Lucie Samokhin

Educational strategies used in paediatric epilepsy

A descriptive literature review

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Author	Lucie Samokhin
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Instructors	Anna-Kaisa Partanen, MNsc, PhD-student (UEF), RN, Senior Lecturer

Paediatric epilepsy is a neurological, life-threatening disorder affecting 5000 children in Finland. Managing children with epilepsy can be challenging, as seizures may not be fully controlled by medication and can lead to behavioural and cognitive comorbidities. Effective self-management is important for improving health outcomes and empowering patients. Patient education is essential, and the whole family's involvement is crucial. Nurses who understand paediatric patients' developmental and educational needs can enhance nursing care and improve children's health outcomes. This thesis aims to describe different educational strategies in paediatric epilepsy and their effectiveness from the children's and parents' perspectives.

Between January and February 2023, a detailed search was conducted using CINAHL, Medline, Pubmed and Medic databases and a manual search to identify articles related to patient education strategies for paediatric patients with epilepsy. After applying inclusion and exclusion criteria, 11 (N=11) articles were reviewed in a descriptive literature review and analysed using inductive analysis. The participants in the selected articles were either children with or without epilepsy or parents/caregivers.

The results showed that educational interventions are essential in improving self-management, safety, quality of life and overall well-being of children with epilepsy and their family. Different educational strategies, such as videos, stories, games, comic books, mobile applications, computer programs, counselling, and discharge education, were found in the studies to increase awareness, reduce anxiety, negative attitude and stigma, and improve seizure control and medication adherence.

Nurses play a crucial role in patient education, and utilising the knowledge gained from the review on educational strategies in paediatric epilepsy can enhance their practice. The thesis highlights the importance of further research on long-term effects, which can improve nursing work and help nurses offer better support and care for children with epilepsy and their families.

Keywords	Paediatric epilepsy, patient education, educational strategies, medication adherence, seizure safety, SUDEP

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Pediatrinen epilepsia on neurologinen ja henkeä uhkaava sairaus, joka vaikuttaa 5000 lapseen Suomessa. Epilepsiaa sairastavien lasten hoitaminen voi olla haastavaa, sillä kohtaukset eivät välttämättä ole täysin hallinnassa lääkityksellä ja ne voivat johtaa käyttäytymis- ja kognitiivisiin oireisiin. Tehokas itsensä hoitaminen on tärkeää terveyden edistämiseksi ja potilaiden voimaannuttamiseksi. Potilasopetus on olennaista ja koko perheen osallistuminen on ratkaisevaa. Hoitajat, jotka ymmärtävät pediatristen potilaiden kehitys- ja koulutustarpeita, voivat parantaa hoitoa ja edistää lasten terveyttä. Tämä väitöskirja pyrkii kuvaamaan erilaisia koulutusstrategioita pediatrisessa epilepsiassa ja niiden tehokkuutta lasten ja vanhempien näkökulmasta.

Tammi-helmikuussa 2023 tehtiin tarkka haku käyttäen CINAHL-, Medline-, Pubmed- ja Medic-tietokantoja sekä manuaalista hakua tunnistaaksemme artikkeleita, jotka liittyvät potilasopetusstrategioihin pediatrisille epilepsiapotilaille. Sisäänotto- ja poissulkukriteerien jälkeen 11 (N = 11) artikkelia käytiin läpi kuvailevassa kirjallisuuskatsauksessa ja analysoitiin induktiivisella analyysillä. Valituissa artikkeleissa osallistujat olivat joko epilepsiaa sairastavia tai sairastamattomia lapsia tai heidän vanhempiaan / hoitajiaan.

Tulokset osoittivat, että opetushankkeet ovat tärkeitä itsehoidon, turvallisuuden, elämänlaadun ja yleisen hyvinvoinnin parantamisessa lapsilla, joilla on epilepsia ja heidän perheellä. Erilaisia opetussuunnitelmia, kuten videoita, tarinoita, pelejä, sarjakuvia, mobiilisovelluksia, tietokoneohjelmia, neuvontaa ja kotiuttamisopetusta löydettiin tutkimuksissa, jotta tiedostavuutta voitaisiin lisätä, vähentää ahdistusta, negatiivista asennetta ja leimaa, parantaa kohtauksen hallintaa ja lääkityksen noudattamista.

Sairaanhoitajat ovat tärkeässä roolissa potilaiden koulutuksessa, ja saadun tiedon hyödyntäminen pediatrisen epilepsian koulutusstrategiasta voi parantaa heidän käytäntöjään. Opinnäytetyö korostaa pitkäaikaisvaikutusten tutkimuksen tärkeyttä, mikä voi parantaa hoitotyötä ja auttaa hoitajia tarjoamaan parempaa tukea ja hoitoa epilepsiasta kärsiville lapsille ja heidän perheilleen.

Avainsanat	Pediatrinen epilepsia, potilaskoulutus, koulutusstrategiat, lääkityksen noudattaminen, kohtauksien turvallisuus, SUDEP

Contents

1 Introduction

Historically, people believed that epilepsy is a punishment for breaking social and religious rules, and they believed that unclean and infectious-looking people are affected. Throughout history it was called by different names such as "illness sent by the gods," "sacred disease," and "the hand of sin." (Renardin, Soares, Soares, Higarashi & Abreu 2019: 1066; Panteliadis, Vassilyadi, Fehlert & Hagel 2017: 457-459.) The earliest description of epilepsy was mentioned around 2500 B.C. in documents from Mesopotamia. Medical texts from ancient Egypt and Babylonian texts also described different types of seizures. The word "epilepsy" originates from ancient Greece and was considered a mystical phenomenon caused by the gods and treated with sacrifices. It was first introduced by Hippocrates in a scientific paper where he described it as a natural disease caused by various factors. (Panteliadis et al. 2017: 457-459.)

Epilepsy affects a significant portion of the global population (Epilepsy Fact Sheets 2019). Parents must be well informed of the signs and risk factors of epilepsy. Patient education is essential for managing paediatric epilepsy, and it is essential to involve the whole family in the process (Kelo, Martikainen & Eriksson 2013: 71-74). Effective self-management and antiepileptic medication adherence are crucial for controlling seizures and improving health outcomes. Parents caring for children with epilepsy often experience depression, anxiety, and stress, so healthcare professionals must support their emotional and mental well-being. Poorly controlled seizures may increase the risk of sudden unexpected death (SUDEP). (Jahri Sheijani, Chehrzad, Reza Masouleh, Kazem Nezhad Leyli & Bidabadi 2020: 66; Sharma, Hussain & Greenwood 2019: 3.) Well-informed and educated patients have a lower level of anxiety, leading to improved health outcomes (Gröndahl, Muurinen, Katajisto, Suhonen & Leino-Kilpi 2019: 2).

Previous studies showed the effect of interventions in patient education on medication adherence and the burden on parents of children with epilepsy (Balouchi, Pahlavanzadeh & Alimohammadi 2021: 5-7; Saengow et al. 2018: 61). These studies show that the burden on caregivers was decreased after the training interventions. The training typically increases the skill and knowledge of caregivers, which has a positive impact on their psychological, physical and social health. Better knowledge and attitudes of families and caregivers result in better care, reduced anxiety, fear, and stigma and improved medication adherence. (Balouchi et al. 2021: 5-7; Saengow et al. 2018: 61.)

To the best of the author's knowledge, a study has not been conducted describing various educational strategies for children with and without epilepsy. Instead, there has been plenty of studies on these two topics separately. However, in the author's opinion, when it comes to patient education, these topics should be studied together, as it is important to describe educational strategies not only from the patient's perspective but also from the perspective of the people around the patient (e.g., relatives, friends, etc.) to reduce stigma around the illness. Therefore, this thesis aims to bridge this gap by performing a descriptive literature review on both topics using scientific databases recommended by Metropolia and performing an inductive analysis of the collected data.

2 Theoretical background

2.1 Paediatric epilepsy

Epilepsy is a common life-threatening neurological disorder characterised by repetitive seizures and is estimated to affect fifty million people worldwide. Every year, approximately 5 million individuals are diagnosed with epilepsy. Higher numbers are seen in countries with low- and middle-income levels (approximately 80% of cases). This contrast is likely due to various factors, such as endemic conditions, road traffic injuries, birth-related injuries, and limited availability of medical care. The occurrence of active epilepsy, or those with ongoing seizures that require treatment, is estimated to be between 4 and 10 per 1000 people. (Epilepsy Fact Sheets 2019.)

Epilepsy in children refers to a group of disorders characterised by the tendency to have epileptic seizures. Sudden, temporary interruptions in electrical activity of the brain cause these seizures. In Finland, an estimated 5000 children are living with epilepsy, with 800 beginning their treatment before age 15. (Finnish epilepsy association 2022.) Epilepsy is a common health issue among infants and children. It is estimated that 5% of children experience seizures (Sharma et al. 2019: 3).

2.1.1 Epilepsy risk factors

In many cases the exact cause of epilepsy is not known. It can typically be caused by various factors, such as brain injury, genetic conditions or chemical imbalances. Examples of chemical imbalances that can trigger seizures include low oxygen levels, low blood sugar, and low blood sodium concentration. Some medical conditions, certain drugs (i.e., cocaine) and alcohol misuse can also increase the risk of epilepsy. However, in many cases, epilepsy occurs without any pre-existing health issues. Children and young people with a non-febrile seizure should visit a healthcare professional as soon as possible for an early diagnosis and an accurate treatment. (Davidson, Eaton & Prosad 2016: 25-26.)

