



The nurse in the face of humanized care for critically ill patients with congenital heart disease – Integrative review



<https://doi.org/10.56238/levv15n39-155>

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ABSTRACT

Introduction: Congenital heart diseases are among the main causes of neonatal morbidity and mortality, with increasing prevalence in the population. They represent about 30% of all congenital malformations and have an incidence of around 9.4 cases for every 1000 live births. **Objectives:** To investigate articles in the literature that address the formation of bonds with humanized care centered on the family of congenital heart disease patients and to identify the interference of early diagnosis of heart disease in the child's quality of life. **Methods:** This is an integrative review, developed through published articles, published in the Google Scholar database, Scientific Electronic Library Online (SCIELO) and Virtual Health Library (VHL). 20 articles were found and, based on the analysis, 17 articles were selected that met the guiding question of the study, published between the years 2019 and 2024. The following descriptors were used: "Congenital Heart Diseases" AND "Neonatal ICU" AND "Nursing". **Results:** In the analysis of the articles, three categories were identified: Profile of children with congenital heart disease; Early detection of congenital heart disease and its interference in the child's quality of life; Bonding with family-centered care. **Final considerations:** Early detection of these conditions is essential to ensure a better quality of life for the affected child. The formation of bonds with the family is essential to promote humanized and comprehensive care for congenital heart disease patients, providing emotional support, adequate information and active involvement of parents in the treatment and recovery process of the child, thus improving the quality of life of affected children, providing healthy development and reducing the risk of future complications.

Keywords: Congenital Heart Diseases, Humanization in Care, Neonatal Intensive Care Unit, Nursing.

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INTRODUCTION

Pregnancy It is divided into three trimesters, in an uneventful pregnancy for the mother and fetus, totaling 42 weeks of gestation. The development of the fetus takes place in a complex environment and depends on many variables that can affect it, as well as the pregnant woman. In a high-risk pregnancy, pathological and/or social complications arise that are factors of aggression to the pregnant binomial fetus, causing physiological and/or hemodynamic instability. They are usually a consequence of congenital disorders, metabolic alterations, prematurity, perinatal asphyxia and problems during pregnancy (Tamez, 2017)

Approximately 3% of babies born worldwide have some form of congenital anomaly. In Brazil, only 1% of newborns are officially registered with congenital anomalies each year. The prevalence of anomalies is three times higher in premature infants than in full-term infants. Between 2010 and 2021, 34,559,375 live births were registered in the Live Birth Information System, of which 285,296 (0.83%) had some congenital anomaly. Children of mothers who have already suffered miscarriages, especially repeated miscarriages, have a higher prevalence of congenital anomalies, such as congenital heart disease (Brasil, 2023).

Congenital heart defects are structural defects of the heart present from fetal development to birth. They represent about 30% of congenital malformations and have an incidence of approximately 9.4 cases per 1000 live births. In Brazil, approximately 28 thousand heart disease patients are born per year. Generally, congenital heart defects detected in the neonatal period require immediate specialized treatment, including cardiac surgery. The diagnosis can be made during pregnancy through ultrasound and fetal echocardiography, as well as after birth through clinical examination, pulse oximetry test and echocardiography. The main objective of fetal diagnosis is to plan appropriate postnatal treatment and guide the family in this situation (Arais, 2020; Brazil, 2022).

The literature describes more than 200 different diagnoses of cardiac anomalies. Among cyanotic congenital heart diseases, one of the most serious is Tetralogy of Fallot, where four anomalies appear in the heart:

Ventricular Septal Defect (septal defect); Pulmonary stenosis (Obstruction of blood flow from the right ventricle to the pulmonary artery); Right ventricular hypertrophy and aortic deextraposition. Usually diagnosed in the first weeks of life, due to the presence of murmur or cyanosis. Among acyanotic heart diseases, one of the most prevalent is the ventricular septal defect, which consists of the abnormal opening of the ventricular septum, where oxygenated blood from the left ventricle passes to the right ventricle. This condition is usually diagnosed at birth or during childhood, and its severity can vary according to the size of the defect (Tamez, 2017; Arais, 2020).

