Neurological Disorders & Epilepsy Journal

Special Issue Article "Epilepsy"

Review Article

Social, Ethical and Economic Challenges in Managing Pediatric Epilepsy in Developing Countries

Rahul Sinha[1], Priyanka Madaan[2] and Sheffali Gulati[3]*

[1]Department of Pediatrics & Pediatric Neurology, Command Hospital, Chandigarh, India

[2]Department of Pediatrics, Post graduate Institute of Medical Education and Research (PGIMER), India

[3]Child Neurology Division, Department of Pediatrics, All India Institute of Medical Sciences, India

ARTICLE INFO

Received Date: January 15, 2022
Accepted Date: February 15, 2022
Published Date: February 18, 2022

KEYWORDS

Epilepsy
Social
Multidisciplinary
Stigma

Citation for this article: Rahul Sinha, Priyanka Madaan and Sheffali Gulati. Social, Ethical and Economic Challenges in Managing Pediatric Epilepsy in Developing Countries. Neurological Disorders & Epilepsy Journal. 2022; 6(1):141.

Corresponding author:
Sheffali Gulati,
Center of Excellence & Advanced Research on Childhood Neurodevelopmental disorders, Chief, Child Neurology Division, Department of Pediatrics, All India Institute of Medical Sciences, New Delhi, India, Tel: 01126594690;
Email: sheffaligulati@gmail.com

ABSTRACT

Epilepsy is one of the chronic disabling neurological disorder which significantly impact social, cultural, and economic aspects of the family and the society. The important challenges in the management of pediatric epilepsy include delayed diagnosis, costly treatment, weight-based drug dosage, consideration as a social stigma, and a need for regular follow-up visits. Although there has been significant improvement in educational and social parameters in the last decade, the changes in the outlook for epilepsy have been largely inconsequential. The associated comorbidities further worsen treatment needs and quality of life in children with epilepsy. Ethically, we are bound to provide the utmost care to our patients. However, many road blocks such as costs related to investigations and treatment, treatment lag, and procurement issues with drugs, etc. need to be tackled for effective epilepsy care in children. The diagnostic and treatment lag in some of the pediatric epilepsy syndromes such as West syndrome is still rampant which has a poor prognostic outcome. An integrated approach focused on capacity building, training of primary healthcare providers, mobilizing public support, and creating awareness, is needed for effective management of this disabling disorder. This article will try to focus on these aspects which are of paramount importance in bridging the gap between aspirations and reality.

INTRODUCTION

The important challenges in pediatric epilepsy management include acute seizure management, chronicity requiring frequent follow-up, pharmaco-resistance, ensuring compliance to therapy, associated comorbidities, and associated social stigma. Besides these, the treatment expense is an important factor in developing countries. Despite the gradual improvement in educational and social parameters in many low-middle income countries, bringing a significant change in the perception of disease and stigma attached to it is a long haul. The associated comorbidities and intractability (in many cases) further worsen treatment needs and quality of life. In fact, in a developing country, a multidisciplinary approach to address the social and economic impact of epilepsy is the need of the hour for better care and rehabilitation. To develop an integrated approach in a public health model, the focus needs to rely on capacity building, service delivery, integration into the existing program, public awareness, and mobilization of public support. The challenges faced in managing pediatric epilepsy in a developing country are manifold and these are further amplified by ignorance, poor educational status, poverty, and other hardcore social issues. A pilot study at our centre also identified knowledge gaps about the core issues of epilepsy management mostly related to social, ethical, and economical aspects. Child neurologists in developing countries often face daunting tasks of managing many such social and economic aspects directly or indirectly.

THE KEY ISSUES

Education

Infantile-onset epilepsies have a huge impact on growth and developmental milestones, more so in resource-limited settings leading to difficulties in going to school, behavioural problems, inattention, and poor academic performance [1-3]. These further add to a growing need for special schools, school drop-outs, and discrimination in school environments. Pediatric epilepsy is associated with various comorbidities and neurodevelopmental disorders which further escalate the cost and stigmatization leading to poor quality of life in the patient and the caregivers. Besides, their tender age also prevents them to understand and speak for their needs. It has been observed that the educational outcomes are often poor because of uncontrolled epilepsy in both urban and rural patients [4-6]. The poor academic achievements and school dropouts may be due to a lack of awareness about epilepsy amongst teachers and peer groups.

