (A) Changes in disease-related concerns scores of family caregivers of epilepsy patients in the two groups; (B) Changes in disease management difficulties scores of family caregivers of epilepsy patients in the two groups; (C) Changes in disease management capacity of family caregivers of epilepsy patients in two groups; (D) Changes in disease-related knowledge scores of family caregivers of epilepsy patients in two groups; (E) Changes in self-assessed quality of life scores of family caregivers of epilepsy patients in two groups.

a preference for content that is customized to their specific circumstances and seek to provide impactful education tailored to their children's needs.

Targeted health education should emphasize critical areas such as epilepsy first aid, treatment decision-making, and lifestyle management, including exercise and diet. However, our findings indicate a notable gap in current health education, which often overlooks the genuine needs of caregivers, leading to content that lacks relevance to their daily caregiving challenges. There is a pressing need for improvement and a shift towards a more caregiver-centric approach in health education strategies.

Caregivers' varying levels of knowledge about epilepsy underscore the diverse educational needs within this group. Factors like the clinical manifestations of epileptic seizures and their unpredictable nature significantly impact the quality of life for both patients and caregivers. Frequent or prolonged seizures can exacerbate psychological comorbidities, social

difficulties, and lifestyle restrictions, imposing a heavy burden on both patients and their caregivers.¹⁶ Additionally, caregivers and families often incur significant indirect costs due to the disease, such as missed work or school, and in some cases, unemployment.⁸

The plight of family caregivers, who frequently navigate numerous challenges in providing care, merits considerable attention and supportive interventions that prioritize their empowerment.⁷ A 2023 study by Cui¹⁷ highlighted the attitudes, knowledge, and practices of Chinese families regarding out-of-hospital management of acute epileptic seizures. Although families generally held positive attitudes, they exhibited limited knowledge and practical experience, which could hinder effective management.

Furthermore, research on the psychological well-being of caregivers following epilepsy surgery reveals that those from less supported social environments are more susceptible to adverse psychosocial outcomes like depression and anxiety.³ This vulnerability is often exacerbated by a lack of sufficient knowledge about epilepsy, contributing to caregivers' emotional and psychological stress.¹⁸

Structured health education has been shown to significantly alleviate distress among caregivers, with one study reporting that such education in glioma-related epilepsy led to a notable decrease in distress scores for both patients and caregivers, with 98% of caregivers experiencing substantial reductions.¹⁹ Participants also reported that receiving health education enabled them to provide better care.

Therefore, it is imperative for healthcare providers to integrate comprehensive educational programs into clinical practice. These programs should aim to enhance caregivers' knowledge, skills, and confidence in managing epilepsy beyond the clinical setting. Adopting this approach will foster a supportive and well-informed caregiving environment, ultimately promoting positive outcomes for both patients and their caregivers.²⁰

In our study, we observed high initial disease management difficulty scores and low management ability scores among family caregivers in both the control and intervention groups. However, the differences between these groups were not initially significant. Post-intervention, we noted a substantial decrease in the basic management difficulty scores and a significant increase in disease management abilities within the intervention group. This suggests that empowering health education enables family caregivers to actively participate in epilepsy patient care, enhancing their capability to identify problems, recognize learning needs, and establish effective management goals and plans. This, in turn, boosts their motivation for proactive caregiving. The empowered approach not only helped caregivers acquire essential skills but also improved their attitudes towards caregiving challenges, culminating in a marked enhancement in their ability to manage the disease. Moreover, the intervention group showed a significantly greater improvement in epilepsy care knowledge compared to the control group, likely due to the deeper understanding fostered by the empowering educational approach.

The primary goal of educational interventions is to effect behavioral, lifestyle, and environmental changes. Empowerment-based education, as suggested by Nygardh,²¹ fosters a democratic relationship between educator and learner, built on shared experiences, encouraging active participation and decision-making.²² This equal and collaborative relationship enables individuals to engage effectively in self-management and tackle various disease-related challenges.²³ Empowerment also stimulates learners' motivation, empowering them to actively seek and master knowledge,²⁴ facilitating a shift from passive receipt to active engagement in their health management, thereby easing adherence to desired behavioral and lifestyle changes.²⁵

Additionally, delegation plays a crucial role in shared family decision-making and management.²⁶ By promoting joint decision-making, medical professionals and caregivers can enhance caregivers' disease knowledge, reduce decision-making conflicts, and increase satisfaction with the services provided. Families are pivotal in promoting health, managing chronic conditions, and facilitating care across all life stages.²⁷ In both primary and specialized care settings, it is vital to establish systems that encourage family involvement, allowing participation in care as desired by the patient.²⁸

