

ANNOTATION

dissertation work of Maksat Abdikadyr on the topic "Improving the organization of rehabilitation care for children with cerebral palsy" for the degree of Doctor of Philosophy (PhD) in the specialty 6D110200 - "Public Health"

Research relevance

The President of the Republic of Kazakhstan K. Tokayev, in his Address to the people "A critical public dialogue is the basis of stability and prosperity of Kazakhstan" (2019), set the task of improving the medical and social security of children diagnosed with cerebral palsy /primeminister.kz/. In pursuance of the instructions of the President, the Government of Kazakhstan is taking measures to "accessibility of rehabilitation centers" for young and middle-aged children. It was also noted that special attention should be paid to families raising children with disabilities (State program "Health Development in the Republic of Kazakhstan for 2020-2025").

According to official data (2020), 80 thousand children are registered with disabilities. The state strives to create equal opportunities for people with special needs.

According to statistics, in Kazakhstan, the incidence of children with cerebral palsy over the past 10 years has increased by 1.6 times. Indicators of nosology of infantile cerebral palsy (G80) in the city of Almaty increased: up to 14 years: from 1700 in 2015 to 2945 in 2021; 15-17 years: from 203 in 2015 to 422 in 2021

Currently, 19,000 children with cerebral palsy need rehabilitation in Kazakhstan, including 153,000 children in remedial education /Sputnik.kz (2020). In other words, out of 626.7 thousand disabled people in Kazakhstan, 11% are children with disabilities.

According to the National Genetic Registry of the Republic of Kazakhstan, from 2,000 to 3,500 children with congenital or hereditary pathologies are born in Kazakhstan annually, which is 0.4-0.7% per 1,000 newborns ("National Plan of the Republic of Kazakhstan on the Rights of Persons with Disabilities and Improving the Quality of Life until 2025 year", 2019)..

The leading place in the structure of childhood disability, from 30% to 70%, is occupied by cerebral palsy, i.e. disease leading to early disability. According to world statistics, cerebral palsy occurs in children on average from 2 to 8 times per 1000 live births; in developed countries, respectively - 2.5-5.9. Although some authors have shown a reduction in perinatal neuropathy due to improvements in obstetric care, treatment and prevention of complications, others believe that the incidence of cerebral palsy has remained stable over a number of years. However, most authors attribute this increase to an increase in morbidity, which is explained by a decrease in mortality among premature and underweight children with a high

risk of developing cerebral palsy (Children of Kazakhstan: statistical collection, 2019).

There are not enough organizations in the country that provide rehabilitation assistance to children with disabilities, there is a low material and technical base of existing centers. The level of professionalism of specialists is also insufficient, and these factors together have a negative impact on the dynamics of children's health and the outcome of the disease.

The low indicators of the quality of life of children with disabilities, the complexity of organizing the rehabilitation care system reflect the medical and social significance of the problems of rehabilitation of children with cerebral palsy, and poses complex challenges to improve the efficiency and effectiveness of care.

Today, children with cerebral palsy are also registered in mothers with a normal pregnancy. However, cerebral palsy is more commonly diagnosed in underweight newborns and in children with central nervous system damage due to adverse birth or trauma.

Research goal

To develop ways to improve the organization of rehabilitation care based on the study of the medical and social status of the patient, clinical diagnostic features and quality of life of children with cerebral palsy.

Research objectives

In order to achieve the goal, the following **objectives** were completed:

1. Conduct a scientific and literary review of the global burden of cerebral palsy and the system of organization of rehabilitation care.
2. To study the medical and demographic status, risk factors in pathogenesis and clinical diagnostic features of patients.
3. To study the socio-hygienic characteristics of families raising children with cerebral palsy.
4. Conduct a comparative assessment of the quality of life of disabled children and healthy children and determine the degree of satisfaction with the organization of rehabilitation care for patients with cerebral palsy.
5. Develop practical recommendations with the creation of a model of integrative activities to improve corrective and rehabilitation care for children with cerebral palsy.

