

ANNOTATION
of the dissertation work of Zhakupova Maya Nurdauletovna
on the topic "Improvement of medical and social assistance
to disabled children with cerebral palsy at the level of primary health
care" for the degree of Doctor of Philosophy (PhD)
in the specialty 6D110200 - "Public health"

The relevance of research. The health of children and adolescents is one of the most important indicators determining the economic, intellectual, cultural and reproductive potential of a nation. In The Message "Strategy Kazakhstan-2050. The new political course of the established state" The President of the Republic of Kazakhstan outlined new principles of social policy, designating the protection of childhood as one of the important priorities of the development of the state in the coming years. In the Message of the Head of State Kassym-Jomart Tokayev to the People of Kazakhstan dated September 02, 2019 the problem of families "... who have children with disabilities in their care is also highlighted. According to official statistics alone, more than 80 thousand children of children with cerebral palsy are registered for disability. The government should develop measures to improve medical and social support for children diagnosed with cerebral palsy ...» [primeminister.kz]

Thus, taking care of children with disabilities is one of the priority tasks of Kazakhstan's healthcare.

According to the World Health Organization (WHO), people with disabilities make up 10% of the world's population. Of these, 150 million are children. According to the National Genetic Register of the Republic of Kazakhstan, from 2000 to 3500 children with congenital and hereditary pathology are born annually in Kazakhstan, which is 20.0-24.3 per 1000 newborns. Cerebral palsy occupies a leading place in the structure of children's disability (from 30% to 70%). In Kazakhstan, according to statistics, more than 80 thousand disabled children are registered, including more than 10 thousand children diagnosed with cerebral palsy.

The increase in the incidence of cerebral palsy in recent decades has attracted the attention of scientists all over the world, including in our country.

This is due not only to improved diagnosis and accounting of such patients, but also to a significant improvement in treatment at the earliest stages: resuscitation of children with severe birth trauma and asphyxia, intensive therapy in the first days of a child's life [Himmelman K., Ovebrant P. 2018].

Cerebral palsy develops under the influence of various causes – prenatal, intranatal and postnatal.

A multifactorial scenario of inheritance of this disease has been identified, which implies the cross-interaction of many genes and environmental factors. The results obtained confirm the assumption that the causes of cerebral palsy go beyond the unfavorable course of events in childbirth [Pak I.A., Makarova S.G., et al. 2019].

Currently, more than 400 factors contributing to the development of cerebral palsy have been described, but in general, the etiology of this disabling disease is still unclear. Insufficient study of the causes of cerebral palsy makes it difficult to plan and carry out targeted measures to reduce its incidence and properly organize patient care.

To reduce the growth of cerebral palsy, it is necessary to identify the most significant risk factors for the development of the disease and develop a system of preventive measures to prevent the occurrence of this pathology in the prenatal, intranatal and postnatal periods of child development.

The purpose of the study

To study medical and social care for children with cerebral palsy and develop scientifically based approaches to improve this care at the level of primary health care.

Research objectives

1. To analyze the prevalence, structure, dynamics of cerebral palsy in the Republic of Kazakhstan.
2. To study the risk factors for the development of cerebral palsy
3. To assess the state of medical and social care for disabled children with cerebral palsy at the level of primary health care.
4. To study the need of children with cerebral palsy in medical and social care.
5. To develop a model for improving medical and social care for disabled children with cerebral palsy at the level of primary health care.

Scientific novelty and theoretical significance of the study:

Up-to-date data on dispensary coverage of children with cerebral palsy at the PHC level have been obtained, which makes it possible to make a forecast about the trend of increasing the incidence of cerebral palsy.

The main risk factors for the development of cerebral palsy are prenatal and neonatal factors in combination with extragenital pathology, there is a combination of two or more risk factors.

The quality of medical and social care for children with cerebral palsy and their families remains at an unsatisfactory level due to low availability of care, late diagnosis of the disease, which leads to untimely treatment and complications and lack of psychological assistance.

A model of improving medical and social care for children with cerebral palsy at the PHC level has been developed and scientifically substantiated, a register of patients with cerebral palsy has been developed, which is an integral part of this model.

Practical significance of the study

It consists in the development of a comprehensive program for early detection of signs of cerebral palsy, which made it possible to improve medical and social care for children with cerebral palsy at the level of primary health care.

Based on the results of the study, data were obtained on the dynamics, level, causes and structure of children's disability, the state of medical and social assistance to disabled children with various pathologies, which are necessary for

bodies and organizations of practical health and social protection of the population to substantiate and develop medical and social measures aimed at timely rehabilitation.

Provisions submitted for protection

There is a tendency to increase the number of patients with cerebral palsy registered at the dispensary, both among the adult population and among children. The indicator of dispensary coverage does not fully reflect the prevalence of cerebral palsy among the population, but as a sign that closely correlates with it, it can serve to determine the epidemiological trends of this disease

The structure of clinical forms of cerebral palsy was dominated by spastic diplegia (33.8%), which was established in every third child. Every fourth child (23.4%) was exposed to a mixed form of cerebral palsy. This pattern allows us to determine a set of measures to train medical workers at the PHC level for early detection of deviations and alertness regarding the development of this pathology.

The data obtained indicate late diagnosis of cerebral palsy in more than half of cases, which leads to untimely provision of medical and social assistance to children, disability and a decrease in the quality of life of children with cerebral palsy and their families. The main reasons for dissatisfaction with the quality of medical and social care are low availability of social services, a short period of rehabilitation, and a low level of professionalism of specialists.

