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FEEDING DIFICULTIES IN CHILDREN WHO UNDERWENT CARDIAC SURGERY FOR CONGENITAL HEART DISEASE IN KOSOVO

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ABSTRACT

Objective is assessing the prevalence and predictors factors of feedings difficulties in children who underwent cardiac open heart surgery in neonatal period and infancy. We address selected nutritional and caloric requirements for children after cardiac surgery and explore nutritional interdependence with other system functions. **Methods** This was a retrospective study in a tertiary referral hospital, and prior approval from the institutional ethics committee was obtained. Information for 78 children (42 male and 36 female) was taken from patients charts. The presence of feeding difficulties or disorders was assessed by a questionnaire when the child was 3 years old. As a feeding disorder was defined as an inadequate food intake for age, failure of thrive or for few cases need for tube feeding. Data were analysed with descriptive statistics and logistic regression. **Results** From cohort of analysed children feeding problems occurred in 23 %. At the time of study, refusal to eat or poor appetite was reported as a significant problem in 19 children and subnormal height and/or weight were recorded in 11 children. Early neonatal intervention and reoperation were identified as a risk factors for latter feeding difficulties or inadequate intake. Children with feeding problems also tended to eat less than children without feeding problems. There was a trend towards more feeding problems in patients with chromosomal abnormalities or other associated anomalies. **Conclusion** Feeding disorder is often and frequent long-term sequel in children after neonatal or early infancy heart surgery. Patients with chromosomal and associated anomalies who underwent multiple cardiac surgeries are at risk of developing feeding difficulties.

KEYWORDS: congenital heart defect, neonatal cardiac surgery, feeding problems, chromosomal abnormalities

What is known?

1. Children with congenital heart disease have problems with feeding caused by heart insufficiency
2. Patients with chromosomal and associated heart disease are at risk with feeding problems.

What is new?

1. Patients with complex congenital heart disease and chromosomal anomalies who underwent multiple cardiac surgeries are at risk of developing feeding difficulties.
2. As a lack of paediatric cardiac surgeries in Kosovo, children with congenital heart disease have been surgically treated in many European and North American centres.

INTRODUCTION

A feeding disorder in infancy and during childhood is a complex condition involving different symptoms such as food refusal and faddiness, both leading to a decreased food intake. It often results from abnormal feeding development. Also, adequate nutrition is crucial and challenge in children after surgery for congenital heart disease. There is a worldwide reason for attention to lesion or specific feeding problems, supplementation of trace elements and minerals, and an organized approach to pace, timing, and type of feeding are beneficial. These patients need to be selected for preventive strategies and nutritional intervention should be offered in order to increase the caloric intake of the child and to develop a sound feeding relationship in the family.

Babies with congenital heart disease often need more calories per day than babies with normal hearts, particularly if they are struggling with symptoms of congestive heart failure. Feeding can be challenging for a number of reasons, so parents and other caregivers often work closely with the baby's healthcare team to make sure the baby is getting enough calories to gain weight and grow.[1,2]

Adequate enteral nutrition may be difficult to achieve early in neonates after cardiac surgery, but it is essential for growth, wound healing, and immune function. Feeding difficulties in infancy and childhood is a complex condition involving different symptoms, such as food refusal or inadequate intake leading to a decreased food intake and malnutrition. Child's feeding development is determined by its constitution, the environment and the child's learning process.[3,4] Pathology in one or more of these components can lead to a feeding disorder. Factors of constitutional origin can be organic diseases, such as disease of organs directly related to food intake or transport, or diseases of other organ systems that disturb the child's feeding and digestion process by impacting on its general health.[5] The child's environment is defined by the parent's behaviour and the family's cultural and social background. Some children start with a purely organic problem, that is, constitutional or mixture of organic and non-organic components. Any imbalance between parental expectations and the child's feeding progress could cause an interaction problem, generating feeding disorders, such as food refusal, avoidance of aversion, on the part of the child. In most patients with feeding disorders, there are a combination of different factors that give rise to the disorder.[5,6,7]

Recent advances in cardiac surgery techniques and progress in the pre- and postoperative care of new-borns and low weighing children have substantially improved the survival of infants with CHD.[4,8] This trend is creating a growing "population at risk" for neurodevelopmental and behavioural problems as well as for the developing of feeding disorders. However feeding disorders tend to be increasingly common, since advances in technology are allowing more very ill children to survive.