2.1.2 Diagnosing epilepsy

A first-hand witness is essential in diagnosing epilepsy, providing crucial information that the patient may not remember. The community practitioner is critical as they may be the first person consulted after a seizure. To find out if someone has epilepsy, doctors usually ask questions about their health history. Epilepsy may appear in various ways, ranging from seizures to abnormal movements to nonspecific symptoms, such as daydreaming or feeling weird. Epilepsy should be considered if a child demonstrates repetitive loss of awareness or blank spells, changes in behaviour, changes in movement, changes in sleep patterns, or a new onset daytime urinary incontinence. (Davidson et al. 2016: 26.)

If a person is suspected of having epilepsy, a specialist may conduct an electroencephalogram (EEG) or a “brainwave test” to help make a diagnosis. This test may present specific changes in the brain that can indicate epilepsy. It is important to note that an EEG alone is not enough to diagnose epilepsy, especially in children and young people. The results of the EEG test may be inconclusive, and the determination of epilepsy should be made taking the person’s medical background into account. Thereby, even though the EEG is negative, the possibility of epilepsy cannot be ruled out. (Davidson et al. 2016: 26.)

2.1.3 Management of epilepsy

Managing a child with epilepsy can be challenging, as some seizures may not be fully controlled by medication (Jahri Sheijani et al. 2020: 66). Epilepsies with onset in early childhood are often connected to behavioural and cognitive comorbidities and are resistant to the treatment and medication (Symonds et al. 2021: 2879). Parents often bear the responsibility of managing their child’s seizures and other neurological disorders. Children with chronic neurological disorders may experience a lack of prognosis and uncertainty, leading to stress for parents and increasing the risk of anxiety, depression, and behavioural problems for the child. (Jahri Sheijani et al. 2020: 66, Kaye 2021: 1.) This uncertainty can also lead to a low quality of life for parents caring for children with epilepsy. These children are dependent on their parents for care, which can be influenced by the parent’s mental and emotional well-being. Moreover, the risk of sudden death may be increased if seizures are not effectively under control. Therefore, healthcare providers, particularly nurses, should know parents’ well-being and mental state to efficiently care for children with epilepsy. (Sharma et al. 2019: 3; Jahri Sheijani et al. 2020: 66.)

Effective self-management is important in epilepsy. It involves the patient and their family managing the disease and participating actively in the treatment. This can improve health outcomes and even empower the patient to develop problem-solving skills. (Tan, Khoo, Burharudin & Shah 2020: 1, 7.) About 70% of children can become seizure-free with the right amount of seizure control medicine, i.e., antiepileptic drugs (AEDs). However, children often do not follow the recommended treatment well. Only about a third of children take the right amount of medicine. As it is not clear how much medication is needed to control the seizure, taking medication as recommended is crucial. Poor medication adherence can lead to more seizures, bad health outcomes and increased healthcare costs. (Shetty, Greene, Mesalles-Naranjo & Kirkpatrick 2016: 469-473.)

2.1.4 Sudden unexpected death in epilepsy

In paediatric epilepsy, a sudden death of a person with epilepsy without a known cause is referred to as a sudden unexpected death (SUDEP). Around 12% of all deaths related to epilepsy in children are caused by SUDEP. (Gayatri et al. 2010: 777.) Studies show that about 2 out of 10,000 people with epilepsy die from SUDEP each year, but the rate is higher for children with more complicated epilepsy, which is linked to neurological and intellectual problems. It is still not known if finding out early who is at risk of SUDEP will help prevent it. Also, healthcare professionals are usually not sure if they should tell paediatric patients or caregivers about the risk of SUDEP, even though the guidelines recommend doing that. (Galli, Vignoli, Canevini, Cerioli & Vegni 2017: 33.)

2.1.5 Seizure safety in paediatric epilepsy

Children often experience seizures originating from e.g., fever, medication or head injury. Around 25 to 40 thousand children have their first seizure each year, and up to almost half of them will develop epilepsy. Even though all children with seizures will not develop epilepsy, it is important to see a doctor to determine what causes it. Seizures are the most common reason children should be referred to a neurologist. Kids with epilepsy have a higher risk of accidents, such as burns, drowning and falls. They also have a higher risk of head injuries and fractures. If a child has a seizure, it can be a scary experience also for the parents. Guidelines have been recommended to help manage seizure safety, such as taking showers instead of a bath, wearing a helmet on the bicycle, etc. The knowledge of emergency seizures for parents and caregivers can be increased by using a so-called standardised Seizure action plan (SAP). It is recommended to also use written patient education material on seizure safety to further help in delivering information. Furthermore, safety counselling should be offered immediately after a first-time seizure. (El-Radhi 2015: 152; Freedman & Albert 2021: 53, 54)

2.2 Patient education in paediatric nursing

Patient education is crucial for the patient and family to manage the illness and to treat it. Even though children may take more control and responsibility in their self-management, they still need help and support from their parents or caregivers, especially during hospital visits. (Kelo, Eriksson & Eriksson 2013: 894, 895.) Negative attitudes from the family and other factors such as anxiety, difficulties learning, language barriers, cultural differences, living situations, and fear of medical treatment can negatively impact health outcomes. That is why it is essential to involve the whole family in the patient education of children. (Kelo, Martikainen & Eriksson 2013: 74.)

Important part of the patient education process is empowerment. It is a concept where the patient and family take control of their life and make informed decisions about their health. Patient empowerment consists of multiple dimensions, including bio-physiological, cognitive, social, experiential, functional, ethical, and economical.

- Bio-physiological empowerment refers to patients knowing their physiological signs and symptoms and the ability to manage them.
- Functional empowerment involves the ability to take control of daily activities.
- Cognitive empowerment involves having the knowledge and ability to improve one's health.
- Social empowerment involves cooperation, interaction, and association with others.
- Experiential empowerment involves considering past experiences and self-esteem.

- Ethical empowerment involves treating patients as unique and respected individuals.
- Economic empowerment involves being able to afford technical aid and other support. (Kelo, Martikainen & Eriksson 2013: 71.)

To effectively address challenges and achieve goals in patient education, it is essential to involve the patient in the process. This means that the education should be patient-centred and interactive, and that the patient's perspective on treatment is included in the objectives. This approach supports patients' commitment to treatment and increases their satisfaction. (Kääriäinen & Kyngäs 2010: 549) Additionally, well-informed and educated patients have lower levels of anxiety, and this has a positive effect on health outcomes (Gröndahl et al. 2019: 2).

It is worth noting that twenty years ago there were no official policies or procedures for patient education in Finland. Education for patients usually happened in hospitals, but there were no formal guidelines for this. Some health education happened during maternal care and dental appointments, but it was mostly local and not widespread. (Ojanlatva 2001: 50.) One key reason for an insufficient patient education in Finland was the heavy workload of nurses which did not have enough time to fulfil patient's needs. However, patient education should be more patient-oriented as it is one of the fundamental rights of the patients. (Johanson et al. 2003: 243.)

2.2.1 Nurses' perspectives in patient education

Educating paediatric patients can be more challenging for nurses than educating adult patients because the nurse needs to understand children's unique perspectives and involve the entire family in education. Knowing how to educate patients, having effective communication skills, and focusing on patient-centred care can enhance nursing care and improve children's health outcomes. (Kelo, Martikainen & Eriksson 2013: 71-72; Gröndah et al. 2019: 2.)

Nurses should deeply understand the child's developmental and educational needs to effectively educate paediatric patients. This includes being able to provide support, dedicating enough time to the education process, and having knowledge of various patient teaching methods. Some examples of these methods include pictures, videos, toys, dolls, children's books, computer educational programs, role play, and demonstrations. (Kääriäinen & Kyngäs 2010: 549; Kelo, Martikainen & Eriksson 2013: 71-72.)

Various factors can affect the education process for paediatric patients. These include a preliminary assessment of the child's needs, developmental level, and learning abilities. (Kelo, Martikainen & Eriksson 2013: 77.) A lack of nursing training, negative attitudes towards patient education, lack of confidence, time, heavy workload, understaffing, cultural barriers, a challenging work environment and complex patients can also affect the education process. (Kääriäinen & Kyngäs 2010: 548; Oyetunde & Akinmeye 2015: 501.)

Assessment, planning, implementation and evaluation are the four steps in the patient education process. These steps should be done together, and nurses should consider the patient's knowledge, needs, motivation, and issues. (Kääriäinen & Kyngäs 2010: 548, 549.)

1. The first step is assessment. The nurse uses observation, documentation, and interviews to assess the patient's learning ability, style, preparedness, and challenges. The nurse also needs to know the patient's disease, treatment, family history, background, previous experiences of anxiety or fear, and ethical issues and rights. (Seyedin et al. 2015: 2; Kelo, Martikainen & Eriksson 2013: 74.)

2. The second step is planning. The nurse should prepare for the teaching and determine the targets based on the patient's educational needs. This includes scheduling the time and place and preparing the necessary material and equipment. The nurse should consider the method and content of the education, family background, patient's diagnosis, and treatment. Education targets should increase trust and safety, and the content should be related to motivation. (Kelo, Martikainen & Eriksson 2013: 74-77.)

