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Mini-review

Childhood Epilepsy: Obstacles in Diagnosis, Treatment, and Social perception

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Abstract

Childhood epilepsy is among the most prevalent chronic neurological conditions, affecting an estimated 0.5–1% of children. This review aims to examine the key challenges surrounding childhood epilepsy, focusing on diagnostic difficulties, treatment barriers, social stigma, and public health policies.Although medical care has advanced in recent years, a shortage of specialized equipment and trained professionals still delays accurate and timely diagnosis. Deep-rooted cultural misconceptions about epilepsy also foster social isolation and discourage families from seeking professional help. Overcoming these obstacles will require integrated measures in healthcare development, community awareness, and state-supported programs to enhance treatment accessibility and reduce discrimination.

Keywords: epilepsy, children, diagnosis, treatment, antiepileptic drugs.

1. Introduction

According to the World Health Organization (WHO), epilepsy accounts for approximately 1% of the global burden of disease and ranks fourth among neuropsychiatric disorders following depression, alcoholism, and cerebrovascular diseases. In terms of its impact on public health, epilepsy is comparable to major malignancies such as breast and lung cancer [1]. Worldwide, more than 70 million people suffer from epilepsy [2]. The condition is characterized by a chronic predisposition to spontaneous epileptic seizures and is associated with a wide range of neurobiological, cognitive, and psychosocial impairments [2,3].

Epilepsy is one of the most common neurological disorders, affecting people of all ages, races, social classes, and geographical regions. It is a brain disorder characterized by a persistent predisposition to seizures, along with the neurobiological, cognitive, psychological, and social consequences of recurrent seizures [5].

The aim of this article is to analyze the current challenges in the diagnosis, treatment, and social perception of childhood epilepsy in the Republic of Kazakhstan, identifying key barriers to effective care and proposing strategies to improve medical management and reduce stigma.

2. Methodology

A literature search was conducted in scientific databases such as PubMed, Web of Science, Cochrane, and Wiley using the keywords: "epilepsy," "children," "diagnosis," "treatment," and "antiepileptic drugs." A total of 52 articles published between 2005 and 2025 were analyzed.

According to modern concepts of epilepsy pathogenesis, seizure types, and their underlying causes, the International League Against Epilepsy (ILAE) has revised its classification system. The most recent update of seizure and epilepsy classification (2017–2022) provides a more precise and clinically relevant framework aimed at improving diagnosis, predicting outcomes, and guiding treatment strategies [6]. Following years of collaborative research, the ILAE released a comprehensive set of documents in 2022 that define and categorize epileptic syndromes in greater detail. An epileptic syndrome is described by the ILAE as *"a characteristic cluster of clinical and electroencephalographic features, often associated with specific etiological factors such as structural, genetic, metabolic, immune, or infectious causes"*.

These revisions emphasize the importance of integrating clinical presentation with electroencephalographic findings and etiology to ensure more accurate classification. The new system allows physicians to tailor therapeutic approaches based on syndrome-specific features, which is particularly valuable in pediatric practice. It also facilitates more consistent communication among healthcare professionals, researchers, and policymakers worldwide. By providing standardized terminology, the classification supports the development of international treatment guidelines and research collaborations. Ultimately, this evidence-based framework is expected to improve patient outcomes by enabling earlier diagnosis and more targeted interventions.

3. Results and Discussion

In Kazakhstan, the number of physicians engaged in research on childhood epilepsy remains very limited. As a result, scientific publications on this subject are rare in both national and international medical journals. A major obstacle is the lack of reliable epidemiological data, as many patients avoid seeking medical assistance due to fear of social discrimination. The persistent stigma surrounding epilepsy discourages clinical registration, which ultimately deprives individuals of timely diagnosis and appropriate treatment. One notable investigation in the country examined the epidemiology of epilepsy by analyzing data from a large administrative healthcare database spanning 2014–2020. Using the Unified National Electronic Health System of Kazakhstan, researchers evaluated incidence and prevalence rates, disability-adjusted life years (DALYs), and all-cause mortality associated with epilepsy [7].