Cultural stigma

Pediatric epilepsy is marred with substantial discrimination and social stigma, especially in developing countries like India. The common belief that epilepsy is due to possession by unnatural spirits or sins of the past life leads to neglect and lack of timely treatment. Such beliefs (common in developing countries) escalate the lead-time-to-treatment which is an important determinant of therapeutic response in some childhood epilepsies like West syndrome [7,8]. The word epilepsy originated from the Greek word which means “to take court, to grab, or to seize” [9]. This led to misinterpretation of epilepsy in an entirely different domain and has further jolted the management strategies. Besides, it is very difficult to change the mindset of the people which further adds to the misery associated with this chronic condition. Many times, in genetic epilepsies, it becomes difficult to explain the uneducated family members regarding the occurrence of genetic disorders in an otherwise healthy family, there by leading to a blame-game regarding the culprit (father or mother) [10]. This further becomes one of the reasons for marital discord and separation. Such issues need to be dealt with empathetic counseling.

Gaps in epilepsy treatment

It is defined as the number of persons with active epilepsy not on treatment or on inadequate treatment, expressed as a percentage of the total number of persons with active epilepsy [11]. It is indicative of epilepsy care quality and access to treatment, thus an increase in the treatment gap would lead to increased disease burden and inadequate care. Strict adherence to antiseizure drugs (ASD) is very important in preventing or minimizing seizures and their total impact on everyday life. Lack of compliance to ASD can result in breakthrough seizures many months or years after a previous episode and can have serious repercussions on an individual’s perceived quality of life and this may generate confusion between the family and the previous treating physician. In children with presumed genetic epilepsy, the cost of exome sequencing is often unbearable for poor families. It is generally seen that more than two-thirds of epilepsy patients on regular treatment achieve long-term remission within 2-5 years of diagnosis. However, the treatment gap in low-middle-income countries is huge and adds to long-term morbidity [12-14]. The treatment gap is mostly related to low literacy rates, poorly skilled manpower, and lack of adequate healthcare facilities.

Financial burden

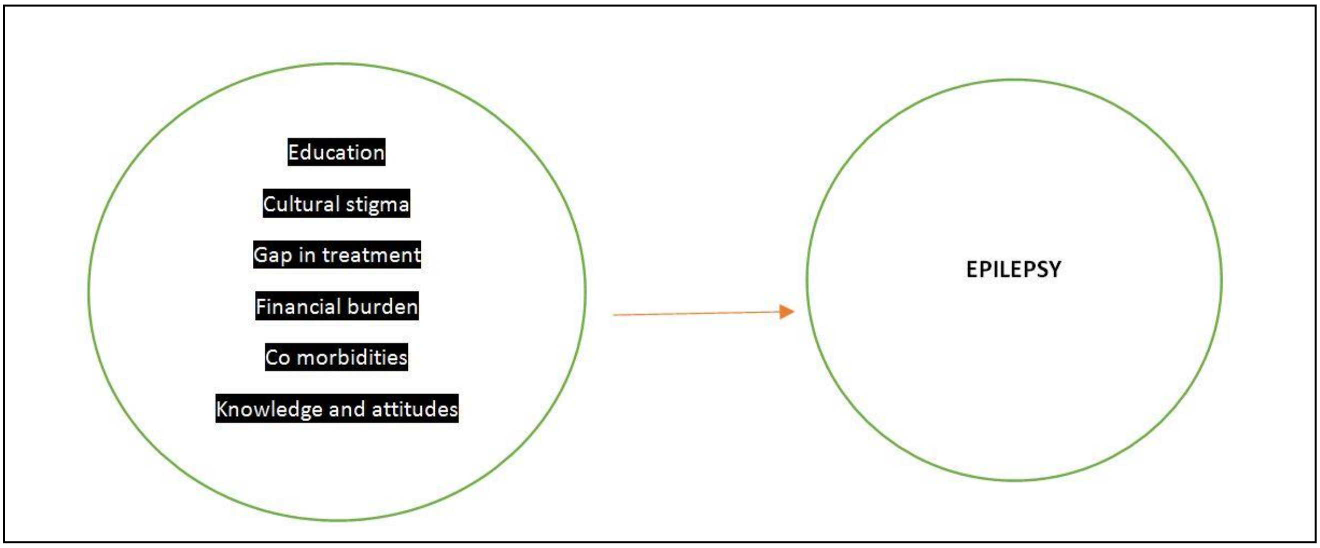
The treatment cost for epilepsy and associated comorbidities leads to a significant financial burden on patients and their families. People from poor backgrounds are worse affected due to their limited paying capacity. The other additional cost involves travel-related costs for periodic review and purchase of medicines. The true financial implications of epilepsy have not been well-studied in low-middle income countries except in few studies [15]. The various types of economic implications involved in epilepsy care can be divided into direct, indirect, and intangible costs [16-18].The direct cost includes the amount related to prevention, diagnosis, treatment rehabilitation, travel, housekeeping, outpatient treatment, investigation charges, radiological investigations, and cost of ASD. The loss of daily income, productivity, and time incurred by the individual and their family adds to the indirect cost. The intangible costs are difficult to measure and include psychosocial pain, stigma, and suffering. Hence, considering the intangible costs, the economic burden due to epilepsy is much more than the available evidence [17].

