

## Nursing care for children with congenital heart disease: a focus on Tetralogy of Fallot

Atención de enfermería para niños con cardiopatías congénitas: un enfoque en la tetralogía de Fallot Cuidados de enfermagem às crianças com cardiopatia congênita: enfoque na Tetralogia de Fallot

#### Abstract

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This study aimed to describe the nursing care provided to children with congenital heart disease with a focus on the Tetralogy of Fallot. A bibliographic review was carried out using the Virtual Health Library database platform to carry out the bibliographic search. According to the theme and the inclusion and exclusion criteria, 5 bibliographies were selected for this research, from which it was possible to identify three categories, nursing care for patients with congenital heart disease, congenital heart disease, nursing care in the tetralogy of Fallot. The knowledge and ownership of the subject is important for the improvement of nursing care for children diagnosed with congenital heart disease, especially the tetralogy of Fallot as described in this study.

Descriptors: Heart Defects, Congenital; Tetralogy of Fallot; Cardiovascular Diseases; Nursing; Nursing Care.

#### Resumén

Este estudio tuvo como objetivo describir los cuidados de enfermería que se brindan a los niños con cardiopatías congénitas, centrándose en la Tetralogía de Fallot. Se realizó una revisión bibliográfica utilizando la plataforma de base de datos de la Biblioteca Virtual en Salud para realizar la búsqueda bibliográfica. De acuerdo con la temática y los criterios de inclusión y exclusión, se seleccionaron 5 bibliografías para esta investigación, de las cuales fue posible identificar tres categorías, cuidados de enfermería para pacientes con cardiopatías congénitas, cardiopatías congénitas, cuidados de enfermería en la tetralogía de Fallot. El conocimiento y la propiedad del tema es importante para la meiora de la atención de enfermería para los niños diagnosticados con cardiopatías congénitas, especialmente la tetralogía de Fallot como se describe en este estudio.

Descriptores: Cardiopatías Congénitas; Tetralogía de Fallot; Atención de Enfermería; Enfermedades Cardiovasculares; Enfermería; Atención de Enfermería.

#### Resumo

Objetivou-se descrever os cuidados de enfermagem à criança com cardiopatias congênitas com enfoque na Tetralogia de Fallot. Realizou-se uma revisão bibliográfica com utilização da plataforma de base de dados Biblioteca Virtual em Saúde, para realização da busca bibliográfica. De acordo com a temática e os critérios de inclusão e exclusão, selecionou-se 5 bibliografias para esta pesquisa, dos quais foi possível a identificação de três categorias, cuidados de enfermagem ao paciente com cardiopatia congênita, cardiopatias congênitas, assistência de enfermagem na tetralogia de Fallot. O conhecimento e apropriação da temática torna-se importante para a melhoria na assistência de enfermagem às crianças com diagnóstico de cardiopatia congênita, sobretudo a tetralogia de Fallot como descrito neste estudo.

Descritores: Cardiopatias congênitas; Tetralogia de Fallot; Doenças Cardiovasculares; Assistência Centrada no Paciente; Cuidados de Enfermagem.



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#### Introduction

This study addresses the topic of Nursing care for congenital heart disorders and the relevance of the topic becomes important since mortality in children under one year of age has primarily focused on perinatal conditions, followed by congenital anomalies, namely malformations. of the circulatory system, one of the most frequent in the first year of life<sup>1</sup>.

After fertilization, the zygote begins to undergo consecutive mitotic divisions, and around the sixth day of fertilization, it spawns. In the endometrium the embryo starts to grow and develop. Fetal circulation occurs from the second week onwards, a period in which blood vessels present themselves in the mesoderm which line the yolk sac, and later between the fourth and eighth week of embryonic development it is possible to investigate structures such as: primitive atrium, heart bulb and primitive ventricle, already formed. During the seventh week, the formation of interatrial and interventricular septa begins. And it is between the sixth and ninth week of gestational development that valve movements are observed<sup>2</sup>.

Integral fetal cardiovascular engineering is designed to meet all prenatal needs and allow for the changes at birth that will enable the adaptability of extrauterine life. Existing intrauterine cardiac structures such as the ductus venosus, foramen ovale and the ductus arteriosus facilitate fetal blood circulation to supply oxygen to organs. However, after birth, there is no longer any need for the structures, and they are then closed at the opportune times<sup>3</sup>.

Tetralogy of Fallot is a structural malformation, being the main cyanotic heart disease, classified as it generates a shunt of blood from the right side to the left side of the heart. It comprises four types of defects, namely, infundibular pulmonary stenosis, right ventricular hypertrophy, ventricular septal defect and aortic dextroposition. There is a higher incidence in the first years of life and the typical characteristic of the cyanotic crisis is to find the child in a knee-chest or squatting position. The child adopts the attitude to increase vascular resistance and keep blood trapped in the lower limbs, reducing the overload on the right side of the heart<sup>4</sup>.