The diagnosis and treatment of congenital heart disease depend on several factors, such as age, weight, nutritional status, and complexity of the disease. Surgical intervention can cause stress

and affect the patient's progress, especially if there are pre-existing nutritional problems. The postoperative period is crucial for tracking patient progress, and nurses must apply their knowledge and technical skills to ensure accurate and effective care. However, technical accuracy is often prioritized over professional feelings (Cabral, 2020).

In this sense, Ordinance NO. 1,727, of July 11, 2017, establishes the National Plan for Assistance to Children with Congenital Heart Disease, which aims to guide the organization of care for children with congenital heart disease, in order to provide comprehensive care for the child at all stages: prenatal care, birth, cardiovascular care, and follow-up (Brasil, 2017).

Also, the National Humanization Policy Program, launched in 2003, promoted changes in the culture of care in health services, focusing on the implementation of new ways of being and doing, respecting the life and autonomy of the human being. In the Neonatal Intensive Care Unit (NICU), humanization is even more important due to the stressful environment for patients and families. The nursing team should seek to promote humanization through actions such as reducing noise and lighting, providing comfort and pain relief, in addition to maintaining open and calm communication with parents so that they can express doubts and anguish, thus helping in the care of the newborn (Brasil, 2013; Silva and Da Silva Magalhães, 2019).

When children and adolescents with congenital heart disease are hospitalized, their family is brought along. One way to alleviate the suffering of hospitalization is to include the family in the child's care with the follow-up of therapies throughout hospitalization. The permanence of parents and family members during hospitalization reduces anguish and maintains affective bonds. To do this, it is necessary to get to know the family by offering comprehensive care. This care is called family-centered care and requires time, preparation, and humanization for humanized care and appreciation of the person as a whole (Hillig, 2020).

Proper communication between NICU team members is essential, especially considering the often excessive workload. In addition, it is important that professionals know how to listen and understand the patient's needs, establishing a bond of trust with the patient and their families. It is essential that the team is up to date both in relation to NICU techniques and procedures, as well as in relation to humanization. Therefore, a permanent education about these subjects is necessary. The Kangaroo Care has stood out as an important humanization tool in the NICU, due to the benefits it offers to neonates and their families (Bazzan et al, 2023).

In this context, the nursing process is fundamental for nurses to establish their care adequately. This includes obtaining relevant information from the assisted clientele, making accurate diagnoses, developing appropriate care plans, evaluating the results achieved, and providing higher quality of care provided. The construction and validation of nursing diagnoses are important tools to improve and direct care, based on scientific knowledge. It is essential to have scientific knowledge



and information from professional practice and reality to provide the best possible result to the patient (Verberne, 2019).

RESEARCH PROBLEM

Is there bonding when providing humanized care centered on the family of children with congenital heart diseases by the Neonatal ICU team?

JUSTIFICATION

Humanization in the Neonatal Intensive Care Unit (NICU) is the basis of all the care that is provided in the sector, mainly because it is an environment in which patients and families live together and is seen as painful and terrifying. Nurses and the nursing team need to promote humanization in this sector whenever possible. Promoting comfort, reducing pain, open and calm communication with parents, promoting a reduction in their fears and anxieties, improving parents' self-confidence so that they can assist in the care of the newborn (Leite et al, 2020).

Good communication between NICU team members is very important and necessary, as this is an environment that also causes stress in professionals, critically ill patients undergoing treatment who often do not resist and a workload that can often be excessive can lead to professional exhaustion and exhaustion (Silva et al, 2022).

Dealing with the deaths that lead to the death of a child can seem helpless and frustrating. In this case, the extreme, the opposite and the undesirable are configured in the NICU scenario, manifesting themselves in different ways and attitudes, as it reflects the individual engagement and coping of each participant involved in the process (Klock, 2019).

