

# THE ROLE OF THE MIDWIFE IN THE CARE OF A NEONATE WITH CLEFT PALATE AND VASCULAR RING – CASE REPORT

Karolina Szczypka<sup>1B,C,D</sup>, Patrycja Ostrogórska-Gonszewska<sup>2D,E,F</sup>, Anna Mierzwa<sup>2A,E,F</sup>

<sup>1</sup>Students' Scientific Group of Neonatal Nursing, Section of Basic Obstetrics Training, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College, Poland

<sup>2</sup>Section of Basic Obstetrics Training, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College, Poland

## Authors' contribution:

A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

## Address for correspondence:

Patrycja Ostrogórska-Gonszewska  
Section of Basic Obstetrics Training  
Institute of Nursing and Midwifery,  
Faculty of Health Sciences  
Jagiellonian University Medical College  
Zamoyskiego 58, 31-523 Kraków, Poland  
e-mail: patrycja.ostrogorska@uj.edu.pl

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## ABSTRACT

Cleft lip and/or palate is the most common craniofacial malformation. Aside from the visual facial defect, it results in numerous difficulties associated with sucking, swallowing, and breathing, as well as with speech and hearing. A variety of heart and vascular defects makes them the most common congenital anomalies. Vascular ring is an anomaly involving abnormal development of large heart vessels. Aim of the study was to present nursing care of a neonate born with a cleft hard palate and bilateral cleft lip, as well as with a vascular ring.

An individual case method was used to prepare the study. To characterise the study neonate, the following research methods were used: observation, measurement of basic parameters, and analysis of the patient's medical records. The study describes a male neonate born to G1P1 by natural delivery at 40 weeks of gestation, who immediately after birth was admitted to the department of neonatal pathology due to a craniofacial cleft and prenatally diagnosed heart defect. The major nursing problems occurring in the child were associated with the craniofacial cleft, resulting in feeding difficulties. Moreover, the malformations diagnosed created a risk of general disorders and required increased observation and provision of emotional support.

The role of a midwife taking care of a neonate with craniofacial cleft and heart defect is primarily careful monitoring of the patient, nursing, and educating the parents to prepare them for the care of the child after completion of hospitalisation.

**Key words:** cleft lip, vascular ring, neonate, cleft palate.

## INTRODUCTION

The birth of a child with a genetic defect is a traumatic experience for the parents and a special challenge for the medical personnel. Stress and strong emotions associated with the disease and hospitalisation of the neonate are comparable to human emotions during natural disasters [1]. The most common defects reported to the Polish Registry of Congenital Malformations include heart and vascular defects, which represent about 27-30% of all reports. Poland belongs to the group of European countries with a high incidence of cleft lip and palate, i.e. one of the most common congenital craniofacial genetic defects [2]. Thanks to advances in the field of medicine, most malformations are already diagnosed *in utero*, which enables mental preparation of the parents and provision of proper medical care at level 3 neonatology units. The choice of topic was motivated by the willingness to expand knowledge regarding the complications described, and

to increase knowledge among the medical personnel providing support for family members.

## AIM OF THE STUDY

The aim of the study was to present the nursing care, and to characterise current and potential health problems, of a neonate born with cleft hard palate and bilateral cleft lip, and with an abnormal position of great vessels producing a vascular ring.

## MATERIAL AND METHODS

An individual case method was used to prepare the study. To characterise the study neonate, the following research methods were used: observation, measurement of vital parameters, and analysis of the patient's medical records (medical history, examination results, fever record, individual order sheet, nursing observation sheet, hospital discharge summary).

## CASE REPORT

A male neonate born to G1P1 by natural delivery at 40 weeks of gestation, Apgar score of 10 at minute 1 and 5, birth weight 3750 g, body length 55 cm, occipitofrontal circumference 35 cm, thoracic circumference 35 cm. Immediately after birth he was admitted to the department of neonatal pathology due to a craniofacial cleft and prenatally diagnosed heart defect: ventricular septal defect and right aortic arch. During pregnancy, amniocentesis and prenatal DNA testing was performed. The result was normal, and no numerical or structural chromosome abnormalities were found. 22q11 deletion causing DiGeorge syndrome was excluded. After birth, the neonate was in a good general condition, cardiovascularly and respiratorily stable, with the heart rate above 100 beats/min. No abnormalities in the structure of the skull, limbs, and abdomen were observed, and the external anus was normal. A cardiac consultation of the neonate confirmed abnormal position of great vessels producing a vascular ring. However, no ventricular septal defect was found. In addition, the child was consulted by a surgeon, which enabled management of the cleft palate. The accessory examinations performed, as well as observations of clinical symptoms, excluded the presence of congenital infection in the neonate. Hypocalcaemia found on examination was stabilised. Observation of the neonate on his first days of life revealed no symptoms of a vascular ring.

