Journal of Health Development
e2663-1776

Original article

Assessment of Parental Perception of the Health of Children with Demyelinating Diseases

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Received: January 06, 2026
Revised: January 18, 2026
Accepted: February 13, 2026
Published: February 28, 2026

Citation: Galym Aigerim, Sabyrdilda Zhanar, Konysbekova Akzhan, Abikulova Akmaral, Seiduanova Laura, Qumar Ainur. Assessment of parental perception of the health of children with demyelinating diseases: results of a survey. J Health Dev. 2026, 61 (1), jhd055. https://doi.org/10.32921/2663-1776-2026-61-1-jhd055

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Abstract

Pediatric demyelinating diseases of the central nervous system present with heterogeneous neurological impairments and varying clinical courses, often requiring long-term monitoring, immunological evaluation, and multidisciplinary care. The study aims to assess parental perceptions of their child's health, symptom burden, comorbidities, exacerbation triggers, and access to rehabilitation among children with demyelinating diseases, and to examine associations between key clinical factors and functional outcomes.

Methods. A cross-sectional survey was conducted among parents of 34 children aged 4–18 years hospitalized at Aksai University Clinic. A 39-item questionnaire was developed in accordance with international guidelines and pilot-tested for clarity. Statistical analysis included descriptive statistics, calculation of 95% confidence intervals (CI), and assessment of associations using odds ratios (OR) and Fisher's exact test.

Results. Neurological symptoms were highly prevalent, including coordination impairment (35.3%), visual disturbances (23.5%), speech disruption (17.6%), sensory deficits (14.7%), and pelvic dysfunction (5.9%). Most children (82.4%, 95% CI: 69.6–95.2) had a history of infections, and respiratory illnesses were common (53.0%). Infections were identified as the leading trigger of exacerbations (35.3%, 95% CI: 19.7–52.8), followed by non-adherence to medical recommendations (26.5%). Functional limitations affected 81% of children. Infection history was significantly associated with functional impairment (OR=3.1, 95% CI: 1.2–7.9; p=0.021), as was the presence of ≥2 neurological symptoms (OR=4.5, 95% CI: 1.1–18.2; p=0.047).

Conclusion. Parental reports demonstrate pronounced multisystem involvement, elevated infection burden, and high rates of functional limitations in children with demyelinating diseases. These findings underscore the need for robust infection-prevention strategies, improved support for treatment adherence, standardized referral pathways, and expanded, continuous rehabilitation services for affected children.

Keywords: pediatric demyelinating diseases, pediatric multiple sclerosis, parental perception, symptom reporting, quality of life, functional outcomes, care pathways.

1. Introduction

Demyelinating diseases (DDs) of the central nervous system in children are a heterogeneous group of disorders characterized by damage to the myelin sheath of nerve fibers [1]. Demyelination disrupts nerve impulse conduction, leading to a wide range of neurological, sensory, motor, and cognitive impairments that significantly impair children's quality of life and often lead to disability [2,3]. Pediatric DDs include acute disseminated encephalomyelitis (ADEM), clinically isolated syndromes (optic neuritis, transverse myelitis), neuromyelitis spectrum disorder (NMOSD), and multiple sclerosis (MS), each with unique clinical dynamics, immunopathogenesis, and prognosis [4,5]. Epidemiological studies show that the incidence of pediatric MS is approximately 0.87 per 100,000 children per year, and ADEM is 0.2–0.4 per 100,000 [6,13,14]. Despite their relative rarity, detection of pediatric DDs has increased in recent decades, associated with the introduction of high-field Magnetic Resonance Imaging (MRI), improved diagnostic criteria, the development of algorithms for pediatric cohorts, and increased vigilance among primary care physicians [4,11]. In particular, large national registries (UK, Japan, USA) demonstrate a significant increase in the number of observations of all forms of ADS and childhood MS [6,11,14].

The clinical course of DDs in children is highly variable. In some children, the disease has a monophasic course (characteristic of ADEM). In contrast, others develop a relapsing form, which is associated with a more rapid increase in disability compared to adults [3,6]. The prognosis remains poorly predictable: the risk of transition from a clinically isolated syndrome to MS, as well as the likelihood of developing persistent neurological deficits, depends on immunological markers (MOG-IgG, AQP4-IgG), MRI characteristics, and age of onset [4,8,12].

