#### ANNOTATION

### of the dissertation work of Sairankyzy Saltanat on the topic «Improvement of medical and social care for children with bronchopulmonary dysplasia» for the degree

Doctor of Philosophy (PhD) in the specialty 6D110200 - «Public Health»

#### **Relevance of the problem**

Preservation and strengthening of children's health is one of the relevant problems of public health. The solution to this problem is of high social significance and is one of the most important priority tasks of the State Health Development Program of the Republic of Kazakhstan «Densaulyk for 2016-2019 [State Program for 2016-2019 «Densaulyk»]. Within the framework of the Program, it is planned to further develop perinatal medicine, improve interaction between obstetric-gynecological and pediatric services, introduce international standards of the World Health Organization (WHO) and diagnostic and treatment protocols for obstetrics, neonatology and pediatrics, developed on the basis of scientific evidence-based medicine. At present, the main reforms started in this program are continued within the framework of the new State Health Development Program for 2020-2025 [State Health Development Program of the Republic of Kazakhstan for 2020-2025].

Thanks to the new criteria for registration of the perinatal period recommended by WHO, in recent years the number of newborns with low and extremely low birth weight has increased in the world. According to the World Health Organization, 15 million babies are born prematurely every year, which is 10% of all newborns. And their frequency is growing in almost all countries. The rate of prematurity in recent years is on average 10.02% in the USA, 8.0% in the UK, 7.7% in Germany, 5.7% in Japan, and 10% in Russia [Martin J.A. et al., 2019; Story L. et al., 2019; Kramarz S., 2020; Takahashi Y. et al., 2017; Shuvalova et al., 2015;]. According to the statistical compilation of the Republic of Kazakhstan, in 2019, 5.5% of pregnancies ended prematurely, and over the past 10 years there has been a tendency to increase this indicator [Statistical digest of the Republic of Kazakhstan, 2020].

One of the most common diseases among premature babies that affect their quality of life is bronchopulmonary dysplasia (BPD). BPD is a severe disease manifested by respiratory failure, recurrent episodes of bronchial obstruction and characterized by a large number of comorbidities [Michael Collaco J. et al, 2011]. Children with BPD outcomes have a high risk of developing chronic obstructive pulmonary disease, which ranks first in terms of disability and mortality among adults and brings a heavy burden to the state [Sokol E.B. et al., 2011]. Therefore, in order to reduce child disability and mortality, as well as for a possible favorable outcome of the disease, dispensary observation and rehabilitation of this contingent of children is especially important. In recent years, a number of scientists have raised this issue and conducted various scientific studies [Ovsyannikov D.Yu., 2017; Kovalova O.M. et al., 2015; Kicha et al., 2018].

In connection with the improvement of nursing of very preterm infants, in recent years in our country there has been an increase in the incidence of BPD. That is why today in the country the problems of BPD are of great interest to specialists working in this field, which can be seen in the publication of a number of domestic scientific articles on BPD [Tusupkaliev B., 2013; Almukhambetova S.M., 2013; Batyrkhanov Sh.K. et al., 2018; Lee T.A. et al., 2018; Baimoldanova A.B. et al., 2020].

The disability of children, the presence of concomitant diseases, the transition in the next decade of children with bronchopulmonary dysplasia to the adult network, the lack of awareness of pediatricians about this disease, the frequency of errors in the diagnosis of the disease and the management of patients - all this gives BPD not only medical but also great social significance [Bronchopulmonary dysplasia in children. – M.: 2012]. However, in domestic and foreign science, there are few studies on the medical and social problems of children with BPD. In addition, these studies were limited to scientific articles only.

All this became the basis for the planning and implementation of this dissertation.

## **Purpose of the study:**

To develop a model for improving the quality and efficiency of medical and social care for children with bronchopulmonary dysplasia, having studied the follow-up of children with this pathology.

To achieve this goal, the following tasks were solved:

1. To determine the frequency and risk factors for BPD in newborns.

2. To analyze the health status of children with BPD in dynamics and to establish outcomes by the age of three.

3. Determine the medical and social characteristics and medical activity of families, identify their needs for the main types of medical and social assistance.

