

Problems of organization of medical and social care for children with bronchopulmonary dysplasia.

Saltanat Sairankyzy¹, Daniyarova Anara², Dossybayev Murat², Datkhayeva Zaure³, Anambayeva Aigul³, Kemelbekov Kanatzhan^{5*}, Kuandykov Yerlan⁴, Makhatova Venera^{4,6}, I Ishigov⁴, J Akhtamanov⁴, R Zhumabekova⁴, A Kulmakhanbetova⁴, S Zhumashov⁴

¹Department of Public Health, Kazakhstan Medical University, Kazakhstan's School of Public Health, Almaty, Kazakhstan

²Department of Public Health, Al-Farabi Kazakh National University, Almaty, Kazakhstan

³Department of Public Health, Kazakh National Medical University Named after SD Asfendiyarov, Almaty, Kazakhstan

⁴Khoja Ahmet Yassawi International Kazakh-Turkish University, Turkistan, Kazakhstan

⁵Department of Public Health, South Kazakhstan Medical Academy, Shymkent, Kazakhstan

⁶Department of Public Health, Center for Continuous Professional Development, Shymkent, Kazakhstan

Abstract

Background: Bronchopulmonary dysplasia is a controversial disease of premature infants, manifested by shortness of breath, recurrent pneumonia and bronchitis. In Kazakhstan, as well as throughout the world, in recent years, bronchial dysplasia is increasingly common in children. However, the problems of bronchopulmonary dysplasia in Kazakhstan are not fully understood. This study will focus on monitoring the medical and social care provided to children with bronchopulmonary dysplasia and their families in Almaty.

Methods: The study involved 34 children with bronchopulmonary dysplasia and their families and 64 children without bronchopulmonary dysplasia and their families. The research was carried out using a specially developed questionnaire.

Results: The average age of parents of children with BPD was higher than in the control group. It turned out that 52.9% of fathers and 5.9% of mothers of sick children smoke. Families with two or three children were more common ($p=0.011$). The share of families with disabled children was 17.6%. Despite this, the monthly income of families is low. The main reason for bad family relations is the child's illness (29.4%). After the birth of a child, only 29.4% of mothers worked in a profession, while the majority of mothers were engaged in household chores (64.7%). 47.1% of fathers had a job; 5.9% were unemployed. It turned out that the parents have good potential to rehabilitate the sick child, but they cannot get all the necessary medical services in the clinic. It turned out that only 17.6% of clinics have pulmonologists, despite the fact that sick children need regular follow-up by a pulmonologist.

Conclusion: The data obtained made it possible to identify the necessary medical and social problems for children with BPD. It is clear that such children and their families need government support.

Keywords: Bronchopulmonary dysplasia, Premature birth, Medical and social care, Family.

Accepted on June 24th, 2021

Introduction

Thanks to the new criteria for registration of the perinatal period recommended by the World Health Organization (WHO), in recent years, the number of newborns with underweight and extremely low birth weight has increased in the world. According to the WHO, 15 million babies are born prematurely every year in the world, which is 10% of all babies. At the same time, its frequency is growing in all countries [1]. For example, over the past ten years, the average birth rate in the United States is 10.1%, in the UK: 7.8%, in France: 7.2%, in Germany: 9%-10%, in Norway: 7.9%, in Hungary and Russia: 10% [2]. According to the statistical digest

of the Republic of Kazakhstan, in 2019 5.5% of pregnancies ended in preterm birth, and this indicator tend to increase over the past decade [3].

High morbidity, disability and mortality are the most common problems among premature babies. Bronchial Dysplasia (BPD) is one of the most frequent diseases of premature infants affecting the quality of life of children. On average, 35%-39% of children under 32 weeks of age and 70% of children born with extremely low birth weight develop BPD [4]. To reduce child disability and mortality, it is important to keep these children under dispensary supervision and rehabilitation. In

recent years, a number of scientists have raised this issue and conducted various studies [5-7].

BPD is one of the most serious diseases, manifested by respiratory failure, recurrent bronchitis and pneumonia [8]. These children also have many additional diseases. Therefore, the social status of their families and the medical activity of their parents play an important role in the recovery of sick children. Many scientists in different years have conducted research on the medical and social problems of families with children with various diseases. However, in domestic and foreign medicine, there are no studies devoted to the medical and social problems of children with BPD. The above factors prompted us to conduct this study. The research is aimed at identifying socio-economic factors affecting the birth of premature babies, and the possibility of further monitoring, to identify typical family problems and rehabilitative potential in order to make possible predictions of the support they need.