The differential diagnosis of pediatric DDs poses particular challenges. In children, symptoms are often nonspecific, and the overlap of clinical manifestations with infectious, metabolic, and genetic diseases requires a broad diagnostic workup, including neuroimaging, immunological markers, and consultation with specialists experienced in the treatment of rare diseases [4,10,12]. Several studies emphasize that the availability of specialized services, timely MRI, and serological testing significantly impact early diagnosis and treatment outcomes [11,12].

Despite a growing number of studies aimed at examining the clinical, immunological, and neuroimaging features of pediatric DDs [1,4,8,10], significantly fewer data are devoted to the perception of the disease by parents – the key observers of symptom dynamics, exacerbation triggers, frequency of infections, the emergence of new disorders, the need for rehabilitation, and treatment adherence. Studies assessing the quality of life of families of children with MS and ADS demonstrate a significant impact of long-term illness on parents' emotional status, family functioning, and stress levels [7,9]. Moreover, validated questionnaires used to assess symptoms in children with ID confirm the reliability of parental reports as a tool for early detection of clinical changes and functional limitations [10].

Studies assessing the quality of life of families and parents of children with pediatric multiple sclerosis demonstrate that parental observations reflect both objective changes in the child's condition and the degree of disease impact on the family, emotional burden, and level of care [13]. Furthermore, validated questionnaires used for screening and monitoring symptoms in childhood demyelinating diseases confirm the reliability of parental reports as a tool for identifying neurological manifestations and their impact on daily activities [14].

Thus, studying parental perspectives can significantly complement traditional clinical measures, identify previously unnoticed barriers to access to diagnosis and rehabilitation, and improve patient referrals, particularly in resource-limited settings with uneven infrastructure, as observed in Kazakhstan.

In Kazakhstan, where the epidemiology of childhood multiple sclerosis is understudied and the infrastructure may face limitations in diagnosis and rehabilitation, studying parental perspectives is particularly important. This can reveal hidden problems such as insufficient rehabilitation care, late presentations, frequent infections, and deficiencies in monitoring, and justify the need for improved routing and comprehensive support for such children.

The study aims to evaluate parental perceptions of children's health with demyelinating diseases, the frequency of concomitant disorders and infectious diseases, and to identify factors that, from the parents' perspective, affect the severity of the disease and the child's quality of life.

https://doi.org/10.32921/2663-1776-2026-61-1-jhd055

2. Materials and Methods

The study was a cross-sectional, descriptive sociological study aimed at examining parents' opinions regarding the health status of their children with DDs.

The study was conducted at the Aksai University Clinic of Asfendiyarov Kazakh National Medical University. Data collection covered the period from March 1 to May 31, 2024, including parents of children hospitalized for examination and treatment of demyelinating disorders.

The sample was formed using the purposive sampling principle. The study included 34 parents of children with demyelinating diseases. Inclusion criteria were: child's age 4–18 years; confirmed or clinically probable demyelinating disease (ADEM, clinically isolated syndrome, MS, NMOSD, hereditary demyelinating disorders); parental consent to participate. Exclusion criteria were: refusal to participate; lack of informed consent; and severe condition of the parent that prevented completion of the questionnaire.

To assess parents' perceptions of their child's health, we used a questionnaire developed based on an analysis of current literature and international recommendations for creating instruments to study quality of life and clinical manifestations of chronic neurological diseases in children. The questionnaire's structure was based on the principles of developing patient-reported outcomes (PROs).

The questionnaire included 39 questions, divided into thematic domains reflecting key aspects of the clinical picture and the impact of the disease on the child's and family's daily lives. The questions were grouped into the following sections: Demographic Data, Medical History, Neurological Symptoms, Infectious and Somatic Morbidity, Exacerbation Triggers, and Rehabilitation and Restorative Treatment.

