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Social portrait of families raising children with bronchopulmonary dysplasia.

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Abstract

Background: One of the serious complications of prematurity and respiratory distress syndrome of the newborn is bronchopulmonary dysplasia. Its frequency is growing all over the world, including Kazakhstan. The role of the family is important for the successful rehabilitation of children with severe bronchopulmonary disease. This study was conducted to study the social characteristics of families raising children with bronchopulmonary dysplasia living in the city of Almaty.

Methods: Using a specially developed questionnaire, 34 parents with children suffering from bronchopulmonary dysplasia or with a history of bronchopulmonary dysplasiaand 64 parents of children without bronchopulmonary dysplasia and no history of bronchopulmonary dysplasiawere interviewed.

Results: Families raising a child with bronchopulmonary dysplasia more often had two or three children (p=0.011); among them, other children with disabilities were found three times more often than in families with a child without the disease. Parents of children with bronchopulmonary dysplasia were statistically significantly older. Despite the education of both parents, many mothers (64.7%) turned out to be house wives; in addition, only 29.4% of mothers worked in their specialty after the birth of an ill child. Almost half of the fathers (47.1%) were workers and unemployed fathers were found only in these families. These families had bigger numbers of smoking fathers and smoking mothers were found to only in them 0.8.8% of children with bronchopulmonary dysplasia lived in unsatisfactory conditions and 17.6% of families only had enough money for food. In many families, after the birth of this child, the financial situation worsened. In addition, the parents of these children indicated the child's illness as the main reason for the bad relationships in the family.

Conclusion: According to the results of this study, the social portrait of families with a child with bronchopulmonary dysplasia living in Almaty turned out to be low. These families require support from the state.

Keywords: Bronchopulmonary dysplasia, Premature birth, Social portrait, Family.

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Introduction

Currently, thanks to antenatal corticosteroids, advanced neonatal care, effective respiratory support devices and surfactant treatment, most premature babies survive [1]. However, increased morbidity, disability and mortality are the main problems of premature babies [2].

In recent years, Bronchopulmonary Dysplasia (BPD), as the most common form of chronic lung disease in the neonatal period, is often the cause of chronic obstructive pulmonary disease [3]. BPD is a serious illness manifested by respiratory failure, recurrent bronchitis and pneumonia and is characterized by a large number of comorbidities [4].

Seriously affecting the survival rate and quality of life of premature infants, BPD brings a heavy burden on the family and society [5].

The birth and upbringing of a sick child is a severe psychosocial stress for parents [6]. In addition, the role of the family is important for the successful rehabilitation of a sick child. It is known that the social and household environment in which children live has an impact on their health, development,

as well as emotional and psychological well-being, especially for children with severe illnesses [7].

For the development and improvement of social services for children with BPD in order to ensure their family well-being and social rehabilitation, further study of the characteristics of their families is necessary. This study was carried out in order to study the social and hygienic characteristics of families raising a child with BPD living in the city of Almaty.

Methods

Study design

This study was carried out in one of the largest cities in Kazakhstan-Almaty. There are 26 perinatal centers equipped in Kazakhstan, which are capable of caring for children with a gestational age of less than 28 weeks.

Of these, the City Perinatal Center of Almaty (CPC of Almaty) is the largest obstetric facility in the city of Almaty and in the republic of Kazakhstan for the provision of specialized and highly qualified obstetric-gynecological and neonatological care to pregnant women, women in labor and postpartum women of high risk groups, as well as for nursing premature babies.

Children and newborns are with pathology of the neonatal period. All premature babies of the Almaty region (the city of Almaty and neighboring districts and rural settlements) undergo rehabilitation on the basis of the CPC of Almaty. Therefore, the main base for this study was the CPC of Almaty.

In the period from 2013 to 2017; 39,255 children were born alive in the CPC of Almaty, of which 0.3% (111 children) with BPD. All babies with BPD were premature; BPD was not diagnosed among babies born at term. The majority of children with BPD (55.0%) were born at 22–27 weeks of gestation, 43.2% of children were born at 28–33 weeks of gestational age.

Extreme body weight at birth was 69.4%, very low body weight 21.6%, and low body weight 9.0% of the infant. Of 111 premature infants with BPD, 31.9% (33 infants) died before 3 months in the CPC of Almaty. The remaining 78 children with BPD were discharged from the II stage of nursing under the supervision of a polyclinic at the place of residence.

The control group consisted of 78 premature babies born in the study period in the CPC of Almaty, comparable in terms of gestation and birth weight without BPD. Further, using the "Register of attached population" database, the numbers of polyclinics of the studied children were determined.

