

Nursing guidelines for family members and caregivers of children with congenital heart disease after discharge: integrative literature review

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1 INTRODUCTION

Among the various existing cardiac malformations, congenital heart defects (CHD) are abnormalities affecting the heart and great vessels, responsible for important functions in live births (CAPELESSO, 2017).

Care for maintaining quality of life in children with heart disease has evolved over the last 60 years. This has provided that, even in the most complex cases, a better prognosis of life is possible. Thus, therapeutic conducts have aimed at comprehensive care for the long-term evolution of the individual (AMARAL, 2019).

CHDs have an impact on children's lives, morbidity and mortality and increased spending on public or private health services. They are part of the major cause of death among cardiac malformations in the first year of life, representing about 2 to 3% of neonatal deaths and an important cause of mortality (ROSA, 2016; CAPELESSO, 2017).

The numerous existing treatments and surgical interventions in the field of cardiology are usual options in the search for a more effective quality of life, although they do not lead to a cure (**AMARAL**, **2019**).

Emerging countries, where access to health is more unfeasible, tend to have higher mortality rates than developed countries, according to national epidemiological studies (BRASIL, 2019). Approximately 36,000 children are born with CHD in the United States of America (USA) each year, corresponding to 1% of all live births. Of this percentage, 44.5% die in their first year of life (KOLAITIS, 2017).

In Brazil, CHD remains the third leading cause of death in the neonatal period. The Ministry of Health estimates that the incidence in the country is 28,846 new cases of CHD per year. However, the notifications of the Unified Health System (SUS) reveal that they reach 1,680 cases per year, demonstrating failures in the diagnosis and identification of the problem (BRASIL, 2017). In addition,



about 23,000 children need surgical treatment in the first year of life, while only 6,000 can operate. In the North and Northeast regions, this rate is quite peculiar, as up to 80% of children with CHD are not diagnosed and undergo treatment (MAIA, 2022).

In underdeveloped countries, access to health is precarious and presents difficulties in different aspects, such as poverty, insecurity, housing issues, education and family understanding regarding the disease, immigration, access to food and difficulties in locomotion and transportation. All these factors contribute to the clinical outcomes of people suffering from cardiovascular diseases, whether they are adults or children (SILVA *et al.*, 2020).

CHD impacts not only the lives of children, but also those of their families/caregivers. Hospitalization in different age groups can generate anxiety and loss of control over the lives of parents and children with CHD. The range of recurrent invasive treatments, surgeries and higher risk of death lead to the development of stress and impaired mental health (MENEZES & MORÉ, 2019; MARCOLINO et al., 2017).

Comprehensive care for children with CHD has been established since 2017, through a federal project of the Brazilian Ministry of Health. The project aims to expand care for children with CHD, increasing the care of these children by 30% per year, with more than 3,400 procedures, totaling around 12,600 procedures per year, bringing direct impact on the reduction of neonatal mortality (SOARES, 2018).

Chronic disease in childhood is accompanied by numerous medication intakes, occupational and functional restrictions, changes in daily life, asthenia and hospitalization that leads to social withdrawal, fear, exams and painful stimuli (KUDO *et al.*, 2018). This reality is confronted with the common characteristics of congenital heart disease, which generate several restrictions, mostly motor, due to clinical signs that can result in changes in routine, care, medications and long hospitalizations (MARI, 2015).

In view of the evolution of the diagnosis and treatment of CHD, there is no requirement for only one professional with specialized training, but rather the work of different professionals with different backgrounds and specialties, who together and in a complementary, integrated and simultaneous way, act in the care of children in this condition. These professionals must develop an active partnership with the public health system, reverberating in more team training, in order to guarantee early diagnosis and adequate treatment (SOARES, 2021).

Nurses are present at various times in the child's life, including at birth. However, the approach to CHD is scarce in their basic training as nurses, as well as in their professional performance, with a shortage of continuing education proposals for the care of children with CHD. The professional who cares for the neonate with CHD needs a preparation that must be implemented systematically and



continuously, through the participation of this professional in the teaching-learning process and in health education with family members (MAGALHÃES *et al.*, 2019).

However, even if the nurse's approach pays attention to the systematization of nursing care (SAE), specific knowledge about nursing care for children with CHD must be continuously improved. In addition, the family caregiver of the child with CHD needs to better understand the disease and develop skills that assist in home care after hospital discharge.

2 OBJECTIVE

Conduct a literature search on nursing guidelines for family members/caregivers of children with congenital heart disease after discharge from hospital for surgical repair.