3. The third step is implementation. Different methods such as demonstrations, plays, telephone counselling, verbal counselling, written materials, or practical training should be used. In addition, an interactive and patient-oriented approach should be applied, meaning the nurse should listen to and support the patient. All areas of empowerment discussed in the previous chapter should be considered in this step. (Kelo, Martikainen & Eriksson 2013: 74-77.)

4. The final step is evaluation. It is crucial to evaluate if the learning was effective and make necessary adjustments. In this step, it is important to verify the patient's capability to manage the illness and treatment. (Kelo, Martikainen & Eriksson 2013: 77).

2.2.2 Patient educational strategies and the effect on health outcomes

Various educational tools, such as comic books, educational stories, videos and drama and the effect on health outcomes were discussed in Cicero et al. (2020: 5), Tekle-Haimanot et al. (2016: 222), Pfäfflin, Petermann, Rau, and May (2012: 11-14) and Wohlrab et al. (2007: 45, 47) and Brabcova, Lovasova, Kohout, Zarubova and Komarek (2013: 182). Video animation is used in patient education in children with epilepsy to educate parents and children. This method is entertaining and easy to understand. It was also shown to improve the awareness which had a positive effect on drug adherence. (Saengow et al. 2018: 60, 61.)

A modular educational program for children, called Famoses, described by Pfäfflin et al. (2012: 11-14) and Wohlrab et al. (2007: 47, 47). It is based on a created fairy-tale in which kids were sailors, and they visit different islands on a boat trip to learn about epilepsy. The goal of the program is to empower parents and children to help themselves, reduce consequences and fear of epilepsy, and gain more self-esteem. This educational program was split into modules. In the first module, called Harbour, the kids got to know each other and discussed their experience of epilepsy. In the second module Rock Island, they learned how epilepsy affected their daily life. In the third module, Volcano Island, the children learned about the cause and different types of seizures. Finally, in the fourth module, Treasure Island, children learn about the tests and diagnose. (Pfäfflin et al. 2012: 11-14; Wohlrab et al. 2007: 45, 47.)

Comic books are another tool that can be used for teaching school children about epilepsy to increase knowledge, positive attitude, and understanding while reducing stigma surrounding the disease (Cicero et al. 2020: 5; Tekle-Haimanot et al. 2016: 219). One example is the educational comic book “Guitar Heroes” that was created by doctors from Latin America and France together with cartoonists. The story is about a girl who wants to become a rock star and meets a boy with epilepsy. Later she gets epilepsy too and the doctor helps her to understand what epilepsy is and how to live with the condition. After her treatment and managing the seizures, she helps the boy to get better too. (Cicero et al. 2020: 3.)

Among popular and contemporary educational tools are the mobile health (mHealth) applications, as well as electronic and digital health (eHealth) learning platforms that are very important especially among people with chronic illness, such as epilepsy. Their popularity increased even more due to the Covid-19 pandemic. The international league against epilepsy (ILAE) recently released a curriculum for epilepsy, and they think that online education will be more important for achieving teaching goals. The main objectives are to support self-care and self-management and help individuals to manage their health more effectively. (Beniczky et al. 2020: 237, 238; Escoffery et al. 2018: 63, 66.)

In Finland, there has been a rise of digitalization in healthcare services, with a continuous increase in the number of e-health services in the last ten years in public as well as in some private practices (Ruotanen et al. 2021: 296, 297). Examples of some e-health and m-health services for patients in Finland are My Kanta, Health Village or Maisa:

- My Kanta (in Finnish, *OmaKanta*) is a patient web-based platform with medical information, prescriptions, lab tests, diagnoses, risk factors and appointments. It helps to the patients to understand what the health care professional told them during an appointment. (Kujala et al. 2022: 2; Eriksson-Backa, Hirvonen, Enwald, & Huvila 2021: 400.)

- Health Village (in Finnish, *Terveyskylä*) is an online public service designed to bring healthcare and social services for everyone. Health Village is aimed to monitor quality of life, symptoms, and lifestyle and providing support for patients living with long-term illnesses. Health Village is accessible 24/7 via the internet and can be accessed from everywhere with the tablet, computer, or smartphone. (Health Village 2022.)

- Maisa is an e-service portal that provides access to social and health services via mobile app. The patients can use Maisa to communicate with the healthcare personnel, book appointments, review test results, access remote visits via video, record data from self-monitoring measures, and request a medication renewal. (Apotti 2023.)

The outcomes of increasing use of electronic health services in Finland include better quality of care, cost-effectiveness and improved communication. Patients are motivated to monitor their own health and use medical records to comprehend and remember what healthcare personnel have advised, leading to better health outcomes and patients' well-being. (Häyrinen 2019: 2; Eriksson-Backa et al. 2021: 407; Kujala 2022: 9.)

3 Purpose, aim and study questions

The purpose of this study is to describe the effectiveness of different patient education strategies used for paediatric patients with epilepsy. This study aims to produce knowledge about the effects of different educational strategies used in paediatric epilepsy to help improve nurses working methods and increase patients' health outcomes.

The study questions being addressed are:

1. What educational strategies are used in paediatric epilepsy?

2. What are the effects of different educational strategies in paediatric epilepsy from the children's and parent's perspectives?

4 Methodology and methods

4.1 Descriptive literature review

Research is a systematic investigation that aims to answer exact questions in order to add new knowledge and increase the quality of nursing practice. The main focus of nursing study is to enhance nursing care and improve patient outcomes. This is achieved by using a variation of research methods to collect and analyse data and applying the findings to inform and improve nursing practice. (Gerrish, Lathlean & Cormac 2015: 4.) The definition of research is mentioned by Graziano and Raulin (2004: 31).

> Research is a systematic search for information, a process of inquiry. It can be carried out in libraries, laboratories, schoolrooms, hospitals, factories, in the pages of the Bible, on the street corners, or in the wild watching a herd of elephants (Graziano & Raulin 2004: 31).

Nursing research can have different goals. These goals can include improving nursing practices, learning more about basic nursing concepts, creating better ways to care for people, and finding out if care is working well. (Gerrish et al. 2015: 6.)

This chapter will focus on the research methodology, including the type of method, data collection, and analysis techniques used to answer the research question. The method used in this research will be divided into the following chapters: data collection method, search, data selection, and analysis method. This will give a comprehensive understanding of the research process, including the methods and techniques used to gather and analyse data and how they are applied to answer the research question.

There are three main approaches to research: Qualitative, quantitative, and mixed methods. For a deeper understanding of the phenomenon being studied, a qualitative method will be used in this research. Qualitative studies typically involve people with similar experiences, and the sample does not need to be representative of a large population. Participants may come from different countries, backgrounds, cultures, genders, or age groups. The qualitative approach aims to perceive the meaning of the problem for individuals or groups of people, and the research process includes questions and procedures for data collection and analysis. The information is gathered by observing and talking to people in their natural environment. The data is not in the form of numbers. The process of understanding the information starts with specific details and leads to a bigger understanding of the subject. Qualitative methodology is a way of collecting and analysing data that focuses on understanding and describing the experiences, behaviour, and interactions of individuals or groups. It is often used in the social sciences, such as sociology and anthropology, and involves methods such as observations, interviews, and focus groups. The goal of qualitative research is to get a complete knowledge of a topic, not to generalise a big group of people with the use of statistics. (Creswell & Creswell 2018: 292-297.)

A qualitative descriptive study is a type of research where the researcher writes a detailed summary of the collected data. The summary should be arranged to match the data, include the theory used, and support the results using quotes from participants. To avoid criticism that the study is inaccurate, the researcher must follow strict guidelines and use strategies such as credibility, authenticity, and integrity. The study may have limitations, such as no requirement for theoretical foundations, but this can be fixed by staying close to the data to analyse it. Qualitative descriptive studies play an important role in healthcare and nursing by helping to improve patient care and outcomes, but it is important to maintain rigour throughout the research process. (Turale 2020: 291.)

4.2 Data collection and selection

The search has been conducted between January and February 2023 using the recommended school databases – CINAHL complete, Medline, and Medic. The key search term has been conducted individually in each of the databases. The key terms were "educational intervention," "psychoeducational interventions," "epilepsy," "childhood epilepsy," "children," "child," "kids," "youth," "parents," "learning," and "education program." The Boolean operators were used (i.e., 'AND' 'OR' and 'NOT') to combine the search in the databases (Gerrish et al. 2015: 96). The selection criteria were language, relevance, and accessibility (Table 1: Inclusion and exclusion criteria). Peer-reviewed articles in the English language not older than 2017 were selected for the review.

Table 1: Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Articles published after 2017	Articles published before 2017
Peer reviewed articles	Non peer reviewed articles
Articles answering the study question	Not answering the study question
Articles with full text available	Articles without full text
English articles	Other than English articles
Participants 0-18 years old or parents/caregivers	Participants - nurses, teachers or adults

The selected materials were about patient education techniques or tools used to educate children with and without epilepsy or parents/caregivers caring for a child with epilepsy. After a database search and putting all exclusion criteria, 36 articles were chosen based on the title. After reading the abstract, 17 articles were chosen. Some articles were studies with adult participants and children, which were also excluded from the study. Two articles were searched manually through references from other studies. After reading the complete text, 11 articles were used in this study. The participants in the selected articles were children with epilepsy, children without epilepsy, or parents/caregivers caring for children with epilepsy. Studies with adults older than 18 years old were excluded. Also, studies with nurses or teachers as participants were excluded. The Joanna Briggs Institute (JBI) verified the relevance of the chosen articles. Systematic review studies are assessed for quality utilising the JBI checklist for systematic reviews. The checklist includes 11 questions that should be answered as "yes," "no," or "unclear" to guide the appraisal of the systematic reviews or meta-analyses. (Joanna Briggs Institute 2017.) The quality of the selected studies was also checked in Publication forum, Julkaisufoorumi (JuFo) in Finnish. The portal is a classification publication forum used by Finnish universities to check the relevance and quality of the journals. (Julkaisufoorumi 2021.)