Scientific novelty of the study. The scientific novelty of the research is based on the following results of the study, many of which were revealed for the first time:

- the medical and social status of the patient, the clinical and diagnostic characteristics of children with cerebral palsy, as well as its dependence on etiopathogenetic factors were studied in accordance with the study period;
- an assessment was made of indicators of satisfaction with the organization of rehabilitation care for children with cerebral palsy;
- the social and hygienic characteristics of families raising children with cerebral palsy in modern society were revealed;

- a comparative assessment of the quality of life of disabled children and healthy children was carried out;
- a model has been developed to improve the organization of complex rehabilitation care for children with cerebral palsy.

Theoretical and practical significance of the research

At the level of the health care system:

Determining the medical and social status of children with cerebral palsy in modern society (demographic characteristics, etiological factors in pathogenesis, clinical and diagnostic characteristics) is important in making professional decisions in practical work by the competent health authorities.

An integrative model of comprehensive rehabilitation care for children with cerebral palsy is of practical importance in the work of specialized rehabilitation centers and departments at different levels.

At the level of a medical organization:

The risk factors identified during the study are important for healthcare institutions that provide assistance to women of childbearing age and newborns in predicting and preventing the development of cerebral palsy in children.

A questionnaire specially developed in the course of the dissertation research can be used to determine the social and hygienic characteristics of children with cerebral palsy and their families, the degree of satisfaction with the provision of medical, social and rehabilitation assistance, as well as the problems and needs in these families.

At the level of medical education institutions:

The results of the study can serve as the basis for thematic training in medical universities and postgraduate education organizations, as well as for the development of work programs for the advanced training of specialists involved in the pathology of the nervous system in medical and neurorehabilitation children's institutions and pediatricians.

Provisions for defense

1. The study of the etiopathogenesis and clinical and diagnostic characteristics of cerebral palsy in children shows the dependence of the disease on risk factors in the pre- and perinatal period. At the birth of children with cerebral palsy, there is a shift in the age of women to the left; the birth of children with cerebral palsy does not depend on the order of pregnancy.
2. A socio-hygienic study of families raising children with cerebral palsy revealed their need for long-term supportive rehabilitation care. The level of the quality of life of a sick child justifies the need of parents for an accessible complex-organized rehabilitation assistance.
3. The study of the medical and social status of the patient, the clinical and diagnostic features of children with cerebral palsy, the level of satisfaction with the organization of care, as well as the experience of the medical organization in providing specialized care, made it possible to create a model for improving the organization of correctional and rehabilitation care based on integrative activities

Conclusions

1. According to the study, children with cerebral palsy were mostly born from the 1st and 2nd pregnancies and first births in women aged 21-30 years. In the development of the disease, the influence of such risk factors as weakness of labor activity is obvious (especially with spastic diplegia - 56%, bilateral hemiplegia - 54.4%), rapid labor, an anhydrous period. Anemia (21.9%) and preeclampsia (13.5%) are often registered during pregnancy. There was a risk of miscarriage (16.3%) due to prenatal causes (kidney and urinary tract diseases, acute respiratory viral infections, diabetes mellitus, diseases of the digestive system and liver, nervous breakdowns), as well as violation of pregnancy due to intranatal causes (30.1%).
2. Among the forms of cerebral palsy, spastic diplegia prevails ($r=0.081$, $p<0.01$), then the proportion of hyperkinetic and mixed forms of cerebral palsy is significant. According to the clinical and diagnostic characteristics, the patients lacked the skills: to sit independently -19.1%, verticalization -32.8%, to move independently -43.3% of patients were not. Among severe forms, with bilateral hemiplegia, 60% did not have the skills of verticalization, 75% could not walk independently; in the hyperkinetic form, hyperkinesia of varying degrees is observed. It is on the 2nd place in the structure of children who cannot walk.
3. When evaluating the effectiveness of organizing rehabilitation care for patients with cerebral palsy, there is a clear difference in a number of indicators characterizing personal development and physical activity, before / after organizing and conducting comprehensive rehabilitation care, $\alpha\leq 0.05$. That is, the complex organization of care fully covers all functional systems (motor, sensory, cognitive and emotional-communicative spheres) and optimally increases patient satisfaction with the effectiveness of the organization of care.
4. The total number of complete families raising children with cerebral palsy was 63.1%. The vast majority of families (88.2%) wanted and desired the birth of a child. In particular, there is a significant proportion of those who worry about the health of a child when another child is born (41.2%). In 87% of cases, support and care for a disabled child is carried out in the form of a "mother and child" dyad. The proportion of parents (41.2% of mothers and 52.9% of fathers) with higher education is high. 61.8% of families have their own housing, 26.5% live in rented housing. 61.8% have completely satisfactory living conditions; although, only 35% answered that the entrance to the house was designed for the disabled. One third of families have enough material resources only for necessary needs. 27.1% attend specialized kindergartens; the majority of children (33.6%) study at home. It was revealed that the possibility of visiting special preschool and educational institutions is directly dependent on the frequency and regularity of visiting rehabilitation events. The demand for a social teacher was 80.5%. Parents are partially satisfied with the activities of preschool institutions (47.4%), general education institutions (1/3), and about half are completely or not at all satisfied with the activities of health care institutions. 22.8% of respondents were not covered by rehabilitation.