The study covered 20 medical institutions providing outpatient - polyclinic care to residents of the Almaty city. Due to migration, as well as difficulties in comparing the data obtained in the CPC of Almaty with the base "Register of attached population", 14 children from the main group and 8 children from the control group dropped out of the study.

In addition, during the study, it was discovered, that 14 children from the main group and 2 children from the control group have died. Thus, 50 families from the main group were included for the survey, of which 16 respondents refused to participate in the study for various reasons, the rest 34 agreed.

While only 5 respondents of the 68 included families from the control group refused, the remaining 63 agreed. A total of 97 families took part in the study.

Characteristics of the studied groups

The criteria for inclusion in the main group were: a child with BPD of varying severity or a child with a history of BPD, any of the sexes, living in a family and consent of parents (guardians) to participate in the study.

The exclusion criteria from the main group were: a child with BPD or a child with a history of BPD, who did not live in the family, and the refusal of the parents (guardians) to participate in the study.

The criteria for inclusion in the control group were: a child without BPD and no history of BPD, of both sexes, living in a family, no acute illness during the last month, and consent of parents (guardians) to participate in the study.

The exclusion criteria from the control group were: a child without BPD and no history of BPD, who did not live in a family, acute diseases suffered within a month before the study, concomitant chronic diseases in the stage of de compensation, and parents' refusal to participate in the study.

Research questionnaire

To determine the social characteristics of the family of a child with BPD, a special questionnaire was developed. The questionnaire included dichotomous, open-ended, closed-ended questions in Kazakh or Russian. Some of the questions were of a retrospective nature.

Taking into account the psycho-emotional peculiarity of the surveyed contingent, as well as in order to exclude associative connections in the answers, some questions were placed in an illogical order and in some cases the same question was asked several times, but in different interpretations, especially if it concerned the well-being of the family.

Questions of an intimate, personal nature, affecting relationships in the family, collective, were not only direct, but also indirect.

The analysis of the answers made it possible to analyze the level of education of parents and the features of their work, the size of the family, the number of children being brought up, the nature of living conditions, the financial situation of the family, the prevailing psychological microclimate in the family.

Collection of information

Before the start of the study, approval was obtained from the Ethics Committee of the Kazakhstan Medical University “Higher School of Public Health” (Protocol No. IRB-A101

dated November 18, 2019). Parents of both study groups were surveyed from December 2019 to February 2020.

Written informed consent was obtained from each parent (guardian) who participated in the study. All personal data were encoded, confidentiality was respected. In general, filling out the questionnaires took 35-40 minutes. The revealed ambiguities and deficiencies in the parents' answers were corrected on the spot by checking the answers to the questions.

Statistical data analysis

Statistical processing and analysis of the data obtained were carried out 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. At p values <0.05, the differences were considered statistically significant.

Results

As the results of the conducted research have shown, in terms of percentage in both groups, children 2-5 years old prevailed (more than 80.0%).

According to the age structure, children were distributed as follows: 1 year old 5.9% in the main group; 7.9% in the control group; 2 years 29.4% in the main group 25.4% in the control group; 3 years 29.4% in the main group 20.6% in the control group; 4 years 8.8% in the main group 19.0% in the control group; 5 years 20.6% in the main group 15.9% in the control group; 6 years 5.9% in the main group 6.3% in the control group; 7 years 4.8% only in the control group.

When comparing the study groups, we found that the number of boys prevailed in the control group (57.1%), in the main group 47.1%.

In the course of the study, data were obtained on the typology of the family (structural composition). The majority of those surveyed were children with complete families (88.2% and 88.9%, respectively).

Families with one child accounted for 14.7% in the main group, 34.9% in the control group; with two children 50.0% in the main group 39.7% in the control group; with three children 20.6% in the main group 11.1% in the control group; 4 children 9.5% only in the control group; with five children 14.7% in the main group 4.8% in the control group.

The share of families with one child was higher in the control group, with two and three children in the main group (p=0.011). The share of families with another child with an established disability was almost three times higher (17.6%) in the main group, and 6.3% in the control group.

However, in statistical analysis, this factor was insignificant and amounted to p>0.05. Most of the parents, 70.6% in the main group and 66.7% in the control group, do not plan to have another child in the near future.

Statistically significant differences in the average age of the parents were found. In the main group, the average age of the mother was 34.4 ± 4.8 years, in the control group 31.9 ± 5.8 years: the median was 35.0 (27; 44) and 30.0 (21; 45), respectively (p=0.046).