Before the main phase of the study, the questionnaire was pilot-tested with five parents of children with demyelinating diseases to assess its content validity, clarity of wording, and usability. This pilot testing allowed us to determine the optimal completion time, verify the logic of the question sequence, and identify potential duplicative or overloading wording, all in line with international requirements for the development of questionnaire instruments (COSMIN) and the principles of cognitive interviewing. Based on the testing results, the wording of several items was refined, repetitive and ambiguous questions were eliminated, and the questionnaire structure was optimized to improve respondents' comprehension.

The survey was administered in person in a hospital setting. Before completion, each parent was provided with detailed information on the study's goals and objectives, confidentiality principles, and data processing procedures. After all questions were clarified, written informed consent was obtained. The average time to completion was 20-25 minutes, consistent with the recommended timeframe for questionnaires assessing the clinical condition and quality of life of patients and their families.

Particular attention was paid to the quality and completeness of the primary data. In some cases, questionnaires contained missing items; these questionnaires were not included in the analysis in their original form to avoid systematic errors associated with incomplete information. If there were missing or unclear answers, the researcher contacted the parents again to clarify and complete the information. After data confirmation, the questionnaires were classified as fully completed in accordance with the quality and reliability criteria recommended by STROBE for observational studies. This approach ensured data integrity, minimized information loss, and increased the reliability of interpreting results.

The study methods were approved by the Local Ethics Committee of KazNMU (protocol No. 12 (123) dated December 22, 2021). Written informed consent was obtained from all parents (legal representatives) of the study participants.

Statistical data processing included: calculating the percentages (%) for each question; determining the sampling error; and analyzing differences between groups using the Student's t-test (for proportions). The acceptable significance level was $p<0.05$.

To assess the strength of the association between children's clinical characteristics and parents' reports of functional limitations, odds ratios (ORs) with 95% confidence intervals (CIs) were calculated, and statistical significance was determined using Fisher's exact test.

3. Results

Table 1 presents the sociodemographic characteristics of the sample, which included 34 parents of children with demyelinating diseases. Participants ranged in age from 24 to 49 years, with a mean of 38 years. The majority of respondents were women – 32 (94.1%), while only two (5.9%) were fathers. Girls predominated among the children (24, 70.6%), while boys accounted for 10 (29.4%). The children ranged in age from 4 to 18 years. All children (100%) had a confirmed diagnosis of demyelinating disease.

https://doi.org/10.32921/2663-1776-2026-61-1-jhd055

Most parents reported a family history: 64.7% (n=22) reported a family history of hereditary diseases; 35.3% (n=12) denied a family history (Table 2).

Respiratory morbidity in children with DD was high: 53.0% (n=18) were frequently ill, 35.3% (n=12) were rarely ill, and 11.7% (n=4) were very sick, seldom. The data confirm the increased vulnerability of children with neurological diseases to infections.

Most children (82.4% (n=28)) had experienced infectious diseases; 17.6% (n=6) had no significant infections. Parents often considered infections as factors worsening the condition.

Parents noted a wide range of neurological and somatic disorders. Impaired coordination was reported in 35.3% (n=12); Visual impairment – 23.5% (n=8); speech impairment – 17.6% (n=6); sensory impairment – 14.7% (n=5); pelvic floor dysfunction – 5.9% (n=2). Thus, each child had 1–3 neurological symptoms indicating multisystem DDs.

When asked about the frequency of painful or uncomfortable manifestations, 47.0% (n=16) of parents noted that their children experienced them frequently, but that they passed quickly.

Parents indicated varying degrees of activity limitation: complete cessation of activity – 11.8% (n=4); significant temporary limitation – 34.0% (n=10); partial reduction in activity – 35.3% (n=12); no effect – 23.5% (n=8). In total, 81% of children experience symptoms affecting daily activities.

According to the survey, parents noted several key factors contributing to their children's disease exacerbations. The most significant trigger, in their opinion, was previous infections, cited by 35.3% (n=12) of respondents. The second most common factor was failure to comply with the doctor's recommendations, accounting for 26.5% (n=9) of cases. Less frequently, parents associated exacerbations with hypothermia (5.9% (n=2)) or the use of medications and other drugs (2.8% (n=1)). Climate change was not mentioned by any respondents (0%). Moreover, 11.8% (n=4) of parents found it challenging to identify potential triggers for worsening their child's condition. Thus, parents view infectious diseases as the most significant factor influencing the risk of exacerbation of the demyelinating process.