The humanization of the NICU seeks to reduce the stressors to the NB, which will significantly reflect on the development, growth and survival. The Ministry of Health has implemented some initiatives in the neonatal hospital environment such as the Kangaroo Mother method, rocking nets, the nest, and the use of Octopus (crochet octopuses bred in Denmark in 2013) with the aim of calming the baby (Rivas, 2020).

In this context, the study aims to investigate articles in the literature that address the formation of a bond with humanized care centered on congenital heart disease patients and to identify the interference of early diagnosis of heart diseases in the child's quality of life.

METHODOLOGY

This is an integrative literature review study. This type of review consists of six stages: (a) elaboration of the guiding questions; (b) search in literature; (c) categorization of studies; (d)



evaluation of studies; (e) interpretation of the results and (f) synthesis of knowledge (Mendes; Scott; Galvão, 2008).

To guide the research, the question was formulated: what has the scientific production published about "the critically ill neonate patient with congenital heart disease"? The research was carried out based on a bibliographic survey in the following databases: virtual library; electronic magazines; Ministry of Health; Scielo and google scholar. As inclusion criteria, articles from the last five years available in full were selected, and as exclusion criteria, abstracts in Annals, books, and master's dissertations.

Searches in the databases were performed using keywords indexed in the Health Sciences Descriptors (DeCS) with proximity operator: "Congenital Heart Diseases" AND "Neonatal ICU" AND "Nursing". The filters applied were from 2019 to 2024, full text and the main subject was humanized care in the Neonatal ICU, communication between parents/family members and the health team, early diagnosis of congenital heart diseases and profile of congenital heart disease patients.

As a criterion for inclusion of the reference, articles between the years 2019 and 2024 were defined, evaluating the title of the article, the year of publication, the origin, the authors and the main results found, in addition to the synthesis by similarity of contents. Articles published in Portuguese, English and Spanish were included. Afterwards, a framework was created for the organization of the articles discussed. The exclusion criteria were: books, master's dissertations and abstracts in Annals. The search for articles took place in March and April 2024.

A total of 20 articles were found in both databases and, based on the critical analysis of the abstracts, 17 articles were selected that met the guiding question of the study. The data collected were organized and grouped into three thematic categories that configure the central scope of this study. After this stage, the selected articles were critically read and discussed.

For the analysis, an exploratory, selective, analytical reading and interpretation of the materials in question was made. All data collection, selection and analysis of bibliographic materials and electronic articles were surrounded by ethical care, preserving their authorship through Copyright No. 12.853, of August 14, 2013.

RESULTS AND DISCUSSION

As for the profile of the selected articles, one was published in 2019, seven in 2020, one in 2022, seven in 2023, and one in 2024.

Regarding the source of dissemination: an article published in the Brazilian Journal of Health Review in 2023; an article was published by the Caderno de Graduação-Ciências Biológicas e da Saúde-UNIT- Alagoas, in 2020; an article was published in the Peruvian Journal of Experimental

Medicine and Salud Publica in 2019; one by the Soc. Cardiol Journal. Estado de São Paulo, one article published in 2023; two articles in the journal Research, Society and Development in 2020 and 2022; two articles in the Brazilian Journal of Implantology and Health Sciences in 2023; one article for Revista Contemporânea in 2024. The Brazilian Journal of Development published an article in 2023; an article in the Electronic Journal Health Collection in 2020; an article by the Revista cir. traumatol. bucco-maxillofacial in 2022; an article by Dialnet Online Magazine in 2020; an article in the UERJ Nursing Journal in 2020; an article in the Brazilian Journal of Maternal and Child Health in 2020; an article in the Nursing Care and Health Journal published in 2020 and an article in Gep News Magazine in 2023. Chart 1 presents the synthesis of the articles evaluated.

Chart 1 Characterization of the Articles. Canoas, 2024.