3 METHODOLOGY

This is an integrative literature review (ILR). The integrative literature review is a specific research method that ensures the synthesis and critical evaluation of theoretical and empirical evidence of a given theme or event. Thus, it allows its product to present a current discussion on what was investigated, assisting in the implementation of effective interventions in health care, cost reduction, construction of multidisciplinary health knowledge and the improvement of public health practices and policies (MOURA *et al.*, 2015).

The present research was developed in six moments: 1 - identification of the problem to be solved and elaboration of the research question; 2 - elaboration of the inclusion and exclusion criteria of the articles; 3 - extraction of pertinent information from the selected studies; 4 - evaluation of the studies selected to compose the integrative review; 5 - reading and interpretation of the studies; 6 - organization, discussion and complete synthesis of the publications (GALVÃO; PANSANI; HARRAD, 2015).

In the first stage, the PICo strategy was used to formulate the guiding question, being P (population), I (intervention), Co (context) (SANTOS; PIMENTA; NOBRE, 2007). Therefore, the following question was elaborated: "What are the nursing guidelines (I) for caregivers of children with congenital heart disease (P) after hospital discharge (Co)?".

In the development of the second stage, the search was carried out between April and July 2022. For the search strategy, the following descriptors present in the established Health Sciences Descriptors (DeCS) and *Medical Subject Headings* (MeSH) were used: "*Nursing Care*"; "*Nursing*"; "*Congenital Heart Defects*"; "*Caregivers*"; "*Children*", related to the Boolean operators *AND and OR*.

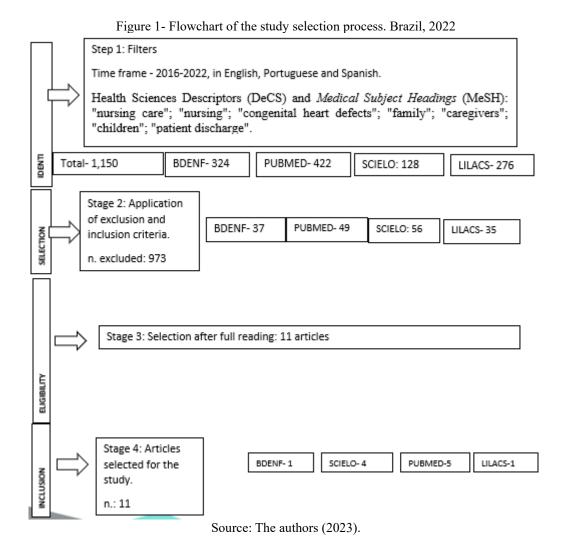
For data selection, articles published in scientific journals were analyzed, using the databases of the Virtual Health Library Portal (VHL), such as: Latin American and Caribbean Literature in Health Sciences (LILACS), PUBMED and Nursing Database (BDENF). For the search in the *Scientific*



Electronic Library Online (SCIELO), the page "scielo.br" was used. The databases used were selected because they are reference in the area of health and nursing.

As for the inclusion criteria, articles were selected that contemplated the theme and were directed to the objective of the study, available in full in electronic media for free, in Portuguese, English and Spanish; published between 2016 and June 2022, considering this time enough to reach the proposal of this study. Exclusion criteria were editorials, publications in event proceedings, theses, dissertations, monographs and incomplete documents; and not being available in full *online*.

From the reading of titles and abstracts, studies that did not address nursing care guidelines for children with congenital heart disease after hospital discharge were excluded, either directly or indirectly. Due to the scarce studies on the theme addressed for the hospital discharge of children with CHD, those related to guidelines and nursing care expressed in general were considered eligible.



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To ensure the quality and reliability of the study, the PRISMA *Guideline* recommendation (*Preferred Reporting Items for Systematic reviews and Meta-Analyses*) was adopted, which is composed of a structured *checklist*, capable of describing all the important and essential steps and approaches for the elaboration of a review, added to the flowchart (FIGURE 1) that discriminates the elements of the methodology of identification, selection, eligibility and inclusion of references (GALVÃO; PANSANI; HARRAD, 2015).

Several classifications are available in the literature, however, the most classic *score* for classification of primary studies was systematized by the Oxford *Centre for Evidence-Based* Medicine (CEBM) in 1998 and its last update was carried out in 2009 (VILLAS BOAS; VALE, 2014).

