

<https://doi.org/10.53498/vqcznp83>
UDC 616.853-082; 76.75.29
IRSTI 616.853; 76.29.51

Review article

Features of the organization of medical care for people suffering from epilepsy

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Abstract

Epilepsy is a chronic non-communicable brain disease that affects people at any age. Epilepsy is one of the most common neurological diseases in the world; it affects about 50 million people. Almost 80% of epilepsy sufferers live in low- and middle-income countries. It is estimated that up to 70% of people with epilepsy can live without seizures, provided proper diagnosis and treatment are provided. The risk of premature death in patients with epilepsy is almost three times higher than the population average. Three quarters of people with epilepsy in low-income countries do not receive the treatment they need.

The purpose of this review article is to study research in the international scientific community on the specifics of organizing medical care for people with epilepsy, as well as to identify factors affecting the quality of medical services and the availability of medicines for people with epilepsy.

Methods: An information search was conducted for scientific articles in the databases PubMed, Web of Science, Cochrane, Wiley, Cyberleninka, using the keywords "epilepsy", "medical assistance to people suffering from epilepsy", "antiepileptic drugs", "epileptic seizure". 68 articles published between 2005 and 2025 were analyzed.

The study concluded that in order to promote the prevention and control of epilepsy, we need coordinated action at the national level to strengthen effective leadership and management. These actions should take into account the special needs of people with epilepsy; implement and implement national health plans for epilepsy; integrate epilepsy management into healthcare and social care, including access to safe, effective, and high-quality antiepileptic drugs.

Key words: epilepsy, medical care for people suffering from epilepsy, antiepileptic drugs, epileptic seizure.

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2025; 1-78: 38-45
Received: 29-02-2025
Accepted: 12-03-2025



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Introduction

Epilepsy is one of the most common neurological diseases and affects people of all ages, races, social classes and geographical locations. Epilepsy is a brain disease characterized by a persistent predisposition to seizures and the neurobiological, cognitive, psychological, and social consequences of recurrent seizures [1].

Epileptic seizures are recurring paroxysmal events characterized by stereotypical behavioral changes that reflect the underlying neural mechanisms of the disease. The differential diagnosis of epilepsy covers a number of clinical conditions characterized by a transient change in consciousness and/or behavior.

In most cases, the disease can be diagnosed with a thorough medical history or by observing a seizure. Although the etiological agent can be identified, in about half of the cases the cause remains unknown [2]. The variable genetic predisposition to seizures and the different distribution of some environmental risk factors may explain the heterogeneity of the frequency, course and consequences of the disease in the world. In addition to the recurrence of seizures, the main cause and side effects of

treatment have neurological, cognitive, psychological and social consequences that significantly affect the quality of life of patients and make the disease a complex nosographic unit.

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Methods

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Epilepsy is one of the most common diseases of the nervous system. Like all chronic diseases, it affects lifestyle and requires long-term monitoring of patients [3]. The duration of follow-up for epilepsy is measured in years due to the fact that even with successful treatment and remission, the duration of taking antiepileptic drugs (AEDs) averages 3-5 years [4]. In addition, as with any chronic disease, it is difficult to talk about a cure for epilepsy, since even if there are no more seizures, it is impossible to rule out their occurrence with certainty in the future.

In this regard, the International Antiepileptic League (International League Against Epilepsy, ILAE) introduced criteria for the resolution of epilepsy, which include reaching a certain age in patients with age-dependent epileptic syndromes or the absence of seizures for 10 years (five of them after the gradual abolition of AED). Despite this, epilepsy is currently one of the most serious chronic diseases. About 60% of patients with newly diagnosed epilepsy achieve long-term remission with proper treatment [5]. In the remaining 30-40%, remission does not occur even against the background of adequately selected therapy, however, the frequency of seizures may decrease significantly. And only about 10% of patients are "absolutely incurable," in these cases, patient management can last for decades or even for life.

An unprovoked attack is an attack that occurs in the absence of provoking factors. Unprovoked seizures include events that occur in the absence of recognized etiological or risk factors (idiopathic and cryptogenic seizures), in patients with previous stable (non-progressive) CNS strokes (distant symptomatic seizures), or in patients with progressive CNS abnormalities such as brain tumors or degenerative conditions (progressive symptomatic seizures).