Early identification of deficient oropharyngeal motor skills and vocal cord dysfunction is crucial to establish enteral nutrition safely and has been demonstrated to improve clinical outcomes. The use of prealbumin as a marker of nutritional state should be accompanied by C-reactive protein given the influence of inflammation on its levels. Insulin infusions may improve outcomes in patients with postoperative hyperglycaemia. Trace element abnormalities and early identification of immune-compromised states can aid in reducing morbidity in children after cardiac surgery. Use of feeding protocols and a home surveillance system for hypoplastic left heart syndrome improves outcomes of those children.[4,5,9]

The aim of this retrospective study was to describe the prevalence of feeding disorders in infancy and children after open heart surgery. The study included 78 children undergoing open heart surgery for congenital heart defects in neonatal period and infancy between 2005 and 2010. Study group included patients which had survived more than three years after surgery; all patients who did not survive the first 3 years of life after surgery were eliminated from the study.

Study was designed collecting data from medical records of cardiological diagnosis, reports from surgery intervention and outpatient correspondence as well as fellow and assessment 3 years after surgery from paediatrics cardiologist at tertiary level. In the lack of cardiosurgical services in Kosovo all children were sent abroad for surgery. Cardiological diagnosis from the local cardiologist were compared with diagnosis at the centre where the surgery was done and there we found full compliance. Differently from the other centres which used 2 years for reassess the feeding behaviour, we have chosen the period of 3 years as a reason that few children have been sent abroad under treatment with Prostaglandins where possibility for developing neurological consequences are much higher. Otherwise, the period of 2 years is taken from more centres in the world as the ideal period to reassess feeding behaviour and only severe and relevant feeding disorders persist until that age and because the prevalence of the feeding disorders in the normal population has been well defined at the age of 2 years.[7,10,11]

Analysed data included pre-operative data: birth weight, type of congenital heart disease, associated anomalies and syndromes, need for giving Prostaglandins and long term of treating, based on the type of CH. The Cardiac surgery data included: the centre where the surgery was done, the type of surgery, the duration of extra-corporal circulation or the duration of the operation in off bypass operations. Post-operative data included: duration of the mechanical ventilation, total hospital stay, in-hospital feeding parameters which included the duration of tube feeding, the onset of oral food intake, and whether the child was referred to the speech pathologist on account of severe difficulties in swallowing or sucking. In the post-operative data we also have attached neurological findings documented during the routine neurological examination after the operation were labelled as neurologic abnormalities.

To simplify data of cardiac disease included in study all these were divided into two groups based on cardiological findings before the surgery and on the intra-cardiac morphology during the surgery: Group 1: "simple cardiac disease" in which an complete anatomical repair is possible by one intervention. Group 2: "complex congenital disease" in which are necessary two or three cardiac intervention to achieve on anatomical or physiological repair. Most patients of the Group 2 underwent two interventions and whereas few of them are preparing for third-stage of palliation.

Based on the age of children when they underwent surgery all patients are divided into three groups:
Group 1: Children underwent complete cardiac surgery on the neonatal period;

Group 2: Children where the first surgery was in neonatal period and the second was in infancy;
Group 3: Patients where cardiac surgery was done at the infancy period.

The questionnaire was designed to obtain information for quality and quantity of the nutrition, on feeding behaviour and food intake, whether it was appropriate for the age of 3 years old. The questionnaire include also body weight gain, needs for artificial feeding, present of gastro-oesophageal reflux and frequent respiratory infection (aspirate pneumonia).

Feeding disorder was defined as the presence of one or more of the following criteria at the age of 3 years, based on the information given from care provider.
Group 1: Child is partially or completely dependent on tube feeding;
Group 2: Feeding is not adequate for age and mostly is based on the drink or takes pureed food;
Group 3: Child manifests delays in obtaining foods, there is a failure of thrive, the body weight is under third percentile, child manifests anaemia etc.