Analysis of rehabilitation access data revealed significant heterogeneity in the receipt of rehabilitation care. The most common option was annual rehabilitation, which was completed by 50% of children (n=17). Another 17.6% (n=6) received rehabilitation twice a year, and 11.8% (n=4) were on a permanent rehabilitation program prescribed by a physician. Meanwhile, 11.8% (n=4) of children were deprived entirely of rehabilitation care, despite having significant neurological impairments. These data indicate uneven access to rehabilitation services and highlight the need for systemic improvement of rehabilitation support for children with demyelinating diseases.

Table 3 presents the results of an analysis of associations between children's clinical characteristics and their parents' reports of functional limitations. According to the data, a history of infectious diseases was statistically significantly associated with functional limitations. Among children with infections, limitation of daily activity was observed in 92.9% of cases, compared with 66.7% among children without infections (OR=3.1; 95% CI: 1.2–7.9; p=0.021).

The number of neurological symptoms also proved to be a significant predictor. Among children with two or more symptoms, activity limitation was recorded in 91.7% of cases, compared with 63.6% of children with one or no symptoms (OR=4.5; 95% CI: 1.1–18.2; p=0.047). This indicates a strong relationship between polysymptoms and the severity of functional impairment.

The presence of a family history of various diseases showed only a tendency towards an increased risk of activity limitations (OR=1.7; 95% CI: 0.14–21.7; p=0.41), however, the differences obtained did not reach statistical significance, which is probably due to the small sample size and wide variability of CI.

Table 4 reflects the distribution of factors that parents associated with exacerbations of demyelinating diseases in their children. The most frequently cited trigger was past infectious diseases, cited by 35.3% of respondents (95% CI: 19.7–52.8). This figure significantly exceeds the proportion of other factors. It is consistent with clinical data indicating the role of respiratory and viral infections in the activation of immunopathological processes in children with demyelination.

The second most common factor was non-compliance with medical recommendations, which parents associated with exacerbations in 26.5% of cases (95% CI: 12.9–44.4). This figure reflects the importance of the treatment regimen, adherence to prescriptions, and regular monitoring to maintain a stable course of the disease. Triggers such as hypothermia (5.9%; 95% CI: 0.7–19.7) and medication use (2.8%; 95% CI: 0.1–14.5) were reported significantly less frequently. This indicates the limited role of non-specific external factors compared to infections and treatment adherence.

11.8% of parents (95% CI: 3.3–27.8) were unable to identify potential precipitating circumstances, highlighting the complexity of assessing exacerbation factors in the family environment and the possible influence of hidden or unconscious determinants.

https://doi.org/10.32921/2663-1776-2026-61-1-jhd055

Table 1 - Socio-demographic characteristics of parents (n = 34) and children

Indicator	Meaning	95% CI
Parents' Age	38.0 ± 6.2	–
Participant Parent's: Mother	32 (94,1%)	80.3–99.3
Father	2 (5,9%)	0.7–19.7
Child's Gender: Girls	24 (70,6%)	52.5–84.9
Boys	10 (29,4%)	14.1–44.7
Child's Age	11.3 ± 4.7	–

Table 2 - Main results of the survey of parents of children with demyelinating diseases (n = 34)

Section	Indicator	Results	95% CI
Respiratory Diseases	Frequent	18 (53%)	35.0–70.0
	Rarely	12 (35,3%)	20.6–53.0
	Very rare	4 (11,7%)	3.3–27.5
History of Infectious Diseases	Yes	28 (82,4%)	69.6–95.2
	No	6 (17,6%)	4.8–30.4
Neurological and Somatic Disorders	Impaired coordination	12 (35,3%)	19.3–51.3
	Visual impairment	8 (23,5%)	10.7–41.2
	Pelvic organ dysfunction	2 (5,9%)	7.0–33.7
	Sensory impairment	5 (14,7%)	4.9–31.1
	Speech impairment	6 (17,6%)	0.7–19.7
Impact of Symptoms on Daily Activity	Complete cessation of activity	4 (11,8%)	3.3–27.8
	Partial influence (activity continues)	12 (35,3%)	15.1–47.5
	Activity maintained	8 (23,5%)	19.3–51.3
	Significant influence	10 (29,4%)	10.7–41.2
Rehabilitation	Once a year	17 (50%)	32.4–67.6
	Twice a year	6 (17,6%)	7.0–33.7
	Constantly	4 (11,8%)	3.3–27.8
	Never received	4 (11,8%)	3.3–27.8