The onset of an attack can be focal (seizures occur in one hemisphere of the brain), generalized (seizures occur in both hemispheres simultaneously), and unknown [6]. Focal

seizures are classified according to whether awareness (a marker of consciousness) is preserved or impaired. Focal and generalized seizures are also divided into motor and non-motor seizures.

Active epilepsy is determined with regular treatment with antiepileptic drugs or when the last attack occurred within the last 5 years [7].

An epileptic status (ES) is an epileptic seizure that lasts long enough or repeats at short enough intervals to cause a stable epileptic state. ES can have long-term consequences, including damage to neurons or death and changes in neural networks, depending on the type and duration of seizures. A new diagnostic classification of ES has recently been proposed [8].

Sudden unexpected death in epilepsy (SUDEP) is a sudden, unexpected, non-traumatic death in patients with epilepsy, with or without signs of a seizure, in which a postmortem examination does not reveal a toxicological or anatomical cause of death [9, 10]. In most cases, sudden death is caused by a seizure, and seizure-induced cardiorespiratory changes are a plausible hypothesis.

Indicators of epilepsy frequency include morbidity, prevalence, and mortality; indicators of epilepsy burden are disability—adjusted life years (DALY) and their components, life years lost, and years of life with disability.

Epilepsy is the cause of the loss of more than 13 million years of healthy life lost as a result of premature death, temporary disability and disability (the DALY index is an indicator estimating the total burden of the disease, defined as the number of years of life lost as a result of premature death or disability) and accounts for more than 0.5% of the global burden of disease (GBD). This disease affects people regardless of their age, gender, race, income level and place of residence. During their lifetime, about 7.6 per 1,000 people develop epilepsy. The incidence of epilepsy is characterized by a bimodal distribution on an age scale, with the highest rates in the youngest age group and the group of people over 60 years of age [11]. Epilepsy can be caused by various causes, in particular, such as genetic, metabolic, infectious, structural, immune, or unknown etiological factors.

According to the Global Burden of Disease 2016

[12], epilepsy represents a significant part of the global burden of disease, accounting for about 46 million people. Almost 80% of people with epilepsy live in low- and middle-income countries, where the prevalence and incidence of epilepsy are higher than in high-income countries [13]. The differences are likely due to different causes, higher injury rates, and lack of access to medical care.

In 2016, epilepsy accounted for >13 million DALY and was responsible for 0.5% of the total disease burden [14]. In terms of age-standardized DALY indicators for all neurological disorders in the global burden of disease region, epilepsy ranked second to eighth in 2016, depending on the geographical region. The burden of idiopathic epilepsy (i.e. caused by a genetic cause or when a diagnostic assessment did not identify a causal factor) was highest in eastern, western, and southern sub-Saharan Africa, Central Asia, Central and Andean Latin America, and Southeast Asia.

The incidence of epilepsy in low- and middle-income countries is higher than in high-income countries (139 and 48.9 per 100,000 person-years, respectively). Epilepsy is associated with a significant increased risk of premature death compared to the same indicator in the general population. It is estimated that the premature mortality rate among people with epilepsy living in low- and middle-income countries is significantly higher than in high-income countries. Excess mortality reported in low- and middle-income countries is most likely due to lack of access to medical facilities and insufficient attention to preventable causes of illness and death, such as drowning, head injuries, and parasitic infections. Theoretically, this excessive rate of premature mortality could be reduced by providing health education about the risk factors of death and improving access to treatment, in particular to anticonvulsants. Approximately half of people with epilepsy have concomitant somatic or mental illnesses [15]. The presence of concomitant pathology in people with epilepsy is associated with a deterioration in their health, an increase in the need for medical care, a decrease in the quality of life and an aggravation of social isolation.

The most common concomitant mental illnesses include depression (23%) and anxiety (20%). Intellectual disabilities are most common in children with epilepsy (30-40%). In addition, epilepsy belongs to the group of neurodegenerative diseases.

Epilepsy is treatable. Up to 70% of people with epilepsy can live without seizures if proper diagnosis and treatment are provided with commonly available and cost-effective anticonvulsant medications. Treatment makes it possible for people suffering from epilepsy to continue living a full and fruitful life or return to it. Despite the very low cost of anticonvulsant drugs, more than 75% of people with epilepsy living in low-income countries do not receive treatment. In the absence of treatment, patients with epilepsy face severe social consequences in the form of stigmatization, discrimination, and human rights violations [16,17].