Article No.	Magazine	Title	Year	Method Type of study
A1	Brazilian Journal of Health Review	Prevalence of congenital heart disease in children born in a maternity hospital from 2017 to 2021 in Teresina-PI	2023	Observational, quantitative, retrospective cross-sectional
A2	Undergraduate Notebook- Biological and Health Sciences- UNIT- ALAGOAS	Clinical and epidemiological profile of children with congenital heart diseases submitted to surgical correction at a reference service in the state of Alagoas.	2020	Transverse
A3	Peruvian Journal of Experimental Medicine and Public Health	Factors associated with one-year survival in neonates with severe congenital heart disease in a hospital in Peru	2019	Kaplan-Meier Methods and the Log-Rank Test
A4	Rev. Soc. Cardiol. Estado de São Paulo	Profile of neonates and infants with heart disease and the interdisciplinary care of cardiology, neonatology and obstetric nursing	2023	Exploratory, descriptive, prospective population-based
A5	Research, Society and Development	Epidemiological study of congenital heart disease in the state of Pará, Amazonia, Brazil	2022	Ecological, descriptive, retrospective
A6	Brazilian Journal of Implantology and Health Sciences	Tetralogy of Fallot – understanding existence	2023	Epidemiological, descriptive
A7	Brazilian Journal of Implantology and Health Sciences	Epidemiological profile of live births with heart disease in Brazilian regions	2023	Epidemiological, descriptive
A8	Contemporary Magazine	Analysis of the prevalence and profile of congenital heart disease in children and adolescents in Brazil between 2000 and 2022	2024	Epidemiological, retrospective and descriptive
A9	Brazilian Journal of Development	Tetralogy of Fallot: Clinical manifestations and importance of early diagnosis - case report	2023	Case report
A10	Research, Society and Development	Congenital heart defects in a pediatric hospital	2020	Exploratory, retrospective, with a quantitative approach
A11	Electronic Journal Health Collection	Increased survival of patients with congenital heart disease after adequate perinatal and neonatal care: case report	2020	Case Report
A12	Rev. cir. traumatol. buco-maxilo-facial	Epidemiological and clinical profile of children hospitalized with congenital heart disease	2022	Cross-sectional study

A13	Dialnet Magazine Online	Family-centered care in the neonatal intensive care unit (NICU): nurse experiences.	2020	Cross-sectional research with a qualitative and interpretative approach
A14	UERJ nursing journal	Family-centered care in neonatology: Perception of professionals and family members	2020	Quantitative descriptive approach
A15	Brazilian Journal of Maternal Health childish	Support offered to parents of newborns by the nursing team	2020	Prospective, descriptive and analytical statistics were used
A16	Rev. Nursing, care and health	Humanization of nursing care in Neonatal Intensive Care Unit	2020	Exploratory, qualitative and descriptive,
A17	Gep News	Affective record for humanization of neonatal care	2023	Qualitative participant-type research with a focus group and Bardin's content-analytical approach

Source: the author herself

From the synthesis by content similarity, it was possible to highlight themes in the authors' discourses, grouped into three categories: (1) Profile of children with congenital heart disease; (2) The interference in the child's quality of life with the early detection of congenital heart disease; 3) Bonding with family-centered care. These themes will be presented in Chart 2, which also details the articles that make up the category.

Table 2. Categories found after analysis. Canoas, 2024.

Categories	Articles
1) Profile of children with congenital heart disease.	A1, A2, A3, A4, A5, A6, A7, A8, A10, A12
2) The interference in the child's quality of life with the early detection of congenital heart disease	A1, A3, A4, A9, A10, A11, A12
3) Bonding with family-centered care	A13, A14, A15, A16, A17

Source: the author herself

CATEGORY 1 - PROFILE OF CHILDREN WITH CONGENITAL HEART DISEASE

The diagnosis of newborns with congenital heart disease must be resolved quickly because treatment can save the lives of some of these babies. The incidence of congenital heart diseases is approximately 1% and, in almost half of patients with complex congenital heart diseases, hospital neonatal mortality rates reach 7%. There is a high frequency of multiple congenital anomalies, syndromes, low birth weight, and long hospital stays. The most frequent anomalies observed during the first week are patent ductus arteriosus, transposition of the great arteries, hypoplastic left heart syndrome, tetralogy of Fallot, and pulmonary atresia (Gomella 2018).