4. Assess the quality of life of children with BPD and survivors of the disease.

5. Develop a scientifically based model for improving medical and social care for children with BPD.

### Scientific novelty

The scientific novelty of the study lies in the fact that, **for the first time** in Kazakhstan, a comprehensive research work was carried out to improve medical and social care for children with BPD. It includes the following provisions, which were first defined in domestic science:

The study determined the frequency of patients with BPD among newborns born in the Almaty City Perinatal Center and identified the main risk factors contributing to the development of the disease.

A comprehensive assessment of the health status of children with BPD after discharge from the II stage of nursing was carried out. The outcomes of the disease in children by the age of three were determined. In the course of the study, medical and social factors affecting the health of a child with BPD were identified through a sociological survey conducted with parents using a specially designed author's questionnaire.

Using the international questionnaire PedsQLtm 4.0, the quality of life of children with BPD and those who had the disease was assessed in polyclinics in Almaty.

A model for improving medical and social care for children with BPD has been developed and scientifically substantiated. For the first time, a register of patients with BPD has been developed, which is an integral part of this model.

## **Practical significance**

### At the health system level:

A register of patients with BPD (bld.bolimi.kz) was created and implemented in polyclinics, which allows collecting a database of patients and monitoring them in dynamics, identifying medical and social problems affecting the health of sick children.

A model has been developed to improve medical and social care for children with BPD, which is an integral system consisting of four interrelated sections (organizational, medical, socio-psychological, educational), aimed at a long-term reduction in morbidity, disability and mortality among children.

At the level of a medical organization:

The risk factors identified in the study can be used to predict and prevent the development of BPD in organizations providing care to newborns and women of childbearing age.

A questionnaire specially developed within the framework of the study (Appendix A) can be used to determine the medical and social problems of families with children with BPD, as well as with premature babies.

At the level of educational organizations:

The results of the research work make it possible to develop a work program for training students of medical universities, postgraduate educational institutions, as well as for advanced training of neonatologists and pediatricians, and can become the basis for the development of new clinical protocols.

### **Provisions for defense**

1. The incidence of multifactorial BPD, which is characterized by an exacerbation of complications among children under one year old, often amounts to mortality rates (18.8%). In addition, the frequency of severe comorbid diseases (28.1%) indicates a high level of disability among children. In accordance with the study period, the dynamics of BPD increased (from 0.2% in 2013 to 0.4% in 2017), especially among preterm infants (from 1.3% in 2013 to 2.9% in 2017). There was established a dependence of risk factors for BPD among children, including antenatal, intrapartum (edema during pregnancy (p=0.009)), abundance of amniotic fluid (p=0.035), antenatal steroid prophylaxis of RDS (p<0.001)) and neonatal risk factors (respiratory distress infant syndrome (p=0.007) with oxygen concentration (FiO2) > 40% (p<0.001)) in the respiratory mixture. As parents age, the chance of developing BPD increases;

2. Families with children with BPD are characterized by a low social and living condition, the need for medical and social support, among them there are high rates of the impossibility of drug provision of the child (44.1%), the need to contact specialists (55.9%). The quality of life of sick children with BPD is lower in all vital parameters compared to healthy children. Especially in children aged 2-4 years, the difference in quality of life is obvious (p<0.001);

3. The organization of care for children with BPD requires improvement in the provision of medical and social care. The model for improving medical and social care is presented as an integrated system based on effective digital development to reduce mortality, morbidity and disability among children. Accelerating the introduction into healthcare practice of the compiled "Register of patients with bronchospasm" will allow to combine all data on patients and timely identify and solve medical and social problems of children.

## **Conclusions:**

1. In the CPC of Almaty, the frequency of BPD among all live births increased from 0.2% (2013) to 0.4% (2017), among preterm infants from 1.3% (2013) to 2.9% (2017). Mortality in children with BPD under the age of 3 months decreased from 29.4% (2013) to 18.2% (2017);

2. According to the results of multiple logistic regression, antenatal and intranatal risk factors for BPD are: arterial hypertension (p=0.042), edema of pregnancy (p=0.009), polyhydramnios (p=0.035), antenatal steroid prophylaxis of RDS (p<0.001), chronic bronchitis (p =0.055); neonatal risk factors for BPD are: respiratory distress syndrome of the newborn (p=0.007), oxygen concentration in the inhaled mixture (FiO2) > 40% (p<0.001). Also, the results of multiple logistic regression showed that the older the age of the parents, the greater the likelihood of developing BPD;