Methods

This study was carried out in one of the largest cities of the Republic of Kazakhstan-Almaty. The study involved 20 medical organizations providing outpatient care to the population of Almaty. The studied children are premature babies born in the City Perinatal Center of Almaty in 2013-2017. The main group consisted of 34 children with BPD and their families, the control group consisted of 63 children without BPD and their families.

A special questionnaire was developed to assess the medical and social assistance provided to children and their families with BPD. The questionnaire consists of two sections. The first part consists of questions to determine the medical and social characteristics of the family. The second section covers issues related to the medical activity of parents, the organization of medical care, the determination of the necessary medical and social assistance. The survey was conducted from December 2019 to February 2020. The survey was conducted by inviting parents to the polyclinic.

Before the start of the study, it was considered at a meeting of the ethical committee of the higher school of public health of the Kazakhstan medical university and a special permit was obtained (protocol No. IRB-A101). Statistical processing and data analysis were performed using the Statistical Package for Social Sciences (SPSS) computer program (version 36.0). During the initial statistical analysis, the frequency (percentage) of the data was determined. To compare data between groups, student's *t*-test and Mann-Whitney test were used. In the case of $P > 0.05$, the differences were considered statistically significant.

Results

According to the results of the study, gender differences were not found. 47.1% of children with BPD were boys and 52.9% girls, in the control group: 57.1% boys and 42.9% girls. By age, children were divided as follows: 1 year old 5.9% in the main group, 7.9% in the control group, 2 year old 29.4% in the

main group, 25.4% in the control group, 3 year old 29, 4% in the main group, 20.6% in the control group, 8.8% in the main group of 4 year olds, 19.0% in the control group, 20.6% in the main group of 5 year olds, 15.9% in the control group, 5.9 in the main group of 6 year olds, 6.3% in the control group, 7 year olds were not found in the main group, 4.8% in the control group. In both groups, more than 80% were children aged 2 to 5 years.

The social and living environment in which children live affects their health, development, and their emotional and psychological well-being. Obviously, this is especially important for sick children. Therefore, in our study, the first was a medical and social description of a family raising a child with BPD. Large families prevailed in both groups: 88.2% in the main group and 88.9% in the control group. The age of mothers and fathers of children with BPD was older than in the control group. The average age of the mother in the main group was 34.4 ± 4.8 years, in the control 31.9 ± 5.8 years: The median was 35 (27;44) and 30.0 (21,45), respectively ($p=0.046$). The average age of the father in the main group was 37.3 ± 5.4 years, in the control 34.2 ± 6.5 years: median -37.0 (29,47), respectively, in the control group 33.0 (23,50) ($p=0.007$).

There were no significant differences between the groups in terms of the mother's education level. Mothers with secondary education accounted for 20.6% in the main group, 31.7% in the control group, mothers with specialized secondary education 38.2% in the main group, 34.9% in the control group, mothers with higher education 41.2% in the main group, 33.3% in the control group% met. Fathers with secondary education 23.5% in the main group, 42.9% in the control group, fathers with secondary specialized education 23.5% in the main group, 27.0% in the control group, fathers with higher education 52.9% in the main group, 30.2% in the control group% met.

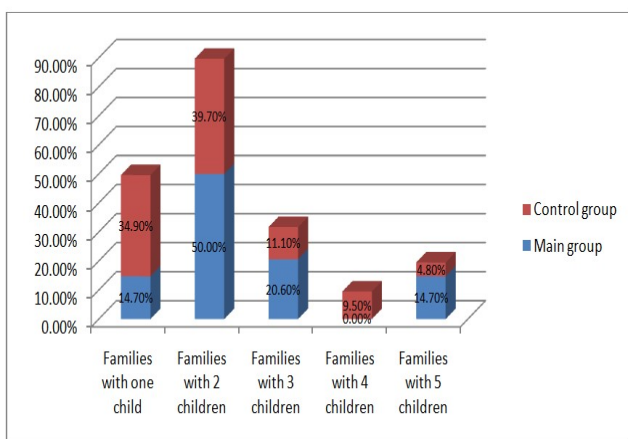
There were more fathers with higher education in the main group, and in the control group with secondary education. In the main group, the number of mothers who worked after childbirth was less than in the control group, amounting to 29.4% and 41.3%, respectively. As noted above, despite the fact that in the main group there were more mothers with secondary specialized and higher education than in the control group, 64.7% of mothers were housewives, while in the control group there were slightly less than 60.3%. Serving mothers made up 17.6% in the main group, 11.1% in the control group, working mothers 17.6% in the main group, 28.6% in the control group. Despite education, working fathers made up 47.1% in the main group and 42.9% in the control group. Office fathers met in the main group 23.5%, in the control group 28.6%, self-employed fathers in the main group 23.5%, in the control group 28.6%. Unemployed fathers make up only 5.9% of the main group.