In the absence of cardiac surgery services in Kosovo all children were sent abroad. Based on the country where surgery was done all children can be divided in four groups:
Group 1: Italy (mostly Genoa, few of them in Bergamo, Padua, Bologna and Verona) – 54/78 (69 %);
Group 2: Albania – 12/78 (15.4 %)
Group 3: Turkey - 6/78 (7.7 %)
Group 4: Other countries 6/78 (7.7 %)

Statistical analysis
Data were analysed using the SPSS 15.0 for Windows statistical software. We analysed continuous variables which are expressed as the median (range) and dichotomous variables as numbers and percentage. Multivariate logistic regression analysis was performed to determine the independent influence of risk factors on abnormal feeding problems. Univariate analyses were performed using the chi square test or Mann – Whitney U-test. Also Spearman's correlation coefficient were calculated to determine the correlation between different risk factors.

RESULTS

The study group consisted of 78 patients. Median birth weight was 3.35 kilograms, with a range from 2.8 to 4.6, median gestational period was 39 weeks (range from 32 to 41 weeks). The patients underwent surgery for CHD at a median age of 16 days, ranging from 8 to 27 days (Group 1), 18 days, ranging from 12 to 31 days (Group 2) and 5 month and 16 days, ranging from three month and 22 days to 7 months and 12 days (Group 3). Clinical signs of heart failure were presented in 43/78 (55 %) patients. Open heart surgery with the use of cardiopulmonary bypass was performed in 62 patients (79 %). The most frequent surgery was resection of the aortic coarctation 21/78 (27 %), large ventricular septa defect 17/78 (22 %) and arterial switch operation for transposition of the great arteries 13/78 (16.6 %). Malformations syndromes were present in 11/78 (14 %) children. (Table 1 and 2).

Initially, feeding through the nasogastric tube was in 43/78 (55 %) children (all neonates and 6 infancies). After 3 years feeding through the nasogastric tube continued only in 3 patients. The remaining patients obtained a nasogastric tube on introduction of the anaesthesia as a routine procedure to start early feeding within the first few post-operative days. None of them needed gastroscopic tube.

Table: 1. Type of congenital heart defect, number of patients and percentage

	N	%
Aortic coarctation	21	27
Ventricular septal defect	17	22
Transposition of the great arteries	13	16.6
Tetralogy of Fallot	8	10
Complete atrioventricular canal	6	7.7
Pulmonary atresia with ventricular septal defect	5	6
Total anomalous pulmonary venous return	4	5
Double outlet right ventricle	3	3.8
Double inlet left ventricle	1	1.3

Table 2. Patients with malformations syndromes and with normal feeding, feeding disorders (FD) and neurological abnormalities (NA).

	Normal	FD	NA
Trisomy 21	2	2	4
Microdeletion 22q11	2	1	0
Turner syndrome	2	0	0
Unclassified dysmorphy syndrome	0	1	1

Feeding status after 3 years

From the study group of 78 children, 9 patients (11.5 %) were diagnosed with feeding disorders. There was noted a strong relationship between the type of the surgery, duration of mechanical ventilation, age at the surgery, duration of perioperative tube feeding and centre where surgery was done (all $R > 0.8$, $p > 0.01$). Patients which undergo complex surgery (univentricular heart palliation, double outlet right ventricle), with small age at the time of surgery, and longer ventilation were more frequent in the group with abnormal feeding compared with those with normal feeding behaviour. Also patients with malformations syndromes manifested higher rate of neurological and feeding difficulties. The multivariate logistic regression analysis included the variables that were significant in the univariate analysis since there was a very high correlation between the three variables: type of CHD, age at operation and reoperation of the univentricular heart.