Articles A1 to A8, A10 and A12 addressed studies related to the profile of patients with congenital heart disease.

A1 analyzed 44 medical records of patients who had congenital heart disease. The prevalence was 40.7% in general malformations and 1.3% in the total number of newborns hospitalized in the

maternity ICUs. Congenital heart diseases are part of the main malformations in newborns, since they are associated with the anatomy and functionality of the heart, causing dynamic repercussions.

Article A2, also in the profile category, analyzed medical records of children from 0 to 11 years of age, evaluating the types of heart diseases. It was observed that 94% of congenital heart diseases were acyanotic, the most frequent being patent ductus arteriosus (33.7%), ventricular septal defect (28.7%), and atrial septal defect (20%). Among the cyanotic patients, tetralogy of Fallot (3.7%) and pulmonary atresia with ventricular septal defect (2.5%) stood out. The association with Down syndrome was observed in 12.5% of the cases, which in most cases was associated with patent ductus arteriosus and ventricular septal defect.

The authors from Lima-Peru, in A3, also point out that congenital heart diseases are the major cause of cardiac complications in neonates and infants, requiring specialized care during hospitalization in the Neonatal ICU in that country. In article A4, cyanotic congenital heart diseases prevailed in 8.36, with indication for reparative surgery and ventricular correction in 47.36%.

On the other hand, the A3 sought to know the factors associated with survival in the first year of life of neonates with congenital heart disease treated at a public hospital in Peru. The most frequent congenital heart disease was pulmonary atresia, with 26.3%. In 33.7% of the children died and 66.3% survived in the first year of life.

The ecological study of A5 describes the clinical-epidemiological profile of cases of congenital heart disease treated at a referral hospital in the state of Pará. In it, 905 patients who had a diagnosis confirmed at least by echocardiogram were analyzed. 52% were over 1 year of age at diagnosis; 75.1% had acyanotic heart disease, the most frequent being ventricular septal defect (21%). Among cyanotic heart diseases, Tetralogy of Fallot was the most frequent (12%), with no predominance of gender. At the time of the evaluation, 55.7% of the patients were awaiting treatment; 33.8% had undergone surgery; 5.3% had undergone surgery and underwent hemodynamic treatment and 5.2% had undergone hemodynamic treatment alone. The lethality rate during the study period was 9.61%, of which 83.9% had undergone surgical treatment.

Article A6 analyzed 943 cases of Tetralogy of Fallot among live births in Brazil from 2012 to 2021. Regarding the variable: Color/Race, 588 (62.35%) were white; 51 (5.41%) were black; 10 (1.06%) yellow; 267 (28.31%) were brown, and 27 (2.86%) were unknown. They concluded that a deep understanding of congenital heart disease not only saves lives, but also significantly improves the quality of life of affected individuals.

In an epidemiological study about the reported cases of live births with Congenital Heart Disease were reported in A7. In Brazil, from 2012 to 2021, 28,789,402 live births were registered, in which children with Congenital Heart Disease corresponded to 0.000875% (n = 25,212). Among live births, 10.6% (n=3,057,372) were premature, while 27.44% (n=6,920) of live births with Congenital

Heart Disease are premature. The southeast region had the highest prevalence of live births with congenital heart disease, as well as males and white races. Prematurity was higher in patients with heart disease than in the rest of live births.

The A8 also analyzed the prevalence and profile of congenital heart disease in children and adolescents in Brazil, but in different periods from the previous article. This analyzed the period between 2000 and 2022 based on SINASC data. A total of 67,258,947 live births were registered, in which those born with congenital heart diseases corresponded to 0.0562%. As in A7, the Southeast region recorded the highest number of cases, with 65%, while the North region had the lowest prevalence, with 3.15%. The occurrence of congenital heart disease was observed in 1,833,462 deaths among children and adolescents, 4.5% of which were due to some type of congenital heart disease. In 84% of all deaths occurred in children under 1 year of age. It is also the Southeast region with the highest prevalence of deaths from congenital heart disease (39.1%), as well as males and white people are also the most prevalent among live births with congenital heart disease.