Organization of medical care for people suffering from epilepsy

Comprehensive patient care includes not only medical services at different levels of the healthcare system, but also other services to meet the complex needs of patients and their families, including psychological, social, educational, and professional issues, all of which pose significant challenges to the coordination of care [18].

While general practitioners typically lack the time, knowledge, and resources to ensure multidimensional

coordination of care for patients with rare diseases, nurse coordinators or patient care managers at the primary care level are uniquely positioned to ensure proper care coordination and management of care transitions. The patient-provider relationship of trust between nurses and patients/families supports active communication and enables prioritization and barriers to comprehensive care and self-management, ensuring holistic, proactive management, continuity of care, and improved patient outcomes [19,20].

In Kazakhstan, medical care for patients with neurological diseases is provided within the framework of the GOBMP. Medical care for patients with diseases of the nervous system is provided in the following forms:

- 1) APP, including primary health care (hereinafter referred to as PHC) and consultative and diagnostic care;
- 2) inpatient care;
- 3) inpatient replacement care;
- 4) emergency medical services and medical assistance in the form of air ambulance;
- 5) rehabilitation treatment and medical rehabilitation.

The following types of PHC services are provided:

- 1) preventive, including the formation and promotion of a healthy lifestyle, the provision of recommendations on rational and healthy nutrition and subsequent dynamic monitoring;
- 2) diagnostic, including examination by a PHC specialist, laboratory and instrumental studies;
- 3) therapeutic, including the provision of emergency and emergency medical care, therapeutic manipulations in accordance with health standards, providing certain categories of citizens with certain diseases (conditions) with free or discounted medicines and specialized medical products at the outpatient level;
- 4) according to the examination of temporary disability in accordance with Order №183 for the purpose of official recognition of the disability of an individual and his temporary release from work duties for the period of illness.

When a citizen first applies to a PHC organization, primary medical records are issued at the PHC registry: an outpatient patient's medical record (Form 025/y "Outpatient patient's medical record") or "Child Development History" (Form 112/y), approved by Order №907.

When providing primary health care, prescriptions for medicines are written out by the attending physician on prescription forms (form 130/u "Prescription" and form 132/u "Prescription free or discounted") approved by Order №907, without specifying a specific pharmacy organization in accordance with the Rules for Providing Medicines to Citizens approved by order of the Minister of Health and Social Development Of the Republic of Kazakhstan dated September 30, 2015 №766 (registered in the Register of State Registration of Regulatory Legal Acts for №12199) [21].

The main factors influencing epilepsy therapy can be divided into: related to the patient (type of course of the disease, economic aspect, compliance), with a doctor or medicine (qualifications; therapeutic and diagnostic base; organization of care, including preferential provision; organization of management and supervision of patients) and related to society (attitude towards a person with epilepsy - stigmatization) [22]. The level of organization of care for patients with epilepsy varies greatly in different

countries of the world due to the fact that diagnosis and treatment of this disease are expensive [23]. ILAE recognizes the need to further improve evidence-based, consistent, epilepsy-specific clinical practice guidelines, and the foundations for this exist. But today they are not followed internationally, as the resources of many regions are limited. At the same time, even in European countries (which have a high level of funding and are often a guideline for providing epileptological care) There are no uniform standards for patient management.

In low- and middle-income countries, despite advances in treatment, society's limited knowledge of epilepsy, as well as inherent infrastructural challenges, pose challenges to effective diagnosis and treatment of epilepsy. Although effective antiepileptic drugs are available to treat epilepsy, up to 90% of people living in low- and middle-income countries do not receive modern treatment standards, and those living in rural areas often receive no treatment at all. Thus, studies in low- and middle-income countries report a large gap in epilepsy treatment, defined as those who do not receive treatment or those who receive inadequate treatment for epilepsy. Due to regional differences in the etiology of epilepsy and the populations of interest, as well as differences in survey methods, the reported size of epilepsy treatment for epilepsy varies significantly in sub-Saharan Africa. However, a systematic review by Meyer and colleagues showed high efficacy of epilepsy treatment, exceeding 95% in several countries; among them Uganda, Nigeria, Tanzania and Zambia. The

causes of such pronounced TG are multifactorial, including economic, infrastructural, and social problems associated with seeking biomedical care.