This study provided one of the first comprehensive assessments of the national epilepsy burden, highlighting significant regional disparities in disease prevalence. The findings underscored the need for improved surveillance systems to capture accurate and up-to-date statistics. Researchers also emphasized the importance of public health initiatives aimed at reducing stigma and encouraging families to seek professional care. Expanding training programs for neurologists and pediatric specialists was identified as a key strategy to enhance early detection and management. Furthermore, the data collected serve as a valuable foundation for shaping evidence-based health policies and guiding future research efforts within Kazakhstan.

The study revealed a range of sociodemographic, mental, behavioral, and neurological factors that significantly influenced the survival rates of individuals with epilepsy. The initial cohort comprised 82,907 participants. Over the observation period, the incidence of epilepsy rose markedly—from 26.15 to 88.80 cases per 100,000 population—while prevalence rates demonstrated a similar pattern, nearly tripling from 26.06 in 2014 to 73.10 in 2020. Although annual mortality rates fluctuated, the highest death rates were consistently observed among elderly patients (9.97) and children (2.98 per 1,000 person-years). Calculations of disability-adjusted life years (DALYs) highlighted the heavy disease burden, with a total of 153,532 DALYs recorded, equivalent to 824.5 per 100,000 population. Some participants were lost to follow-up at various stages, which may have influenced the accuracy of long-term survival estimates.

Comorbidities such as cerebral palsy (adjusted hazard ratio [aHR] 2.23) and central nervous system atrophy (aHR 27.79) were strongly associated with increased all-cause mortality. Elevated mortality risk was also observed in patients with extrapyramidal and movement disorders (aHR 2.16, p=0.06) and demyelinating diseases of the central nervous system (aHR 6.36, p = 0.06). These findings underscore the need for early detection and aggressive management of comorbid conditions in order to improve patient outcomes. The dramatic rise in incidence and prevalence rates over the study period may reflect both improved diagnostic capacity and a genuine increase in disease occurrence. Strengthening community awareness and access to specialized neurological care could help reduce mortality, particularly in vulnerable groups such as children and the elderly. Moreover, the results highlight the importance of integrating routine screening for neurological comorbidities into national epilepsy management protocols. Finally, targeted research on the mechanisms linking epilepsy with other neurological disorders may provide valuable insights for preventive strategies and treatment optimization.

One of the major problems in Kazakhstan is the lack of epilepsy centers in major cities. Currently, the only epilepsy center in the country is located in Astana, within the Hospital of the Medical Center of the Presidential Affairs Administration, which has been operating since 2018. Epileptologists at this center specialize in presurgical evaluation of epilepsy in both adults and children.

Kazakhstan faces a critical shortage of specialists in the field of epileptology. Many physicians avoid this area of practice, perceiving it as overly complex and showing limited interest in treating patients with epilepsy. The number of trained neurologist-epileptologists who provide academic instruction in medical universities is also very small. Yet, the role of an epileptologist demands an extensive skill set, including expertise in EEG acquisition and interpretation, MRI evaluation, familiarity with epilepsy treatment protocols, accurate prescription of antiepileptic medications, and the ability to promptly identify and diagnose diverse forms of epilepsy.

A second major concern is the presence of seizure episodes that outwardly resemble epilepsy but actually stem from other medical conditions. This represents a worldwide diagnostic difficulty, with reported misdiagnosis rates reaching 40–70% even in leading epilepsy centers. Seizure-like manifestations may be linked to diverse underlying causes, including cardiac arrhythmias, cerebrovascular abnormalities, and endocrine disorders involving the adrenal glands, gonads, pituitary, or thyroid. Among young people, excessive intake of energy drinks has also been identified as a potential trigger for such events, adding another layer of complexity to accurate diagnosis.

These non-epileptic seizures often require different management strategies, making proper identification crucial to avoid unnecessary use of antiepileptic drugs. Detailed patient history, continuous EEG monitoring, and comprehensive cardiovascular and endocrine evaluations are essential to distinguish these episodes from true epilepsy. Failure to recognize the underlying condition can delay appropriate treatment and increase the risk of serious complications. Public education campaigns are needed to raise awareness of these alternative causes among both healthcare providers and the general population. Ultimately, improving diagnostic accuracy through multidisciplinary collaboration can help ensure that patients receive targeted, effective care rather than prolonged or inappropriate therapy.

The third critical challenge concerns the restricted availability of antiepileptic drugs (AEDs). Although around 35 different AEDs are used in clinical practice worldwide, only 11 are officially registered in Kazakhstan.

