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RESEARCH ARTICLE OPEN ACCESS

THE EXPERIENCE OF A PARENT WHO HAS A CHILD WITH A CARDIOLOGICAL PROBLEM AND HIS RELATIONSHIP WITH PHYSOTHERAPY

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ABSTRACT

Purpose: To investigate the relationship of the parent with physiotherapy and the pediatric patient after heart surgery. **Methodology:** The research was conducted in Thessaloniki in the period of September-March, 2021-22. The questionnaire was distributed to 55 parents of pediatric patients and consisted questions about the parent's relationship with respiratory physiotherapy and how it affects the child's emotional state and consequently the parent. **Results:** Respiratory physiotherapy helps to manage the emotional state of the pediatric patient andparents feel calmer with the contribution of this intervention. **Conclusion:** The experience of the family with respiratory physiotherapy is positive as it offers prosperity to the pediatric patient and consequently to the whole family through its different techniques. It is necessary to conduct a study with a larger sample to collect more results.

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INTRODUCTION

1% of all live births have congenital heart disease in the US each year (2010). In Greece about 1000 / 100,000 births every year are reported to have a structural abnormality of the heart. (Hellenic Society of Cardiology). The survival of people with congenital heart disease is related to the severity and form of congenital heart disease (Stefanadis 2005, Kokkinos D, Rammos., 2000; Toutouzas 1999, Lolas, 1991). About 10/1000 births are affected by some type of heart abnormality and about 1/3 of them require surgery (Amorim et al., 2008; Hoffman JI, Kaplan.2002).In addition to congenital heart disease, children can later develop acquired heart disease such as arrhythmias, cardiomyopathy, rheumatic heart disease and complications of Kawasaki disease (Uzark et al., 2008). Preoperative and postoperative respiratory physiotherapy reduces significantly the risk of pulmonary complications (Mellion et al., 2014). In general, sports activity, especially in older children, should be an important part of their daily life in order to have good physical condition and also for their smooth integration into society. Also families with children with heart problems experience feelings of fear, anxiety, guilt, and even depression (Uzark, Jones 2003; Lawoko, Soares 2006).

Classification of Heart Diseases: Heart disease can be congenital or acquired. A small percentage is due to genetic factors and an even smaller percentage to exogenous factors. Heart disease can be both symptomatic and asymptomatic. Also can be distinguished in cyanotic and non-cyanotic based on the degree of cyanosis. The classification based on the anatomy, divides them into stenotic and obstructive, into blood-mixing diseases between the two circulations due to inaccurate connections of parts between them or in combinationsof them. (Thiene, Frescura.2010) Classification can also be made based on the presence of heart failure or not. Some forms of congenital heart disease are silent until adulthood.

Prenatal - Postnatal Control: Prenatal care aims to maintain the health of the fetus and the pregnant woman. Checks for possible diseases and complications during pregnancy. In high-risk pregnancies, the first ultrasound is performed in the 12th-14th week. The postpartum period is critical. Most maternal and neonatal deaths occur in the first month after birth.

Surgery-Complications: 3.2-8.4% of children with congenital heart disease undergoing heart surgery may need extracorporeal membrane oxygenation in the postoperative period (Baslaim et al., 2006; Raithel et al., 1992; Ghez et al., 2005) Cardiopulmonary bypass surgery

related to CPB leads to a number of respiratory complications (Undern-Sternberg et al., 2007) such as atelectasis and pneumonia. Invasive cardiology is an alternative transdermal treatment instead of surgery (Matthew, Frank 2010). There are also hybrid surgeries that combine surgical methods (Bacha, Hijazi.2005).

Relationship Between the respiratory system and congenital heart Disease: When congenital heart disease is present, the heart's ability to increase systemic and pulmonary blood flow is limited. The partial pressure of oxygen may be reduced. So heart disease affects the respiratory system in children. It causes changes in blood flow causing hemodynamic disorders. It also causes changes in ventilation with water retention in the lungs and pulmonary edema which it compresses the airways (Sotiria C Apostolopoulou.2017). Increased work of the breath indicates respiratory distress. However, this increased breathing can be caused by fear, crying and anxiety. Some cases that can be referred to as respiratory problems are heart failure. Urgent treatment is the supply of oxygen and the administration of diuretic drugs.