Bilateral cleft lip and palate were associated with significant problems with feeding of the neonate. On the first day of life, the neonate had difficulties receiving bottle milk. He choked, revealed decreased saturation, and feeding lasted more than 30 minutes. Due to difficulties with sealing the nipple and disorders in the child's general condition, he was initially fed using a nasogastric tube. An adequately selected bottle and nipple for children with cleft lip and palate made it possible for the child to slowly learn how to take in food. Despite a prolonged feeding time, the neonate took in more and more food every day, and achieved normal weight gain. Improvement was observed on the following days, and the neonate slowly learned to have full portions from a bottle. Feeding the baby involved its body position with the head lifted higher, with frequent intervals for burping, and with the use of a special nipple for children with cleft lip and palate. The amount of food and feeding rhythm was adequately adjusted. An attempt was made to breastfeed the child, but it was unsuccessful. Early child screening was performed, and vaccination was started according to the vaccination calendar. During hospitalisation, the parents were educated on proper care and nursing of the neonate, and actively participated in those activities. The parents were advised about the principles and techniques of feeding a neonate with cleft lip and

palate, and were informed about the "Cleft Dreams" Foundation (pol. Fundacja "Rozszczepowe Marzenia"). On day 9 of life, the child was discharged home.

Nursing diagnoses were established during hospitalization.

**Nursing diagnosis 1.** Risk of general condition impairment due to a diagnosis of vascular ring and hypocalcaemia

Aim of care:

- Minimisation of risk of general condition impairment, and early identification of possible symptoms of general condition impairment.

Planned interventions:

- Measurement of body temperature, monitoring of heart rate and saturation with pulse oximetry, and immediate intervention in the case of abnormal parameters of the general condition.
- Regular control of respiration and patency of the respiratory tract, and monitoring of symptoms indicating dyspnoea and breathing difficulties.
- Monitoring of skin and mucosa colour.
- Control of the number of used diapers, to observe diuresis and stool.
- Ensuring proper nutrition and hydration by regular feeding 8 times a day in accordance with an individual order sheet.
- Careful feeding and observation of the moment of swallowing.
- Collection of venous or capillary blood for diagnostic tests in accordance with an individual order sheet, and interpretation of the achieved results.

**Nursing diagnosis 2.** Difficulties in food intake and a risk of food aspiration to the respiratory tract caused by bilateral cleft lip and palate

Aim of care:

- Facilitating food intake and minimisation of the risk of food aspiration to the respiratory tract caused by bilateral cleft lip and palate.

Planned interventions:

- Monitoring of general condition parameters, skin colour, possetting and choking, and coordination of sucking, breathing, and swallowing.
- Instructions and attempt to breastfeed – the use of high position and deep latch, tightening the cleft with a skin fold.
- Feeding the baby in a position with its head higher, frequent breaks for burping, and leaving the child in a high position for about half an hour after feeding.
- Attempts to feed the baby using a bottle with a special nipple for children with cleft lip and palate.
- Placing the nipple at the correct depth in the oral cavity and reducing taking out the nipple and the possibility of air swallowing. Using light and continuous pressure on the bottle bottom.
- Adjusting the volume of the food flowing out of the nipple to the ability of sucking, swallowing, and breathing synchronization.

- Slow feeding of the neonate in the amount compliant with the individual order sheet and controlling the feeding duration to not exceed 30 minutes. Adjusting an optimal feeding rhythm for the neonate.
- Insertion of a nasogastric tube and supplementary feeding of the neonate in the case of difficulties taking in a sufficient amount of food by the child.

**Nursing diagnosis 3.** Neonate anxiety caused by accumulation of mucous discharge in the oral cavity and nose

Aim of care:

- Reduction of neonate anxiety.
- Planned interventions:
- Ensuring proper oral and nasal hygiene and care of vermilion of the child.
- Regular control of airway patency.
- If necessary, performance of nasopharyngeal suctioning.
- Assessment of the amount and type of discharge.
- Using child positioning facilitating evacuation of discharge from the respiratory tract.