A total of 100 publications were identified, of which 77 were excluded after applying the filters and inclusion and exclusion criteria, leaving 23 articles. Subsequently, the selection was made by reading in full the articles considered potentially eligible, whose titles and abstracts informed evidence on the subject, totaling 11 articles (Figure 1).

The selection steps were carried out, for the storage, transcription and analysis of the articles, a protocol was prepared by the authors. After defining the sample, a database was prepared in *Microsoft Excel software*® 2016 that allowed organizing and compiling information from the selected studies.

The presentation of the results and their discussion was carried out in a descriptive manner, enabling the reader to assess the applicability of the literature review in order to positively impact nursing practice by providing an organized way to review the evidence on a topic.

The level of evidence of the selected studies was based on the classification of Melnyk and Fineout-Overholt (2010), which categorizes research into 7 levels of evidence, where 1 is the level of greatest evidence: I- systematic reviews with meta-analysis of clinical trials; II- randomized clinical trial; III- clinical trial without randomization; IV- cohort, case-control; V- systematic review of descriptive works; VI- single descriptive or qualitative study; VII- opinion of expert committees or authorities (MENDES; SILVEIRA; GALVÃO, 2008).

4 DEVELOPMENT

In this integrative literature review, eleven articles from the original sample were analyzed. For better organization of the selected studies, information such as author, year, title, database, origin of the study and journal of publication were extracted, facilitating the process of interpreting the results obtained and the articles selected for the composition of this study (Chart 1).

The articles were published predominantly two in 2020 (18%) and six in 2019 (54%), two in 2017 (18%) and one in 2016 (9%), with the majority of publications in Portuguese. Of the eleven studies, 6 (54%) were conducted in Brazil and 5 (46%) in the United States. The journals that contributed most were those in the nursing area (63%), followed by the medical area (37%) (Chart 1).



Chart 1- Articles selected for the integrative review, following those listed, year, author, title, origin of the study, database and journal. Brazil, 2022.

Year	Title	Author	Origin of the study	Database	Periodicals
2020	A1: Educational demands of family members of children with special health needs in the hospital-home transition.	f children needs in Precce ML, Moraes JRMM, Pacheco STA, Silva LF, Conceição DS Rodrigues FC		Scielo	Rev Bras Enferm
2020	A2: Meanings attributed by family members about the diagnosis of chronic disease in children.	Xavier DM, Gomes GC, Cesar- Vaz MR.	Brazil	Scielo	Rev Bras Enferm
2019	A3: Training of family members of children and adolescents for home care.	Witkowskia MC, Silveira RS, Duranta DM, Carvalho AC, Nunes DLA, Antona MC, Marquesa MF, Zarthb SM, Issib HB, Goldan HAS.	Brazil	Scielo	Rev Paul Pediatr
2019	A4: Having to be the one: mothers providing home care to infants with complex cardiac needs.	Imperial-Perez, MN, RN, CNS-BC.	USA	Medline	Am J Crit Care
2019	A5: Parental emotional and hands-on work experiences of parents with a newborn undergoing congenital heart surgery: a qualitative study	Thomi MSc, RN, RM, Jean- Pierre Pfammatter MD, Elisabeth Spichiger PD.	USA	Medline	Journal Pediatric Nursing
2019	A6: Promoting parent partnership in developmentally supportive care for Infants in the pediatric cardiac intensive care unit.	Klug, MSN, RN, CCRN; Christine Hall, BSN, RN, CCRN; Emily A. Delaplane, LCSW; Caitlin Meehan, CCLS; Karli Negrin, MS- CCC-SLP; Dana Mieczkowski, Sarah K. Russell, PT; Bridy O. Hamilton, OTR/L; David A. Hehir, MD; Erica Sood,.	USA	Medline	Advances in Neonatal Care
2019	A7: Mothers' needs regarding partnerships with nurses during care of infants with congenital heart defects in a paediatric cardiac intensive care unit.	Uhm, Ju Yeon Mi Young Choi .	USA	Medline	Intensive Crit Care Nurs
2019	A8: Neonatal nursing care for babies with congenital heart disease: integrative review.	Magalhães, Simone Silveira; Queiroz, Maria Veraci Oliveira; Chaves, Edna Maria Camelo.	Brazil	Lilacs	Online braz. j. nurs.
2017	A9: The care partnership as seen by parents of children with special health needs.	Alves JMNO, Amendoeira JJP, Charepe ZB.	Brazil	Scielo	Rev Gaúcha Enferm
2017	A10: Pediatric nurse's perception of support for families with children with congenital heart defects.	Bruce, Elisabeth Karin Sund.	USA	Medline	Jounals Sage
2016	All:Technology dependent child and the demand for medication care.	Okido ACC, Cunha ST, Neves ET, Dupas G, Lima RAG.	Brazil	Scielo	Rev Bras Enferm

Source: The authors (2023).