PHYSICAL THERAPY

Preoperative physiotherapy: Preoperative respiratory physiotherapy significantly reduces the risk of children developing lung complications after heart surgery (Josiane Marques Felcar et al., 2008). It is essential for the prevention of pulmonary complications such as secretion retention, pneumonia and atelectasis (Felcar, Guitti, Marson et al., 2008). Contributes to proper ventilation and successful intubation of the pediatric patient (Nicolau CM, Lahóz., 2007).

Postoperative physiotherapy: Postoperative physiotherapy includes: Postoperative physiotherapy includes techniques aiming at maintaining adequate lung ventilation, removal of bronchial secretions as some children have difficulty developing their lungs, or may not be able to discharge mucus after surgery. It also aims to prevent complications (Felcar et al., 2008) andreturn the patient to his best physical condition (Christara A.2009). The physiotherapist can use practical techniques that help to expand the child's lungs, better ventilation and mobilization of secretions such as breathing exercises (Main et al., 2004), shocks - vibrations (Felcar et al., 2008; Balachandran et. Al., 2005; Main et al., 2004; Silva et al., 2006), compression (Silva et al., 2006), position changes (Felcar et al., 2008; Balachandran et al., 2005), mobilization (Felcar et al., 2008).

Kinesiotherapy: At the same time, kinesiotherapy that takes part in the postoperative treatment includes exercises aiming to obtain a full range of movements of the cervical spine, shoulder girdle and chest, mobilization of the upper and lower limbs for all movements in all joints. Kinesiotherapy starts fromperiphery and continues to the center. Mild exercises are performed and corrections are made in the patient's posture. Proper posture aims to better ventilate the lungs and prevent deformities of the chest and spine. Exercises to strengthen the muscles of the back and spine are performed (Shepherd 1995, Frownfelter 1985). Exercises are also performed on the lower extremities to maintain their mobility. During exercises, the vital signs of the child are observed andbreaks are made depending on the patient's endurance. The pediatric patient's tolerance should be checked regularly during treatment. Hemodynamic parameters and oxygen saturation should be monitored.

Respiratory Physiotherapy

Relaxation positions: Relaxation positions help control breathing, better lung ventilation and prevent shortness of breath. The patients posture may be supine, semi-supine, semi-prone, lateral, high lateral, seated on the heels, seated in a chair, and upright.

Position changes: Position changes (Felcar et al., 2008; Balachandran et al., 2005) are performed to improve ventilation, reduce apnea episodes, and remove secretions.

Impacts: Impacts is a technique in which the physiotherapist performs percussion with his hand or with a hollow object on the bronchopulmonary department that needs to be drained. Power and rhythm vary. Impacts should not be strong and offer a negative feeling. Specificallythis technique should not be applied on bone protrusions and kidneys. Impacts are applied on the anterior and posterior surface of the chest. Impacts mobilize secretions, increase the depth of respiration and cause cough. Impacts in some cases can lead to oxygen desaturation (Beningfield A., Jones. A.)

Massage: The massage is applied with the palm with slow and circular movements on the anterior and posterior surface of the chest. Massage reduces painful muscle contractions that are often due to poor ventilation. This way blood begins to circulate faster and this leads to better oxygenation. Sandra L. Staveski et al., (2019) in their study found that postoperative massage in children after cardiovascular surgery reduced stress levels.

Huffing: It is a modified form of accelerated exhalation which is performed by exhaling from moderate to high lung volumes through an open glottis. Initially the pediatric patient takes a deep slow inhale holding the breath for 1-3 seconds and then performs a dynamic and prolonged exhalation with the glottis open.

