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Exploring the Psychological Status of Pediatric Epileptic Patients in China

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ABSTRACT

In this research, the psychological well-being of children with epilepsy in China is being addressed by emphasizing on the discomfort that epilepsy brings in the life of the kid and their families. The study employed a qualitative analytic approach to examine ten pediatric patient families from a hospital in Hunan Province, China. It included semi-structured interviews, field observations, and audio recordings to delve deeply into participants' experiences in pediatric neurology wards, ensuring a comprehensive analysis. The findings indicate that epilepsy is a complex illness that affects many aspects of a child's development and functioning. As a result, many of these youngsters are more likely to have bad school experiences, trouble socializing with peers, inadequate social skills, and low self-esteem. Also, people with epilepsy and their family may encounter discrimination, rejection, prejudice, and other widespread beliefs that epilepsy is incurable, infectious, or the result of morally repugnant behavior, which can isolate people and discourage them from seeking treatment.

Keywords: Pediatric, Epileptic Patients, and Psychological Status.

INTRODUCTION

Epilepsy affects over 9 million people in China, and with an annual growth of approximately 400,000 cases, it has become the country's second most common neurological disorder. Epilepsy's rapid, unpredictable, and long-term pharmaceutical characteristics not only cause pain and anguish for the patient, but also impose a significant long-term burden on the epilepsy family. If the family is maladjusted, it will almost certainly have negative consequences for both the epileptic patient and the family.

Qi Ruihua (2023) investigated the effects of nursing case management in children with epilepsy and discovered that nursing case management could improve medication adherence and quality of life scores while also lowering anxiety and depression scores, which was superior to conventional care. Zheng Lei et al. (2023) investigated the effects of medication self-management training on correct medication administration and well-being in epilepsy patients and discovered that the use of medication self-management training had a significant impact on medication effectiveness, correct medication administration rate, and well-being.

Yang Chunsong et al. (2023) conducted a thorough evaluation of the current state of self-management affecting factors, interventions, and management styles in Chinese epilepsy patients in order to give evidentiary support for safeguarding epilepsy patients' outcomes. The findings revealed that self-management of Chinese patients with epilepsy is insufficient, with a single set of influencing factors and interventions, and a lack of integrated interventions and management models based on different levels of the individual, family, healthcare system, and society. An evidence-based self-management approach should be developed to increase self-efficacy and self-management in epilepsy patients.

Scholars have investigated various approaches of care for pediatric epilepsy. Liu et al. (2023) investigated the value of continuity of care for juvenile epilepsy patients using a microblogging platform. The findings revealed that using the WeChat platform to provide continuity of care for juvenile epilepsy patients had a substantial impact. Li Lixue and Huang Shuixiu (2023) investigate the impact of a multidisciplinary collaborative care approach on quality of life and family members' negative emotions in juvenile epilepsy patients. The findings revealed that using a multidisciplinary collaborative care model in the care of pediatric epilepsy patients improves cognitive function, which can effectively improve the patients' self-care ability and quality of life while also alleviating the family's negative emotions.

The available literatures has employed qualitative research methodologies to investigate the shame and family experiences of epileptic patients, with older and younger groups, but few studies have focused on the family members of epileptic children. Children with epilepsy require thorough care from family members, therefore their family's epilepsy-related experience is critical in their recovery. As a result, this study focuses on the psychological status and family experiences of children with epilepsy in order to better understand the issues and psychological transformations they face on a daily basis, as well as to assist future families with pediatric epilepsy in understanding and preventing the situation in the first place. The study used a qualitative analysis method to evaluate 10 pediatric patient families in Hunan Province of China.

STATEMENT OF THE PROBLEM

The purpose of this study was to learn about the psychological well-being of children with epilepsy in China by focusing on the inconvenience epilepsy causes in the child's and family's lives. Based on the findings, focused methods are offered for future families with epileptic children in order to enhance their care. The study's findings may give future care experiences for families of paediatric epilepsy patients, as well as contribute to the child's recovery.

RESEARCH DESIGN

The study used a qualitative analysis method to evaluate 10 pediatric patient families from one of the hospitals in Hunan Province of China. The study used semi-structured interviews, field observations, and audio recordings to dive thoroughly into participants' experiences on pediatric neurology wards, assuring a complete analysis. The interviews will be informal and casual exchanges in which participants can openly express their ideas. However, to ensure that the conversation remains clear and coherent, the researcher will give a semi-structured interview guide to lead the talk if it deviates from the topic.