**Nursing diagnosis 4.** Pain and stress of the neonate related to performance of medical and nursing procedures

Aim of care:

- Reduction of pain and stress of the neonate.
- Planned interventions:
- Skilful and precise performance of activities with the neonate.
- Reduction of stressful stimuli by cumulation of nursing activities.
- Avoiding sudden sound and light effects, reduction of lighting, ensuring peace and quiet in the child's surroundings.
- Ensuring adequate positioning and tucking the child.
- Monitoring of the neonate's behaviour and symptoms indicating stress, e.g. tachycardia or crying.
- Assessment of the child's pain severity using the N-PASS scale at least once a day or as needed.
- Using non-pharmacological methods to ease pain before painful procedures, e.g. tucking, kangarooing, sucking a dummy, feeding, oral supply of glucose or sucrose solution.
- Using pharmacological methods to ease pain – supply of analgesics in accordance with an individual order sheet.

**Nursing diagnosis 5.** Parent anxiety caused by lack of knowledge on proper feeding of a child with bilateral cleft lip and palate

Aim of care:

- Reduction of parent anxiety.
- Planned interventions:
- Identification of parental knowledge deficits.
- Arranging a conversation with attending physicians.
- Presenting the cause of difficulty in feeding the baby.
- Presenting a high position for feeding the neonate.

- Presenting a method of holding a bottle and exerting constant pressure on the bottom, and placing the nipple at the right depth in the oral cavity.
- Educating about the necessity to reduce taking out and rotating the nipple while feeding in order to minimise the possibility of air swallowing.
- Recommending frequent breaks for burping.
- Recommending feeding the neonate on demand according to its own rhythm – feeding should be slow and should not last longer than 30 minutes.
- Recommending observation of skin and worrying symptoms while feeding.
- Presenting a correct position after feeding.

**Nursing diagnosis 6.** Maternal knowledge deficit on the correct technique of natural milk expression and storage

Aim of care:

- Presenting the mother with knowledge on the correct technique of natural milk expression and storage.
- Planned interventions:
- Identification of maternal knowledge deficits.
- Having a conversation about the rules of breastfeeding and nutrition of lactating women.
- Encouraging the mother to initiate lactation and express milk as early as possible.
- Educating about natural milk expression, and the time and method of storage.
- Providing the mother with information brochures and reliable sources of knowledge on expression and storage of natural milk.
- Suggesting consultations with a Certified Lactation Counsellor.

## DISCUSSION

Cleft lip and palate is a congenital malformation involving complete or partial lack of anatomical structure integrity in the primary palate – cleft lip, or in the secondary palate – cleft palate [3]. The defect may affect the lip only, the lip and alveolar process, the palate only, or each of these body parts simultaneously. 70% of clefts occur as isolated defects, i.e. with no other malformations. In the remaining cases, they occur as complex congenital defects combined with defects of the cardiovascular system, limbs, or other anomalies [4-6]. The most common are left-sided and bilateral clefts, with right-sided ones being the least common [6]. The incidence depends on the population and is on average 1.7 per 1000 births. In Poland, around 800 children are born with cleft lip and/or palate annually [3]. The defect is associated with numerous dysfunctions related to breathing, sucking, swallowing, chewing, speech disorders, and with an increased risk of upper respiratory infections [3].

Craniofacial cleft anomaly develops between 5 and 8 weeks of gestation [3]. The process of the

secondary palate formation is one week longer in females, resulting in a higher incidence of cleft palate in girls, while cleft lip is more common among boys [4, 7]. A variety of possible cleft lips and palates has resulted in numerous classifications, which divide the defect with regard to morphology and embryology [8].