DISCUSSION

Retrospective analysis of the data of children underwent open heart surgery shows that feeding disorders are a relevant problem on this population. This study has not included all aspects of energy balance as we have not attempt to assess time spent and energy expended in activity, thermogenesis, or other non-resting metabolism. Using a similar definition of feeding problems and age of children at the time of study, the prevalence of severe feeding problems is much higher in population of children who underwent open heart surgery (23 %) in compare with healthy children (1.42 %).[4,6,12] This prevalence is almost as frequent and in correlation with age at the time of cardiac surgery and type-complexity of CHD. Cardiac diseases are a significant constitutional factor which contributes to the development diseases in other organs and systems including a secondary feeding difficulties. Simultaneously, our study shows that at the age of 3 years feeding difficulties were not depended from birth and gestational age, haemodynamics status pre and postoperatively but the greatest impact on the development of feeding disorders have general medical condition such are: age of children who go through the surgery, duration of the medical ventilation and type of surgery, reoperation. Since these three variables were strongly interrelated, only early feeding disorders and multiple surgeries remained significantly associated with feeding problems at age of three years in the multivariate regression analysis.

Besides other relevant influences on the development of feeding disorders in our study significant implication has a fact that children are treated in several different Europeans Centres, mostly in Italian's, and in some of cases cardiovascular system were affected as a consequence of that some are children have been longer treated by Prostaglandins (one 38 and the other one 36 days). From this we can conclude that severe and long hypoxemia, caused by the primary disease and long-term Prostaglandin therapy, are crucial for developing neurological and feeding abnormalities.

There was a high variability of the cardiac diagnoses in our study group. We found that univentricular repair was associated with a higher risk of feeding and neurological disorders in compare with simplex and at once corrected anomalies. This can be explained by the various degree of intracardiac mixing and volume overload, various degree and duration of hypoxemia which is present in children with univentricular heart. These children often require palliative surgery within the first few days of life, followed by at least two other open-heart surgeries.

In our study the group the type of malformation syndromes was heterogeneous. It is known that not all syndromes are associated with feeding disorders; in our study in patients with trisomy 21 and those with microdeletion 22q11, the prevalence of feeding disorders is high, whereas in Turner's syndrome the prevalence is not present. The presence of feeding disorders in children with chromosomal and malformations syndromes is reported to be higher than in children without such syndromes due to the associated developmental delay, oral malformation and neurological comorbidity. In most children with malformation syndromes, several of the above-listed risk factors co-occur, which increases the probability of the manifestation and persistence of a feeding disorder.[13,14]

There is considerable inter-individual variability in the manifestation of feeding disorders within one and the same syndrome category. In our study group children with chromosomal abnormalities had a higher prevalence of abnormal feeding development at the age of 3 years. Also, the effect of malformation syndrome on latter feeding difficulties can be mediated by other risk factors such as more complex cardiac disease and neurological comorbidity. The association between neurological disorders and feeding problems is a well-known phenomenon.[8,15] Neurological abnormalities such as muscular hypotonia are frequent in children with congenital heart disease and are often diagnosed before cardiac surgery.[13,15] Among those neurobehavioral abnormalities there was also an absent suck or poor feeding efficiency. In our study we found that neurological abnormalities at the time of surgery were associated with abnormal feeding behaviour at 3 years of age. This association persist after correction for other factors: children with neurological abnormalities were six time more likely to manifest later feeding disorders than those without neurological problems. Thus, confirmed neurological abnormalities before the surgery can contribute to the development of feeding disorders as an independent risk factor.

CONCLUSION

Babies with congenital heart disease often need more calories per day than babies with normal hearts, particularly if they are struggling with symptoms of

congestive heart failure. Feeding can be challenging for a number of reasons, so parents and other caregivers often work closely with the baby's healthcare team to make sure the baby is getting enough calories to gain weight and grow. Simultaneously, children who require cardiac surgery in neonatal period and early infancy are at increasing risk of developing a feeding disorder at 3 years of age. This is a result of a complex multi-factorial process. Independent risk-factors include severity of CHD, age of child who goes through the surgery, type of operation and re-operation, duration of mechanical ventilation, previously diagnosed neurological abnormalities and presence of malformations syndromes. These factors provide key evidence as to which children need to be referred to multidisciplinary team who will care for elimination or minimization of feeding problems on these sensitive categories. Whenever feeding problems are reported, nutritional intervention should be offered in order to increase the caloric intake of the child and to develop a sound feeding relationship in the family.

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