Cough: Controlled or directed or voluntary cough. For the cough to be effective, the patient must take a deep breath, hold it for 2-10 seconds. Then exhale deeply and slowly. Towards the end of the exhalation the patient should cough voluntarily with contraction of the abdomen or in the exhalation phase to cough three times in a row. The patient's color is constantly observed during the procedure. The patientposition should be is seated. If the procedure is not effective, help for better contraction of the abdomen with the hands can be used. This will help to develop more intra-abdominal pressure.

Chest vibrations – pressures: Vibrations are performed by the physiotherapist's hand or by using an electric toothbrush in a newborn. Pressures and vibrations will not be performed when the baby is breathing more than 40 to 50 breaths per minute.

Active cycle breathing technique: Active cycle breathing is a combination of diaphragmatic breathing, thoracic expansion and accelerated exhalation. Initially the patient performs a controlled diaphragmatic breath followed by chest expansion and finally accelerated exhalation. The above cycle of breaths is repeated until all secretions have been removed from the lungs. A voluntary cough follows if not caused by the accelerated exhalation. The patient may be in a supine or sitting possition.

Autogenic drainage technique: This technique is applied at the age of 12 and over and to people without mental deprivation as it requires concentration, attention and knowledge of the process. Initially the patient makes a quick exhalation. Where sound is heard indicates where the mucus is. Then breathing exercisesfollow. The patient breathes in low respiratory volumes and exhales up to the expiratory reserve volume to remove the secretions. Then the patient breathes in a normal respiratory volume and exhales till the expiratory reserve volume, facilitating the movement of secretions to the trachea. Breathing in these ventilatory volumes allows secretions to travel to medium-sized airways. The patient then breathes deeply into high respiratory volumes and uses accelerated exhalation to remove secretions. For autogenous drainage to be successful it requires training and guidance.

Non-invasive ventilation: Non-invasive ventilation serves as a means of mobilizing the cells (Futier et al., 2011; Lapinsky et al., 1999). It is considered to be a device to prevent atelectasis or intubation (Jaber et al., 2010; Perrin et al., 2007; Jolliet et al., 2001; Matte et al., 2000). It also helps the respiratory muscles by providing respiratory support (Hansmann 2017).

Continuous Positive Airway Pressure (CPAP): Continuous positive pressure is provided in both inhalation phase and exhalation phase. The patient's breathing is automatic. It must produce all inspirational effort. It is a useful therapeutic tool for treating respiratory distress in premature and low birth weight infants (Kawaza 2014).

Bubble CPAP: BCPAP can be used as a therapeutic way to treat severe pneumonia in children (Shann 2015). Positive pressure is provided in premature infants from birth and in the severe stages of respiratory disfunction (Machen 2015).

Breathing exercises: Breathing exercises help to remove mucus after surgery (Main et al., 2004). They can be done passive, assisted and energetic with movements of the upper limbs and with pressure during the exhalation in various parts of the chest. The goal of these exercises is to improve ventilation, better mobility of the chest, facilitate the elimination of secretions and to relax respiratory muscles (Christara-Papadopoulou, Georgiadou, Papadopoulou 2014). Exercises can be active exercises or directed by a physiotherapist. They can be combined with toys such as inflating a balloon, blowing pieces of paper, making bubbles in the water.

Diaphragmatic breathing: Diaphragmatic breathing is taught. The physiotherapist helps with his hands and with verbal encouragement in learning this technique. Diaphragmatic breathing or otherwise abdominal breathing is an economical breathing as it helps to reduce the work of breathing. Improves the ventilation of the main lung sections. Facilitates breathing. This way the patient puts it under his control during a shortness of breath. It is a breathing exercise and helps to strengthen the diaphragm. The diaphragm performs 80% of the respiration.

Aids – Devices: Flutter is a small portable device. Aims at expectoration of bronchial secretions, improves lung function and oxygenation. Initially, inhalation is performed outside the device through the nose or mouth. Then hold of breath is made for 2-3 seconds. The patient then places the mouthpiece into the mouth and performs a slow and full exhalation with moderate force. Other devices used are: Triflo, Positive Expiratory Pressure mask, Cornet and Acapella devices that help clear the airways. In these devices the patient blows and creates a controlled oscillating positive pressure which returns topatient's chest. Another device used is the chest wall oscillator (HFCWO) which uses a mechanical chest wall oscillator.