3. BPD is characterized by regression of clinical signs of the disease as the child grows. The main outcome of BPD by the age of three was a clinical recovery of 62.5%; chronic bronchitis was diagnosed in 15.6% of children. However, a high mortality rate among children with BPD was determined (21.9%). Of these, mortality up to a year was 18.8%. In children with BPD, the following comorbidities were diagnosed with a high frequency: psychomotor retardation 65.6%, cerebral palsy 17.2%, retinopathy 62.5%, anemia 39.1%, protein-energy malnutrition 15.6%. The presence of no less severe comorbidities determined the high disability among children with BPD (28.1%). Of these, BPD disability was detected in 4.7% of children;

4. The lack of immunization against RSV infection led to an increase in the frequency of exacerbations, pneumonia, and hospitalizations of sick children. The frequency of exacerbations was statistically significantly higher in the first (p<0.001), second (p=0.016), third (p=0.013) years of life in a child with BPD. The frequency of hospitalizations due to exacerbations was significantly more often detected in the first year of life (p=0.041). Pneumonia was also significantly more often diagnosed in children with BPD at the first (p<0.001), second (p=0.004), and third (p=0.005) years of life;

5. The medical and social characteristics of a family with a child with BPD or a child who has had the disease is characterized by an older age of the mother (p=0.046) and father (p=0.007). More than half (52.9%) of fathers of children with BPD smoke (38.1% in the CG), smoking mothers (5.9%) were found only in these families. These families are characterized by a low socio-economic status. There was a high frequency of families in need of receiving medicines (44.1%) and examination by specialists 55.9 %;

6. The quality of life of children with BPD and survivors of the disease is lower than that of peers without BPD in all respects. Especially the quality of life is significantly low (p<0.001) in children aged 2-4 years. The total score was  $67.52\pm17.3$  (in the CG  $86.5\pm9.12$ ). In children aged 5-7 years, the overall score was also low and amounted to  $69.91\pm17.86$  ( $80.13\pm16.44$  in the CG). However, no statistically significant differences were found in this group in terms of quality of life parameters (p>0.05);

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

#### **Publications**

The materials of the dissertation work were published in 13 scientific papers, of which 1 article in a journal indexed in the Scopus database, 6 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 - "Bulletin of KazNMU", "Astana Medical Journal", "Pediatrics and pediatric surgery", 6 publications in the collections of international conferences: "Integration of the Scientific Community to the Global Challenges of Our Time" Materials of the V International Scientific - Practical Conference. (Tokyo, Japan, 2020); XV international scientific and practical conference of young scientists and students "Modern problems and promising directions of innovative development of science" (Tajikistan, 2020); Of international scientific – practical conference of students and young researchers "Apsatar reading: "New vectors in science of the 21st century: questions, hypotheses, answers" (Almaty, 2019), Proceedings of the scientific and practical conference with international participation "Innovative technologies in Service of Perinatology and Pediatric Cardiac Surgery" in honor of the 30th anniversary of the Independence of the Republic of Kazakhstan and the 10th anniversary of the opening of the Center for Perinatology and Pediatric Cardiac Surgery (Almaty, 2021), Materials of the IX Congress of Pediatric Doctors of Kazakhstan "Achievements and Prospects for the Development of Pediatrics and Pediatric Surgery" (Almaty, 2021), Materials of the IV International Scientific and Educational Forum "Mother and Child" (Almaty, 2021), Materials of the IX Congress of Children's Doctors of Kazakhstan "Achievements and Prospects for the Development of Pediatrics and Pediatric Surgery" (Almaty, 2021).

### Implementations

Acts of implementation of the "Register of Patients with BPD" were received in polyclinics in Almaty (CP No. 1, CP No. 2, CP No. 22, CP No. 23,

# CP No. 25).

# Innovative patents, copyright certificates

1. Author's certificate No. 16560. «Questionnaire to study the medical and social characteristics and medical activity of families with children with bronchial dysplasia» 2021.

2. Copyright certificate No. 21378. «Register of patients with bronchopulmonary dysplasia» (bld.bolimi.kz) 2021.

# The structure and scope of the dissertation

The dissertation is presented on 170 pages and consists of an introduction, a review of the current state of the problem, research methodology, 5 chapters of personal research, conclusions, findings, practical recommendations, a list of references. The dissertation contains 42 tables, 33 figures, 226 literature sources.