In the main group, the average age of the father was 37.3 ± 5.4 years, in the control group 34.2 ± 6.5 years: the median was 37.0 (29; 47) and 33.0 (23; 50), respectively (p=0.007).

Table 1 provides a comparative analysis of the social assessment of parents. 58.8% of mothers in the main group, 81.0% in the control group were Kazakh, 23.5% of mothers in the main group were Russian, and mothers of other nationalities accounted for 17.6%.

This trendoccursrarer than in the control group, among them Russian mothers made up 11.1%, other nationalities 7.9%. Kazakh fathers made up 58.8% in the main group, 79.4% in the control group; Russian fathers 26.5% in the main group, 7.9% in the control group; fathers of other nationalities 14.7% in the main group, 12.7% in the control group. The control group had more children with Kazakh fathers and fewer children with Russian fathers (p=0.042).

Indicators		**Group**				**P**
		Main		**Control**		
		Abs.	**%**	**Abs.**	**%**	
Mother's nationality	Kazakh	20	58.8%	51	81.0%	0.069
	Russian	8	23.5%	7	11.1%	
	Other nationality	6	17.6%	5	7.9%	
Father's nationality	Kazakh	20	58.8%	50	79.4%	0.042*
	Russian	9	26.5%	5	7.9%	
	Other nationality	5	14.7%	8	12.7%	
Mother's education	Secondarygeneral	7	20.6%	20	31.7%	

	Secondaryspecial	13	38.2%	22	34.9%	0.479
	Highereducation	14	41.2%	21	33.3%	
Father's education	Secondarygeneral	8	23.5%	27	42.9%	0.066
	Secondaryspecial	8	23.5%	17	27.0%	
	Highereducation	18	52.9%	19	30.2%	
Social status of the mother	employee	6	17.6%	7	11.1%	0.392
	worker	6	17.6%	18	28.6%	
	housewife	22	64.7%	38	60.3%	
Social status of the father	employee	8	23.5%	18	28.6%	0.194
	worker	16	47.1%	27	42.9%	
	self-employed	8	23.5%	18	28.6%	
	unemployed	2	5.9%	-		

Table 1. Social assessment of parents. *: Differences between groups are statistically significant.

Among the parents of the main group, persons with higher education prevailed (41.2% of mothers and 52.9% of fathers). While the mothers of the control group were evenly distributed by education, and among the fathers there were more (42.9%) people with secondary general education.

In terms of social status, mothers of children of the main and control groups were distributed as follows: employees 17.6% and 11.1%, respectively; workers 17.6% and 28.6%; housewives 64.7% and 60.3%. Among the fathers, the largest share was occupied by workers, who accounted for 47.1% of the respondents in the main group and 42.9% in the control group, 5.9% of children from the main group were brought up in a family where the father was unemployed, there were no such families in the control group. Almost half (41.3%) of mothers in the control group worked in their specialty after the birth of this child, compared with 29.4% of mothers in the main group.

An analysis of the presence of bad habits in parents showed that fathers smoked more in both groups, but more in the main group (52.9%), with only 38.1% in the control group. Smoking mothers were found only in the main group (5.9%). The data are presented in Figure 1.

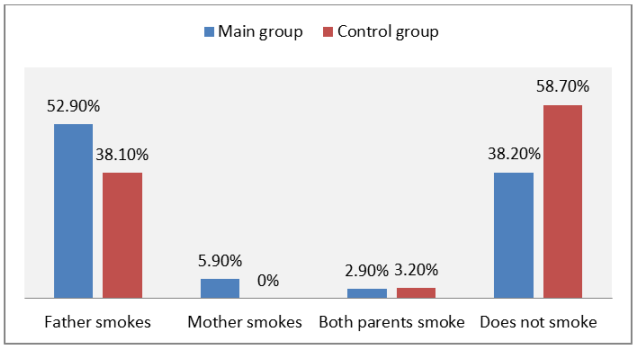

Figure 1. Parental smoking.

In order to judge the conditions and way of life of the studied families, their material situation and living conditions were studied. An assessment of living conditions showed that a child with BPD generally lived in good living conditions (61.8%). In the control group, there were 47.6% of such families.

However, in both groups there were quite a few families living in satisfactory conditions, 29.4%in the main group, 47.6% in the control group. Also, in the main group there were more (8.8%) families living in unsatisfactory conditions, than in the control group (4.8%).

The results of assessing the financial situation of the family in recent years have shown that in the main group twice as often (17.6%) money is enough only for food.

In addition, the majority of parents from the main group believe that after the birth of this child, the financial situation of the family has deteriorated, which amounted to 26.5% and 14.3%, respectively.