Like A2, A4 and A5, article A10 also evaluated the prevalence of congenital heart disease in a pediatric hospital in 2016 and 2018. It found some type of heart disease in 30.06%, the most prevalent being the ventricular septal defect type, in the age group of children under 01 year of age and males.

A12 presents a study with the epidemiological and clinical profile of children with congenital heart disease admitted between 2018 and 2019 to a reference hospital in Pernambuco. The main maternal risk factors were infection during pregnancy (21.3%) and advanced age (15.8%). The patient's predisposing factors were prematurity (16.1%), low birth weight (17.7%), trisomy 21 (17.7%) and extracardiac malformations (7.1%).

The hemodynamic instability that newborns with congenital heart diseases present was addressed in E1. It also refers to greater nutritional difficulty with malabsorption of nutrients and increased metabolic demands. This causes shorter stature in these patients compared to the standard. In addition, it is a reason for the patient to have less resistance and immunity. The use of echocardiography is the gold standard for early diagnosis and helps in effective treatment, which evaluates which structures are affected.

The same A1 also points out that the interdisciplinary interface between obstetrics, neonatology and cardiology is essential for nursing practice. In this scenario, the professional develops competencies and skills to provide comprehensive care in the health-disease process, due to the complexity and specificity of the care required by patients with congenital heart diseases undergoing treatment.

The main characteristics of congenital heart disease were seen in this first category, highlighting the greater involvement in premature infants and mortality in children under one year of

age. Acyanotic heart disease is the most prevalent, especially ventricular septal defect, and among cyanotic heart diseases, tetralogy of Fallot is the most frequent. The articles pointed to a higher prevalence in males and white among live births with congenital heart disease.

CATEGORY 2 – THE INTERFERENCE IN THE CHILD'S QUALITY OF LIFE WITH THE EARLY DETECTION OF CONGENITAL HEART DISEASE

Congenital heart defects consist of structural or functional anomalies in the embryonic development of the fetus. Tetralogy of Fallot is the most common cyanotic congenital heart disease. It presents four anatomical-functional alterations: the defect in the interventricular septum; deviation of the aorta to the right at the exit of the heart; pulmonary stenosis and right ventricular hypertrophy (Lippert; De Carvalho, 2023).

This category included articles A1, A3, A4, A9, A10, A11, A12.

A9 addresses the early diagnosis of Tetralogy of Fallot, which after the appearance of signs and symptoms makes it possible to carry out an adequate follow-up, interfere when decompensations appear, and perform surgical correction at the opportune and convenient time for the patient's clinical status. It was evidenced that the early diagnosis of these malformations is extremely important, since it enables targeted therapy and a better prognosis, reducing severe and potentially fatal complications.

For A10, congenital heart defects are important malformations that can be detected in the first days of life or intrauterine life. The article also addresses early diagnosis, allowing a timely and more accurate assessment in the face of the need for intervention. They emphasized the importance of early diagnosis so that adequate treatment is possible as soon as possible and thus allows a better prognosis, allowing a prolonged survival of the individual.

Articles A1 and A3 address the importance of prenatal care as a moment of early diagnosis. Episode A1 points out the importance of identifying possible heart diseases through prenatal consultations, screening exams and fetal echocardiography, in order to reduce high morbidity and mortality rates, in addition to providing better quality of life to patients. Also, the importance of fetal echocardiography as a fundamental piece for the early diagnosis and treatment of these patients, in order to reduce morbidity and mortality. In article A3, they reported that prenatal diagnosis increases survival in the face of severe congenital heart disease and allows for timely surgical treatment.

The A4 reiterates that early intrauterine diagnosis could enable the conduct of delivery without risk of fetal suffering, as well as the postpartum evolution of greater resolution with the presence of professionals to care for neonates with heart disease, minimizing the risk of aggravations and sequelae, as well as better therapeutic conduction in a specialized institution.