It was found that 100% of the studies expressed level of evidence 4 and described outcomes that point to the importance of the family attributing the meaning of the disease with the interaction with health professionals so that care is effective. Manaus, AM, Brazil, 2022 (Chart 2).

Chart 2- Articles selected for the integrative review, following the ones listed, study, study design, level of evidence, objective and outcome.

Study	Study design	Level of evidence	Objective	Results and Conclusions/Outcomes
A1	Qualitative study.	Level 4	To analyze the educational demands of family members of children with special health care needs in the transition from hospital to home.	The information was analyzed and synthesized into three thematic categories Recognizing congenital heart disease; Caring for the neonate in the intensive care unit; the family and care for the neonate. There is a need for greater professional involvement in the care of these children and there are gaps in the production of nurses' knowledge that show this reality, in order to subsidize evidence-based clinical practice.
A2	Exploratory- descriptive research, with a qualitative approach.	Level 4	To understand the meanings attributed by family caregivers about the diagnosis of chronic disease in the child.	The family attributed meanings to the discovery of their child's chronic disease diagnosis when interacting with nursing/health professionals. The interaction of the family with the nursing/health team contributes to the meaning attributed by the family member to the diagnosis of chronic illness of the child.
A3	Descriptive cross- sectional study	Level 4	To present the experience of training family members of children and adolescents participating in a multiprofessional program at home.	This study presented the results of the training of family caregivers of children and adolescents for home care. In conclusion, it was shown that the process of dehospitalization of children and adolescents can be feasible, safe and effective through training.
A4	Exploratory- descriptive research, with a qualitative approach	Level 4	To describe the perceptions and experiences of mothers of babies discharged from hospital after surgery for complex congenital heart disease.	Analyses led to the development of 1 category, "having to be the only one," which had 3 properties: having no choice but to provide complex care at home, coping with unexpected roles, and coping with the possibility of death. Highlighting the experiences of mothers providing medicalized care at home for their infants after complex cardiac surgery. The role of the caregiver is vital but demanding. Mothers' care at home can be enhanced by nursing interventions such as routine screening, as well as assessment of changes in family coping.
A5	Qualitative, descriptive and exploratory study.	Level 4	To explore the experiences of mothers and fathers from prenatal or postnatal diagnosis of newborn congenital heart disease to first discharge after cardiac surgery.	Between the child's diagnosis and discharge from hospital after cardiac surgery l, the main theme for parents was coping with demanding emotional and practical work. Healthcare professionals should establish trusting relationships with parents while continuously following up with families, providing consistent and straightforward information and expressing appreciation for parents' exceptional emotional and practical work. Health professionals' awareness of



				parents' experiences is vital to compassionate
				family-centered care.
A6	Qualitative, descriptive and exploratory study.	Level 4	To create and test a visual bedside tool to increase parents' partnership with nursing in developing supportive infant care after cardiac surgery.	Hands-on staff training and informal bedside education in developmental care are needed to educate staff on how to support parents in providing appropriate physical and developmental stimulation for their infants.
A7	Exploratory- descriptive research, with a qualitative approach.	Level 4	To investigate the needs of mothers to partner with nurses from the postoperative recovery of children in a pediatric cardiac intensive care unit.	The mothers wanted information about the postoperative stability of their babies in the early stages of recovery and hospital discharge. The condition of the babies strongly influenced the mothers' needs for partnerships. Thus, the nurse in providing information to mothers individually and encouraging them to participate in care.
A8	Descriptive research, with a qualitative approach.	Level 4	To analyze the educational demands of family members of children with special health care needs in the transition from hospital to home.	The educational demands of family members of children with special health needs in the transition from hospital to home come from the child's body care clinic, and they originate from complex and continuous, technological, modified habitual, medicated, developmental and mixed care.
A9	Qualitative, descriptive and exploratory study.	Level 4	To understand how the care partnership was experienced by parents of children with special health care needs.	As partnership opportunities, parents' empowerment and decision-making in partnership, established in a dynamic, singular and continuous relational process, were observed. Partnership opportunities are fundamental assumptions for the provision of care focused on the child and the parents as their resources.
A10	Descriptive research, with a qualitative approach.	Level 4	Illuminating pediatric nurses' (PNs) perceptions of supporting families with a child with a congenital heart defect.	The analysis revealed that nurses perceive that letting parents be involved in their child's care is of great importance in supporting families. Although they have a paternalistic attitude towards families, they also stated that nurses should inform parents about child care, create a good relationship with the family and build trust between all parties involved.
A11	Qualitative, descriptive and exploratory study.	Level 4	To understand the experience of mothers of technology-dependent children in relation to drug care.	The mothers' experience with drug care is permeated by daily challenges, including maternal overload and feelings of anxiety. It is also suggested that nursing develop family-centered care, acting as a facilitator in the process.