While writing a systematic review or meta-analysis, the PRISMA reporting form must be used to guarantee accurate and transparent reporting of the research process. It is essential to properly describe the research process in the studies to ensure accurate and reliable findings. The flow diagram visualised the search process (Figure 1: Prisma Flow Diagram).

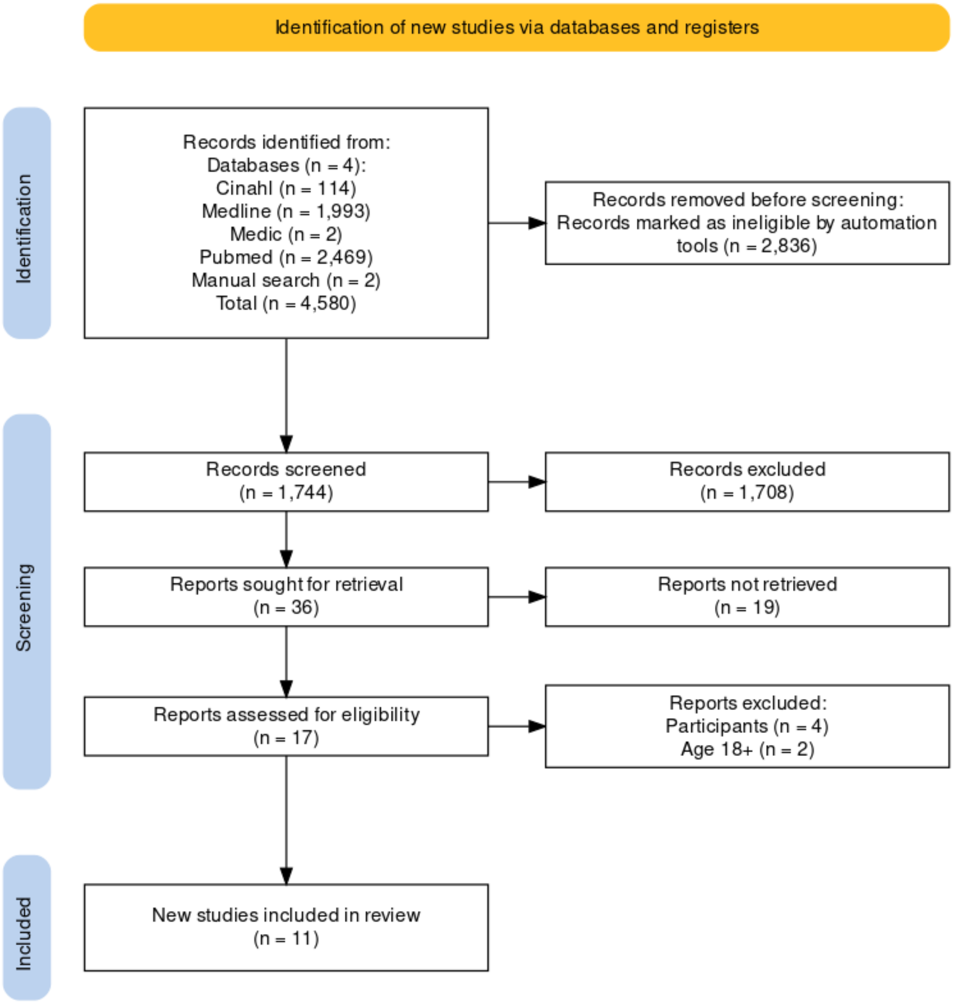

Figure 1: Prisma flow diagram of articles search

4.3 Data analysis method

The data that have been collected are analysed using a method called inductive content analysis. Inductive content analysis is used in qualitative research to analyse and interpret data. It involves identifying patterns and themes within the data and then using them to develop an understanding of the topic being studied. It is called 'inductive' because it starts with the data and then develops theories and concepts. Inductive content analysis starts by reading and rereading the data, coding it, identifying themes, and then interpreting the findings. Researchers read the information often, group similar ideas, and then explain what they learned. It is a flexible method that allows the researcher to explore the data and come up with new insights. (Kyngäs, Mikkonen & Kääriäinen 2020: 14; Elo & Kyngäs 2008: 114.)

Table 2: Examples of content analysis

Meaning unit	**Coding**	**Sub-category**	**Generic category**	**Main category**
"Parents have misconceptions and intense concerns about approaches to seizures" (Güven et al. 2020: 8)	Concerns about seizures	Seizure control	Effect on safety	Effect of different educational strategies
"Medication adherence was reported to be significantly improved post-disclosure in this study" (Kumari et al. 2022: 5)	Improved medication adherence	Medication adherence	Effect on medication adherence	Effect of different educational strategies
"Interventions using educational game and educational story had long-term positive Effect. " (Brabcova et al. 2021: 6)	Positive effect of educational story and game	Educational media	Educational strategies	Educational strategies used in paediatric epilepsy

5 Findings

This chapter discusses the findings of a literature review that examined the educational strategies used in paediatric epilepsy to enhance the knowledge and their effect on the

patient and the family. The study analysed children's and parent's perspectives to identify the most effective educational strategies. The findings aimed to answer the following study questions, what educational strategies are used in paediatric epilepsy, and what are the effects of different educational strategies in paediatric epilepsy from the children's and parent's perspectives?
The findings were categorised into sub-categories, generic and main categories, to answer the research question. The main categories were educational strategies used in paediatric epilepsy and the effect of different educational strategies (Table 3: Results of the inductive content analysis).

Table 3: Results of the inductive content analysis

Sub-category	Generic category	Main category
Educational stories	Educational media	Educational strategies used in paediatric epilepsy
Educational game		
Educational videos		
Educational comic book		
Computer programs	Software tools	
Mobile application		
Eight educational modules: four for children and four for parents	Modular educational program	
SUDEP counselling	Parental consultation	
Discharge education		
Stigma	Effect of educational strategies on well-being	Effect of different educational strategies
Anxiety		
Attitude		
Quality of life		
First aid education	Effect of educational strategies on safety	
Safety improvement		
Seizure control		
Medication adherence	Effect on medication adherence	
Medication self-management		

This study provides a comprehensive review of educational strategies by analysing 11 studies, including one quantitative and ten qualitative studies conducted in various countries over the past five years. The selected articles were sourced from different continents, including Europe (n=2; Czech Republic and USA), Africa (n=1; Madagascar), and Asia (n=6; India, Turkey, Korea, and Malaysia). The study participants were primarily parents caring for children with epilepsy (n=8) or children with or without epilepsy (n=6). The table of selected articles for this review is available in the appendix for easy reference. (Table 2: Studies selected for the review)

5.1 Different educational strategies used in paediatric epilepsy

5.1.1 Educational media

Educational stories, videos, and games were used among school children to test their knowledge about epilepsy and reduce stigma and negative attitudes (Brabcova, Kohout, Weberová & Komárek 2017: 13; Brabcova, Kohout, Kosikova & Lohrova 2021: 2). The educational video in the study was a Czech translation from the original Danish animation "Turen der Gik I Fisk" (Adventures While Fishing). The animation story is about children on a boat on a fishing trip, and one child has a seizure. (Brabcova et al. 2017: 13; Brabcova et al. 2021: 2.)

Educational stories are effective for children from 9 to 11 years old. The educational story was a transcription of the educational video Adventures While Fishing. The story has 15-20 minutes and is read by one of the authors. (Brabcova et al. 2017: 13.) The limitations of the educational story may be that it depends on the narrator's reading style. If the narrator does not read the story in an interesting way, the children will not pay attention. (Brabcova et al. 2021: 6; Brabcova et al. 2017: 16.)

In the educational board game, " Action Zone! " kids played in teams of three, answering 20 questions about epilepsy. If the answer was correct, their team moved forward on the board, but if they did not answer or answered wrong, the team stayed. The game finished when all teams stopped moving. The whole game took around 45 minutes. The children also got a break from the game and did some physical exercise if they were tired. The kids got smiley faces to evaluate the game. (Brabcova et al. 2021: 5.)

The educational Comic-book by Mioramalala et al. (2021) is in the Malagasy language called "Ao Tsara." It is translated from French, and it should raise understanding and awareness about epilepsy and reduce stigma among children after just one reading. The comic book positively affected school children and could be used as an effective tool. (Mioramalala et al. 2021: 1, 2.)

5.1.2 Software tools

Common educational strategies used in patient education among parents and children with epilepsy are software tools, such as web-based educational programs or mobile applications (Neville, McCaffery, Baxter, Shellhaas & Romanowski 2020; Schmidt et al. 2022; Fong, Seet, Ong, Lim & Lua 2019; Fong, Lim, Kong, Lua & Ong 2017; Güven, Dalgiç & Duman 2020). Access to reliable information is crucial in effective epilepsy management (Güven et al. 2020: 9). Güven et al. (2020: 6) showed that there are 50 available websites. However, the content and quality are very low in most of them. Parents with children with epilepsy are often searching on the internet for information about epilepsy, and they experience problems related to insufficient information about epilepsy and its treatment (Güven et al. 2020: 7; Fong et al. 2017: 9). The parents in this study by Fong et al. (2017: 9) often obtained information about epilepsy and SUDEP from the internet without input from a healthcare professional. The web-based educational epilepsy program (WEEP) was developed with content from reliable international websites. The WEEP received a high score for usability and reliability with high-quality content. Youth were mostly searching for information about epilepsy, antiepileptic drugs, first aid, driving, hormonal changes due to epilepsy or stress management, or information about daily life, nutrition, sleep, social life, and school life. (Güven et al. 2020: 4.)