The knowledge and performance of nursing about Tetralogy of Fallot is essential for satisfactory care, as it prevents the patient's condition from becoming complicated, such as in the hyper cyanotic episode or hypoxia crisis. In 2010, according to the Information Technology Department of the Unified Health System, of the 25,757 cases of congenital heart disease estimated worldwide, only 1,377 were notified in the Brazilian territory. The incidence rate of this deficiency is 0.34 children per 1000 live births in the world<sup>5</sup>.

However, the incidence of congenital heart disease in the world is 9 per 1000 live births, knowing that this rate varies according to per capita income, geographic region, in addition to maternal risk factors<sup>6</sup>.

With reference to Tetralogy of Fallot (TF), it is classified as the most common among cyanotic congenital heart diseases. In general, the diagnosis is made within the first year of life. However, in some cases the disease is only Gonçalves SAV, Matias GF, Gonçalves ALR, Silva BBE, Santos F diagnosed in adolescence or adulthood, delaying surgical repair, and increasing the chance of aggravation by complications and even leading to death<sup>7</sup>.

The role of the nursing team during surgical repair is essential, as when trained, they are responsible for carrying out the applicability of the safe surgery checklist, in addition to being able to interrupt any stage of the process if they deem it necessary. This instrument was created with the aim of improving patient safety in the pre, intra and postoperative period. In this way, reducing or preventing adverse outcomes or avoidable harm<sup>8</sup>.

The present study has as a guiding question: What is the main nursing care provided to children with Tetralogy of Fallot? From this perspective, the research aims to: describe the Nursing Care to children with congenital heart disease with a focus on Tetralogy of Fallot.

#### Methodology

This is a literature review study. The search for articles was performed through the virtual health library. As a criterion for inclusion of studies in the database platform, the period of publication between the years 2016 and 2021, Portuguese, English and Spanish languages, and full texts were applied. The selection of studies to compose the review took place in March 2021.

With the descriptors congenital heart disease, nursing care and Tetralogy of Fallot, and the use of the Boolean operators AND and OR, it was possible to complete the searches with a total of 5 bibliographies. Bardin's content analysis was used to analyze the results<sup>9</sup>.

#### **Results and Discussion**

According to Bardin, the application of the method foresees three fundamental steps, namely: pre-analysis, exploration of the material and treatment of the obtained results and interpretation<sup>9</sup>.

During the analysis of the bibliographies found, some relevant points for the present study were grouped, among which the following categories stand out: (1) congenital heart diseases; (2) Nursing care for patients with congenital heart disease; (3) Nursing care for patients with tetralogy of Fallot.

## Congenital heart diseases

The research showed that congenital heart disease becomes a very broad topic and requires a multidisciplinary team for its study, which necessarily requires approaches from different perspectives. In this way, we can observe a diversity of professional categories, of the main authors who research, write, and publish on the subject. It is important to point out that in relation to the professional categories in the health area that publish on the subject, the articles demonstrate that Medicine is still, indisputably, the area that gathers the most scientific productions published mainly in the MEDLINE database.

Medicine is followed by Nursing and then Psychology when it comes to this issue. It is important to emphasize that, despite reflecting only the data referred to the main author of each publication, the associations



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between professional areas observed among the publications studied point to a trend of multidisciplinary teams in the approach to quality of life linked to childhood and adolescence and the network of support from that patient.

In 2017, the National Plan for Assistance to Children with Congenital Heart Disease was launched to integrate levels of care and expand access to services related to congenital heart disease, such as diagnosis during prenatal care, diagnosis in the neonatal period, safe transport of newborns and children with heart disease, surgical care, and multidisciplinary care. Ordinance No. 1,727, of 11 July 2017, is a watershed by unifies and makes this communication between the spheres of care and treatment of this patient more fluid. Uniting primary, secondary and tertiary care, facilitating the patient's access to care<sup>10</sup>.

## Nursing care for patients with congenital heart disease

The execution of care for neonatal diseases involves actions taken from the admission of the patient to the neonatal intensive care unit (NICU) - such as monitoring of important data, laboratory analysis, ventilatory support and nutrition, medication management and specific procedures, such as hemodialysis and peritoneal dialysis - even welcoming and taking care of the newborn's family's mental health, so that such action will not deprive the care and contact of the neonatal patients in the hospital, but they will be included in care effectively and will significantly reduce anxiety and later the gradual improvement of the patient. Bringing together technology and the humanization of care will make it possible to convert the environment into a place of hope<sup>11</sup>.

In some studies, it was possible to observe the importance of the nurse's educational action with the family, explaining each process and action, such as when the patient affected by heart disease should undergo surgery, as the joy of the child's coming into the world gives a place for feelings of fear, incapacity and concern, as well as active listening to the family member who, several times, renounces a routine and adjusts to receive a completely different one. Changes in states and regions, daily routines, and tasks, including employment to achieve a better quality of life for the patient, were evidenced. Devising an action plan that emphasizes emotions is an effective strategy for reducing anxiety<sup>12</sup>.