Source: The authors (2023).

5 DISCUSSION

The articles were separated and composed two categories for discussion called: care needs pointed out by family caregivers and educational demands that can be met by nurses.

Care needs pointed out by family caregivers

Hospitalization in childhood is characterized as a period of fear and uncertainty for the child and his family that needs the help of nursing professionals, especially when it comes to coping with a chronic disease (ALVES, 2017). In study A2, , the contribution of these professionals to a participatory



assistance focused on the care of children with chronic diseases and their families, agreed in line with the needs of the child, is observed.

The family suffers when they receive the incurable diagnosis of the child, mainly because they have difficulty dealing with this reality. Chronic diseases in childhood, because they are incurable, cause, over time, sequelae, imposing limitations on the child, requiring special care skills and competencies of their family members and caregivers for their rehabilitation, requiring training, supervision and observation of care (IMPERIAL, 2019).

In this sense, it is perceived that the family, when interacting with the nursing team, seeks to share feelings and perceptions in the face of the finitude and fragility of the human condition that a chronic and severely serious illness imposes.

The experiences of children with complex CHD after hospitalization, and family care at home can be enhanced by nursing interventions such as routine screening for infant distress, as well as assessment of changes in family coping or relational challenges that threaten family function were evidenced in study A4. According to the authors the analyses led to the development of a perception that few professionals address the care *versus* the experiences of parents caring for infants with complex congenital heart disease who are discharged from hospital.

Aiming at an approach, based on a constructivist paradigm, study A5, reports the need for health professionals to establish trusting relationships with parents, while following up with families continuously, providing consistent and direct information and expressing appreciation for the exceptional emotional and practical work of parents. Health professionals' awareness of parents' experiences is vital for compassionate family-centered care.

Study A7 investigated the needs of mothers to form partnerships with nurses from the postoperative recovery of children in a pediatric cardiac intensive care unit. The nurse is considered a component of the multiprofessional team, a facilitator of knowledge and with scientific training capable of collaborating positively in the process of promoting the care of children with morbidities in the home return, longing and many doubts about how to care for these children before hospital discharge begin to arise from this moment of postoperative recovery.

In A8, the study demonstrated the need for greater involvement of nurses to improve nursing care for these children, carefully emphasizing that there are still gaps in the production of knowledge by nurses that show this reality, in order to subsidize evidence-based clinical practice. Considering that the path to improving care is always that of science, with the development of studies that will strengthen this care, unifying theory and practice is a dialogical integration for the construction of knowledge (SOUSA *et al.*, 2023).



The complex care required by these children, such as feeding, care for the surgical scar, return to daily routine habits, and also a continuous medication regimen, cause doubts and overload of family caregivers at home (GOES, 2017).

In this sense, study A11 addresses the need for knowledge of the disease, the importance of treatment and mastery of the care technique, significantly reducing the levels of anxiety and stress of these caregivers. Thus, according to the study, communication between family-health service is essential for the construction of knowledge and empowerment of the caregiver.

Educational demands that can be met by nurses

The A1 study brings the educational demands related to the care clinic and in this context, indicates that the nurse's performance must be closely related to the preparation of family caregivers for the development of care in the hospital with a view to discharge. However, discharge needs to be conceived in a procedural way, to include the planning and preparation of families. Therefore, it is up to the nurse, in the health-disease transition, to mediate innovative, complex and continuous care, in addition to instrumentalizing the family member to care, respecting their knowledge, stimulating reflection, action and empowerment (VIANA *et al.*, 2018).

In study A3, the process is addressed in which, while the dedication of trained family members is necessary for the care of children and adolescents after hospital discharge, some prerequisites are essential so that the child can go home safely, leading to successful rehabilitation.