From the point of view of health systems, barriers may include inadequate medical supplies, the cost of ED, a shortage of qualified health workers, and limited access to medical facilities. There is a shortage of specialized neurology services in Africa, while sub-Saharan Africa has the lowest density of neurologists in the world [24].

Sixty-five stakeholders (36 neurologists, 10 nurses, 10 patients, and nine caregivers) participated in the study conducted by Posa and a number of scientists from Spain. Six key steps on the patient's path were identified: emergency care, diagnosis, drug therapy, follow-up, referral, and interventional treatment. Of these, follow-up was the most significant step affecting the provision of high-quality patient care, followed by drug therapy and diagnosis. Emergency care was considered a hotspot stage that had an impact throughout the patient's journey. Communication (between doctors and between doctors and patients) has been an obstacle to providing high-quality care at several stages of the patient's journey, including drug therapy, follow-up, referral, and interventional treatment. The availability of resources was an obstacle for diagnosis (especially for confirmation), drug therapy (availability of drugs), and referral (lack of specialists and specialized centers, as well as long waiting lists).

Patient satisfaction as an indicator of quality assurance of medical care

The quality of medical care is a multifactorial concept that requires an integrated approach to its assessment. It was recognized that the satisfaction of the population with the quality of medical care directly depends on the level of expectations of patients, most of which are subjective.

Improving the quality of medical care and creating quality management systems is one of the priorities for the development of healthcare systems in the world. In this regard, one of the most difficult tasks is the problem of assessing the quality of medical care. A study of international experience in improving the quality of medical care has shown that there is no ready-made scheme that fully satisfies both sides, and all countries have their own approaches to assessing the quality of medical care applied to the healthcare system. According to the definition of the World Health Organization (WHO), the satisfaction of the population with medical services is one of the indicators of their quality [25].

A high level of quality medical care for patients is a comprehensive goal of all healthcare systems around the world. Already in the 1980s, determining the quality of services and products became a key task for service providers. The quality of services has many dimensions, so evaluating it is really difficult. Parasuraman et al. considered it necessary that the most objective quality indicators be introduced into all services provided, including medical services. According to Parasurman et al., it is the client/patient who determines the quality of service, which is a product of their perception and expectations.

According to a number of studies, patients' expectations are one of the dominant factors that significantly affect their satisfaction with medical care. Other data indicate that the quality of the relationship between the patient and the medical staff also has a direct impact on the level of satisfaction [26].

Medical institutions, identifying gaps in the services

provided, subject them to an objective and detailed analysis in order to eventually implement appropriate compensatory/corrective actions. The World Health Organization (WHO) recommends the use of patient satisfaction indicators in treatment programs to guide efforts to improve the quality of care provided. On kavi et al. A significant relationship was shown between patient satisfaction, the therapy process, and maintenance of treatment outcomes.

Almost all over the world, managers of medical institutions are expected to improve the quality of medical services provided to patients by ensuring the highest possible quality of care in the organizations they manage. Nadi et al. noted that the problem of inadequate quality of medical care affected mainly those institutions that were not focused on understanding and meeting the needs and requirements of patients. According to the authors, heads of medical institutions should identify themselves with the priorities of their clients, setting their own policy models based on customer/patient feedback. The lack of direct relationships with clients/patients is a major obstacle to learning and meeting their expectations.

Today, the sociological survey remains an effective tool for everyday use in the study of consumer satisfaction with medical services. A number of authors believe that the data from sociological studies on opinions on satisfaction with the quality of medical services can be used as an indicator of continuous quality improvement [27].

Thus, determining the degree of patient satisfaction with the quality of medical care is a comprehensive measure based on the provisions of relevant regulatory legal acts, various methods of conducting the process of studying and evaluating the results.

