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Review Article

The burden of childhood epilepsy and its impact: Parental perspectives

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ABSTRACT

A chronic childhood illness directly impacts the overall support system, which also plays a role in parental stress, thus leading to the disturbing family process. Children with long-term disease may exhibit behavioral problems that are more common in epilepsy. Epilepsy is a neurological condition with recurrent spontaneous seizures in children. This article examines the multifaceted nature of the crisis burden among young children living with severe epilepsy in their initial years of life and their parents. Childhood epilepsy is often related to family socioeconomic and psychosocial factors. It gives a road map for the future care of children with epilepsy and even their family members to strengthen their epilepsy control and care efforts in the early years of life.

1. Introduction

Epilepsy is one of the chronic neurologic non-communicable diseases related to the brain affecting 0.5% to 1% of the childhood population.[1] More than 50% of seizures have their onset in childhood.[2] It denotes the episodes of unwarranted, excessive, recurrent attacks involving abnormal or synchronous neuronal activity in the brain. The reported incidence rate is from 41-187 per 1,00,000 children and the prevalence rate of epilepsy in children ranges from 3.2 -5.5 to 3.6 -44 per 1000 children in developed and underdeveloped countries, respectively.[3]

Even in many parts of the world, families, and people with epilepsy suffer from stigma and discrimination, and it plays a substantial reason for the world's disease burden.[4] But there is inadequate knowledge and literature about the overall disease burden of childhood epilepsy.[1,5] Epilepsy is a disease and a societal challenge for children with epilepsy and their families.[6] Lack of educational and cultural support in underdeveloped areas also has led the people to perceive the disease as demonic possessions, curses, or divine punishment.[7,8] This has aggravated the stress and negative perceptions of families and children living with epilepsy. The physical consequences of epilepsy and its psychological effects on a child make epilepsy an overwhelming neurological condition. But, around 70% of patients can be seizure-free with compliance to the first line of anti-epileptic drugs as immediate treatment.[9] Still, a large majority, nearly 90% of the people, are living in the shadow of the "Treatment Gap" regardless of the availability of an enormous supply of efficacious anti-epileptic drugs.[10–12]

Social support to family members and parents of children living with epilepsy has been considered to escalate their support system to overcome stress and even reduce morbidity and mortality.[13] In addition to financial support for children with epilepsy, resilient parents and their positive attitudes directly affect the progress of children.[14] Children are too young to perceive the comprehensive view and treatment aspects of epilepsy in their initial developmental years. Such erroneous judgment about broader aspects of illness and its outcome may disturb their thoughts and

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self-esteem regarding marriage, education, employment, and social life later in life.[15,16] There has been much less evidence on the burden of illness and how to adapt to overcome our country's existing limitations and stress. Consequently, this study aims to qualitatively examine the data available and cluster together with the views from parents, and assess the influence of childhood epilepsy and its burden on the functioning of the family.

2. Methodology: Data Extraction

In the past five decades, a considerable amount of research has contributed to improving the lives of children with epilepsy. Our search strategy focused on recent studies published from 1971 to 2022 through electronic databases google scholar and PubMed. The electronic search included a different combination of key terms mentioned in the title and abstract: childhood epilepsy, burden, early seizures, parental anxiety, family, and perspectives. All related comprehensive studies, including systematic reviews, have been included for further analysis to comply with our inclusion criteria.

3. Cultural Literacy on Epilepsy

Around the globe, some beliefs link epilepsy to divine punishment, such as an infectious disease. A type of demonic possession or curse or a psychiatric disorder are frequent and ineffective therapies in a single approach may cause specific adverse outcomes in child care like the stigma that leads to abandonment and child neglect, including isolation of child.[17,18] Although these social practices vary across countries, stigmatization and discrimination are often very difficult to overcome as epilepsy itself. Stigma supersedes the self-confidence of people with epilepsy and may discourage access to health care and treatment.[4]

Cultural explication often contributes to banishing people with epilepsy from educational domains and productive work areas, which aggravates their psychological hardship favoring an unhealthy decision of treatment gap (WHO, 2004). A widely held belief that evil spirits can induce epilepsy exists in a diverse continent like Africa.[19] Mauritania Moorish populations believe that the diet originates from seizures: the word "iguindi" is mentioned for all clinical symptoms, including convulsions credited to uncontrolled overconsumption.[20] Bini of Nigeria believes that epilepsy is a disease in which a kind of foam blocks the heart and disturbs the circulation producing seizures. In Uganda, it is said that epilepsy is a result of dizziness caused by a spinning lizard in circles in the head. And in Malawi, it is thought to be due to motile insects in the stomach.[21]