A precise aetiology of craniofacial cleft defects is unknown, but numerous studies show evidence of factors increasing the risk of development of this defect in a neonate [5]. The occurrence of cleft lip or palate results from the effect of various environmental and genetic factors. The most common and specific risk factor, however, is a positive family history [9]. The probability of having a child with the defect for a parent with a cleft malformation is 3%. If the anomaly occurs in a sibling, the probability is 5%, and if in both a parent and sibling, the risk reaches 10% [5, 9]. Craniofacial clefts are highly correlated with genetic abnormalities. Cleft lip is associated with more than 200, and cleft palate with around 400 genetic syndromes, e.g. Pierre-Robin syndrome and Di George syndrome [3-6]. Moreover, an increased frequency of clefts in children was observed in the case of mothers with MTHFR gene mutation [5]. Numerous studies of social and ethnic factors show that the highest risk of a craniofacial cleft defect occurs in the yellow race people, especially in the region of Japan, Korea, and China, while the lowest probability is observed in Africa [10]. Maternal exposure to negative environmental factors, especially in the first trimester of pregnancy, increases the risk of craniofacial cleft diseases. Both passive and active smoking, drinking alcohol, and using drugs by pregnant women is a confirmed risk factor [3, 5]. Another risk factor is being employed in the agriculture or hairdressing sectors and being exposed to harmful substances at the place of work [10]. Maternal metabolic or infectious diseases, and infections occurring during pregnancy, especially those involving fever, may increase the probability of the defect. Also, medications taken by a pregnant woman during these diseases is of importance [10, 11]. A predisposing factor is inadequate diet, obesity, insufficient supply of folic acid, zinc, and excess of copper, as well as vitamin A and E deficits, and older age of parents. Studies suggest that paternal age above 40 years is related to a 58% increase, and maternal age above 40 years to a 28% increase, in the risk of having a child with the defect [5, 12].

Cleft lip and palate may be diagnosed using ultrasound scanning during foetal life, as early as before 20 weeks of gestation. A diagnosis of craniofacial cleft defect necessitates extension of diagnostics to exclude additional congenital anomalies and genetic syndromes involving cleft lip or palate [3, 5]. Children with cleft lip or palate often have difficulties eating, speaking, and hearing; therefore, it is necessary to include such patients in the interdisciplinary

treatment [5]. Impossibility of effective holding of the breast or bottle nipple and of creating negative pressure in the child's oral cavity due to anatomical abnormalities results in problems with sucking and swallowing [13, 14]. Lack of tightness in the nasal cavity, increased air intake, and fatigability of the child results in a longer feeding time and the necessity of more frequent burping. It is important to use a suitable feeding method to achieve effective nutrition because studies show that children with cleft palate have slow weight gain [15]. The use of adequate techniques makes it possible to breastfeed children with cleft lip; however, it is a serious problem for neonates with cleft palate or a defect involving both the lip and palate; therefore, such children are usually fed with a bottle using a special nipple [13]. Due to a positive effect of mother's milk on the development of a neonate, women who cannot breastfeed should be encouraged to express milk and administer it to the child [15]. The type and size of the cleft lip defect determines feeding difficulties, but these may be normally minimised by adequate positioning of the child. In the case of unilateral cleft lip, the preferred position is a so-called football hold, or side-sitting, which enables covering the defect by the breast tissue and increase tightness around the nipple. Bilateral cleft lip makes it much more difficult to breastfeed, due to the impossibility of ensuring tightness around the nipple. In this type of defect, the recommended breastfeeding position involves holding the child's chin and pressing it to the areola and nipple with 3 fingers positioned in such a way that the index finger and thumb form the letter U. The above breastfeeding techniques may also be effective in the case of cleft soft palate. If breastfeeding is impossible or ineffective, the child should receive supplementary feeding with a bottle and nipples adjusted for children with clefts. They enable achieving the correct milk flow rate and seal the oral cavity, thus preventing food from entering the nasal cavity [15]. In feeding a baby with cleft palate, palatal plates/prostheses may also be used to compensate for the lack of integrity of the palate [13]. While feeding a baby with cleft lip and/or palate, it is important to ensure 2-3 breaks for burping, as well as the most upright positioning of the baby. The total feeding time should not exceed 30 minutes [15]. The main purpose of treatment is to restore anatomical integrity at the site of the cleft lip or palate. Lip repair surgery is usually done when the baby is around 2-6 months old and is performed under general anaesthesia using a Fisher or Millard technique [3, 9]. One of the most popular methods of treating cleft palate is the Veau-Wardill-Kilner technique. The term of palatal reconstruction may, however, have a significant effect on the child's functioning: early surgery facilitates normal speech

development, while later surgery is beneficial for the development of the facial skeleton [3, 9].