Directions for improving the quality of medical care for people with epilepsy

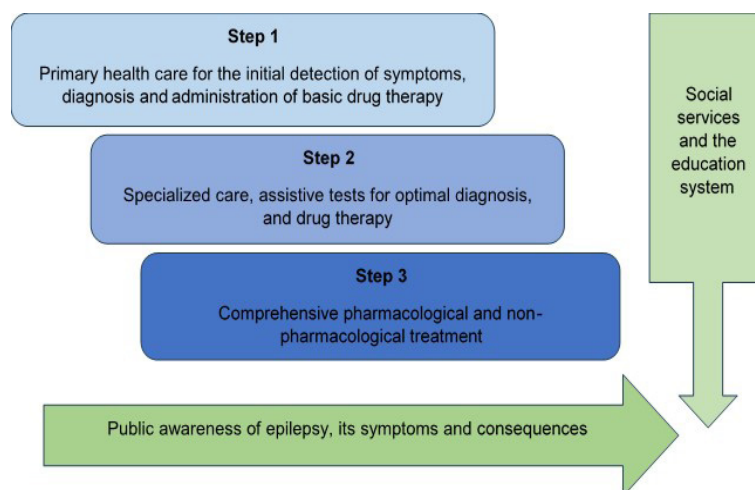
The diversity of medical care needs among people with epilepsy and their families can be considered as the

basis for a step-by-step approach to care: starting with diagnosis and continuing, if necessary, up to the appointment of non-drug treatment methods (for example, surgery) for pharmacoresistant epilepsy. At the same time, treatment of concomitant diseases should be one of the most important components at all levels of care. Interdisciplinary teams of specialists who provide people-centered care (for example, doctors, nurses, pharmacists, psychotherapists, and social workers) play an important role in the implementation of

the step-by-step approach. To increase access to all people in need of epilepsy treatment services, it is important to provide community-based care.

Social services and the education system should provide personalized support to people with epilepsy at all levels of care and should continue to provide them with this support, as needed, even if the attacks of the disease are no longer observed.

Applying a step-by-step approach to improve the quality of care for people with epilepsy



Although, to our knowledge, there are no studies that specifically examine the experience of caring for patients with MI, including epilepsy or seizures, and their families, studies of related patient groups (for example, patients with MI, early refractory epilepsy, or epilepsy associated with mental retardation) show that as a general organization, a multidisciplinary, integrated assistance, as well as various aspects of this assistance (for example, transition of care or coordination of care) are insufficient [28].

Fragmented health and social care systems do not meet the expectations and needs of patients and families, there is a lack of support in navigating complex care paths, and insufficient communication between professionals and sectors, especially at care transition points. Due to a lack of knowledge and awareness about these rare diseases, patients and families may not be adequately provided with the necessary information about the disease, its expected course, prognosis, possible comorbidities, as well as available services and support, including psychological support and peer support groups.

There is also a lack of patient education, empowerment, and inclusion in overall decision-making. In some cases, the developed information materials do not meet the needs of patients and caregivers in terms of content and form (for example, preferences for information on the Internet compared to written information). It is important to note that the needs of patients and families change over the course of the clinical course of the disease, so they need to be repeatedly assessed and appropriately addressed [29,30]. Those caring for children with THEM note that these disadvantages are especially burdensome outside of highly specialized institutions when faced with specialists who are not familiar with the child's illness [31].

A distinctive feature of rare diseases with metabolic and epileptic emergencies is their unpredictability

and often associated uncertainty, which causes even greater anxiety, depression, and other psychological and emotional problems for caregivers. These facts, which are associated with difficulties in decision-making, require close communication with specialists, which is sometimes perceived by patients as very difficult [32]. Finally, the organization of care and the quality of services are extremely uneven between countries, and sometimes within countries [33,34].

To promote the prevention and control of epilepsy, we need coordinated action at the national level to strengthen effective leadership and management. These actions should take into account the special needs of people with epilepsy; implement and implement national health plans for epilepsy; integrate epilepsy management into healthcare and social care, including access to safe, effective, and high-quality antiepileptic drugs.

Conclusion: The study concluded that in order to promote the prevention and control of epilepsy, we need coordinated action at the national level to strengthen effective leadership and management. These actions should take into account the special needs of people with epilepsy; implement and implement national health plans for epilepsy; integrate epilepsy management into healthcare and social care, including access to safe, effective, and high-quality antiepileptic drugs.

Conflict of interest: The author declares no conflict of interest.

This material has not previously been published and is not under consideration by other publishers.

Financing: absent.

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Эпилепсиямен ауыратын адамдарға медициналық көмекті ұйымдастырудың ерекшеліктері (Шолу)

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Түйіндеме

Эпилепсия - кез-келген жастағы адамдарға әсер ететін созылмалы инфекциялық емес ми ауруы. Эпилепсия - әлемдегі ең көп таралған неврологиялық аурулардың бірі, оған шамамен 50 миллион адам әсер етеді. Эпилепсиямен ауыратындардың 80% - ға жуығы табысы төмен және орташа елдерде тұрады.