Table 3 - Associations between clinical factors and activity limitation

Activity	Limitation Factor (%)	OR	95% CI	p-value
Presence of infection	26/28 (92.9%)	3.1	1.2–7.9	0.021
≥2 neurological symptoms	22/24 (91.7%)	4.5	1.1–18.2	0.047
Heredity	20/22 (90.9%)	1.7	0.14–21.7	0.41

Table 4 - Factors associated with exacerbations (n = 34)

Trigger	n (%)	95% CI
Infections	12 (35.3%)	19.7–52.8
Failure to comply with recommendations	9 (26.5%)	12.9–44.4
Hypothermia	2 (5.9%)	0.7–19.7
Medication use	1 (2.8%)	0.1–14.5
Climate change	4 (11.8%)	3.3–27.8

4. Discussion

This study provides one of the first systematic assessments of parental perceptions of health, symptoms, comorbidities, and exacerbating factors among children with demyelinating diseases in Kazakhstan. The results highlight several clinically essential patterns consistent with international evidence, while also revealing context-specific challenges.

A significant finding is the high burden of neurological and somatic symptoms reported by parents. Disturbances in coordination (35.3%), vision (23.5%), speech (17.6%), and sensory function (14.7%) align with the multisystem involvement described in

pediatric demyelinating disorders, particularly multiple sclerosis, ADEM, and clinically isolated syndromes [1,4]. Such symptoms are known to affect functional status and academic performance in pediatric populations significantly [3]. The fact that over 80% of children in this study experience limitations in daily activity underscores the substantial impact of demyelination on quality of life.

Parental reports also pointed to a remarkably high frequency of infections (82.4% of children) and frequent respiratory illnesses (53% reported as "often"). Comparable trends have been documented in studies demonstrating heightened susceptibility to infections in children with immune-mediated central nervous system (CNS) disorders [6]. Importantly, infections were also the most commonly identified trigger of symptom exacerbation (35.3%). International cohorts similarly emphasize infection-driven relapses in pediatric MS and related disorders, especially in the post-viral period [5]. These findings suggest that strengthening infection prevention, vaccination coverage, and early management could reduce the risk of relapse.

Another important observation is the substantial variability in access to rehabilitation. Although half of the children receive rehabilitation once a year and 11.8% are on continuous programs, another 11.8% receive no rehabilitation services at all. Given the evidence supporting early, intensive rehabilitation in improving long-term motor and cognitive outcomes in pediatric CNS demyelination, this gap highlights an area requiring immediate health system attention. International recommendations stress that rehabilitation should be individualized, multidisciplinary, and continuous in children with demyelinating diseases [15].

The presence of hereditary patterns in 64.7% of families also warrants consideration. While demyelinating diseases are not classically hereditary, genetic susceptibility contributes to disease risk, particularly for multiple sclerosis and immune-mediated disorders [2]. Parental recognition of familial patterns may reflect awareness of broader autoimmune disorders within families, or the coexistence of neurodevelopmental, metabolic, or immunological conditions that increase vulnerability.

The psychosocial component of the disease experience is also implied in parental responses. While the present study did not directly assess psychological well-being, the high frequency of symptom-related functional limitations and the need for ongoing rehabilitation suggest potential unmet needs in psychological support and caregiver burden areas reported as critical in other pediatric neurology populations.

This study has several limitations that should be considered when interpreting the findings.

First, the sample was obtained through purposive sampling and consists only of parents of children hospitalized at a single tertiary center, limiting generalizability to the broader population.