Vascular ring is a rare defect representing about 1% of congenital malformations of the cardiovascular system, which may occur as an isolated defect or together with other malformations. A vascular ring is the name for an abnormal position of the aorta and its branches, which by surrounding the trachea and oesophagus may cause compression of these structures. It is difficult to estimate the incidence of this anomaly because approximately 66% of less complicated cases remain undiagnosed. No significant differences in the incidence of this defect have been observed with regard to sex, race, or geographical location [16]. This defect is characterised by a multitude of anatomical forms and non-specificity of symptoms [17]. When the abnormally located vessels completely encircle the oesophagus and trachea, one may speak of a complete vascular ring. On the other hand, when they do not form a full circle but compress the organs, they are called a partial vascular ring [16]. With regard to the positioning of the aorta and its branches, 4 basic types of vascular ring may be distinguished: double aortic arch (DAA), right aortic arch (RAA) with aberrant left subclavian artery with retro-oesophageal course, RAA with mirror image branching of brachiocephalic vessels, and left aortic arch (LAA) aberrant right subclavian artery with retro-oesophageal course and arterial duct, producing a partial vascular ring [16, 18].

Vascular ring-associated symptoms depend on the compression exerted on the oesophagus and respiratory tract. The defect may also be largely asymptomatic and remain undiagnosed. Stridor, coughing, breathing difficulties, cyanosis, and feeding problems are common symptoms among children in the first months of life. Later in life, the defect may be manifested as recurrent pulmonary infections and expiratory wheezing, often mistaken for bronchial asthma [17, 18]. Dysphagia, slow feeding, and difficulties with food intake may only occur in children when solid food is introduced in the diet [16]. Taking a detailed medical history and performing a physical examination may reveal problems resulting from compression on the oesophagus or trachea, which should always suggest the occurrence of a vascular ring [16]. A precise diagnosis is made with imaging examinations, which may visualise an existing defect. A radiographic examination of the chest is the first element of diagnostics. On the basis of frontal and lateral radiographs, the aortic course, possibly the type of anomaly, and the aortic position against the trachea are established [16]. It is also recommended that a radiographic examination with barite pulp contrast be performed, enabling visualisation of the upper gastrointestinal tract and assessment of the position of the aortic arch against the oesophagus. The above-

mentioned radiographic examinations are reliable diagnostic methods, whose normal results allow the exclusion, with great certainty, of the presence of vascular rings. However, because it is impossible to precisely visualise the defect, they are frequently replaced with cross-sectional imaging techniques: computed tomography, computed tomography angiography, and magnetic resonance imaging [16, 17]. A diagnostic examination that allows direct assessment of the site and scope of compression exerted by the aorta or its branches on the respiratory tract is bronchoscopy. This examination represents initial diagnostics in the case of undiagnosed abnormalities and breathing difficulties in infants. It is thought that this examination should be performed in all symptomatic patients who require surgical treatment, in order to precisely determine the degree and scope of tracheal stenosis, and the ring type [16]. Another examination diagnosing the defect is echocardiography, which enables anatomical assessment of the heart and large blood vessels, and, in the case of Doppler echocardiography, also of the organ blood flow. Despite the higher accessibility of this examination, it is not considered authoritative or most important in diagnosing vascular rings [16, 17]. Vascular rings may be diagnosed at the stage of foetal life. Prenatal ultrasound scan examinations may reveal anomalies in the course of the aorta, suggesting the presence of vascular rings. In the case of 3-dimensional ultrasound scanning, it is also possible to determine the defect type [16].

The treatment of vascular rings in symptomatic patients involves surgical correction. It should be performed as early as possible after diagnosing the defect, thus minimising the effects of compression exerted on the respiratory tract, and related complications. The surgical procedure, involving ring separation, is typically performed via left-sided thoracotomy or video-assisted thoracoscopic surgery, usually without the need of extracorporeal circulation [16, 17]. The surgery typically results in complete resolution of symptoms, but discomfort related to tracheal compression may be felt for a few weeks or months post surgery. Vascular rings without clinical symptoms require no surgical treatment.

## CONCLUSIONS

The role of a midwife taking care of the child with cleft lip and/or palate, and with heart defect is primarily careful monitoring of the patient, quick reaction to disturbing changes, care of the child, and minimising unfavourable factors affecting the child's development. Neonatal observation is an important source of information on the child's condition, and it enables further medical interventions to be made by doctors. The midwife participates in the initiation of

feeding of the child with craniofacial cleft, and he/she chooses the rhythm and method of feeding that is the most suitable for the patient. Moreover, the midwife is a source of information for the parents; he/she educates them on topics related to feeding and nursing, thus preparing them for the care of the child after hospitalisation. He/she also provides mental support for the parents in those difficult moments. Therefore, it is justified to educate midwives on problems related to feeding, and to update their knowledge on a regular basis.

### Disclosure

The authors declare no conflict of interest.

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