The belief of connection between the moon and convulsive attacks has also been made from ancient periods. It is still believed that the full moon provokes seizure activity by direct influence.[22] Americans had different beliefs from Africans and Asians as a noteworthy disease in pre-Columbian cultures. Chipaya people called this "tukuri" and believed that witchcraft that makes a way through the nose and the head in the form of wind, causes epilepsy. Tukuri is handled by a ritual of sacrificing an animal called willacha and taking by infusions of bird's blood and insects.[19]

4. Epilepsy in Asia

While economic progress and the simultaneous improvement of health care services and approaches have been observed, Asia continues to be a continent with limited resources. A great deal of research has been done on Asian attitudes and belief systems. Many communities have the negative feeling that the person with epilepsy cannot contribute like other healthy people.[23] In Srilanka, it is said that men will be unwilling to accept a proposal from women with epilepsy which often leads women to remain single throughout their life. If it's exposed or disclosed after marriage, either woman will be sent back to her home or ill-treated, beaten, or even divorced by her husband. Therefore, epilepsy is regarded as a valid reason for divorce.[24]

Epilepsy has a historical association with spirits and religion, and supernatural powers are it a demon or divine. Greeks and Hippocrates referred to epilepsy as a sacred disease and associated it with mystics and prophets.[25]

4.1. Therapeutic modalities for childhood epilepsy

Children with epilepsy can now access treatment facilities from private and public health care facilities based on their choice. "Epilepsy is an incurable disease and can only be treated by reducing the frequency of seizures by using anti-epileptics (AED)[26]". Pharmacological therapy always remains the mainstay of the treatment choice. There is a cluster of anti-epileptic medications that can be administered in various routes. Be it monotherapy or polytherapy. There are no newer medications to convince that they are superior to older ones in potency and interactions.[27] The higher costs lack of adequate supply in rural and grass-root levels are the key elements to be improvised in our public health system. These needs emphasize not to hinder the deliverance of effective treatment choices and drug supplies.[28]

Despite the best available and accessible pharmacotherapy, children do not receive or follow the compliance of anti-epileptic pharmacotherapy, which is called a treatment gap. This may be triggered by obstacles faced by local health care infrastructure shortage of health care personnel due to attention towards most emergent cases in health care settings. The determination of the treatment gap is essential for planning comprehensive medical care, both on an individual and public health level.

This treatment gap is a significant reason for the suffering of children and further worsening of clinical conditions, creating a socioeconomic burden of the disease.[29]

The best non-pharmacological treatment options include surgical approaches such as lesionectomy, callosotomy, hemispherectomy and ketogenic diet, and vagus nerve stimulation. The ketogenic diet has proven its effectiveness in children with drug-resistant epilepsy. Significantly higher cost, expected outcome, pre and post-operative care and complications like hemianopia, hemiparesis and disphaisa leading to anxiety and fear may be the reasons that confuse parents not to opt for them.[30] Seizure reccurrence after ungergoing surgeries is poorest predictor contributing to the outcome of surgery in children with epilepsy.[30] These options anyway are available in a few of the tertiary care centers. Epilepsy surgery can be in various options, such as vagal nerve stimulation and corpus callosotomy.[31]

It is unfortunate that even with our progressive economic growth, a vast treatment gap is growing day by day, which is very much a reality. People even choose multiple healing systems at the same time. It is doubtless that the treatment gap is a huge challenge for health care providers as well as policy makers.[31] The timely planning and good deliverance of health care services and adopting necessary actions in a socio-culturally appropriate manner will bridge the treatment gap, which is essentially the need of the hour.

4.2. *Psychosocial effects on children living with epilepsy*

Epilepsy is a disorder where clinical symptoms vary from child to child based on the frequency of seizure attacks, type, and intensity of seizure activity. Children continue to experience epileptic episodes, sometimes even after regular treatment with AEDs. Meanwhile, children with epilepsy will impact many aspects of life, including academic or learning problems, emotional and behavioral issues, and social life problems.[32] Moreover, a child's physical and psychological development is profoundly affected by the diagnosis of epilepsy among young people. It may reduce some of the life limitations of parents of children with epilepsy.[33]

5. Academic/Learning issues

Children living with epilepsy have an increased risk of learning disabilities and high neurodevelopmental needs.[34] These children are at greater risk for academic underachievement and at risk for learning problems.[35] Though some children possess average intelligence, they may show deficits in some regions of learning and thinking abilities like memory, organizational skills, attention, and concentration that may lead to challenges for learning in school years.[36,37] Few children may have minor difficulties, whereas others may have as serious as global developmental delay/learning problems based on the extent of brain tissue involved with pathological changes. Other factors that may cause impairment in learning can be AEDs or even fatigue leading to transitory changes in education, resulting in Transient Cognitive Impairment (TCI).[38] Consideration of teaching and learning strategies, such as intensive curricula, contributes to children's academic improvement.[32]