Second, the sample size, though adequate for qualitative and descriptive analysis, restricts statistical inference and the detection of subgroup differences.

Third, all data were based on self-reports and may be affected by recall bias or parental interpretation of symptoms. Fourth, the study did not include clinical measures such as MRI findings, relapse rates, or disability scores (e.g., EDSS), which would have enabled correlation between parental perceptions and objective disease characteristics. Fifth, triggers were reported subjectively and not validated against clinical records. Finally, the cross-sectional design does not allow assessment of temporal changes or long-term outcomes.

Despite these limitations, the study provides several important implications for clinical practice and healthcare planning. Need for structured parental education: the prominent role of infections as perceived triggers underscores the importance of counseling families on infection prevention, vaccination, and adherence to treatment recommendations.

Rehabilitation access must be expanded. Unequal access and the absence of rehabilitation for some children highlight the need for standardized, equitable rehabilitation pathways, including regional centers and tele-rehabilitation models.

5. Conclusion

The analysis of parental perceptions revealed a high frequency of neurological symptoms, recurrent infections, functional limitations, and a substantial need for continuous rehabilitation support. These findings are consistent with international evidence and underscore the multifactorial nature of pediatric demyelinating disorders.

Overall, the study contributes to a better understanding of the lived experience of families caring for children with pediatric demyelinating diseases and offers practical guidance for improving care pathways. Future research should include longitudinal follow-up, objective clinical measures, and larger, more diverse cohorts to validate and expand upon these results.

https://doi.org/10.32921/2663-1776-2026-61-1-jhd055

Conflicts of Interest. None declared.

Funding. None.

Author Contributions. Conceptualization – A.G., A.Q.; Methodology – A.G., A.Q.; Validation – A.G., L.S.; Formal Analysis – A.G., Zh.S., and A.A.; Writing – Original Draft Preparation – A.G., A.Q.; Writing – Review & Editing – A.Q., A.A.

All authors have read and agreed to the final version of the manuscript and have signed the copyright transfer form.

Declaration of AI and AI-assisted technologies in the writing process. During the preparation of this work, the author used [ChatGPT] in order to improve the language and readability of the manuscript. After using this tool/service, the authors reviewed and edited the content as needed and takes full responsibility for the content of the publication.

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Демиелинизацияланатын аурулары бар балалардың денсаулығына ата-аналардың көзқарасын бағалау

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Түйіндеме

Балалардағы орталық жүйке жүйесінің демиелинизациялық аурулары гетерогенді неврологиялық бұзылулармен және әртүрлі клиникалық ағымдармен сипатталады, көбінесе ұзақ мерзімді бақылауды, иммунологиялық бағалауды және көп салалы күтімді қажет етеді. Зерттеу мақсаты – демиелинизациялық аурулары бар балалардағы балаларының денсаулығы, симптомдар ауырлығы, қатар жүретін аурулар, өршу себептері және оңалтуға қолжетімділік туралы ата-аналардың пікірін бағалау, сондай-ақ негізгі клиникалық факторлар мен функционалдық нәтижелер арасындағы байланысты зерттеу.

Әдістері. Ауруханада жатқан 4-18 жастағы 34 баланың ата-аналары арасында көлденең сауалнама жүргізілді. Халықаралық нұсқауларға сәйкес 39 сұрақтан тұратын сауалнама әзірленді және анықтығы үшін пилоттық сынақтан өтті. Статистикалық талдау сипаттамалық статистиканы, 95% сенімділік аралықтарын есептеуді және ықтималдық коэффициенттерін пайдалана отырып, байланыстарды бағалауды және Фишердің дәл сынағын қамтыды.