In contrast, families whose financial situation improved after the birth of a child were more from the control group (33.3%), compared with the main group (14.7%).

Analyzing relationships in the family, we found that in almost all families, 85.3% in the main group, 79.4% in the control group, the relationship turned out to be calm and benevolent.

However, some parents who noted family relationships as calm and benevolent, nevertheless indicated the reason for the poor family relationships.

We assume that the question of indicating the main causes of poor relationships was in the form of a control question. As follows from Table 2, the main reason for poor relationships in families raising children with BPD, unfortunately, was the child's illness (29.4%), in the control group there was a lack of free time (31.7%).

Indicators		Groups				p
		1		2		
		Abs.	%	Abs.	%	
Main causes of poor family relationships	Feeling tired, hopeless	3	8.8%	3	4.8%	0.191
	Intervention by the parents of the spouses	2	5.9%	4	6.3%	
	Child's illness	10	29.4%	12	19.0%	
	Disagreement in parenting	5	14.7%	2	3.2%	
	Material difficulties	5	14.7%	12	19.0%	
	Heavy burden on a mother	2	5.9%	10	15.9%	
	Lack of free time	7	20.6%	20	31.7%	

Table 2. Causes of bad family relationships.

Discussion

The study showed that families with a child with BPD do not differ in most of the indicators from the control group. However, among the factors that shape the conditions and lifestyle of families raising children with severe chronic pathology, there is a significant number of risk factors that can affect their health.

The average age of the parents of a child with BPD was greater than that of parents whose children did not develop BPD. Similar results have been obtained in other comparable studies [8,9]. For example, in a study conducted by Bogdan et al. about respiratory outcomes in premature infants, the mean age of mothers was also high and amounted to 30.81 years, median 34, standard deviation ± 7.73 years. In addition, in the study conducted by us, the average age of fathers of children with BPD was greater than in the control group. This demonstrates the need to rethink the conventional notion of "preparing women" when planning pregnancy, and shows the importance of preconception training for both parents.

The results of the study showed that more than half of the fathers of children with BPD smoked, in addition, mothers who smoke were found only in this group. Numerous previous studies have shown that maternal smoking is closely associated with preterm birth, low birth weight and impaired lung function in the infant [4,8-10]. In a study conducted in the USA, it was found that the smoking mother doubled the likelihood of having a premature baby with BPD (p=0.02). In addition, maternal smoking was associated with prolonged mechanical ventilation and respiratory support while in the neonatal intensive care unit. Also, premature babies exposed to maternal smoking had higher rates of late respiratory disease [11]. There is also evidence that smoking during pregnancy is a risk factor for impaired lung function and respiratory diseases in term infants [12-14]. An analysis of several cohort studies has shown that maternal smoking during pregnancy increases the risk of asthma at 4–6 years of age by 39%–65% [13]. An interesting result was obtained when studying the nationalities of the parents. The parents of children with BPD were more often Russian or of other nationalities, while the parents of children without BPD was mostly of Kazakh nationality. This data is of great interest and suggest the need for a deeper study of BPD in our republic from the point of view of a possible genetic predisposition, which in recent years has begun to receive more and more attention in the world. Parents of prematurely born children have a higher prevalence of depressive symptoms, which further leads to post-traumatic stress syndromes [15]. Perhaps for this reason, most parents from both the main and control groups do not plan to have another child in the near future.

Raising a sick child requires significant material costs, which negatively affects the financial situation of the family. It was found that families raising a child with BPD, after the birth of a child, are almost twice as likely to worsen their financial situation to the level that the financial resources are enough only for food. In addition, among these families there were more with two or three children, as well as with another child with an established disability. All this affects the family environment, where the main cause of bad relationships was the child's illness. Despite the fact that many parents have higher and secondary specialized education, they have not realized their labor activity. Due to the need for constant childcare, many mothers are forced not to work. It turned out that only 1/3 of mothers work in their specialty after the birth of an ill child; many of them have the status of housewives. The proportion of fathers with the status of a worker was greater in the study group, and also fathers who were unemployed were found only in this group.

Conclusion

Thus, the results of the study made it possible to determine the social characteristics of a family raising a child with BPD

living in the city of Almaty. A family with a child with BPD is characterized by older parents, smoking parents, poor housing and material conditions, low social status of the parents, and in most cases unwillingness to have another child. The data obtained indicate that the majority of families raising children with BPD are socially unprotected and require constant support from the state.

Taking into account that in modern conditions social factors are increasingly influencing the health status of children, the study of the social characteristics of families should be used in a comprehensive study and monitoring of the health status of children.

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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.

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