5. In all age groups of children with disabilities, the parameters of QoL are significantly lower than in healthy children, and they need constant long-term rehabilitation and support. For children aged 2-4 and 5-9 years, responses from parents were recorded; for other age groups, responses were recorded from patients and their parents. Physical functional (FF) parameters of the quality of life are significantly lower than the others. Any of the indicators of QoL of children in the control group is significantly higher than those of children with disabilities: physical function is more than 3 times, the parameters of social function (SF) are more than 2 times. The statistical difference between the data of the parents of the compared groups is obvious: the role function is assessed as unsatisfactory. In general, all indicators of QoL in patients with cerebral palsy are relatively lower than in healthy children, which directly indicates the need for long-term rehabilitation and support for this category of patients.
6. The medical and social significance and prevalence of the disease dictate the need to strengthen the children's rehabilitation service in the country by improving the organization of effective and comprehensive rehabilitation care for children with cerebral palsy, as well as to strengthen the material and technical base with the provision of specialists to provide integrative care. The developed model of rehabilitation and correctional development, based on the results of the study, scientifically substantiates the functional model of organizing rehabilitation care for children from an early age, and is applicable in practical healthcare.

Publications

The dissertation materials were published in 8 scientific papers, of which

- 1 article in a journal indexed in the Scopus database,
- 3 articles in journals recommended by the Committee for Quality Assurance in Education and Science of the Ministry of Education and Science of the Republic of Kazakhstan
- 4 publications in international conference proceedings:
 - VI Халықаралық «Фараби оқулары» ғылыми конференциясының материалдарында (Алматы, 2019);
 - Жас ғалымдар мен оқытушылардың «Фараби оқулары: Денсаулық сақтау қызметтерін жалпы қамтудағы АМСК ролі» халықаралық ғылыми-практикалық конференциясында (Алматы, 2019);
 - «Жалпыұлттық «Бөбек» қозғалысы мен Қазақстан ғалымдары Конгресінің біріккен ассоциациясының «Global science and innovations 2020: Central Asia» XI халықаралық ғылыми-практикалық конференциясында (Нұр-Сұлтан, 2020);
 - «Эразмус ПЛЮС бағдарламасының Орталық Азиядағы университеттерінің жоғары білім беру әлеуетін арттыруға әсері» халықаралық білім және ғылым конференциясында (Алматы, 2021).

Implementations

The results of the study were discussed and implemented in the practice of the following organizations, implementation certificates were received:

- Public association «Қазақ медициналық қоғамы»;
- Rehabilitation center "Ardi", Almaty;
- Social Assistance Center «Шапағат», Almaty;
- Neurological Center of Aksai Children's Clinical Hospital;
- SE polyclinic №10 емханасы, Almaty

Innovative patents, copyright certificates

1. Certificate of authorship № 11561. ««MaksatMed» реабилитациялық орталығын» іске қосу жоспарына». 2020.

2. Certificate of authorship № 25473. «Церебральді сал ауруымен ауыратын балаларға қалпына келтіру көмегін жетілдіру үлгісі». 2021.

The structure and scope of the dissertation

The thesis is presented on 163 pages and consists of an introduction, a review of the current state of the problem, research methodology, 5 chapters of own research, conclusions, practical recommendations, a list of references. The dissertation contains 41 tables, 43 figures, 172 sources of literature (of which 82 are in a foreign language) and 7 appendices.