The Interactive epilepsy educational programme (IAEEP) is a computer program that educates people about epilepsy. A university and hospital in Malaysia created it. The IAEEP contains ten important topics about epilepsy, safety, first aid, school and social life, medication, and sudden unexpected death in epilepsy. It can be used on computers or tablets. The programme is easy to use and has received good feedback from parents, children, teachers, and students. Parents reported improvement in quality of life after using this programme. (Fong et al. 2019:53.) To reduce the risk of receiving insufficient information, the parents prefer face-to-face counselling with written and online material (Fong et al. 2017:11).

The eACT is a simple, informal and trustworthy mobile application. It is an artificial system for knowledge designed to simulate a conversation with an expert using different forms of media, such as text, videos and images, to understand the information better. Parents can talk to the system by choosing topics from the list. The system keeps track of the user's progress. The study by Schmidt et al. (2022: 2, 9) found that the learning system improved life and reduced stress and negative feelings.

Seizure action plan (sZAP) is a digital guideline to help families manage seizures outside of the hospital. The form was given to caregivers of children with epilepsy or seizures. The sZAP was designed to provide key information about managing seizures outside the hospital. It was given to the families of children with seizures or epilepsy during their clinic visits to improve understanding of the diagnosis, treatment plan, and managing emergency seizures. Before this, no standard form was used, and different providers used different forms at different times. The new form, called the "Smart Form," was created as an electronic medical record. The new form had access to patient's medical charts. The Smart form could be printed as a letter, electronically signed or sent to the health care professional. The form was designed to be clear and easy to use, only showing the information important to the patient. (Neville et al. 2020: 60-62.)

5.1.3 Modular educational program

The modular educational program is described by Gürhopur and Dalgic (2018: 212). It is an educational tool for parents and their children with epilepsy. The program includes eight educational modules, four for parents and four for children. The parts for children are teaching about epilepsy, how to manage seizures, how epilepsy affects them, and their social life. In the part where children talk about themself, they use words or drawings to express their feeling about the illness and what effect epilepsy has on their everyday life. And the part where children describe their social life, they are using role-playing and videos. The modules for parents are similar but focus on how epilepsy affects their children. The modular program uses teaching methods to help the children and parents understand and manage epilepsy, such as videos, slides, guidelines, role-playing, brainstorming, group activities, discussion, and drawing pictures. (Gürhopur & Dalgic 2018: 212.)

5.1.4 Parental consultations

SUDEP counselling for parents with children with epilepsy was described by Kumari, Garg, Sharma & Pemde (2022: 2-5) and Fong et al. (2017: 7). In the study by Fong et al. (2017: 7), parents used an educational software program, and in the study by Kumari et al. (2022: 2), they went through three-steps counselling. They watched a 5-minutes video, received written information, and had a face-to-face discussion with the doctor. The study showed that most parents preferred a combination of video, reading material, and counselling with a doctor to learn about SUDEP. They felt it would help them learn better about epilepsy without extra anxiety. Most paediatric neurologists do not discuss the risk of SUDEP with parents. The study supports the importance of discussing SUDEP with parents and guides in an appropriate setting. (Kumari et al. 2022: 4, 5.)

Another educational strategy for parents discussed Lee, Choi, Kim & Kang (2019: 18). Discharge education can help parents manage their child's medication when they leave the hospital. Discharge education teaches important information about medications, such as adverse effects, storage information, and dosage, and helps parents feel more confident caring for their child at home. The study aimed to understand what parents thought about the discharge education and how it affects the management of their child's medication. Additionally, the study described different factors, such as parents' and child's characteristics, that affected discharge education and medication management. (Lee et al. 2019: 18.)

5.2 Effect of different educational strategies in paediatric epilepsy

5.2.1 Effect of educational strategies on medication adherence

Medication adherence is very crucial in epilepsy management, especially in paediatric patients. The studies discovered that educational strategies are effective in medication adherence. Four studies talked about patient education and the effect on medication adherence. (Lee et al. 2019: 18; Schmidt et al. 2022: 8; Neville et al. 2020: 62; Kumari et al. 2022: 5.) All the studies had positive outcomes in medication adherence after patient education. The Seizure action plan improved the parents' knowledge about emergency medication. They knew the medication name, when to administer it, and what to do if the medication does not work properly (Neville et al. 2020: 62). Lee et al. (2019: 18) found that the amount of anti-epileptic medication (AEDs) affects the quality of medication management by parents. The more medication the child takes, the more side effects they have and the parent's ability to manage medication decreases. This makes parents more interested in patient education and learning about medication. The study also shows that if the child takes more medication, healthcare personnel give parents better education at discharge. (Lee et al. 2019: 18.)
In the study by Schmidt et al. (2022: 9), a mobile-based educational program, "eACT", helps the caregiver of a child with epilepsy manage better the child's medication. It provides strategies for medication management. This program was found to be effective in promoting anti-epileptic medication adherence, which is great for seizure control. (Schmidt et al. 2022: 9.)

After SUDEP counselling, the parents said they got better at giving their kids medicine at the right time and knowing what to do in an emergency. At the start of the study, most people were already good at taking their medicine as told, so there wasn't much improvement after being given more information. But after they were told more information about SUDEP, they got significantly better at taking their medicine properly. (Kumari et al. 2022: 5.)

5.2.2 Effect of educational strategies on safety

Epilepsy is different from other diseases due to the unexpected occurrence of seizures. It has a serious impact on children's and parents' psychological and physiological functions and has a negative effect on disease management. The studies showed that giving parents and children accurate information about epilepsy improves their understanding of the condition and helps to manage the disease and control seizures. (Neville et al. 2020: 62; Gürhopur & Dalgic 2018: 216; Güven et al. 2020: 6.) It is crucial to educate parents and children on the right actions and behaviours they should have when living with epilepsy. The module educational program covered subjects about seizure management and safety which are the most important topics. Improving parents' knowledge about epilepsy also improves confidence, disease management and seizure safety. (Neville et al. 2020: 62; Gürhopur & Dalgic 2018: 216.) Educating parents on each visit with a Seizure action plan gives them better knowledge about the seizure type and how to handle emergency situations when the child has a seizure (Neville et al. 2020: 62). Güven et al. (2020: 7) showed a significant contrast in the results before and after parental education. The study showed that the parents had misunderstandings and worries about how to handle seizures. They lacked confidence in managing seizures on their own. The information about First aid was searched the most in the WEEP, which showed that this area needs to be improved in patients' education. Overall, the WEEP helped improve knowledge, confidence and attitude about epilepsy and seizure management (Güven et al. 2020: 7). The study by Mioramalala et al. (2021: 4) showed that the knowledge among school children about first aid and seizure safety did not improve significantly after reading a comic book.

5.2.3 Effect of educational strategies on well being

The studies described the effect of the educational strategies mentioned above on stigma, anxiety, attitude and quality of life.

Three studies by Brabcova et al. (2017), Mioramalala et al. (2021) and Brabcova et al. (2021) described the impact of educational interventions on children's awareness about epilepsy and their level of stigma towards it. The education was done among children in the Czech Republic and Madagascar using tools such as videos, stories and comic books. The studies showed that after the interventions, the children had more knowledge about epilepsy, and their level of stigma decreased. The decrease in stigma continued even after a six-month follow-up period. One study was done with preschool children, and the goal was to grow the number of preschools where they implement the interventions. The studies showed that educating school children can be a good way to reduce stigma towards epilepsy (Brabcova et al. 2017: 14-16; Brabcova et al. 2021: 6; Mioramalala et al. 2021: 8).

The studies by Schmidt et al. (2022), Güven et al. (2020) and Gürhopur and Dalgic (2018) conducted research among parents with children with epilepsy. The parents are worried that their children will be stigmatized and discriminated in society. They hide their children's illnesses and avoid getting professional help. It may lead to insufficient information and a lack of knowledge about the treatment and epilepsy management. It can have a negative impact on children's health and the family's ability to manage the illness effectively. (Güven et al. 2020:5; Gürhopur & Dalgic 2018: 216.)

Güven et al. (2020) and Fong et al. (2019) investigated the impact of epilepsy education on parents' anxiety about children with seizures. The level of knowledge and self-management increased, and seizure anxiety levels decreased in the parents who received accurate information from the web-based educational program and IAEEP (Fong et al. 2019: 57; Güven et al. 2020: 4,8). The study showed no significant adverse effect on the mental state of the parents. The study supports the idea that education about epilepsy can help reduce anxiety levels among families of children with seizures. (Güven et al. 2020: 4, 8; Fong et al. 2019: 57.)