According to the research, more than half of fathers of children with BPD smoke, which is 52.9%, and in the control group 38.1%. In addition, smoking mothers were found only in the main group and amounted to 5.9%. In one family of the main group, in two families of the control group, both parents

smoked, 2.9% in the main group and 3.2% in the control group. Families with one child accounted for 14.7% in the main group, 34.9% in the control group, families with two children 50.0% in the main group, 39.7% in the control group, families with three children 20.6% in the main group, 11.1% in the control group, families with four children did not meet in the main group, but accounted for 9.5% in the control group, 14.7% of families in the main group and 4.8% in the control group had five children. Families with one child were more in the control group, while families with two and three children were more in the main group. The differences between the groups were significant ($p=0.011$). The details are shown in Figure 1. The share of families with other disabled children was almost three times higher in the main group, 17.6% in the main group and 6.3% in the control group.

Figure 1. Number of children in the family.

The average monthly income per family member in the study is shown in the table below (Table 1). In the analysis of the financial security of families raising children with BPD, in both groups, in more than 80.0% of cases, the income per family member was less than the subsistence level (82.4% and 84.1%). At the time of the study, the subsistence level in Kazakhstan was 29,698 tenge [9]. However, per family member income of up to 10,000 tenge and families earning from 10,000 to 15,000 tenge were more common in the main group, 32.4% and 26.5%, in the control group such families were 19.0% and 17.5%.



Indicators	Groups				P value	
	1		2			
	Actual number	%	Actual number	%		
Average monthly income per 1 family member	Up to 10,000 tenge	11	32.4%	12	19.0%	0.158
	From 10,000 to 15,000 tenge	9	26.5%	11	17.5%	
	From 15,000 to 20,000 tenge	5	14.7%	15	23.8%	
	From 25,000 to 30,000 tenge	3	8.8%	15	23.8%	
	From 30,000 to 35,000 tenge	3	8.8%	2	3.2%	
	More than 35,000 tenge	3	8.8%	8	12.7%	

Table 1. Average monthly income of families.

Families whose financial situation deteriorated after the birth of a child were also more common in the main group, at 26.5% and 14.3%, respectively. Unfortunately, the main reason for the poor relationship in the family raising a child with BPD is the

child's illness (29.4%). The main reason for poor family relationships in the control group was the lack of free time of parents (31.7%). The reasons for poor family relationships are shown in more detail in Table 2.

Indicators		Groups				p
		1		2		
		Actual number	%	Actual number	%	
The root cause of poor family relationships	Feeling tired and hopeless	3	8.8%	3	4.8%	0.191
	Parental involvement of spouses	2	5.9%	4	6.3%	
	The child's illness	10	29.4%	12	19.0%	
	Disagreements in child rearing	5	14.7%	2	3.2%	
	Financial difficulties	5	14.7%	12	19.0%	
	The mother is overburdened	2	5.9%	10	15.9%	
	Lack of free time	7	20.6%	20	31.7%	

Table 2. Causes of bad family relationships.

Further, in addition to providing medical and social assistance to children with BPD, an analysis of issues related to their health services and needs was conducted. Medical literacy and activity of parents are very important in the rehabilitation of children with serious illnesses. The rehabilitation potential of the parents plays an important role in the recovery of a child with a chronic disease or in the more effective prognosis of the disease. In this study, special attention is paid to this issue and special analytical work is carried out.

