

DOI: <https://doi.org/10.36489/saudecoletiva.2021v11i64p5570-5581>

Congenital heart diseases: challenges and perspectives for nursing care

Enfermedades congénitas del corazón: desafíos y perspectivas de la atención de enfermería

Cardiopatias congênitas: desafios e perspectivas para o cuidado de enfermagem

ABSTRACT

Objective: To analyze the scientific evidence on dressing care for children with congenital heart disease. **Method:** This is an integrative review carried out in the MEDLINE, LILACS and BDNF databases, through the VHL, and SciELO in the period from August to September 2020, based on the combination of the selected descriptors. 39 articles were identified and, after inclusion and exclusion criteria, 9 studies were obtained that comprised the sample. **Results:** From the data, two thematic categories emerged: Nursing performance in caring for children with congenital heart disease and Care for the family of children with congenital heart disease. The studies highlight the importance of systematic care for children with congenital heart disease, in addition to the growing need to involve the family in the care process. **Conclusion:** The important role of the nursing team is highlighted, directing assistance from established priorities which contributes to the implementation of comprehensive and individualized care.

DESCRIPTORS: Congenital heart disease. Nursing care. Pediatric Nursing.

RESUMEN

Objetivo: Analizar la evidencia científica sobre el cuidado del vendaje de niños con cardiopatías congénitas. **Método:** Se trata de una revisión integradora realizada en las bases de datos MEDLINE, LILACS y BDNF, a través de la BVS, y SciELO en el período de agosto a septiembre de 2020, en base a la combinación de los descriptores seleccionados. Se identificaron 39 artículos y, luego de criterios de inclusión y exclusión, se obtuvieron 9 estudios que conformaron la muestra. **Resultados:** De los datos surgieron dos categorías temáticas: Desempeño de enfermería en el cuidado de niños con cardiopatías congénitas y Atención a la familia de niños con cardiopatías congénitas. Los estudios destacan la importancia de la atención sistemática a los niños con cardiopatías congénitas, además de la creciente necesidad de involucrar a la familia en el proceso de cuidado. **Conclusión:** Se destaca el importante papel del equipo de enfermería, orientando la asistencia desde las prioridades establecidas que contribuyen a la implementación de una atención integral e individualizada.

DESCRIPTORES: Cardiopatías congénitas. Cuidado de enfermera. Enfermería pediátrica.

RESUMO

Objetivo: Analisar as evidências científicas sobre cuidados de enfermagem à criança com cardiopatia congênita. **Método:** Trata-se de uma revisão integrativa realizada nas bases de dados MEDLINE, LILACS e BDNF, por meio da BVS, e SciELO no período de agosto a setembro de 2020, a partir da combinação dos descritores selecionados. Foram identificados 39 artigos e, após critérios de inclusão e exclusão, obtiveram-se 9 estudos que compuseram a amostra. **Resultados:** A partir dos dados emergiram duas categorias temáticas: Atuação da enfermagem no cuidado à criança com cardiopatia congênita e Cuidado à família da criança com cardiopatia congênita. Os estudos destacam a importância dos cuidados sistematizados à criança com cardiopatia congênita, além da crescente necessidade de envolver a família no processo de cuidado. **Conclusão:** Destaca-se o importante papel da equipe de enfermagem, direcionando a assistência a partir de prioridades estabelecidas o que contribui para a implementação de cuidados integrais e individualizados.

DESCRIPTORES: Cardiopatias congênitas. Assistência de enfermagem. Enfermagem Pediátrica.

RECEIVED ON: 01/21/2021 APPROVED ON: 02/01/2021



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INTRODUCTION

Currently, congenital heart defects are among the main causes of neonatal morbidity and mortality with increasing prevalence in the population. Despite all advances in care, congenital heart defects (CHD) are associated with increased fetal losses, being present in up to 85% of deaths in stillbirths, newborns and infants.¹⁻²

The incidence of CHD is 8 to 10 per thousand live births, or 1 in every 100 births, ranging from 0,8% in more developed countries to 1,2% in underdeveloped countries. In Brazil, about 28.900 children are born with CHD per year (1% of the total births), of which about 80% (23.800) require cardiac surgery, half of them in the first year of life.³⁻⁴