The model of improving medical and social care for children with cerebral palsy is a comprehensive system based on the development of digitalization, taking into account not only medical, but also social aspects, the implementation of which can contribute to reducing mortality, disability and morbidity among children.

Materials and methods of research

Research materials:

Official statistics of Medinfo, RSEZ at the National Center for E-Health".

Primary medical documentation of participants and their mothers: an extract from the maternity hospital (form No.113/y), the history of the development of a newborn (form No. 097/y), the history of childbirth (form 096/y), an exchange-notification card or an individual card of a pregnant woman (form 111/y), the history of the development of a child (form 112/y), discharge from the hospital (form 027/y).

Questionnaire for parents on the study of medical and social care for children with cerebral palsy at the level of primary health care.

Research methods:

1. Information and analytical
2. Statistical
3. Sociological (questionnaire method)
4. Predictive

Conclusions:

1. Analysis of statistical data showed that during the study period, there was a general trend towards an increase in the incidence of cerebral palsy among the population of the Republic of Kazakhstan.

In dynamics, the incidence of cerebral palsy in the Republic, during the study period, increased by 29%. In the North Kazakhstan region (North Kazakhstan region), from 54 cases in 2013, it increased to 96 cases in 2022 by 55%. Similarly, in the South Kazakhstan region (SKR), from 67.2 in 2013, there is a tendency to increase to 97.5 in 2022 by 33%. In the West Kazakhstan region (WKO) from 23 in 2013 to 33.7 in 2022 by 34%. In the East Kazakhstan region (East Kazakhstan region) from 38.9 in 2013 to 68.6 in 2022. the incidence rate increased by 39%.

The incidence of cerebral palsy among the population of Almaty exceeds the same indicator in the Republic of Kazakhstan during the entire study period by an average of 1.5 times.

2. The main risk factors for the development of cerebral palsy were premature birth (52.1%), burdened obstetric history (86.0%), low women's health index, complicated pregnancy (infectious diseases (up to 45.3%), hypertensive complications (up to 44.7%) and prenatal or premature rupture of fetal membranes (45.3%), pathology placenta (acute placental insufficiency – premature detachment of the normally located placenta (7.3%) and chronic placental insufficiency (14.6%).

3. Children with cerebral palsy have severe intrauterine asphyxia (74.7%), birth trauma (up to 16%). The main risk factors for the development of cerebral palsy in newborns in the neonatal period are prematurity and immaturity (52.1%), severe intrauterine asphyxia (81.4%), hyperbilirubinemia of full-term newborns (38.7%) and premature infants (55.3%), nuclear jaundice (36.7%), hemolytic disease of newborns (38.0%), severe infections with septic condition (38.0%), convulsions (16.0%), injury of the cervical spine (16.0%).

Also, the leading risk factors for the development of cerebral palsy in neonatal infants are hypoxic-ischemic encephalopathy (25.3%), grade II cerebral ischemia (70.7%), cerebral excitability (46.0%), cerebral depression (28.7%), neonatal coma (27.3%), grade II intraventricular hemorrhages (76.7%), periventricular leukomalacia (47.3%), severe metabolic acidosis (25.3%), hypocapnia (19.3%).

4. Statistically significant risk factors for the formation of hemiplegic cerebral palsy were: the age of the mother over 30 years ($p=0.030$), untreated anemia ($p=0.028$), concomitant diseases – epilepsy ($p=0.017$), encephalopathy ($p=0.030$). Statistically significant risk factors for the development of dyskinetic form were: the age of the mother over 30 years ($p=0.03$), microcephaly ($p=0.021$), tight cord entanglement ($p=0.017$). The atonic form of cerebral palsy was more often observed at birth from mothers older than 30 years ($p=0.030$). The mixed form of cerebral palsy was more common with tight umbilical cord entanglement with fetal intrauterine hypoxia ($p=0.017$).

5. The most common reason for not providing the necessary services is the lack or absence of specialists and the absence of the necessary staffing in medical organizations. All families are recipients of social support measures at the Center for social protection of the population, but remain dissatisfied with the quality of social services.

The main reasons for dissatisfaction with the quality of social services - 43% of parents noted that a small period of time is allocated for classes with specialists and lack of access to assistance, 23% - lack of professionalism of specialists, 34% indicated a large number of necessary documents.

When studying the social and living conditions of living, 21.4% of family members identified the need for employment. When determining the sources of income of families, they mainly pointed to wages – 78.6%, benefits - 21.4%.

6. The results of the study indicate a high need for families to expand the volume and improve the quality of medical and social care provided, take urgent measures to improve the accessibility of the environment, landscaping, adaptation of places of residence and revision of the educational process for children with cerebral palsy.

7. The model developed based on the results of the study to improve medical and social care for children with cerebral palsy can help reduce morbidity, disability and mortality among children.

8. The developed project of the information database (register) of children with cerebral palsy makes it possible to dynamically monitor the patient's condition and allows analyzing the data obtained to achieve the best results of a clinical, scientific, economic and social nature.

Publications

12 scientific papers have been published on the topic of the dissertation, including: 2 articles indexed in the Scopus database; 4 - in scientific journals recommended by the Committee for Quality Assurance in the Field of Science and Higher Education of the Ministry of Science and Higher Education of the Republic of Kazakhstan; 5 scientific papers published in collections and materials of international scientific and practical conferences; 4 - in the domestic and 1 - in a foreign scientific publication.

Structure and scope of the dissertation

The dissertation is presented on 151 pages of computer text, consists of an introduction, 5 chapters, conclusions, practical recommendations, a list of references, including sources, of which 60 are in Russian and 136 in foreign languages. The dissertation is illustrated with 32 tables, 49 figures, and contains appendices.