According to the results of the study, 67.6% of parents in the main group and 61.9% in the control group considered themselves fully acquainted with the information about the child's illness, 11.8% in the main group and 14.3% in the control group showed the lack of any knowledge, 20.6% of parents in the main group and 23.8% in the control group considered themselves as partially familiar with the information about the child's illness. It was found that the studied children can receive all the necessary medical services from the clinic under medical supervision only in the main group: 44.1%, in the control group: 44.4%. 26.5% of parents in the main group and 25.4% in the control group said they could not get help. The remaining 29.4% of the main group and 30.2% of the control group answered to this question with not regularly. It was found that 88.2% of parents in the main group and 68.3% in the control group were treated by doctors of children's clinics in a timely manner. The difference in these data was statistically significant ($p=0.049$). This may be due to the severity of the child's condition and the parents' concern for the child's health. In both groups, the vast majority of parents said they would follow a doctor's advice, but there were more in the main group, at 94.1% and 87.3%, respectively. The rest of the parents said that they partially follow the doctor's advice, which is 5.9% and 12.7%, respectively.

BPD is a chronic lung disease that develops mainly in premature infants. In our study, all children with BPD were

born prematurely. That is why we pay attention to the opportunities and interests of parents in the development of premature babies. Thus, 29.4% of the information necessary for the development of the child in the main group, 42.9% in the control group parents get from medical workers, 14.7% in the main group, 20.6% in the control group from the scientific and educational literature, 26.5% in the main group, 17.5% in the control group from the Internet, 8.8% in the main group, 7.9% in the control group from the advice from parents, acquaintances and friends, 20.6% in the main group, 11.1% in the control group from development centers. In case of illness, 55.9% of parents in the main group, 58.7% in the control group said that they seek medical help on the first day of illness, 38.2% in the main group and 38.1% in the control group said that they seek medical care on the second or third day of illness, 5.9% in the main group and 3.2% in the control group that they seek medical help only after the third day, if the child's condition does not "improve".

73.5% of parents in the main group and 68.3% in the control group believed that their child should be monitored by a pediatric pulmonologist. Although children in the control group do not have bronchopulmonary diseases, the parents of these children also believe that the baby should be monitored by a pulmonologist. This is probably due to the concerns of parents about the premature birth of children in this group. However, despite the fact that the vast majority of children need a pulmonologist, only 17.6% of pediatric clinics in the main group and 11.1% in the control group had pulmonologist available.

A list of necessary measures was provided to identify the necessary medical and social assistance to families raising children with BPD. The number of selected answers is not limited. The needs of a family raising a child with BPD are shown in Table 3.

Indicators		Groups				P-value
		1		2		
		Actual number	%	Actual number	%	
Organization of child care	Yes	6	17,6%	17	27,0%	0,331
	No	28	82,4%	46	73,0%	
Get a referral to a rehabilitation center for rehabilitation treatment	Yes	11	32,4%	21	33,3%	1,000
	No	23	67,6%	42	66,7%	
Organization of examinations by specialists (doctors)	Yes	19	55,9%	42	66,7%	0,379
	No	15	44,1%	21	33,3%	
Physiotherapy, massage, physical therapy	Yes	16	47,1%	25	39,7%	0,523
	No	18	52,9%	38	60,3%	
Sanatorium treatment	Yes	18	52,9%	28	44,4%	0,524
	No	16	47,1%	35	55,6%	
Getting medicine for the child	Yes	15	44,1%	14	22,2%	0,036
	No	19	55,9%	49	77,8%	
A house adapted to the child's needs (presence of a ramp, daily elevator, ground floor, spacious yard, etc.)	Yes	5	14,7%	5	7,9%	0,313
	No	29	85,3%	58	92,1%	
Legal advice	Yes	2	5,9%	3	4,8%	1,000
	No	32	94,1%	60	95,2%	
Psychologist's advice	Yes	8	23,5%	10	15,9%	0,416
	No	26	76,5%	53	84,1%	
Psychological help, helping the child to find friends	Yes	3	8,8%	2	3,2%	0,340
	No	31	91,2%	61	96,8%	
Financial assistance	Yes	12	35,3%	12	19,0%	0,089
	No	22	64,7%	51	81,0%	

Table 3. Types of necessary medical and social assistance.

According to parents, the majority of children need to be examined by specialists (doctors), 55.9% in the main group and 66.7% in the control group. It can be seen that the least needed type of assistance was the advice of a lawyer, the rate of legal advice was 5.9% and 4.8%. 52.9% in the main group and 44.4% in the control group indicated that their children needed sanatorium treatment. 47.1% of parents in the main group and 39.7% in the control group expressed the need for physiotherapy, massage, physical therapy.

44.1% of children with BPD, 22.2% in the control group need medication. This difference was statistically significant ($p=0.036$). At the same time, in the main group, parents indicated that they needed financial assistance in the majority, 35.3% in the main group and 19.0% in the control group. The proportion of parents who need the advice of a psychologist is more common in the main group, 23.5% and 15.9%, respectively.