Congenital heart disorders are often related to the occurrence of heart failure, impairment of the pulmonary system and hypoxemia. The assistance of a multiprofessional team is essential in the face of the process of caring for children with CHD, with emphasis on the nurse, who performs comprehensive care based on care planning, considering that such clinical conditions require individualized interventions that include maintenance and the monitoring of cardiac and pulmonary functions, the accumulation of fluids and electrolytes

and measures related to infection prevention.⁵⁻⁶

In view of the complications associated with CHD and the consequences of frequent hospitalizations, it is important to highlight that the disease has repercussions not only on the newborn's life, but also on the family, with the presence of anxiety, feelings of helplessness, guilt and fear being common, which makes the support of health professionals essential, providing guidance on health and treatment.⁷

In addition to the care directed at the child and the need to include the family in the process, the nursing team is considered essential in the investigation of the diagnosis of CHD, as the clinical evaluation of these professionals allows the early identification of clinical manifestations considered important in the neonatal period, such as: presence of heart murmur, progressive tachypnea, tiredness at feeding, cyanosis, hypotension and cardiac arrhythmias.⁸

In general, after confirmation of the diagnosis of CHD, there is an indication for surgical correction, which depends on several factors such as: age, weight, nutritional conditions, type of heart disease and surgical intervention itself. Thus, understanding the complexity of the care activities provided to the cardiac patient, the use of the Nursing

Process (NP) as instrumentalization of the Nursing Care Systematization (NCS) is of fundamental importance to support the nursing diagnosis, planning and implementing interventions according with the needs of the individual and family.⁹

In this perspective, the study is relevant to expand the knowledge of health professionals about the theme, contributing to the quality of nursing care for children with CHD by favoring the development of strategies and interventions that can meet the real needs of this population. Therefore, this study aims to analyze the scientific evidence on nursing care for children with congenital heart defect.

METHODS

This is an Integrative Literature Review, in which the following steps were taken: problem identification, with the definition of the research question; establishment of criteria for inclusion and/or exclusion of studies to search for scientific literature; definition of the information to be extracted from the studies; evaluation of studies; interpretation of results and presentation of the review/synthesis of knowledge.¹⁰ In view of the objective previously described, the following research question was

defined: "What is the scientific evidence about nursing care for children with congenital heart disease?".

The search was carried out in three databases: Medical Literature Analysis and Retrieval System Online (MEDLINE), Latin American Caribbean Literature in Health Sciences (LILACS) and Nursing Databases (BDENF) through the Virtual Library Portal in Health (VHL). To better select the files, the Scientific Electronic Library Online (SciELO) journals database was also used.

The search was made operational based on the use of terms identified in the vocabulary on the basis of Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH). Thus, a combination of descriptors was used: "Cardiopatas congênitas"; "Assistência de Enfermagem"; "Enfermagem pediátrica", separated by the Boolean operator "AND".

Data collection took place from August to September 2020, being carried out by two researchers, independently. Inclusion criteria were defined: publications in the form of an article, full text, published from 2010 to 2020, in Portuguese, Spanish and English. It should be noted that publications such as: theses, dissertations, monographs, course completion papers, literature review, manuals, previous notes and studies that did not address the proposed theme were excluded.

For the selection of studies, we followed the recommendations of the Preferred Reporting Items for Systematic reviews and Meta-Analyses method - PRISMA ¹¹ (Figure 1). Thus, the articles were initially selected by title and abstract and later read in full, including those that contained relevant information about nursing care for children with congenital heart defect.

The results were displayed by means of Charts and grouped into thematic categories. The analysis of articles was performed in a descriptive manner, with the synthesis of the evidence of each publication.

RESULTS

Initially, a total of 39 publications were identified. After the identification, screening and eligibility steps, the sample consisted of 9 articles. Figure 1 shows a flowchart of the search and selection process for articles by database.

To facilitate the analysis of the data, an instrument adapted from the literature by the authors was used, which includes characteristics of identification of the article such as: title, authors, year, database, methodological description (type of study and approach) and the objective.

Regarding the databases where the articles were indexed, MEDLINE was the one with the most publications, six (60%). It was found that eight (80%) articles were published in international journals and two (20%) in national journals. The periodical with the highest number of publications was the American Journal of Critical Care, with three studies (30%).