This study innovates by integrating empowering health education into the caregiving process for epilepsy, focusing on a tailored, caregiver-centric approach that enhances both understanding and management skills. Unlike traditional methods, our intervention encourages active caregiver participation and decision-making, significantly improving the caregiving experience and outcomes. This approach not only addresses specific educational needs but also actively involves caregivers in a collaborative and informed care process, setting a new standard in epilepsy management. Despite its strengths, this study has limitations. The follow-up period was short, restricting our ability to evaluate the long-term

effects of empowerment-based education on caregivers of epilepsy patients. In clinical practice, health education should be continuous and iterative, with regular assessments to identify and address knowledge gaps. In this study, only a sixsession educational course was provided, which may not fully meet the ongoing needs of patients and caregivers. Future research should explore the optimal duration and frequency of empowerment-based educational interventions to better support caregivers of epilepsy patients. Nonetheless, this study provides valuable insights into how empowerment-based educational interventions can significantly impact caregivers' ability to manage the challenges associated with caring for epilepsy patients, ultimately reducing caregiver burden and enhancing their quality of life.

Conclusion

Empowerment-based education has shown to be effective in improving disease management skills, disease knowledge, and overall quality of life for caregivers of epilepsy patients. It has also proven to be instrumental in effectively reducing the challenges and difficulties faced by caregivers when managing the disease.

Data Sharing Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Consent for Publication

Informed consent was obtained from all individual participants included in the study.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the 1964 helsinki declaration and its later amendments or comparable ethical standards. This study is approved by the Ethics Committee of Ganzhou People's Hospital. Written informed consent was obtained.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Disclosure

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

References

- 1. Ghosh S, Sinha JK, Ghosh S, Sharma H, Bhaskar R, Narayanan KB. A comprehensive review of emerging trends and innovative therapies in epilepsy management. *Brain Sci.* 2023;13(9). doi:10.3390/brainsci13091305
- 2. Musekwa OP, Makhado L, Maphula A. Caregivers' and Family Members' Knowledge Attitudes and Practices (KAP) towards Epilepsy in Rural Limpopo and Mpumalanga, South Africa. *Int J Environ Res Public Health*. 2023;20(6):5222. doi:10.3390/ijerph20065222
- 3. Phillips NL, Widjaja E, Smith ML. Changes in caregiver depression, anxiety, and satisfaction with family relationships in families of children who did and did not undergo resective epilepsy surgery. *Epilepsia*. 2020;61(10):2265–2276. doi:10.1111/epi.16672
- 4. Conway L, Smith ML, Ferro MA, et al. Correlates of health-related quality of life in children with drug resistant epilepsy. *Epilepsia*. 2016;57 (8):1256–1264. doi:10.1111/epi.13441
- 5. Ostendorf AP, Gedela S. Effect of Epilepsy on Families, Communities, and Society. Semin Pediatr Neurol. 2017;24(4):340-347. doi:10.1016/j. spen.2017.10.007