Эпилепсиямен ауыратын адамдардың шамамен 70% - ы тиісті диагностика мен емдеуді қамтамасыз ете отырып, аурудың шабуылынсыз өмір сүре алады. Эпилепсиямен ауыратын науқастарда мезгілсіз өлім қаупі популяцияның орташа деңгейінен үш есе дерлік жоғары. Табысы төмен елдердегі эпилепсиямен ауыратын адамдардың төрттен үш бөлігі қажетті ем ала алмайды.

Бұл шолу мақаласының мақсаты эпилепсиямен ауыратын адамдарға медициналық көмекті ұйымдастырудың ерекшеліктері туралы халықаралық ғылыми қоғамдастықтағы зерттеулерді зерттеу, сондай-ақ медициналық қызметтердің сапасына және эпилепсиямен ауыратын адамдардың дәрі-дәрмекпен қамтамасыз етілуіне әсер ететін факторларды анықтау болып табылады.

Әдістері. PubMed, Web of Science, Cochrane, Wiley, Cyberleninka дерекқорлары бойынша "эпилепсия", "эпилепсиямен ауыратын адамдарға медициналық көмек", "эпилепсияға қарсы препараттар", "эпилепсиялық ұстама" кілт сөздері бойынша ғылыми мақалаларды ақпараттық іздеу жүргізілді. 2005-2025 жылдар аралығында жарияланған 68 мақала талданды.

Зерттеу нәтижесінде эпилепсияның алдын алу мен бақылауды жеңілдету үшін тиімді көшбасшылық пен басқаруды нығайту үшін ұлттық деңгейде үйлестірілген әрекет қажет деген қорытындыға келді. Бұл әрекеттер эпилепсиямен ауыратын адамдардың ерекше қажеттіліктерін ескеруі керек; эпилепсияға арналған ұлттық денсаулық сақтау жоспарларын енгізу және жүзеге асыру; эпилепсияны басқаруды Денсаулық сақтау мен әлеуметтік көмекке, соның ішінде қауіпсіз, тиімді және сапалы эпилепсияға қарсы препараттарға қол жеткізуді біріктіру.

Түйін сөздер: эпилепсия, эпилепсиямен ауыратын адамдарға медициналық көмек, эпилепсияға қарсы препараттар, эпилепсиялық ұстама.

Особенности организации медицинской помощи лицам страдающим эпилепсией (Обзор)

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Резюме

Эпилепсия – хроническое неинфекционное заболевание головного мозга, поражающее людей в любом возрасте. Эпилепсия является одним из самых распространенных неврологических заболеваний в мире, ею страдают порядка 50 миллионов человек. Почти 80% страдающих эпилепсией проживают в странах с низким и средним уровнем дохода.

По оценкам, до 70% людей с эпилепсией могут жить без приступов болезни при условии обеспечения надлежащей диагностики и лечения. Риск преждевременной смерти у больных эпилепсией почти в три раза превышает средний показатель по популяции. Три четверти людей с эпилепсией в странах с низким уровнем доходов не получают необходимого им лечения.

Целью данной обзорной статьи является изучение исследований в международном научном сообществе об особенностях организации медицинской помощи лицам страдающим эпилепсией, также определить факторы влияющие на качество медицинских услуг и обеспеченность лекарствами лиц страдающих эпилепсией.

Методы: Был произведен информационный поиск научных статей по базам данных PubMed, Web of Science, Cochrane, Wiley, Cyberleninka, по ключевым словам «эпилепсия», «медицинская помощь лицам страдающим эпилепсией», «антиэпилептические препараты», «эпилептический приступ». Было проанализировано 68 статей, опубликованные в период с 2005 по 2025 год.

В ходе исследования был сделан вывод что для содействия профилактике и контролю эпилепсии нам нужны скоординированные действия на национальном уровне для укрепления эффективного руководства и управления. Эти действия, должны учитывать особые потребности людей с эпилепсией; внедрять и реализовывать национальные планы здравоохранения для эпилепсии; интегрировать управление эпилепсией в здравоохранение и социальную помощь, включая доступ к безопасным, эффективным и качественным противоэпилептическим препаратам.

Ключевые слова: эпилепсия, медицинская помощь лицам страдающим эпилепсией, антиэпилептические препараты, эпилептический приступ.