"Are you monitored in the catamnesis office?" or "Have you been in control before?" 26.5% of parents in the main group, 39.7% in the control group answered "yes", 8.8% in the main

group and 4.8% in the control group answered "not always". Despite the fact that all the studied children are premature infants, the low proportion of people under observation in the catamnesis room can be attributed to the opening of catamnesis rooms in Almaty only in the second half of 2017. Currently, two catamnesis rooms in Almaty serve premature babies. The first is located in the City Perinatal Center in Almaty, the second in the Center for Perinatology and Pediatric Cardiac Surgery.

Discussion

It can be seen that families with children with BPD do not differ from the control group in many aspects. However, a number of medical and social factors affecting the health of a sick child have been identified. It is noteworthy that the age of mothers with BPD is much older than children without this disease. This is related to the results of other studies [10,11]. In a study conducted in Romania (2019) in determining the respiratory results in premature infants, the average age of the mother among the antenatal factors was 30.81, the median was

34, and the standard deviation was ± 7.73 years. In addition, the study found that fathers of children with BPD were older than the control group. This highlights the importance of preconceptive preparation for both parents by reconsidering the generally accepted view that only the mother should be prepared for pregnancy.

Many recent studies have shown the effects of smoking on the development of respiratory diseases in children [8,10-13]. According to our research, more than half of the fathers of children with BPD are smokers and mothers who smoke are identified only in this group of children. According to the research of Agarkov et al., the data content of the father's smoking more than 20 cigarettes per day during pregnancy in a child with BPD was 90.8, which took 1st place among the negative lifestyles of parents [12]. Another study by Russian researchers found that 25.7% of mothers of preterm infants with BPD smoked before and after pregnancy, as well as during breastfeeding [13].

This is characterized by low socio-economic living conditions of families. Despite the high share of families with two or three children and children with disabilities, there is a low monthly income. It has been established that the main cause of poor family relationships is the child's illness. Although most parents have higher or specialized secondary education, they were not employed. The share of working mothers after the birth of a child is small, most mothers are housewives, and most fathers are workers or do not have a permanent job.

Although parents have a good potential to rehabilitate their children, they have not been able to get all the necessary medical services from the clinic. Despite the fact that sick children need regular monitoring by a pulmonologist, almost all clinics show a shortage of pulmonologists or no specialists at all.

Numerous studies have confirmed the inflammatory process in the pathogenesis of BPD [14]. It has been proven that children with BPD suffer from an inflammatory process in the respiratory tract after the neonatal period, breastfeeding and early childhood, and even older. It affects the lungs, disrupts their development and leads to aggravation of the disease, an adverse outcome of the disease [15]. Therefore, Inhaled Glucocorticoids (IGCS) are widely used in the first years of life after the neonatal period. However, there are conflicting opinions about the use of IGCS in children with BPD. Data on the possibility of inhibition of the process of alveolarization in children, the effect on the nervous system, the high mortality rate among children using IGCS are alarming [16-18]. Currently, there is a need to continue research to assess the efficacy/safety ratio of inhaled steroids in children with disabilities [19].

According to the protocol of diagnosis and clinical treatment of BPD, which appeared in our country in the perinatal period, Budesonide was included in the outpatient treatment in the absence of exacerbation of the disease [20]. However, the study found that children with BPD needed twice as much medication as the control group. These drugs include pulmicort. Given the fact that palivuzimab vaccine is not given

to at-risk children in our country, we can see that the importance of this issue is growing day by day.

Conclusion

Thus, the data obtained from the study will help to identify issues in the organization of medical and social care for children with BPD in Almaty. Children with BPD have a higher risk of developing chronic obstructive pulmonary disease in adulthood. It is obvious that such cases bring great burdens to sick families and the state. Therefore, sick children and their families need continuous medical and social support from the government.

Acknowledgements

We express our gratitude to the chief physicians and deputy chief physicians of the Almaty city polyclinics for the assistance provided during the survey. We also thank all the parents of the children for participating in the survey.

Contributions

All authors substantially contributed to this work.

Conflict of interest

The authors declare that they have no competing interests, and all authors confirm accuracy.

Availability of data and materials

The data used to support the findings of this study are available from the corresponding author upon request.