A study about SUDEP counselling by Kumari et al. (2022) and Fong et al. (2017) was conducted among Malaysian and Indian parents of children with epilepsy. Most parents wanted to know about SUDEP, and many had good feelings after receiving more information about it. No increase in depression, anxiety, or stress was reported after discussing SUDEP. After being told about SUDEP, some parents felt overwhelmed, but post-disclosure counselling and speaking with the doctor helped to reassure them. The study found no significant difference in the level of emotional discomfort after SUDEP education (Kumari et al. 2022: 4, 5; Fong et al. 2017: 10).

The modular educational program in the study in Turkey by Gürhopur and Dalgic (2018) increased parental knowledge and helped reduces their fear. But it also made the parents more aware of the severity of the condition, which increased their anxiety level. The study found that meeting with other families of children with epilepsy and sharing their experiences may help reduce anxiety. (Gürhopur & Dalgic 2018: 216.) These studies by Brabcova et al. (2017), Brabcova et al. (2021) and Mioramalala et al. (2021) focused on children 5-11 years old and their attitudes about epilepsy. Comic-book, videos and stories were used to improve knowledge about epilepsy among school children (Brabcova et al. 2017; Brabcova et al. 2021; Mioramalala et al. 2021). The studies found that these educational tools effectively improve understanding and attitude (Brabcova et al. 2017: 15; Mioramalala et al. 2021: 6). Before they read the comic book, their knowledge and understanding of epilepsy were very little, and the children had negative attitudes towards people with it. However, the study showed improvement in knowledge, the attitudes and practice still had limited changes (Mioramalala et al. 2021: 7). The study by Brabcova et al. (2017: 15) did not have the information about children's knowledge and attitude before the educational interventions. Hence, it is impossible to know the exact impact on attitude over time. Education school children can greatly impact positive attitudes towards people with epilepsy (Mioramalala et al. 2021: 8).

Research shows that attitudes towards people with disabilities start to form at the age of 4-5 years based on their experiences. The study by Brabcova et al. (2021) with pre-school children found that teaching children 5-6 years old about epilepsy and its impact can be more complicated. They may not have had previous experience with epilepsy, so how the information is taught can affect their attitudes. Little research has been done to understand how preschool children feel about people with epilepsy and how to measure it. Studies have looked at how language affects attitudes in older children and adults but not in pre-schoolers. (Brabcova et al. 2021: 6.)
Güven et al. (2020) found that using the web-based educational program helped improve the knowledge, attitudes, and confidence of young people with epilepsy and their parents. Before using the website, there was a noticeable difference in their understanding and confidence, but after using it, the results showed improvement (Güven et al. 2020: 8).

The study by Fong et al. (2017) showed that the educational interventions among parents in Malaysia increased alert and negative, more restrictive attitudes 3-6 months after the intervention, which can have a negative impact on the children's daily functions.

After being informed about SUDEP, parents increased the supervision and monitoring of the child's medication. (Fong et al. 2017: 9, 11.)

A study focused by Gürhopur and Dalgic (2018) on the quality of life among children with epilepsy. The disease and treatment can impact their daily life and independence. But modular educational programs helped improve the children's quality of life. The children reported feeling better after the training. It's important to continue the training regularly. The results also showed a strong relationship between the training and the children's self-confidence and quality of life (Gürhopur & Dalgic 2018: 216). The educational program IAEEP helped improve the parents' knowledge about epilepsy which had a positive effect on parents' quality of life. The parents also reported that the child's quality of life improved in social interaction. (Fong et al. 2019: 57.)

6 Discussion

6.1 Ethics and Validity

In humanities, social and behavioural sciences, it is crucial to adhere to ethical principles when conducting research. The Finnish National Board on Research Integrity (TENK) provided guidelines that must be followed when conducting studies involving human participants. These guidelines must be followed throughout the entire research process. TENK is a government agency in Finland that promotes ethics and integrity in research. The organisation’s mission is to ensure that research conducted in Finland is of high quality and meets the principles of good scientific practice. TENK provides guidance and support for researchers, universities, and other organisations on ethical issues related to research, such as plagiarism, data integrity, and conflict of interest. TENK also investigates allegations of research misconduct and makes recommendations for addressing any issues that are identified. Overall, TENK is important in maintaining research integrity in Finland and ensuring that it is conducted ethically and responsibly. (TENK 2019: 6-9.) Although human participants were not involved in this study, ethical considerations had to be taken into account to ensure that the research was conducted in a responsible and trustworthy manner. Proper citing of sources in the article review study was important to avoid plagiarism. This included using quotation marks and proper citation and referencing methods. Following these ethical considerations ensured that the article review study was trustworthy.

Validity, or in other word trustworthiness, in nursing research ensures that the study correctly captures the information that is meant to measure. In qualitative research is the concept of validity more complex, and it involves the interpretation of researchers and the honesty of participants. Incorrect or incomplete data can be threat to validity. There are different types of validity, but all of them are important to ensure the study results are correct and can be used to help patients. This is important in nursing research because it helps make sure the information used to take care of the patients is accurate and reliable. (Gerrish 2010: 355; Holloway & Galvin 2016: 305). To ensure the validity of this thesis, the collected data were from scientific articles, peer-reviewed and searched from reliable sources recommended by Metropolia university, such as CINAHL, Medline, Pubmed and Medic, and the quality of the journals was checked in Publication forum portal. Guarantee that there was no plagiarism, Metropolia recommended using Turnitin program.

6.2 Discussion of the results

The purpose of the study was to describe different educational strategies and their effectiveness in paediatric epilepsy. Interventions in patient education are essential for enhancing the quality of life for paediatric patients with epilepsy. These interventions aim to increase the knowledge and understanding of the condition among children and their families, which can significantly affect the overall well-being of the child. The main educational strategies mentioned in the studies used in paediatric epilepsy were educational stories, videos (Brabcova et al. 2017: 13; Brabcova et al. 2021: 2.), board games (Brabcova et al. 2021: 5.), comic books (Mioramalala et al. 2021: 1), discharge education (Leet al. 2019: 18.), modular educational program (Gürhopur & Dalgic 2018: 212), mobile application (Schmidt et al. 2022: 2), computer programs (Neville et al. 2020: 62; Güven et al. 2020: 6; Fong et al. 2019: 53; Fong et al. 2017: 9) and SUDEP counselling (Kumari et al. 2022: 2). In the previous studies were already discussed educational tools and their impact on the children's and family life, such as educational video, educational drama (Brabcova et al. 2013: 180), comic book (Cicero et al. 2020: 2; Tekle-Haimanot et al. 2016: 219), or educational story (Wohlrab et al. 2007: 45). These educational interventions can help to improve the children's awareness about epilepsy and reduce negative attitudes towards the condition. Videos, stories, games and comic books have been used to reduce stigma and increase knowledge (Brabcova et al. 2017: 14-16; Brabcova 2021: 6; Mioramalala et al. 2021: 8). The previous research by Cicero et al. (2020: 5) described the positive impact of reading educational comic book for high school children without epilepsy. Tekle-Haimanot et al. (2016: 221) from Ethiopia found that despite general awareness of epilepsy, the children had limited knowledge of its causes, with traditional beliefs and misconceptions, such as the evil spirit or curse is the cause of epilepsy. The comic played a significant role in improving their understanding of epilepsy's causes.

The modular educational program was developed for children with epilepsy and parents to teach them about epilepsy to manage the illness using various teaching methods, such as videos, drawing pictures, and roleplaying. The program encourages the children to express their feeling about epilepsy. (Gürhopur & Dalgic 2018: 212.) The modular educational program was mentioned in the studies by Wohlrab et al. (2007: 45,47) and Pfäfflin et al. (2012: 11-14). The program called Famoses was developed to empower children and parents and reduce fears about epilepsy.

Electronic programs such as web-based educational programs and mobile applications have also been used to provide access to reliable information about epilepsy management (Güven et al. 2020: 6; Neville et al. 2020: 60-62; Fong et al. 2019: 53; Fong et al. 2017: 9). The Interactive epilepsy educational program, the eACT, and the Seizure Action Plan are examples of computer programs that educate people about epilepsy and improve understanding and quality of life. (Schmidt et al. 2022: 2; Neville et al. 2020: 60-62). The study results showed that these programs are effective, easy to use and have received positive feedback from parents, children, and healthcare professionals. However, some parents still prefer written and online materials together with face-to-face counselling to reduce the risk of receiving insufficient information. (Kumari et al. 2022: 4, 5). Previous studies talked about the importance of digitalization and the use of mobile and computer tools in patient education. Online learning helps to increase the quality of care, communication, and patient information, and it is time- and cost-effective. It also helps to empower patients and supports self-care and self-management to manage their health more effectively. (Beniczky et al. 2020: 237, 238; Escoffery et al. 2018: 63, 66; Häyrinen 2019: 2; Eriksson-Backa et al. 2021: 407; Kujala 2022: 9.)