Emotional State of Parent and Child: Prevention of the various health problems of parents with children with congenital heart disease, is important for the well-being of children and their family (DeMaso et al., 2012; Ernst et al., 2018; Ernst et al., 2002). In their study Uzark and Jones (2003) showed that parental stress is not related to the severity of the disease. A mother with a sickchild smiles less at her child, does not seek eye contact, does not touch it often, and does not singoften during the feeding process. The prevailing emotions are guilt and anxiety. They experience depression and poor quality of life (Uzark, Jones 2003; Lawoko, Soares 2006). The involvement of fathers in the care of infants and children with chronic diseases has been associated with positive outcomes in terms of health, quality of life, adherence to medical regimen and maintaining a better relationship between spouses and the whole family. (Gavin et al., 2006; Swallow et al., 2012; Yogman et al., 2016). Elnur Tahirović et al., (2011) concluded that children after heart surgery have a lower quality of life than their healthy peers. One in 5 children who are ill experiences reduced psychosocial function compared to healthy children. Karen Uzark et al., (2008) reported that children with more severe cardiovascular disease have worse physical and psychosocial quality of life. Freitas et al., (2013) showed that patients with cyanotic congenital heart disease and a history of surgery had a low quality of life and finally Culbert et al., (2003). showed that in children with large artery permutation the quality of life had higher scores compared to the general population in addition to the score on their self-esteem.

METHOD- MATERIALS

Collection method: The sample consisted of parents who have a child with a heart problem and were admitted to the pediatric cardiology ward of the University Hospital. The questionnaire is distributed to 55 parents with a child with a heart problem. The questionnaire is anonymous and confidential. All data are strictly used only for the present research. Its completion time is less than 5 minutes. Contains 21 closed-ended questions. Specifically, questions 1-7 concern the demographic data of the respondent. That is the parental relationship with the pediatric patient, the age group, the number of children in the family and the patient's age. It was also asked the place of residence, the level of education of the parent and the monthly income. Then questions 8-14 concern the pediatric patient's upbringing. Specifically, it is questioned whether or not the parent was assisted in the upbringing, the existence or non-existence of the parent's free time and the imposition or not of rules and limits on the child. It is investigated if there was and if so from where the counseling and psychological support provided and also about how the information was achieved about the development of pediatric cardiology that concerns the parent. The following questions 15-21 concern the pediatric patient who has undergone some surgery. These questions are related to respiratory physiotherapy and how long it took place. Also, if programs are done at home. How does this help manage a child's stress? Finally, the last question concerns the provision of state aid, if any.

METHOD OF ANALYSIS

SPSS software was used for statistical data processing. Kendall was used as the ranking correlation coefficient and a = 0,01 was set as the minimum level of significance.

RESULTS

As shown in the table below, the sample of the study was 55 participants of whom most of the respondents were the mothers of the patients who amounted to 46 (83.63) and the remaining 9 (16.37) were their fathers.

Table 1. Distribution of participants based on demographic characteristics

		N (%)
Relationship of parent	Mother	46 (83,63)
with pediatric patient	Father	9 (16,37)
Age group	20-30	7 (12,72)
	31-40	20 (36,36)
	41-50	19 (34,54)
	>51	9 (16,36)
Number of children	1	19 (34,54)
	2	27 (49,09)
	3	7 (12,72)
	4	2 (3,63)
Age of pediatric patient	0-30 days	2 (3,63)
	30 days – 2 years	14 (25,45)
	2 years – 5years	17 (30,90)
	5 years - 12 years	12 (21,81)
	12 years – 18 years	10 (18,18)
Place of residence	Farming district	7 (12,72)
	Semi urban district	12 (21,81)
	Urban district	36 (65,45)
Level of education of the	None typical education	0 (0)
parent	Basic education	1 (1,81)
	Lower secondary education	3 (5,45)
	University education	10 (18,18)
	Post -secondary education non - University	16 (29,09)
	University education	23 (41,81)
	Post -graduate education	2 (3,63)
Monthly income	500-1.000	25 (45,45)
	1001-1.500	23 (41,81)
	1.501-2.000	5 (9,09)
	More than 2000	2 (3,63)