Significance for public health

Diseases of the respiratory system occupy one of the leading places in the structure of morbidity in premature infants and affect the indicators of infant mortality and child disability. In recent years, bronchopulmonary dysplasia has come to the fore in terms of frequency and clinical significance as the most common form of chronic lung disease in the neonatal period, which is often the cause of chronic obstructive pulmonary disease. The results of the first study conducted in Kazakhstan on this topic will help healthcare organizers understand the need to take measures to improve medical and social assistance to children with this disease.

References

1. Born too soon: The global action report on preterm birth. World Health Organization. Geneva. 2014.
2. Bashmakova NV. The earliest premature delivery: New results. Optimization of clinical outcomes of premature delivery: Ural federal department's experience. Status Presents 2014; 12:13-23.
3. Health of the population of the Republic of Kazakhstan and the activities of health care organizations in 2019: Stat Collection Nur-Sultan 2020.

4. Bolibok AM. Optimization of management of patients with bronchopulmonary dysplasia based on the study of the pathomorphism of the disease: Diss Cand Honey Sciences. Moscow 2017.
5. Ovsyannikov DY. Pulmonary rehabilitation of children with bronchopulmonary dysplasia: Problems and solutions. Rehabilitation for Children and Adolescents 2017; 1:10-8.
6. Kovalova OM, Pokhilko VI, Goncharova YA, et al. Medical and social substantiation of the model of rendering medical care to prematurely born children with bronchopulmonary dysplasia at the post-hospital stage. Family Medicine 2015; 3:239-43.
7. Kicha DI, Poshibailova AV. Medical and social characteristics of bronchopulmonary dysplasia and its prevention according to informative signs and prognostic models. Syst Anal Managein Biomed Syst 2018; 4:1036-40.
8. Collaco JM, Choi SJ, Riekert KA, et al. Socio-economic factors and outcomes in chronic lung disease of prematurity. Pediatr Pulmonol 2011; 46(7):709-16.
9. On the republican budget for 2019-2021: Law of the Republic of Kazakhstan No.197-VI November 30.
10. Leal MC, Esteves-Pereira AP, Nakamura-Pereira M, et al. Prevalence and risk factors related to preterm birth in Brazil. Reprod Health 2016; 13(Suppl 3):163-74.
11. Bogdan RD, Rusu L, Toma AL, et al. Respiratory outcome of the former premature infants. J Med Life 2019; 12(4): 381-94.
12. Agarkov NM, Poshibailova AV. Analysis of the relationship of bronchodilator dysplasia and socio-hygienic risk factors on the basis of informative indicators. Integrative Trends in Medicine and Education 2018; 4:73-4.
13. Panov PV, Akhmadeeva EN, Panova LD, et al. Perinatal history and genetic aspects of BPD formation in deeply premature infants. Practical Medicine 2013; 7:131-35.
14. Dirk Bassler. Inhaled budesonide for the prevention of bronchopulmonary dysplasia. J Matern Fetal Neonatal Med 2017;30:2372-4.
15. Mesconen S, Eronen M, Malmberg LP, et al. Controlled trial of dexamethasone in neonatal chronic lung disease: An 8-year follow-up of cardiopulmonary function and growth. Acta Paediatr 2003; 92(8):896-904.
16. Bassler D, Shinwell ES, Hallman M, et al. Long-term effects of inhaled budesonide for bronchopulmonary dysplasia. N Engl J Med 2018; 378(2):148 -57.
17. Shah SS, Ohlsson A, Halliday HL, et al. Inhaled versus systemic corticosteroids for the treatment of bronchopulmonary dysplasia in ventilated very low birth weight preterm infants. Cochrane Database Syst Rev 2017; 10(10):CD002057.
18. Filippone M, Nardo D, Bonadies L, et al. Update on postnatal corticosteroids to prevent or treat bronchopulmonary dysplasia. Am J Perinatol 2019; 36(S 02):S58-62.
19. Shinwell ES, Portnov I, Meerpohl J, et al. Use of inhaled corticosteroids for the prevention and/or treatment of bronchopulmonary dysplasia in preterm infants: A systematic review protocol. Syst Rev 2015; 4(127):1-5
20. Clinical protocol "Diagnosis and treatment of bronchial dysplasia occurring in the perinatal period", Ministry of Health of the Republic of Kazakhstan, 2015.

***Correspondence to**

S. Sairankyzy

Department of Public Health, Kazakhstan

Medical University Kazakhstan's School of

Public Health, Almaty, Kazakhstan,

Tel: +7(777)4003374.

E-mail: Sairankyzy.saltanat@gmail.com