The effect of patient education on medication adherence is discussed in four studies, Lee et al. (2019: 18), Schmidt et al. (2022: 8), Neville et al. (2020: 62), and Kumari et al. (2022: 5). All the studies found positive outcomes in medication adherence after patient education. For instance, the Seizure action plan improved the parents' knowledge about emergency medication and made them more confident in administering it correctly. The study by Lee et al. (2019: 18) also found that the amount of anti-epileptic medication (AEDs) affects the quality of medication management by parents and that if the child takes more medication, the healthcare personnel provide better education at discharge. Schmidt et al. (2022: 9) explored the use of a mobile-based educational program, "eACT", which helps the caregiver of a child with epilepsy manage their child's medication. The program provided strategies for medication management and was found to be effective in promoting anti-epileptic medication adherence, leading to better seizure control. Finally, after SUDEP counselling, the parents in the study by Kumari et al. (2022: 5) reported that they became better at giving their children medicine at the right time and handling emergencies. The study showed that although most people were already good at taking their medicine as directed, they still improved significantly in taking their medicine properly after receiving more information about SUDEP. Tan et al. (2020: 7), Shetty et al. (2016: 469), Seangow et al. (2018: 60) and Kaye (2021: 8) described in their studies how educational strategies and increased knowledge among children with epilepsy and their parents affect medication adherence and self-management. Medication adherence is crucial in epilepsy management, and only one-third of children take the recommended dose. Poor adherence can lead to worse health outcomes and greater healthcare costs.

Studies (Neville et al. 2020: 62; Güven et al. 2020: 6; Gürhopur & Dalgic 2018: 216.) showed that providing accurate information about epilepsy to parents and children improves their understanding and management of the condition, leading to better control of seizures. Improved knowledge also leads to improved confidence and better handling of emergency situations during a seizure. (Neville et al. 2020: 62; Gürhopur & Dalgic 2018: 216.) Educational interventions, such as psychoeducation or educational fictional story, in previous studies, had a positive impact on seizure management. (Kaye 2021: 8; Pfäfflin et al. 2012: 15) Parental education on each visit, with a Seizure action plan, has been shown to be effective in improving knowledge and confidence in managing seizures (Neville et al. 2020: 62). The same result after using Seizure action plan showed a study by Freedman and Albert (2021: 53, 54). One study found that parental education through the WEEP program was helpful in improving their knowledge, confidence and attitude about epilepsy and seizure management (Güven et al. 2020: 7). However, another study by Mioramalala et al. (2021: 4) showed that a comic book aimed at educating school children on first aid and seizure safety did not significantly improve their knowledge. A different result was in the study of Tekle-Haimabot et al. (2016: 220), where the comic book improved the children's knowledge about first aid and seizure safety.

Stigma towards epilepsy can have negative impacts on children's health and the ability of families to manage the illness effectively. To address this issue, various educational interventions have been studied to increase knowledge and reduce stigma among children and parents. Three studies by Brabcova et al. (2017: 14-16), Brabcova (2021: 6) and Mioramalala et al. (2021: 8) found that educational interventions using tools such as videos, stories, and comic books can significantly improve children's awareness about epilepsy and reduce their level of stigma. The previous research by Cicero et al. (2020: 5) described the positive impact of reading educational comic books for high school children without epilepsy to reduce stigma towards children with epilepsy. However, parents of children with epilepsy may worry about their children facing stigma and discrimination in society, leading them to hide their children's illnesses and avoid seeking professional help. Studies by Schmidt et al. (2022: 8), Güven et al. (2020: 5), and Gürhopur and Dalgic (2018: 216) have shown that this lack of knowledge and information about epilepsy can have negative consequences for children's health and the ability of families to effectively manage the illness. These findings present the importance of increasing awareness about epilepsy and reducing stigma through educational interventions.

Studies have found that educational tools such as comic books, videos, and stories can effectively improve understanding and attitudes towards people with epilepsy (Brabcova et al. 2017: 15; Mioramalala et al. 2021: 6). These strategies had positive effects on children's knowledge and attitudes towards epilepsy, although their practices still showed little change. Education can significantly impact more positive attitudes towards people with epilepsy. (Mioramalala et al. 2021: 7.) Same positive results were found in the studies from Tekle-Haimonot et al. (2016: 221) and Cicero et al. 2020: 5) using a comic book. Research by Brabcova et al. (2021: 6) has found that attitudes towards people with disabilities form between ages 4-5 based on direct and indirect experiences. The study by Güven et al. (2020: 8) of web-based educational programs also helped improve the knowledge, attitudes, and confidence of young people with epilepsy and their parents. However, educational interventions for parents in Malaysia increased alert and restrictive attitudes towards their children, which can have negative impacts (Fong et al. 2017: 9,11).

Epilepsy education has been found to reduce anxiety levels in parents of children with seizures, according to studies by Fong et al. (2019: 57) and Güven et al. (2020: 4,8). A web-based educational program and IAEEP increased the parents' knowledge, self-management skills, and health literacy, decreasing seizure anxiety. No significant adverse effects were reported on the mental state of the parents. (Fong et al. 2019: 57; Güven et al. 2020: 4,8.)

In a study on SUDEP counselling by Kumari et al. (2022: 4,5) and Fong et al. (2017: 10), most parents wanted to know about SUDEP and had good feelings after receiving information. No increase in depression, anxiety, or stress was reported, but some parents felt overwhelmed. Post-disclosure counselling and speaking with the doctor helped to reassure them. (Kumari et al. 2022: 4, 5; Fong et al. 2017: 10.) This study produced different results compared to the previous studies by Galli et al. (2017: 37) and Gayatri et al. (2010: 5) on SUDEP counselling. The parents felt anxious and worried after receiving information about the risk for SUDEP, but also felt hope, and the level of anxiety decreased three months after the counselling. A modular educational program in Turkey (Gürhopur & Dalgic 2018: 216) increased parental knowledge, reduced fear, and heightened awareness of the condition's severity, leading to increased anxiety. Sharing experiences with other families of children with epilepsy may help reduce anxiety levels.

The study by Gürhopur and Dalgic (2018: 216) found that modular educational programs helped improve the quality of life of children with epilepsy. The children reported feeling better after the training, and the results showed a strong relationship between the training and the children's self-confidence and quality of life. The IAEEP program was also found to improve the parents' knowledge about epilepsy and positively impact their quality of life and their child's social interaction. (Fong et al. 2019: 57.) Same results were found after using the Modular educational program Famoses (Wohlrab et al. 2007: 47.)

6.3 Strength and limitation

The strength of this study is that the participants from the collected articles are not only children with epilepsy and their parents but also a school- and preschool children without epilepsy. This allows us to see what different educational strategies are used among children and can be helpful in educating others, such as siblings or classmates. This can help to reduce the stigma about epilepsy and increase knowledge about first aid and seizure safety. The limitation of this study is due to the limited availability of studies from European countries in the recommended databases by Metropolia. The collected data are from publications only from a five-year period from a few countries, mainly in Asia and the USA. The findings in this study are not reflecting the experience of the whole population with epilepsy, and further study with a more varied sample is required to address the limitations.

7 Conclusion and Recommendation

Education interventions are essential for enhancing the quality of life for families and paediatric patients with epilepsy. Various educational strategies, such as videos, stories, games, comic books, mobile applications, computer programs, discharge education, modular educational programs, and SUDEP counselling, were found in the articles. These strategies aim to increase knowledge and awareness of the condition, reduce anxiety, negative attitudes, and stigma, improve seizure control and better handling emergency situations, better medication adherence, empower parents and children with epilepsy, and provide support, leading to improved quality of life and overall well-being.

The results showed that computer programs and mobile applications were effective in providing reliable information about epilepsy management and promoting medication adherence. However, some parents still prefer face-to-face counselling to reduce the risk of receiving insufficient information. Despite the positive impact of educational interventions, some parents of children with epilepsy may still worry about stigma and discrimination, which can impact their willingness to seek professional help.

However, the study found that not all educational strategies are always effective. For instance, education with the use of a comic book aimed to educate school children on first aid and seizure safety, but the comic book did not significantly improve their knowledge in this area.

In conclusion, nurses play an essential role in patient education and can utilise the knowledge gained from the studies on paediatric epilepsy educational strategies to enhance their practice. Using appropriate educational interventions, nurses can help patients and their families to better manage epilepsy, improve their quality of life, and empower them to take an active role in their health care. The findings of the review on medication adherence can also guide nursing practice in epilepsy management. Nurses can use Seizure Action Plan can improve patients' knowledge about emergency medication and increase their confidence in administering it correctly. Nurses can also use the software educational programs to improve medication management and promote epileptic medication adherence.

Overall, the study highlights the importance of patient education among parents and children with epilepsy. Further research in this area can give a better knowledge of the long-term effects of educational programs and the knowledge to improve nursing work.

Nurses can offer better support and care for children with epilepsy and their family, which can have a major impact on the overall health and quality of life.

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2. Brabcová, D., Kohout, J., Weberová, V., & Komárek, V. (2017). Educational video and story as effective interventions reducing epilepsy-related stigma among children. *Epilepsy & Behavior*, *69*, 12-17.

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8. Güven, Ş. T., Dalgiç, A. İ., & Duman, Ö. (2020). Evaluation of the efficiency of the web-based epilepsy education program (WEEP) for youth with epilepsy and parents: A randomized controlled trial. *Epilepsy & Behavior*, *111*, 107142.

9. Gürhopur, F. D. T., & Dalgiç, A. I. (2018). The effect of a modular education program for children with epilepsy and their parents on disease management. *Epilepsy & Behavior*, *78*, 210-218.

10. Kumari, S., Garg, D., Sharma, S., & Pemde, H. K. (2022). Effect of counselling of parents of children with epilepsy focusing on sudden unexpected death in epilepsy. *Epilepsy Research*, *186*, 106992.

11. Fong, C. Y., Lim, W. K., Kong, A. N., Lua, P. L., & Ong, L. C. (2017). Provision of sudden unexpected death in epilepsy (SUDEP) information among Malaysian parents of children with epilepsy. *Epilepsy & Behavior*, *75*, 6-12.