SUMMARY OF FINDINGS, CONCLUSIONS, AND RECOMMENDATION

Psychological Effects of Epilepsy on Children

Some of the observed psychological consequences include emotional effects that might lead to melancholy and anxiety, jealousy and low self-esteem, a lack of emotional reactivity, uneasiness, and anxieties. Participant 1 stated that their epileptic kid frequently "worries about having a seizure in public or being teased by others". They also stated that it has an impact on the child's mental health, since he frequently experiences poor self-esteem and loneliness. Participant 3 also said that epileptic children frequently have emotional problems such as fear, anxiety, impaired self-esteem, and social difficulties. Participant 6 mentioned "trauma" as a psychological consequence and stated that epilepsy might impair a child's IQ. Pediatric patients with epilepsy will have widespread discomfort in the early stages of the condition, as well as being easily aroused, distracted, angry, critical of different aspects of life, and losing their temper with their parents, among other things. They may also be quickly angered, disturbed, irritable, critical of their surroundings, and furious at their parents. According to Massachusetts General Hospital (2020), 30 to 50% of children with epilepsy suffer behavioral or mental health issues. Attention deficit, hyperactivity, anxiety, depression, aggression, and autism spectrum disorder are among the behavioral and psychological difficulties associated with epilepsy.

Effects of Epilepsy on Family Members

Based on the study findings, epilepsy affects bonding among family members, time and energy usage, leads to financial issues, and psychological stress. The stigma and discrimination associated with epilepsy might be more difficult to overcome than the actual seizures. Individuals with epilepsy and their families may suffer prejudice. Pervasive beliefs that epilepsy is incurable, contagious, or the result of morally abhorrent behavior can isolate and discourage people from seeking treatment. Children and their families' lives are influenced by a variety of psychological, behavioral, social, educational, and cultural factors. Previous study has indicated that more than half of caregivers for children with epilepsy have psychopathological symptoms such as post-traumatic stress disorder, depression, anxiety, and high levels of stress, as well as problems sleeping. Caregivers' mental state and ability to cope with illness are important factors influencing children's recovery (Yu et al., 2022).

Having an epileptic partner or kid can have a big impact on daily life. Not simply physically, such as doing extra household work, but also emotionally. The epileptic kid or spouse may have always been self-sufficient, but as a result of their epilepsy, they have become significantly more dependent on family members. Participant 10 stated that as a result of this reliance, "the quality of family life will be relatively reduced" since they will be left to care for and focus more on the epileptic patient, canceling plans and spending more time with the patient. According to Participant 8, it has also "affected the relationship between husband and wife, the relationship of the family members has become bad". Seizures and epilepsy affect whole families and the bonds they form with one another. Everyone is influenced on some degree, albeit in different ways. Seizures can leave a person feeling helpless, afraid, nervous, or any number of other feelings.

Furthermore, caregivers of epileptic patients typically face considerable challenges in treating and rehabilitating children owing to a lack of self-management abilities. Caregivers typically experience anxiety because they are terrified of seizures at any time and must continually monitor the child's condition. Parents must also cope with particular diets, activity restrictions, long-term medicine and adverse effects, academic and social challenges, and stigma (Yu et al., 2022).

A research conducted by Benson, A. et al. (2019) discovered that families with epilepsy experienced stigma through social isolation, activity limits, teasing/bullying, and an intrinsic unfavorable attitude toward epilepsy. This manifested itself in family talks when the issue was avoided. O'Toole, S. et al. (2019) investigate the difficulties that parents of children with epilepsy have when addressing epilepsy and epilepsy-related concerns with their children. According to the authors, parents should instill a feeling of normalcy in their children, eliminate anxieties of generating worry, and educate them about epilepsy.

Finally, it was discovered that among the family burden of sickness of children with epilepsy, the economic cost was the greatest, which was greater than moderate. Families with epileptic children whose dads have unpredictable employment, a poor yearly family income, epilepsy co-morbidity, a low frequency of outdoor activities, inefficient seizure management, and many medications require further care. The availability and use of an at-home medicine to stop long-term or recurring seizures, as well as in seizure emergencies, improves the quality of life for patients and their families. Fewer emergency department visits result in a decreased economic burden for families and the healthcare system (O'Dell et al., 2018).