5.1. *Emotional and behavioral issues*

Emotional and behavioral difficulties are also unreasonably high in children with epilepsy. The most commonly observed emotional disturbances are anxiety, irritability, hyperactivity, depression. A study found that 24.6% of children had more significant behavioral problems in the six months preceding the diagnosis of seizures.[39]

Aicardi in 1996, added that the causal mechanism for such behavioral changes is epileptiform discharges that impair brain function.[40] Another study reported that anti-epileptic drugs might even cause specific changes in brain regions and aggravate the behaviors of child.[41] The emotional changes are well controlled by reducing triggers in the school setting during such a period. The child may sometimes require additional medications to control the symptoms or alterations in existing therapy.

Parents, the most incredible support system for children, need to assess their strengths and coping mechanisms to equally share with school personnel in handling and caring for the child. Children with visual or linguistic disabilities may require special care and consideration. Irritating environmental factors should be immediately handled and provide a soothing and safer environment for the child. If necessary, the child may be involved in psychotherapies, psychotropic medications, or behavioral therapies after consulting a physicist.[42] Early identification of these issues in children and appropriate treatment provides the best possible outcome and keeps the child safe. Early detection of these problems in children and proper treatment provide the best possible result and ensure the child's safety.[43]

5.2. *Social issues*

In the initial years, children involved with peer groups in physical activities such as play and social engagement have a more significant positive impact on later life. But children with epilepsy due to frequent seizures or related risks of injury and fall and associated secondary problems keep them away from such engagements. Even the acquired disease's emotional disturbances and low self-esteem may change their thought process to exclude them from others. Parents may focus on a child's safety instead child's school or educational growth. Concern over a child's health outcome takes priority over social skills development. Further isolation from social learning may lead to negative self-perception, doubt, and acceptance of 'not okay' with oneself.

Parents must advocate for extra support and care in the school and social system to facilitate interactions with other children. Promoting social and physical development can be fostered by a sense of emotional wellbeing created by participating in school activities for children with epilepsy. These children need multi-disciplinary assessment and collaborative support through the health and educational sectors.[44]

5.3. *Parental concers and their coping strategies*

Despite the issues and significant difficulties faced by children with epilepsy, their parents, siblings, and family members have the most prominent role in accepting the challenges concentrating on their wellbeing too. Parents of children living with epilepsy express various challenges that tackle their children. Parents themselves are also at higher risk of mental health changes. The SEEN report has highlighted that there is a need to understand the needs of parents to support them in a better way.[34] It showed that mothers of children with epilepsy had outweighed the fathers in measurements of sleep, fatigue, and emotional functioning scores.

A study revealed the difficulties faced in accessing knowledge about epilepsy among parents. They wanted to be informed about the developmental and behavioral challenges associated with epilepsy. These findings showed a need for a family-based approach to care for children with epilepsy and consider the family as a whole.[34]

6. Conclusion

Childhood epilepsy has a profound and far-reaching impact on the parents and family of a child with epilepsy. In this regard, nurses can ensure that children adhere to treatment protocols, without which better clinical outcomes are often unsuccessful and essential if the child is too young. The parents should be aware of the information regarding treatment aspects of the child and the frequency of seizures occurring in children.[45] Initial and sudden episodes of recurring seizures in children often leave parents anxious, apprehensive, panicked, and helpless. Such vulnerable situations can even interfere with their ability to understand and interpret clinical improvement in children. Parents should be encouraged to voice their doubts, concerns, and painful emotions in these challenging times without fear of healthcare providers' rejection.[46] Family-centered care and child care for long-term illness are always preferred to improve the family process.

Parents appreciate clinicians when delivering clinical care in partnership with their parents to their children, which leads to empathy and compassionate care. Parents must be offered peer support and those who are informed about unexpected impairment in their child and about expected function.[47] Parents should accept situations filled with emotions such as grief, anger, and fear of outcome in a child's future life. They must assist them in choosing treatment options to provide quality of life to children is equally important as strengthening their support system. In this concern, the team effort will significantly benefit the child care and clinical outcome. The active participation of both parents in the consultations or of the entire family in the custody of the children would allow them to overcome the challenges and requirements efficiently.

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8. Conflict of Interest

None.

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