The care provided to the NB, from the family to the nursing team, is considered essential to aid in the diagnosis of heart disease. As these professionals are the first to carry out the consultations, it was possible to identify signs and symptoms that appear at the beginning of extrauterine adaptation. The heart test, for example, used for screening by the team, allows identifying hypoxemia even before cyanosis sets in. In addition to being possible to avoid the negative impact on the newborn's bodily systems<sup>11</sup>.

To systematize this care, nursing diagnoses indicated in the literature are vital in the process of planning and implementing the nursing intervention. In this sense, care and diagnosis are the basis of care for newborns who Gonçalves SAV, Matias GF, Gonçalves ALR, Silva BBE, Santos F are affected by congenital heart disease, and it is essential to support research on this topic.<sup>11</sup>.

## **Nursing Assistance in Tetralogy of Fallot**

In Brazil, 28,000 newborns are born with congenital heart disease, so recognizing the pathology and its symptoms is essential for an early diagnosis and proper treatment. During the period in which the newborn remains in the hospital, the nursing teams must be attentive to detect the main signs that may not have been observed at birth, such as cyanosis, tachypnea, tachycardia and sucking fatigue<sup>7,13</sup>.

Regarding treatment, there are quick relief measures for patients with moderate symptoms until surgical correction is performed. Such as the use of oxygen, morphine, and beta blockers such as propranolol, phenylephrine which increase blood flow to the body, or the technique of bending the knees to the chest of the newborn or infant, increasing blood flow to the lungs. In older children a measure of relief is to instinctively squat the patient as it increases blood flow towards the lungs.<sup>13</sup>.

However, the effective treatment for this type of heart disease is surgery, including intracardiac repair or a temporary procedure known as a shunt (a procedure by which blood flow to the lungs increases). If not surgically corrected, Tetralogy of Fallot is potentially fatal, with one-, three-, and ten-year survival odds of 66%, 49%, and 24%, respectively. There are some less invasive methods such as using an inflated balloon in the pulmonary valve to widen its opening, but it is only a temporary measure<sup>13</sup>.

Both in the evolution of the disease and after surgical intervention, some complications may occur, such as ectopic junctional tachycardia, which usually occurs within the first 24 hours, residual pulmonary stenosis with predominant valve lesions, aneurysm at the level of the aortic root, late arrhythmias, long-term pulmonary insufficiency term, occasionally low cardiac output syndrome and sudden death that occurs between 1% and  $3.5\%^{14}$ .

Nursing care in pediatric cardiology must be individualized, providing them with comfort, quality, safety and always clarifying their doubts, in addition to the doubts of those responsible. It is essential that the team provide assistance not only to the child but also to their families. Hospitalized children with congenital heart disease have specific care needs aimed at maintaining and monitoring cardiac function, fluid and sodium accumulation, cardiac needs, tissue oxygenation and oxygen consumption<sup>12</sup>.

Therefore, it is essential to carry out hemodynamic monitoring, which change according to severity and postsurgical recovery, in which changes in heart rate, blood pressure and urinary output are detected. It is important that a joint planning of care provided by the entire multidisciplinary team is carried out for the clinical management and recovery of these patients. Attention to family reactions and concerns should also be included in care. An adequate relationship between the multidisciplinary team and the family is necessary so that



doubts and other points can be clarified, providing humanized care, and encouraging family involvement<sup>12</sup>.

During hospital discharge, the participation of those responsible for the child is essential so that information is passed on regarding the importance of care provided at home, use of medications, prevention of endocarditis, care of the surgical wound and signs and symptoms of infection, possible complications, nutrition and clear instructions on when to seek medical care, as well as fundamental as some factors can interfere with the child's development, whenever possible involve them in actions for the child's well-being, inform about the signs of possible behavioral disorders and show how your support and actions with nursing are important.<sup>12</sup>.

## **Final Considerations**

The objective and guiding question of this study were met through the analysis and discussion of the results. It is extremely important that further studies be carried out by other researchers on the theme for the appropriation of nursing professionals in the care of children with congenital heart disease, just as we carried out a critical analysis of studies carried out previously by several researchers from different training groups. It is necessary that Nursing Gonçalves SAV, Matias GF, Gonçalves ALR, Silva BBE, Santos F empowers itself with this issue for a more qualified assistance.

Through this study, we can conclude that the nurse, when providing care to the patient and their family in a holistic and integral way, aiming at the promotion, maintenance, and recovery of health, technically and scientifically grounded, together with nursing technicians, who have a fundamental role in this care, it achieves, through the SAE (Nursing Care Systematization), autonomy in its comprehensive, holistic, human, systematic and effective care. Joining forces with the multidisciplinary health team, they achieve a better prognosis, quality of life, safety, and patient improvement.

It is believed that the knowledge revealed by this study can collaborate with the expansion of possibilities for a better foundation of nursing care planning and that they are used by nurses who work in teaching, research or care, in addition to raising the most concrete levels of direct impact on the provision of care to patients with such congenital heart diseases in general and specifically the tetralogy of Fallot, which is a topic so little explored by our niche, despite being prevalent among heart diseases, as evidenced in this same study.

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