While this range is generally adequate for treating the most common types of epilepsy, the absence of certain medications for rare or drug-resistant forms can result in worsening patient outcomes.

Despite this limitation, it is noteworthy that all anticonvulsant medications included in the national formulary are provided to patients free of charge. The government ensures the supply of AEDs, but the restricted list often fails to address the needs of individuals with pharmacoresistant epilepsy. Modern, personalized treatment protocols remain uncommon, particularly in rural and regional healthcare settings, and surgical interventions are available only in a few highly specialized centers.

This shortage of advanced therapies underscores the necessity of expanding the national registry of approved medications and improving access to innovative treatments. Strengthening the distribution system could help reduce disparities between urban and rural populations. In addition, increased investment in specialized epilepsy surgery programs would offer hope for patients whose seizures cannot be controlled by medication alone.

At present, one of the major problems in Kazakhstan remains the late diagnosis of epilepsy, particularly in rural regions.

This is due to insufficient public awareness, limited access to qualified neurological care, and a shortage of modern diagnostic tools such as video-EEG monitoring and high-resolution magnetic resonance imaging (MRI) [8].

In addition, overdiagnosis and misinterpretation of clinical manifestations are frequently observed, especially in children. This can lead to the unnecessary prescription of antiepileptic drugs or, conversely, to an underestimation of the severity of the condition [9].

Social stigma often causes many patients to hide their diagnosis, avoid seeking medical help, or discontinue medication out of fear of public disclosure. This significantly worsens the prognosis and reduces quality of life [10]. There is also a lack of data on genetic epilepsy in Kazakhstan, despite its unique clinical course and management implications [11].

Issues related to the individualization of therapy also remain unresolved. Physicians often have to prescribe treatment “blindly” due to the unavailability of genetic and metabolic testing, which could help in selecting the most effective therapy for pharmacoresistant forms of epilepsy.

A number of international guidelines and evidence-based publications provide a strong framework for improving the diagnosis and treatment of childhood epilepsy and can serve as a reference for health policy development in Kazakhstan.

The **International League Against Epilepsy (ILAE)** released an updated classification and definition of childhood-onset epilepsy syndromes in 2022. This document details self-limited focal epilepsies, generalized epilepsies, and developmental and/or epileptic encephalopathies, offering essential guidance for standardized terminology, diagnostic criteria, prognostic assessment, and therapeutic planning [12].

The **National Institute for Health and Care Excellence (NICE)** published the clinical guideline *Epilepsies in children, young people and adults* (NG217) in 2025. This guideline provides comprehensive recommendations on diagnostic pathways, pharmacological management, and referral criteria for specialized epilepsy centers across different levels of care [13].

ILAE has also issued a consensus statement on the **diagnosis and management of anxiety and depression** in children and adolescents with epilepsy. The document highlights the need for routine mental health screening and early intervention, given the strong association between psychiatric comorbidities and poor quality of life in pediatric epilepsy (ILAE Pediatric Psychiatric Task Force, 2022).

For the neonatal population, the guideline *Treatment of Seizures in the Neonate: Guidelines and Consensus-Based Recommendations* provides detailed recommendations on first- and second-line pharmacological treatment, optimal duration of therapy, and criteria for discontinuation of antiepileptic drugs [14].

Earlier but still highly relevant is the clinical practice guideline *Diagnosis and Management of Childhood Epilepsy* (Wheless et al., 2007), which systematically reviews diagnostic principles, treatment strategies for common and refractory epilepsies, and management of status epilepticus [15].

Additional literature includes the updated review on **classifying childhood-onset epilepsy syndromes**, which integrates recent ILAE terminology and provides practical insights into syndrome identification and treatment selection [16]. Another comprehensive review, *Diagnostic approach of epilepsy in childhood and adolescence*, outlines modern diagnostic tools, including neuroimaging and genetic testing, to improve accuracy in pediatric epilepsy diagnosis [17].

Collectively, these international guidelines and publications establish a robust evidence base that can be adapted to Kazakhstan’s healthcare system to enhance early diagnosis, optimize therapy, and improve long-term outcomes for children living with epilepsy.