In terms of age group, the predominant groups were between 31-40 with a number of 20 people (36.36) and 41-50 with a number of 19 (34.54) people, while fewer people, only 7 (12.72) belonged to the age group of 20-30. Most of the respondents, 27 (42.09) had 2 children while only 2 (3.63) had 4 children. The age of the pediatric patient concerned 17 (25.45) families in the infant group (2x-5cm) while only 2 (3.63) children belonged to the neonatal group (0-30 days).

			Rules to the patient	Anxiety with the management of the patient
Kendall's tau_b	Rules to the patient	Correlation Coefficient	1,000	-,022
		Sig.(2-tailed)		,851
		N	55	55
	Anxiety with the management of the patient	Correlation Coefficient	-,022	1,000
		Sig.(2-tailed)	,851	
		N	55	55

Figure 1. Statistical correlation between the enforcement of rules to the pediatric patient and anxiety management from the parent

			Contribution of respiratory physiotherapy in management of the emotional state of pediatric patient	Trust of parent in the intervention of respiratory physiotherapy
Kendall's tau_b	Contribution of respiratory physiotherapy in management of the emotional state of pediatric patient	Correlation Coefficient	1,000	,579**
		Sig.(2-tailed)		<,001
		N	32	32
	Trust of parent in the intervention of respiratory physiotherapy	Correlation Coefficient	,579**	1,000
		Sig.(2-tailed)	<,001	
		N	32	32

Figure 2. Correlation between respiratory contribution and parental confidence in this intervention and its outcomes

Above the average of 36 respondents (65.45) lives in an urban area. Regarding the level of education a large group, 23 (41.81) have university education and 16 (29,09) Post-secondary education non-University. In addition, the monthly income of 25 (45.45) respondents amounts to 500-1000 euros and 23 (41.81) respondents to 1.001-1.500. As shown in Figure 1 there is no statistical correlation between rule enforcement in relation to stress in patient management at a significance level of 0.01 because the correlation coefficient was less than 0.3.

DISCUSSION

A percentage of congenital heart disease can be diagnosed at the prenatal check-up (SWEDCON.2018) and after birth to immediately support the sick newborn and the family with the appropriate services. In later life, children may develop acquired heart disease such as rheumatic fever and Kawasaki disease (Halimiasl et al., 2012). Therapeutic intervention for the pediatric cardiologic patient may be non-surgical as is the case with cardiac catheterization (Matthew, Frank 2010). Medication and physiotherapy complete the treatment plan. Effective coughing, autogenic drainage, change of position, impacts and vibration are techniques performed to successfully remove patient secretions. Breathing exercises (Main et al., 2004) and learning diaphragmatic breathing offer relaxation through calm breathing. Preventing the various health problems of parents with children with congenital heart disease offers better well-being throughout the family (DeMaso et al., 2012; Ernst et al., 2018; Ernst et.). Often it is difficult to manage the pediatric patient. The athletic activity of these children is often limited. Regarding the results of the study, the correlation between the contribution of respiratory physiotherapy in the management of the emotional state of the pediatric patient and the parent's trust in this intervention is high. Parents feel calmer with the contribution of respiratory physiotherapy and the results it brings throughout the course, as the pediatric patient has a better emotional state. It is necessary to conduct a study with a larger sample to collect more results. Intervention of respiratory physiotherapy protocol preoperatively and postoperatively would be important. The measurement of the results of the intervention will give important data for the emotional state of the children and the parent through a reliable scale which will bring complete results. The picture will be clearer in order to take drastic measures and changes in the management of these patients and also in providing more services.

CONCLUSION

The results of the present study give us a first picture of the situations experienced in the daily life of a group of parents who have a child with a heart problem. The family experience with respiratory physiotherapy is positive as it offers well-being to the pediatric patient and consequently to the whole family through its different techniques.

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