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Of the nine articles selected, it was

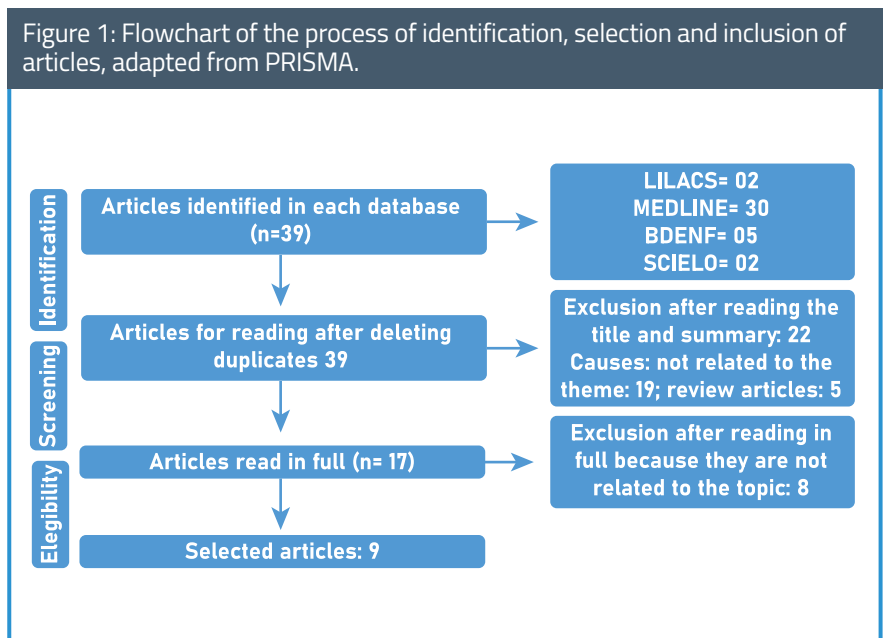


Chart 1: Distribution of articles selected for the integrative review. João Pessoa (PB), Brazil, 2020.

YEAR	AUTHOR/TITLE/JOURNAL	DATABASE
2019	Uhm JY, Choi MY. Mothers' needs regarding partnerships with nurses during care of infants with congenital heart defects in a paediatric cardiac intensive care unit. <i>Intensive Care Nursing</i> . ¹²	MEDLINE
2017	Bruce E, Sundin K. Pediatric Nurses' Perception of Support for Families With Children With Congenital Heart Defects. <i>Clinical Nursing Research</i> . ¹³	MEDLINE

2017	Lisanti AJ et al. Maternal Stress and Anxiety in the Pediatric Cardiac Intensive Care Unit. American Journal of Critical Care. ¹⁴	MEDLINE
2016	Connor JA et al. Measurement of Quality Practice in Congenital Cardiac Care. American Journal of Critical Care. ¹⁵	MEDLINE
2015	Silva VG et al. Diagnósticos de Enfermagem em crianças com cardiopatias congênitas: mapeamento cruzado. Acta Paulista de Enfermagem. ¹⁶	SCIELO
2013	Hickey PA. The Effect of Critical Care Nursing and Organizational Characteristics on Pediatric Cardiac Surgery Mortality in the United States. The Journal of Nursing Administration. ¹⁷	MEDLINE
2012	Melo HC et al. The Being-Nurse in the face of child care in the immediate postoperative period of cardiac surgery. Esc. Anna Nery Rev. Enferm. ¹⁸	LILACS
2012	Hickey PA et al. Pediatric Cardiovascular Critical Care in the United States: Nursing and Organizational Characteristics. American Journal of Critical Care. ¹⁹	MEDLINE
2011	Benítez ERD. Younger infant with alteration of basic needs secondary to congenital heart disease. Revista Mexicana de Enfermería Cardiológica. ²⁰	BDEF

Source: research data, 2020.

noted that the average publication in the applied time frame was one to two articles per year, however, in the years 2012 and 2017, two articles (20%) were published, followed by one publication in the others years. It should be noted that, in the years 2010 and 2014, no publication was found that met the crite-

ria of this study. In Chart 2, we present the synthesis of the studies included in this review, regarding the method used in the research and the purpose of each publication. There was a predominance of descriptive studies (66,6%), with the qualitative approach being the most prevalent (55,5%).

DISCUSSION

The results were grouped into two thematic categories considering the most relevant findings: Nursing performance in caring for children with congenital heart defect; Care for the family of the child with congenital heart defect.

Chart 2: Distribution of studies on nursing care for children with congenital heart disease, according to the characteristics of the articles. João Pessoa (PB), Brazil, 2020.