Comorbidities

The associated comorbidities of epilepsy in children are mostly behavioural and psychiatric problems. The important ones being impulsivity, hyperactivity, inattention, autistic features, headache, affective disorder, and sleep disturbances [19]. These comorbidities further add to the financial burden and poor compliance.

Knowledge and attitudes

The major influence on recovery and quality of life in children with epilepsy depends on knowledge, attitudes, and practices. The improper prescription of ASDs, inadequate ancillary testing facility, and a relative scarcity of pediatric epilepsy surgery services are the common factors leading to apparent refractoriness of pediatric epilepsy, especially in developing countries like India [20,21]. The abrupt discontinuation of epilepsy treatment because of poor awareness further aggravates the situation. The belief of people that epilepsy is a form of insanity and evil spirit further leads to ineffective treatment and poor compliance.



Quality of life (QOL)

The high impact of the stigma associated with epilepsy has led to significant obstacles for effective epilepsy care. The chronicity of the problem further jeopardizes timely access to healthcare and adherence to treatment. The varied responses of caregivers towards children with epilepsy include anxiety, depression, sadness, and guilt resulting in major psychosocial issues like social withdrawal, isolation, lower self-esteem, and even occasional instances of suicide [22]. The long-term use of ASD can affect behaviour and cognition leading to adverse impact on the quality of life.

Multidisciplinary integrated approaches for Epilepsy care,rehabilitation, and prevention

Epilepsy care: The timely and appropriate diagnosis of epilepsy and epilepsy syndrome should remain the prime focus for effective epilepsy care. Also, the uninterrupted drug supply will ensure a better compliance. At the national level, we need to develop a national epilepsy control program to close the wide treatment gap. Implementation of the public health approach model needs to be done by utilizing existing healthcare facilities and training paramedical staff and primary health care doctors for effective epilepsy care [23,24]. The various approaches for effective epilepsy treatment depend on the availability of the resources, training of manpower, integration of epilepsy care in primary healthcare, mobile clinic approach, organizing medical camps, and training of general practitioners in epilepsy care.

Need for rehabilitation: A holistic approach with the involvement of child psychologists, paramedical staff including nursing, primary care physician, and pediatric neurologist trained in epilepsy care is urgently required. Awareness about epilepsy should spread through media, audio-visual communication channels, street play models, mobile apps especially in schools, workplaces settings, and the community. An awareness programme about epilepsy control should also be formulated. Due to a high disease burden, there should be involvement of non-governmental organizations to facilitate the inclusion of epilepsy patients into the mainstream society.

Focus on prevention: A vast majority of epilepsy cases in developing countries occur due to perinatal asphyxia and early neonatal infections which can be prevented through proper obstetric care, neonatal care, immunization, health hygiene, vector control, and improved food hygiene. Also, new government programs related to maternal and child health, prevention of childhood infectious diseases and injuries can significantly contribute to a reduction in epilepsy incidence. An integrated approach should be formalized for better epilepsy care especially in developing countries.

CONCLUSION

Most of the global burden of pediatric epilepsy is borne by developing countries that are poorly equipped to tackle the enormous medical, social, and economic challenges posed by this chronic disabling condition. The widespread poverty, illiteracy, and inefficient and unevenly distributed healthcare systems that are prevalent in developing countries have hindered the implementation of epilepsy care programs. A holistic approach needs to be followed for the effective management of epilepsy in developing nations.

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