In the same context as A4, article A11 reinforces that there is an increase in the survival of patients with congenital heart diseases after adequate neonatal care and the correct indication for interruption of labor. The importance of adequate postnatal screening in relation to tachycardias and apneas provides the patient with an early treatment, and consequently a better prognosis than if he had been diagnosed in adulthood, a period in which the diagnoses of corrected transposition of the great arteries (AGCT) prevail.

On the other hand, the E12 states that respiratory signs and symptoms were the main reason for hospitalization, with dyspnea (55.8%), cough (30.3%), and pulmonary auscultation alterations (16.1%). The reason for hospitalization was the presence of cyanosis (20.3%). A heart murmur was present in most patients (80.0%). In 16.8% of the cases, the diagnosis occurred during hospitalization. Knowledge about the profile of congenital heart diseases helps in the diagnosis.

The importance of early diagnosis was seen in the second category to enable adequate treatment as soon as possible, allowing a better prognosis, resulting in prolonged survival. Prenatal care, intrauterine diagnosis, and echocardiogram were highlighted as important in the early diagnosis of these patients, in order to reduce morbidity and mortality. Also the importance of a multidisciplinary team prepared to care for neonates with heart disease immediately after birth. It was seen that there is still a large percentage of congenital heart diseases that are diagnosed through signs and symptoms during hospitalization.

Cyanotic heart diseases and the presence of other extracardiac congenital anomalies reduce survival if surgical interventions are not performed or if complications are presented. It is necessary to implement measures to educate and raise awareness among the population about the importance of adequate prenatal care and medical follow-up during pregnancy, in order to reduce risks and improve outcomes for newborns with congenital heart disease.

CATEGORY 3 – BONDING WITH FAMILY-CENTERED CARE

The practice of family-centered care in the Neonatal ICU is a practice based on scientific evidence, providing relief from suffering and well-being, which should be constant in scenarios where family members accompany their premature or at-risk newborns and the nurse, due to the strong close relationship with them, generally assumes the role of assisting families (Fonseca et al, 2020).

To organize this category, articles A13, A14, A15, A16 and A17 were selected.

In the study of A13, the nurses understand the importance of family presence for the recovery of the newborn and for the development of parenthood. They conclude that there are still conceptual limitations regarding the understanding of the meaning of family-centered care and the consolidation of this approach in practice.

In line with article A13, we have A14 on the same theme. In it, nursing professionals who work in neonatal ICUs and parents of hospitalized children were interviewed in order to understand how parents and professionals perceived family-centered care. It was seen that the parents perceive the team's bond in welcoming the family. But professionals centralize decision-making. They conclude that family-centered care occurs in an incipient way in the view of professionals and family members, unaware of its other consequences and ways of putting it into practice.

On the other hand, A15 highlights the support that parents of neonates receive from the nursing team during their child's hospitalization. The mothers declared that they were supported mainly in the instrumental and informational domains. There was a positive correlation between the emotional, appreciative and informative domains. For most of the participants, in the informative domain, there was a demand for knowledge provided by the team, inclusion in decisions and encouragement to ask questions. In terms of emotional support, the concern with the well-being and attention to the mothers' anguish was highlighted.

The humanization of nursing care in the neonatal ICU of a private hospital is highlighted in A16. It was observed that the professionals understand humanization as an experiential process, acquired through clinical practice under an affective bias and from the science of nursing itself. They highlighted the importance of the practice of humanization in the provision of nursing care to the newborn, as well as being extended to their families. The professionals pointed out the importance of family involvement in the humanization process, which goes through mutual trust to the empowerment process generated in the parents by the team.

Still on the involvement of the family in the humanization of the Neonatal ICU, the authors of A17 addressed the use of affective records to improve bonding and stimulate humanization. They conducted a focus group with mothers, who wrote down representative characteristics of their children. The initiative brought mothers closer to their children and the multiprofessional team, encouraging the transition from the imaginary baby to the real baby and strengthening humanization.