4. Conclusions

Therefore, overcoming the current challenges calls for a broad, multi-level strategy. Key priorities include enhancing the training of primary care physicians and neurologists, establishing specialized centers for accurate diagnosis and advanced treatment, expanding the list of government-funded antiepileptic drugs to include newer generations of medications, launching nationwide public education campaigns, and creating programs that support social adaptation and patient assistance. Only through such coordinated actions can the quality of life of people with epilepsy be improved and the societal burden of the disease in the Republic of Kazakhstan effectively reduced.

In addition, greater investment in research will help identify local epidemiological trends and guide evidence-based policy decisions. Collaboration with international epilepsy associations could accelerate the adoption of best practices and innovative therapies. Digital health tools, such as telemedicine and electronic monitoring systems, should be integrated to improve access to care in remote regions. Finally, involving patient advocacy groups in decision-making processes will ensure that reforms reflect the real needs and experiences of those living with epilepsy.

Conflict of Interest. The authors declare no conflict of interest.

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References

1. Ali A. (2018). Global Health: Epilepsy. Seminars in neurology, 38(2), 191–199. https://doi.org/10.1055/s-0038-1646947
2. Epilepsy. World Health Organization, 2024. Website. [Cited 23 May 2025]. Available from URL: https://www.who.int/news-room/fact-sheets/detail/epilepsy
3. Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J. H., Elger, C. E., Engel, J., Jr, Forsgren, L., French, J. A., Glynn, M., Hesdorffer, D. C., Lee, B. I., Mathern, G. W., Moshé, S. L., Perucca, E., Scheffer, I. E., Tomson, T., Watanabe, M., & Wiebe, S. (2014). ILAE official report: a practical clinical definition of epilepsy. Epilepsia, 55(4), 475–482. https://doi.org/10.1111/epi.12550
4. Thijs, R. D., Surges, R., O'Brien, T. J., & Sander, J. W. (2019). Epilepsy in adults. Lancet (London, England), 393(10172), 689–701. https://doi.org/10.1016/S0140-6736(18)32596-0
5. Fisher, R. S., van Emde Boas, W., Blume, W., Elger, C., Genton, P., Lee, P., & Engel, J., Jr (2005). Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). Epilepsia, 46(4), 470–472. https://doi.org/10.1111/j.0013-9580.2005.66104.x
6. Beniczky, S., Trinka, E., Wirrell, E., Specchio, N., Cendes, F., & Helen Cross, J. (2025). Updating the ILAE seizure classification. Epilepsia, 66(6), 1824–1826. https://doi.org/10.1111/epi.18399
7. Akhmedullin, R., Kozhobekova, B., Gusmanov, A., Aimyshev, T., Utebekov, Z., Kyrgyzbay, G., Shpekov, A., & Gaipov, A. (2024). Epilepsy trends in Kazakhstan: A retrospective longitudinal study using data from unified national electronic health system 2014-2020. Seizure, 122, 58–63. https://doi.org/10.1016/j.seizure.2024.09.022
8. Bilalova, Z. A., Kulmirzaeva, D. M., Telmanova, Z. B., Kozhakhmetova, Z. Z., Orozbaev, S. T., & Igisinov, N. S. (2021). Tendency of incidence with epilepsy in Kazakhstan. Redakcionnaja kollegija, 1(5-6). https://elibrary.ru/download/elibrary_48417101_60252511.pdf
9. Kalinina, D., Aimyshev, T., Muxunov, A., Utebekov, Z., Kyrgyzbay, G., Kimadiyev, D., ... & Sarria-Santamera, A. (2025). Prescription Patterns of Antiepileptic Drugs and Co-prescribed Medications in Patients with Epilepsy in Kazakhstan (2021-2023). https://doi.org/10.20944/preprints202509.2587.v1
10. Tashkenbayeva L.R. Social stigma in epilepsy: the perspective of Kazakhstani society. Sociology and Health. 2019;(4):15–20.
11. Bayanova, M., Bolatov, A. K., Bazenova, A., Nazarova, L., Nauryzbayeva, A., Tanko, N. M., Rakhimova, S., Satvaldina, N., Samatkyzy, D., Kozhamkulov, U., Kairov, U., Akilzhanova, A., & Sarbassov, D. (2023). Whole-Genome Sequencing Among Kazakhstani Children with Early-Onset Epilepsy Revealed New Gene Variants and Phenotypic Variability. Molecular neurobiology, 60(8), 4324–4335. https://doi.org/10.1007/s12035-023-03346-3
12. Specchio, N., Wirrell, E. C., Scheffer, I. E., Nabbout, R., Riney, K., Samia, P., Guerreiro, M., Gwer, S., Zuberi, S. M., Wilmshurst, J. M., Yozawitz, E., Pressler, R., Hirsch, E., Wiebe, S., Cross, H. J., Perucca, E., Moshé, S. L., Tinuper, P., & Auvin, S. (2022). International League Against Epilepsy classification and definition of epilepsy syndromes with onset in childhood: Position paper by the ILAE Task Force on Nosology and Definitions. *Epilepsia*, *63*(6), 1398-1442. https://doi.org/10.1111/epi.17241
13. Epilepsies in children, young people and adults, NICE guideline, Reference number: NG217, Published: 27 April 2022, Last updated: 30 January 2025. [Cited 23 May 2025]. Available from URL: https://www.nice.org.uk/guidance/ng217
14. Glass, H. C., & Shellhaas, R. A. (2022). Safety of Early Discontinuation of Antiseizure Medication After Acute Symptomatic Neonatal Seizures—Reply. JAMA neurology, 79(1), 91-92. https://doi.org/10.1001/jamaneurol.2021.4112
15. Naik, N. Expert committee on pediatric Epilepsy, Indian academy of pediatrics. Guidelines for Feb, 4(291), 5.