Nº	TYPE OF STUDY AND APPROACH	OBJECTIVE
E1	Descriptive study with a quantitative approach.	Investigate the needs of mothers in forming partnerships with nurses, based on postoperative recovery in pediatric cardiac ICU.
E2	Descriptive study with a qualitative approach.	To know the perceptions of pediatric nurses (PNs) in support of families with a child with a congenital heart defect.
E3	Descriptive study with a quantitative approach.	To explore the stressors and the stress response of mothers whose babies with congenital heart disease were being cared for in a pediatric cardiac ICU.
E4	Descriptive study with a qualitative approach.	To evaluate the current status of measuring the quality of pediatric cardiovascular nursing in independent children's hospitals in the United States.
E5	Cross-sectional observational study with a quantitative approach.	To evaluate the current status of measuring the quality of pediatric cardiovascular nursing in independent children's hospitals in the United States.
E6	Descriptive study with a qualitative approach.	This study explored critical pediatrics, nursing care and organizational factors that impact hospital mortality for cardiac surgery patients in children's hospitals in the United States.
E7	Descriptive study with a qualitative approach.	Understand the care of the child during the immediate postoperative period of cardiac surgery from the perception of the nurse.
E8	Descriptive study with a quantitative approach.	Describe and understand the nursing and organizational characteristics of cardiovascular care in children's hospitals.
E9	Descriptive study with a qualitative approach.	Identify the basic needs of a baby with congenital heart disease and develop a nursing process using Virginia Henderson's approach.

Source: research data, 2020.

Nursing performance in the care of children with congenital heart defect

With the objective of correlating standardization of diagnoses, interventions and nursing results in relation to systematic care for children with congenital heart defect, a study¹⁶ highlighted the following nursing diagnoses: decreased cardiac output, risk of infection, ineffective breathing pattern, activity intolerance, impaired gas exchange. He also stressed the importance of early recognition of complications, in addition to ensuring monitoring of blood pressure, breathing pattern, pulse oximetry, respiratory rate, maintenance of mechanical ventilatory support, among others.¹⁶

Taking into account the complexity of congenital heart defects, patients are more prone to infections, which can provide an increase in hospital stay and a higher mortality rate. Several elements can provide the development of nosocomial infections in children, such as the delayed maturation of the immune system, the partition of objects between pediatric patients, malnutrition, the appearance of congenital anomalies, medication (mainly corticosteroids) and hemato-oncological diseases.¹⁷

The area of nursing in pediatric cardiology requires a highly qualified team, with the knowledge and experience necessary to manage possible complications in this population, requiring measures that demonstrate the impact of the care provided to patients and family members. Thus, the Congenital Heart Care Consortium - Measurement of Nursing Practice (C4-MNP) was created, in which nursing leaders with clinical, administrative and research experience in pediatric cardiovascular programs in the United States were selected, with the objective of identifying nursing care actions or measures in complex pediatric cardiovascular care settings.^{15,17}

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tive of understanding child care during the immediate postoperative period of cardiac surgery from the perception of the nurse-being showed that child care is conceived through the relationship between hard technologies and subjectivity, but when the the focus of assistance is focused on the disease and the procedures involved in treatment, care loses its totality, as the human dimensions that surround it do not acquire their due prominence.¹⁸

Care for the family of the child with congenital heart defect

Regarding the support of family members of children with CHD, authors reinforce the importance of the nurse in the support in allowing the involvement of parents in the process of caring for this child, making them active in this context. In this sense, the nurse must inform the parents about the child's care, create a good relationship with the family and build the trust of all parties involved. In addition, the nursing team must provide security and self-esteem to the family throughout the child's care; thus, it becomes a relationship of trust with the team and with other family members, facilitating care and exhausting tension.¹³⁻¹⁴

In addition, the nurse stands out in the observation of these factors, as this has an impact on adult life, where the nursing team and parents must implement interventions that enable psychomotor development. The results of a study²⁰ emphasize that children need physical contact and stimulation for their recovery or cooperation in treatment. Thus, the nursing team and parents must be partners: parents are essential to provide support and authorization for the practice of nursing care.

It is established that the partnership between parents and nurses is a relationship based on cooperation with each other to provide optimal child health and care. Information, when

shared, allows care to be performed in an easy way. Within neonatal and pediatric intensive care units, parents need precise, timely and understandable explanations, especially mothers, who eventually tend to stay with their children for longer and participate in the care provided to the child.¹²

CONCLUSION

In view of the proposed objective, the importance of nursing care to children with congenital heart defect is evident in terms of the early identification of signs and symptoms, in

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addition to carrying out actions aimed at preventing and treating complications.

The study also points to the growing need to involve the family in the care of children with CHD, given that health professionals must work with family caregivers to develop strategies for implementing care, promoting and recovering health. The small number of publications in the sample is a limitation, requiring the development of new research to help improve the quality of care for children with CHD, considering the relevance of this problem in childhood. ■

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