Table 1: Results of the database search

Database	Search terms	Without limitations	Limitations	Hits	Selected based on title	Selected by abstract	Selected by whole text
Cinahl	Educational intervention AND epilepsy AND children OR child OR kids	N=12	Year 2017-2023, Language English, Age 0-18 years old, peer reviewed	N=5	N=0	N=0	N=0
	Epilepsy education OR educational interventions AND epilepsy OR children OR kids OR youth OR child	N=89	Year 2017-2023, Language English	N=21	N=5	N=1	N=1
	Educational intervention AND epilepsy AND children OR parents	N=13	Year 2017-2023	N=6	N=0	N=0	N=0
Medline	Educational intervention AND epilepsy AND children OR child OR kids	N=73	Year 2017-2023, Language english	N=33	N=9	N=3	N=2
	Epilepsy education OR educational interventions AND epilepsy AND children	N=222	Year 2017-2023, Language english	N=79	N=11	N=5	N=3
	Educational program OR educational intervention AND epilepsy	N=265	Year 2017-2023, Language english	N=110	N=8	N=4	N=2
	Education program AND epilepsy AND children OR parents	N=59	Year 2017-2023, Language english	N=19	N=3	N=1	N=1
	Psychoeducational interventions OR learning AND epilepsy AND children OR parents	N= 1374	Year 2017-2023, Language english	N= 509	N=1	N=1	N=0

PubMed	Epilepsy education OR educational interventions AND epilepsy AND children	N = 2469	Year 2017-2023, Language english, Age 0-18	N= 960	N=5	N=0	N=0
Medic	Educational intervention AND epilepsy AND children OR parents	N=2	Year 2017-2023, Language english	N=0	N=0	N=0	N=0
Manual search		N=2		N=2	N=2	N=2	N=2
Total		N= 4580		N= 1744	N=36	N=17	N=11

Table 2: Studies selected for the review

Autho Year, Country	Title/Topic	Research design/ Methods/ Analysis	Sample	Aim	Main Outcomes	Limitations
1 Lee et al. 2019 Republic of Korea	Medication self-management and the quality of discharge education among parents of children with epilepsy	Quantitative Cross-sectional survey	N = 47 parents of children with epilepsy	“Investigate the perceptions regarding the quality of discharge education among parents of children with epilepsy and assess the impact of their perceptions on medication self-management"	Effective medication self-management can be achieved through discharge education. Establishing a consistent and better strategy for discharge and offering communication skills training ar eessential for ensuring effective delivery. The transition from hospital to home can be improved by the teach-back method.	The sample was taken from a single hospital, so it might not exactly reflect the experiences of all population with epilepsy. Participants were not selected from different age groups. Possibility of bias due to direct reliationship between the participants and the nurse.
2 Brabcová et al. 2017 Czech Republic	Educational video and story as effective interventions reducing epilepsy-related stigma among children	Quantitative,Randomized controlled trial.	N1 = 89 N2 = 93 children 9–11 years old	“The aim is to valuate the effectiveness of two interventions focused on the reduction of epilepsy-related stigma in children aged 9–11 years.”	Previous studies have shown that there is minimal connection between epilepsy knowledge and the degree of stigma associated with it.	Age, gender and knowledge about epilepsy was different in the study groups. The influence of the narrator on the story and the acceptance by the children,

3 Fong et al. 2019 Malaysia	Improving awareness, knowledge, and attitude among Malaysian parents of children with epilepsy using an Interactive Animated Epilepsy Education Programme (IAEEP)	Quantitative,Prospective study.	N = 78 Parents of children with epilepsy 8–18 years old	“Baseline level of epilepsy awarenes, knowledge, attitude of Malaysian parents of children with epilepsy and explore potential characteristics associated with low levels of AKA; Effectiveness of the IAEEP in improving parental AKA, and whether these effects remained stable over time; Effects of the IAEEP on parental mental state and perception of their child's quality of life.”	The Interactive Animated Epilepsy Education Programme is a computer-based educational tool that teaches parents about epilepsy. It helps to understand the condition and the effect on their child. After using the program, parents felt good about themselves and their quality of life increased.	Since only school children without comorbidities participated in the study, it is possible that the findings cannot be applied to the whole population. The study did not ask the childrens own experience and relied on the parent proxy report about the childs QOL. The study was conducted with children without comorbidities so it may not fit for the whole population.
4 Brabcová et al. 2021 Czech Republic	Educational interventions improving knowledge about epilepsy in preschool children	Quantitative,Randomized controlled trial	N = 101 Children 5–6 years old	“Developing effective interventions using the educational board game Action Zone! and a technique known as educational story, and by focusing on the acquisition of knowledge.”	Research showed that using an educational game as an intervention resulted in a improvement in long-term knowledge, although there was a slight decline from immediate post-intervention testing to retesting a month later.	The study focuses just on the knowledge about epilepsy and not on attitude or stigma against people with epilepsy.
5 Mioramalala et al. 2021 Madagascar	Effects of an educational comic book on epilepsy-related knowledge, attitudes and practices among schoolchildren in Madagascar	Quantitative,Randomized controlled trial	N = 244 Chidren 8–12 years old	“Evaluating the effect of a single reading of this comic book on epilepsy related knowledge, attitudes and practices (KAP) in schoolchildren in Madagascar.”	The attitudes, knowledge, and behaviors of primary school children in Madagascar were improved by using a comic book as a teaching strategy. This method was well-received and has the potential to significantly increase awareness about epilepsy in the country.	The study is not testing children with epilepsy but regular public population. Only includes two schools, which could intordce socio-cultural biases.

6 Schmidt et al. 2022 USA	Learning experience design of an mHealth intervention for parents of children with epilepsy	Qualitative, Formative evaluation study	N = 9 Parents/ caregivers of children with epilepsy	“Describe the interactive design, development, and evaluation of a novel mHealth learning environment for parents of children with epilepsy.”	The study shows that eACT mHealth learning platform is easy to use and well-suited for caregivers of children with epilepsy, and that the majority of users had a positive experience using it.	A small study that looks at the experience of a few people. The sample was nearly all white, female-identified. The study does not give complete understanding of the topic.
7 Neville K. L. et al. 2020 USA	Implementation of a Standardized Seizure Action Plan to Improve Communication and Parental Education	Quantitiative Experimental study	N = 505 Children 0–18 years old and their caregivers	“Creating a user-friendly sZAP to improve provider utilisation rates of a standardized form. Assessing if routine utilisation of the sZAP improved parental knowledge of their child’s epilepsy diagnosis, treatment plan, and comfort in emergency seizure management”	The seizure action plan can enhance the education of caregivers on key elements of epilepsy diagnosis and seizure emergencies.	Dropout bias due to a large proportion not fot filling out second questionnaire. Difficulty obtaining follow-up questionnaire due to canceled visits.
8 Güven et al. 2020 Turkey	Evaluation of the efficiency of the web-based epilepsy education program (WEEP) for youth with epilepsy and parents: A randomized controlled trial	Quantitative,Randomized controlled trail	N=70 N = 35 Children 9–18 years old with epilepsy and N = 35 parents	“Evaluating the content, quality, usability, and efficacy of ourweb-based epilepsy education program (WEEP) that we developed for youth with epilepsy and their parents.”	The web based epilepsy education program (WEEP), which has strong content, quality, and usability, was shown to be successful in raising awareness, attitudes, and self-efficacy.	Participants with access to internet were included in the study. Only a tertiary hospital. The study’s 12-week time frame was insufficient to assess the long-term impacts of teaching.
9 Gürhopur et al. 2018	The effect of a modular education program for	Quantitative,Randomized controlled trial	N = 184 (N=92 children	“The objective of this study was to evaluate the efficacy of the	The Modular Education Program for parents and children was successful in controling the condition.	The research is only one in the country in which parents and children with epilepsy are educated.

Turkey	children with epilepsy and their parents on disease management		with epilepsy, N=92 parents)	Modular Education Program for Children with Epilepsy and their Parents on disease management.”		The study did not finish the 6 months period for follow up.
10 Kumari et al. 2022 India	Effect of counselling of parents of children with epilepsy focusing on sudden unexpected death in epilepsy	Quantitative,Single-arm, pre- and post-intervention study design	N = 120 parents of children with epilepsy	“Assessing the effect of SUDEP counselling on the epilepsy-related childcare behavior and practices, and emotional distress, among parents of children with epilepsy.”	Indian parents and children prefer to talk to someone face-to-face or use videos for the SUDEP counselling. After SUDEP counselling depression, anxiety or stress did not increase.	The study only included parents with primary education or hugher. Lack of control group. The change in anxiety, depression was not assessed post counselling.
11 Fong et al. 2017 Malaysia	Provision of sudden unexpected death in epilepsy (SUDEP) information among Malaysian parents of children with epilepsy	Quantitative,Prospective cohort study	N = 127 parents (84 mothers) of children with epilepsy	“Our prospective cohort study consisted of multiethnic parents of children with epilepsy (CWE) seen in a tertiary hospital in Malaysia. Information on SUDEPwas delivered to parents using an epilepsy educational software program.”	Most parents and children with epilepsy wished to recieve more information about epilepsy and SUDEP. After the couselling, parents did not have negative feeling. SUDEP counselling should be necesary part of the patients care.	The study findings may not apply to all paediatric epilepsy patients. The results may have been affected by the high number of fathers in the study.