Proposed Strategies

This program was created to offer a thorough awareness of the problems and experiences of epileptic patients and their families, as well as the emotional and social difficulties they face. Participants will investigate the important findings of a research that examined the experiences of families with epileptic children, and the recommended approach is directed at future families with epileptic children in order to enhance the care of children with epilepsy throughout their lives.

Objectives	Content	Teaching and Learning Activity	Resource person	Learning Evaluation
1. Evaluating the Status of Children with Epilepsy	Highlighting the psychological, sociological, physical, and academic effects of epilepsy on children with epileptic disease.	- Lecture: Present findings and discuss evidence on the status of epileptic children in China	Doctors, nurses, Healthcare practitioners, carers, epileptic children, and families of epileptic children.	- Focus Group: Analyze different perspectives on the status of epileptic children.
2. Evaluating the Status of Families with Epileptic Children.	Inculcating several effects such as how it affects family bonding, consumes time and energy, financial concerns, and psychological stress.	- Case studies: Analyze scenarios related to the status of families with epileptic children.	Resource: Consult with doctors, nurses, and therapists specialized in this field for the recommendations	- Quiz: Evaluate understanding of factors affecting families with epileptic children.
3. Determining the Experiences in Caring for Epileptic Patients.	Evaluate and analyze some of the critical issues experienced by the carers of epileptic patients. The experiences will be determined based on the subthemes of social relationship problems, frequent medications, lifestyle and diet specifications, and the need for a comfortable living environment.	- Thematic analysis workshop: Understand how themes are sorted in collating experiences	- Discuss findings	- Research project: Design a study to investigate factors influencing epileptic patients.
4. Understanding Parents' Efforts to Assisting	- Collate the experiences of the parents regarding the efforts the put into assisting the epileptic patients such as	Workshop: Discuss the components of the program and its potential impact.	- Specialist: Consult with other specialists and researchers of	- Group project: Develop a strategic program for improving

Epileptic Patients.	provision of support, education of oneself, self-development and hobbies, seeking professional help, and non-pharmacological treatments.		similar topics	care of epileptic patients.
5. Summarize key findings and conclusions from the study.	- Provide summary, conclusions and recommendations on the effects of epilepsy on children and their families	- Interactive presentation: Discuss and reinforce key conclusions.	Resource Person: Study participants (family of epileptic children)	- Debate: Discuss whether demographic factors should be considered in designing epileptic management program.

Conclusion

Based on the summary of findings, the following conclusions are formulated:

1. Epilepsy is a complex disorder that influences many aspects of a child's development and functioning. As a result, many of these youngsters are more likely to have bad school experiences, trouble socializing with peers, inadequate social skills, and low self-esteem. As a result, a continuous collaboration between educators, family members, and health care professionals is required to construct and assess a plan for academic achievement, as well as a plan for safety, emotional or behavioral dysregulation management, and active social integration.
2. The stigma and discrimination associated with epilepsy might be more difficult to overcome than the actual seizures. People with epilepsy and their family may encounter discrimination, rejection, prejudice, and other widespread beliefs that epilepsy is incurable, infectious, or the result of morally repugnant behavior, which can isolate people and discourage them from seeking treatment.
3. Families and caregivers of epileptic children may encounter major challenges throughout the treatment and rehabilitation of epileptic patients. Caregivers typically experience anxiety because they are terrified of seizures at any time and must continually monitor the child's condition. Parents must also cope with particular diets, physical activity restrictions, long-term medicine and side effects, academic and social challenges, and stigma.

Recommendations

Based on the summary of findings, the following conclusions are formulated:

1. Schools and healthcare institutions may raise awareness of epilepsy and epileptic patients, as well as the obstacles they face, in order to educate the general public about the condition and eliminate discrimination and ignorance.
2. The government may adopt laws to reduce some of the financial pressures placed on families of epileptic patients and assist them in their efforts to care for the patients.
3. Future researchers may conduct additional research on epilepsy and epileptic patients in order to generate more information on the various challenges and experiences of patients and their families, as well as to raise awareness and educate the general public, thereby helping to alleviate the pains and burdens of epilepsy on victims and their families.

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