16. Specchio, N., Wirrell, E. C., Scheffer, I. E., Nabbout, R., Riney, K., Samia, P., ... & Auvin, S. (2022). International League Against Epilepsy classification and definition of epilepsy syndromes with onset in childhood: Position paper by the ILAE Task Force on Nosology and Definitions. Epilepsia, 63(6), 1398-1442. https://doi.org/10.1111/epi.17241

17. Iliescu, C., & Craiu, D. (2013). Diagnostic approach of epilepsy in childhood and adolescence. Maedica, 8(2), 195.

Балалар эпилепсиясы: Диагностикалау, емдеу және қоғамдағы қабылдау қиындықтары

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Түйіндеме

Балалар эпилепсиясы – ең кең таралған созылмалы неврологиялық аурулардың бірі, ол балалардың шамамен 0,5–1%-ын қамтиды. Осы шолудың мақсаты: балалар эпилепсиясына қатысты негізгі мәселелерді, соның ішінде диагноз қоюдағы қиындықтарды, емдеудегі кедергілерді, әлеуметтік стигманы және денсаулық сақтау саясатына қатысты аспектілерді талдау. Соңғы жылдардағы медициналық көмектің дамуына қарамастан, арнайы жабдықтар мен білікті мамандардың жетіспеушілігі дер кезінде әрі дәл диагноз қоюды әлі де баяулатады. Эпилепсия туралы терең тамыр жайған мәдени қате түсініктер әлеуметтік оқшаулануға және отбасылардың кәсіби көмекке жүгінуін тежейді. Бұл кедергілерді еңсеру үшін денсаулық сақтау инфрақұрылымын дамыту, халықты ақпараттандыру және мемлекеттік бағдарламаларды іске асыру бағытында кешенді шаралар қажет.

Түйін сөздер: эпилепсия, балалар, диагностика, емдеу, антиэпилептикалық препараттар.

Эпилепсия у детей: Трудности диагностики, лечения и общественного восприятия

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Резюме

Детская эпилепсия относится к числу наиболее распространённых хронических неврологических заболеваний, затрагивая примерно 0,5–1% детского населения. Цель данного обзора: рассмотреть ключевые проблемы, связанные с детской эпилепсией, включая трудности диагностики, барьеры в лечении, социальную стигматизацию и вопросы государственной политики здравоохранения. Несмотря на прогресс в развитии медицинской помощи, дефицит специализированного оборудования и подготовленных специалистов по-прежнему приводит к задержкам в своевременной и точной диагностике. Укоренившиеся культурные заблуждения об эпилепсии способствуют социальной изоляции и препятствуют обращению семей за профессиональной помощью. Преодоление этих барьеров требует комплексных мер в развитии системы здравоохранения, просвещении населения и реализации государственных программ для улучшения доступности лечения и снижения дискриминации.

Ключевые слова: эпилепсия, дети, диагностика, лечение, антиэпилептические препараты.