Thus, the third category highlights humanization as a driving force for the team's care for the newborn and family from the perspective of family-centered care. The team's bond with the child's family must be increasingly strengthened.

FINAL CONSIDERATIONS

The analysis of the articles allowed us to identify the profile of the main congenital heart diseases in children, especially in neonates. The highest frequency of congenital heart diseases are acyanotic, such as patent ductus arteriosus and ventricular septal defect. Among the cyanotic diseases, tetralogy of Fallot and pulmonary atresia stand out. It is prevalent in males, Caucasians. The most prevalent maternal age group at the time of delivery was between 30 and 34 years old, full-



term births and cesarean deliveries. Low birth weight and premature neonates were also found in this profile, with a higher prevalence of other congenital anomalies, most of whom underwent surgical treatment. There was a higher occurrence of deaths in children under 1 year of age. The Southeast region of Brazil has the highest prevalence of cases of congenital heart disease and also the highest number of deaths from this condition, combined with the increase in full-term births and cesarean deliveries.

It was evidenced that prenatal diagnosis plays a fundamental role in reducing the risk of mortality. In view of this, early diagnosis, carried out during pregnancy, makes it possible to conduct childbirth safely, avoiding fetal suffering. The importance of identifying possible heart diseases through screening tests and echocardiography is paramount to reduce high morbidity and mortality rates and provide better quality of life to patients.

Nursing recognizes the importance of family presence for the recovery of the newborn and for the development of parenthood. Factors such as concepts and beliefs of the subjects involved and the organizational culture of the hospital institution interfere in this process and also the lack of material, infrastructure and human resources; the lack of discussions in the team to plan and evaluate the care offered; the difficulty of relating to family members and especially the contradictory notion of providing specialized care, but at the same time to judge the ability of parents to participate in these actions.

The immediate hospitalization of the newborn after birth interrupts an important moment of formation of family affective bonds and generates insecurity and vulnerability in the parents. Physical fatigue and emotional stress are additional factors that compromise the well-being of the newborn's family members, making it even more difficult to provide care to the newborn.

To facilitate family-centered care, effective communication is key. Nursing professionals must be available to provide support during processes and complications, ensuring that parents feel welcomed and well informed. In addition, it is necessary to establish institutional policies and guidelines that support the presence and participation of parents in the neonatal unit. This may include creating adequate spaces for family members to accommodate, making visiting hours more flexible, and providing educational materials so that parents feel more empowered and confident to actively participate in the care of the newborn.

We suggest the implementation of prenatal diagnosis programs in all health units, with the purpose of identifying possible heart diseases early and offering the necessary support for a safe pregnancy and adequate delivery. In addition, it is important to invest in the training of professionals specialized in neonatal cardiopathic care and in the creation of institutions specialized in this type of care, in order to ensure a more effective postpartum evolution and minimize the risk of



complications. It is also necessary to ensure access to targeted therapies and treatments, ensuring a favorable prognosis and prolonged survival for individuals affected by congenital heart disease.

Thus, it is essential that nursing professionals receive adequate training on the importance of family-centered care and how to implement it in practice. This includes developing effective communication skills, empathy, and cultural sensitivity, to better understand parents' needs and expectations. The presence of professionals specialized in the care of cardiac neonates as well as a specialized institution ensure a more effective postpartum evolution, minimizing the risk of aggravation and complications.

Nurses play a fundamental role in the humanized care of children with congenital heart disease. The nurse plays a crucial role in emotional support for both the child and the parents. Through their empathy and communication skills, the nurse is able to establish a bond of trust with the child, helping them to cope with the physical and emotional challenges associated with the disease. In addition, the nurse also offers support to parents, who are often facing a stressful and unfamiliar situation. By educating the family about the child's condition and providing guidance on post-treatment care, the nurse plays a key role in promoting self-care and improving the quality of life of these children and their families. With their dedication, knowledge and sensitivity, the nurse is essential to ensure that children with congenital heart disease receive humanized and comprehensive care.



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