- He G, Zhu J, Li B. Parent/caregiver reported health-related functioning in Chinese children with epilepsy: a cross-sectional, parents-responded, hospital-based study. *Medicine*. 2023;102(12):e33168. doi:10.1097/md.000000000033168
- Etemadifar S, Heidari M, Jivad N, Masoudi R. Effects of family-centered empowerment intervention on stress, anxiety, and depression among family caregivers of patients with epilepsy. *Epilepsy Behav.* 2018;88:106–112. doi:10.1016/j.yebeh.2018.08.030
- O'Dell C, Wheless JW, Cloyd J. The personal and financial impact of repetitive or prolonged seizures on the patient and family. J Child Neurol. 2007;22(5 Suppl):61s–70s. doi:10.1177/0883073807303070
- 9. Dawes A, Attipoe S, Mittlesteadt J, et al. Measuring the impact of epilepsy on families. *Epilepsy Behav.* 2020;111:107254. doi:10.1016/j. yebeh.2020.107254
- Poochikian-Sarkissian S, Sidani S, Wennberg RA, Devins GM. Psychological impact of illness intrusiveness in epilepsy comparison of treatments. Psychol Health Med. 2008;13(2):129–145. doi:10.1080/13548500701294515
- Westphal-Guitti AC, Alonso NB, Migliorini RC, et al. Quality of life and burden in caregivers of patients with epilepsy. J Neurosci Nurs. 2007;39 (6):354–360. doi:10.1097/01376517-200712000-00006
- 12. Shore CP, Perkins SM, Austin JK. The Seizures and Epilepsy Education (SEE) program for families of children with epilepsy: a preliminary study. *Epilepsy Behav.* 2008;12(1):157–164. doi:10.1016/j.yebeh.2007.10.001
- 13. Rodgers BL. Concepts, analysis and the development of nursing knowledge: the evolutionary cycle. J Adv Nurs. 1989;14(4):330–335. doi:10.1111/j.1365-2648.1989.tb03420.x
- Kruahong S, Tankumpuan T, Kelly K, Davidson PM, Kuntajak P. Community empowerment: a concept analysis. J Adv Nurs. 2023;79 (8):2845–2859. doi:10.1111/jan.15613
- 15. Tang TS, Gillard ML, Funnell MM, et al. Developing a new generation of ongoing: diabetes self-management support interventions: a preliminary report. *Diabetes Educ*. 2005;31(1):91–97. doi:10.1177/0145721704273231
- 16. Ejem D, Stockdill M, Edwards R, et al. "It's Not Just the Seizures": brain Tumor Caregivers' Experiences and Educational Needs in Out-of-Hospital Seizure Management. J Palliat Care. 2023;38(3):316–325. doi:10.1177/08258597231165898
- 17. Cui C, Li S, Chen W, Zhou H, Zheng X. Chinese families' knowledge, attitudes, and practices regarding seizure management for children with epilepsy: a mixed-methods study. *Front Public Health.* 2023;11:1081720. doi:10.3389/fpubl.2023.1081720
- Elliott J, Shneker B. Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy. *Epilepsy Behav.* 2008;12(4):547–556. doi:10.1016/j.yebeh.2007.11.008
- Kuramochi I, Oga K, Iwayama T, et al. One-day psychosocial education program for people with epilepsy: a continuation study of the "Epi-school". *Heliyon.* 2023;9(8):e19311. doi:10.1016/j.heliyon.2023.e19311
- Wasilewski A, Serventi J, Ibegbu C, Wychowski T, Burke J, Mohile N. Epilepsy education in gliomas: engaging patients and caregivers to improve care. Support Care Cancer. 2020;28(3):1405–1409. doi:10.1007/s00520-019-04968-x
- 21. Nygårdh A, Malm D, Wikby K, Ahlström G. The experience of empowerment in the patient-staff encounter: the patient's perspective. *J Clin Nurs*. 2012;21(5–6):897–904. doi:10.1111/j.1365-2702.2011.03901.x
- 22. Stern JM, Cendes F, Gilliam F, et al. Neurologist-patient communication about epilepsy in the United States, Spain, and Germany. *Neurol Clin Pract.* 2018;8(2):93–101. doi:10.1212/cpj.0000000000442
- Owens S, Sirven JI, Shafer PO, et al. Innovative approaches reaching underserved and rural communities to improve epilepsy care: a review of the methodology of the Connectors Project. *Epilepsy Behav.* 2019;90:273–283. doi:10.1016/j.yebeh.2018.09.029
- 24. Anderson RM, Fitzgerald JT, Gruppen LD, Funnell MM, Oh MS. The Diabetes Empowerment Scale-Short Form (DES-SF). *Diabetes Care*. 2003;26(5):1641–1642. doi:10.2337/diacare.26.5.1641-A
- Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns.* 2016;99(12):1923–1939. doi:10.1016/j.pec.2016.07.026
- 26. Wyatt KD, List B, Brinkman WB, et al. Shared Decision Making in Pediatrics: a Systematic Review and Meta-analysis. *Acad Pediatr.* 2015;15 (6):573–583. doi:10.1016/j.acap.2015.03.011
- O'Toole S, Benson A, Lambert V, Gallagher P, Shahwan A, Austin JK. Family communication in the context of pediatric epilepsy: a systematic review. *Epilepsy Behav.* 2015;51:225–239. doi:10.1016/j.yebeh.2015.06.043
- Cené CW, Johnson BH, Wells N, Baker B, Davis R, Turchi R. A Narrative Review of Patient and Family Engagement: the "Foundation" of the Medical "Home". Med Care. 2016;54(7):697–705. doi:10.1097/mlr.00000000000548

Neuropsychiatric Disease and Treatment

Dovepress

Publish your work in this journal

Neuropsychiatric Disease and Treatment is an international, peer-reviewed journal of clinical therapeutics and pharmacology focusing on concise rapid reporting of clinical or pre-clinical studies on a range of neuropsychiatric and neurological disorders. This journal is indexed on PubMed Central, the 'PsycINFO' database and CAS, and is the official journal of The International Neuropsychiatric Association (INA). The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit http://www.dovepress.com/testimonials.php to read real quotes from published authors.

Submit your manuscript here: https://www.dovepress.com/neuropsychiatric-disease-and-treatment-journal

If y in DovePress

1967