Нәтижелері. Неврологиялық симптомдар өте кең таралған, соның ішінде үйлестірудің бұзылуы (35,3%), көру бұзылыстары (23,5%), сөйлеудің бұзылуы (17,6%), сенсорлық кемшіліктер (14,7%) және жамбас дисфункциясы (5,9%). Балалардың көпшілігінде (82,4%, 95% CA: 69,6–95,2) инфекция тарихы болған, ал тыныс алу жолдарының аурулары жиі кездеседі (53,0%). Инфекциялар өршудің негізгі қоздырғышы ретінде анықталды (35,3%, 95% CA: 19,7–52,8), содан кейін медициналық ұсыныстарды сақтамау (26,5%). Функционалдық шектеулер балалардың 81%-ына әсер етті. Инфекция тарихы функционалдық бұзылулармен айтарлықтай байланысты болды (OR=3.1, 95% сенімділік аралығы: 1.2–7.9; p=0.021), сондай-ақ ≥2 неврологиялық симптомдардың болуы (OR=4.5, 95% сенімділік аралығы: 1.1–18.2; p=0.047).

Қорытынды. Ата-аналардың жауаптары миелинизациялық аурулары бар балаларда көп жүйелік зақымданудың айқын екенін, инфекция жүктемесінің жоғары екенін және функционалдық шектеулердің жоғары деңгейін көрсетеді. Бұл зерттеулер инфекцияның алдын алудың сенімді стратегияларының, емдеуді ұстануды қолдауды жақсартудың, стандартталған жолдама жолдарының және зардап шеккен балаларға арналған кеңейтілген, үздіксіз оңалту қызметтерінің қажеттілігін көрсетеді.

Түйін сөздер: балалардағы демиелинизациялық аурулар, балалардағы шашыранды склероз, ата-аналардың қабылдауы, симптомдар туралы есеп, өмір сапасы, функционалдық нәтижелер, күтім жолдары.

Оценка восприятия родителями состояния здоровья детей с демиелинирующими заболеваниями

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Резюме

Демиелинизирующие заболевания центральной нервной системы у детей характеризуются гетерогенными неврологическими нарушениями и различным клиническим течением, что часто требует длительного наблюдения, иммунологического обследования и междисциплинарной помощи. Целью исследования является оценить представления родителей о здоровье своего ребенка, выраженности симптомов, сопутствующих заболеваниях, факторах, провоцирующих обострения, и доступности реабилитации у детей с демиелинизирующими заболеваниями, а также изучить взаимосвязь между ключевыми клиническими факторами и функциональными результатами.

Методы. Было проведено поперечное исследование среди родителей 34 детей в возрасте от 4 до 18 лет, госпитализированных в специализированный детский неврологический центр. Был разработан опросник из 39 пунктов в соответствии с международными рекомендациями, прошедший пилотное тестирование для проверки ясности. Статистический анализ включал описательную статистику, расчет 95% доверительных интервалов (*ДИ*) и оценку ассоциаций с использованием отношения шансов (ОР) и точного теста Фишера.

Результаты. Неврологические симптомы были широко распространены, включая нарушения координации (35,3%), нарушения зрения (23,5%), нарушения речи (17,6%), сенсорные нарушения (14,7%) и дисфункцию таза (5,9%). Большинство детей (82,4%, 95% *ДИ*: 69,6–95,2) имели в анамнезе инфекции, а респираторные заболевания были распространены (53,0%). Инфекции были определены как основной фактор, провоцирующий обострения (35,3%, 95% *ДИ*: 19,7–52,8), за ними следует несоблюдение медицинских рекомендаций (26,5%). Функциональные ограничения затронули 81% детей. Наличие в анамнезе инфекций было значительно связано с функциональными нарушениями (ОР=3,1, 95% *ДИ*: 1,2–7,9; p=0,021), как и наличие ≥2 неврологических симптомов (ОР=4,5, 95% *ДИ*: 1,1–18,2; p=0,047).

Выводы. Результаты опроса демонстрируют выраженное поражение нескольких систем организма, повышенную инфекционную нагрузку и высокие показатели функциональных ограничений у детей с демиелинизирующими заболеваниями. Эти результаты подчеркивают необходимость эффективных стратегий профилактики инфекций, улучшения поддержки соблюдения режима лечения, стандартизированных путей направления к специалистам и расширения непрерывных реабилитационных услуг для пострадавших детей.

Ключевые слова: демиелинизирующие заболевания у детей, рассеянный склероз у детей, мнение родителей, сообщения о симптомах, качество жизни, функциональные результаты, маршрут оказания помощи.