Children with CHD need to go through all points of care in the health system, including primary care, specialized care and home care

The existence of a chronic disease establishes the need for continuous and effective care to avoid worsening the clinical picture (SILVA *et al.*, 2018). The lives of children who start to live with chronicity are marked by numerous transformations, which can confer limitations and require changes in habits and attitudes due to the treatment and care inherent to their health condition (SOUZA *et al*, 2021).

Sharing information about developmentally supportive care provided by parents during each duty shift, generating opportunities for parents to initiate care for their children, was the focus of study A6, which aimed to strengthen the importance of the bedside care partnership in parent preparation, family well-being and child outcomes by providing comfort, assisting in the daily care routine of these children.

Important nurse attitudes such as respect, trust, empathy and advocacy were identified in study A8, . These attitudes are described as attributes of the partnership model. Relationships established



between parents and health professionals that meet these requirements are characterized as promoting parental empowerment.

The adaptation of parents to care for the child at home requires a wide network of family and social support, with the close involvement of health professionals. Nursing care based on the philosophy of family-centered care and the care partnership model is considered ideal to help them fulfill the role they will play (MENDES, 2019).

Illuminating the perceptions of pediatric nurses about supporting families with a child with a congenital heart defect was the view of study A9, creating a good relationship with the family and generating trust between all parties involved is of great importance in this context. Empowerment, understood from simple oral health care, brings subsidy to structure educational interventions developed by nurses, with practices guided by applied knowledge (CRUZ *et al.*, 2017).

However, it is essential to understand this experience and to show that the constant changes in the health sector and in the labor market increasingly require the development of the professional, after all, among the variables present for the non-adoption of a systematized care process can generate failures and impact the acquisition of knowledge, technical and relational skills. It is no longer possible to postpone the fulfillment of the desires to provide quality nursing care, favoring the acquisition of skills in the activities developed (OLIVEIRA, 2019).

The main nursing care is described according to the studies selected for the composition of this RIL. In this context, it is noteworthy that among the main care among the articles analyzed in this research, aspects related to food, oral health, leisure and physical activity, care with medications and with the surgical wound, as well as the need to offer support to the family of these children.

Such care is closely related to that offered by the nursing team during hospitalization, as well as after discharge. By having direct access to the child and his caregiver, nurses occupy an important place in this care, thus having greater opportunities to identify needs.

The limitations of this study are the small number of studies on the subject investigated and the delimitation of texts in Portuguese, English and Spanish. It should be emphasized that in the search for materials for this survey, a literary scarcity was identified on the proposed theme, which constituted a limitation, since the articles found were very old.

With this, the search for new research that seeks to highlight the main nursing care and strategies aimed at the family and/or caregivers of children with CHD is highlighted.

Thus, studies such as this contribute to the awakening of a new look in search of the development of strategies that reach and accompany the families of children with CHD since their birth, hospitalization, discharge and growth. This nursing practice corroborates the formation of public policies capable of fostering the establishment of care. However, it remains a great challenge to address this issue with such clarity and objectivity.



6 FINAL CONSIDERATIONS

The articles analyzed in this research show evidence of the theme on nursing care for children with CHD and the development of guidelines for family members and caregivers that will assist in a more reliable and attentive practice in home care. In the health field, although the disease is old, there is no specific nursing booklet aimed at children with CHD, both in childhood and in the adult phase.

CHD provides family members/caregivers with an often negative understanding of the disease, surrounded by pain, suffering, uncertainties, doubts, losses and lack of control. Many are the adversities influenced by the disease, causing caregivers to give up their lives to accompany their baby or child, meeting their demands and needs. In general, they show satisfaction and make a point of following the whole process, whether during the discovery of the disease, through hospitalization until hospital discharge, not caring about the fact that they detach themselves from their daily lives, starting to follow life according to hospital routines and treatment requirements.

The production and propagation of health and care represent the incorporation of the theme and the logic of informatics, favoring the practices of humanized care, based on needs and that can reinforce the continuous action of the proposal, through more platforms that contribute to the practices and care aimed at family members / caregivers of children with CHD.

Therefore, this study guides nursing to take advantage of activities that promote innovative strategies such as educational care technologies and other interventions that favor the best monitoring of the transition to the home for the correct development of care for children with congenital heart disease after discharge from surgical correction.

It is hoped that, through the dissemination of the results of this work, health education initiatives may arise through new educational care approaches via the Internet for the population, since these can serve to complement and enrich actions aimed at this theme.

7

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