UFSM

REUFSM
REVISTA DE ENFERMAGEM DA UFSM

ISSN 2179-7692
OPEN ACCESS

Rev. Enferm. UFSM, v.14, e12, p.1-18, 2024 •
Submission: 12/22/2023 • Acceptance: 07/10/2024 • Publication: 08/19/2024

Original Article

Maternal daily care practices for children with congenital heart disease at home*

Práticas maternas de cuidados diários à criança com cardiopatia congênita no domicílio

Prácticas maternas de cuidado diario de niños con cardiopatías congénitas en el hogar

Flavia Melo de Castro[I], Sandra Teixeira de Araujo Pacheco[II], Marialda Moreira Christoffel[I], Emília Gallindo Cursino[III], Elisa da Conceição Rodrigues[I], Juliana Rezende Montenegro Medeiros de Moraes[I]

[I] Universidade Federal do Rio de Janeiro, Rio de Janeiro, Rio de Janeiro, Brazil
[II] Universidade do Estado do Rio de Janeiro, Rio de Janeiro, Rio de Janeiro, Brazil
[III] Universidade Federal Fluminense, Niterói, Rio de Janeiro, Brazil

*** Extracted from the dissertation "Maternal experiences of care for children with congenital heart disease at home", Graduate Program of the College of Nursing, State University of Rio de Janeiro, 2016.**

Abstract

Objective: to analyze maternal care practices in daily activities for children with congenital heart disease at home. **Method:** descriptive study, with a qualitative approach, carried out in the city of Rio de Janeiro, Brazil. Thirteen mothers of children with congenital heart diseases participated. The interviews took place between March and June 2016, which were audio-recorded, transcribed in full and submitted to Bardin's Content Analysis. **Results:** the daily activities of the children with heart disease were considered restricted and not restricted. Mothers compared their children with normal children, strategies are used during play to reduce physical effort and understand that the school environment and daycare favor good growth and development. **Conclusion:** passive games are better tolerated by mothers because they do not require physical effort. Thus, they prevent cardiac decompensation and aggravation of the disease in their children.

Descriptors: Mothers; Congenital Heart Diseases; Child Care; Nursing; Empathy

Resumo

Objetivo: analisar as práticas maternas de cuidado nas atividades diárias à criança com cardiopatia congênita no domicílio. **Método:** estudo descritivo, de abordagem qualitativa, realizado no município do Rio de Janeiro, Brasil. Participaram 13 mães de crianças com cardiopatias congênitas. As entrevistas ocorreram entre março e junho de 2016, as quais foram audiogravadas, transcritas na íntegra e submetidas à Análise de Conteúdo de Bardin. **Resultados:** as atividades diárias da criança cardiopata foram consideradas restritas e não restritas. As mães compararam seus filhos com crianças normais, estratégias são utilizadas durante o brincar para diminuição do esforço físico e compreendem que o ambiente escolar e a creche favorecem para o bom crescimento e desenvolvimento. **Conclusão:** brincadeiras passivas são mais bem toleradas pelas mães por não exigirem esforço físico. Assim, impedem a descompensação cardíaca e o agravo da doença em suas crianças.

Descritores: Mães; Cardiopatias Congênitas; Cuidado da Criança; Enfermagem; Empatia

Resumen

Objetivo: analizar las prácticas de cuidado materno en las actividades cotidianas de niños con cardiopatías congénitas en el hogar. **Método:** estudio descriptivo, con enfoque cualitativo, realizado en la ciudad de Río de Janeiro, Brasil. Participaron 13 madres de niños con cardiopatías congénitas. Las entrevistas tuvieron lugar entre marzo y junio de 2016, las cuales fueron grabadas en audio, transcritas en su totalidad y sometidas a Bardin Content Analysis. **Resultados:** las actividades diarias de los niños con cardiopatías se consideraron restringidas y no restringidas. Las madres compararon a sus hijos con niños normales, durante el juego utilizan estrategias para reducir el esfuerzo físico y entienden que el ambiente escolar y la guardería favorecen un buen crecimiento y desarrollo. **Conclusión:** los juegos pasivos son mejor tolerados por las madres ya que no requieren esfuerzo físico. Así, previenen la descompensación cardíaca y el empeoramiento de la enfermedad en sus hijos.

Descriptores: Madres; Cardiopatías Congénitas; Cuidado del Niño; Enfermería; Empatía

Introduction

Congenital heart disease is a disease characterized as a defect, imbalance or structural abnormalities in cardiovascular function, and is also defined as congenital heart malformation because it has been present since the birth of the baby.[1-3] This condition occurs due to embryonic changes in normal structures or due to developmental failure.[3]

In their forms of presentation, congenital heart diseases can be classified as cyanotic, since the cardiac structure allows shunt from right to left, causing a bluish color in the skin and mucosa, and acyanotic when the shunt is generated from left to right. Another classification is related to lung flow. In this, there may be hyperflow, in the presence of hypervolemia and hypoflow, when referring to hypovolemia. In addition, it can be characterized in the case of an obstruction of extra-cardiac blood flow.[2]

It is considered an important public health problem, which affects the world sphere, as it is the most frequent of the congenital malformations reaching a high mortality rate in the first year of life in Brazil and the second cause of death up to 30 days of life. Of newborns with critical coronary disease, 97% reach the age of one year, but 95% who are born with non-critical coronary disease reach the age of 18 years. It is estimated that about 40% of these children will need surgery in the first year of life.[3-5] It is noteworthy that congenital heart diseases can also be pointed out as crucial in the cause of cardiac arrest until the age of 24 years, and their variability is 84% in the first two years of age and 21% in the second decade of a human being.[2]

The repercussions caused by congenital heart disease are manifested by the presence of some symptoms such as cyanosis, tiredness, dyspnea and tachycardia, which can have negative effects in the development of these children,[3] in view of the social and emotional discomfort generated in them and their families at home.

Therefore, by knowing the reality experienced by this public and the factors that interfere with the management of the disease at home, it becomes possible to provide timely and individualized care to the mothers of children with congenital heart diseases.

When the daily self-care activities or those performed by mothers to their children with congenital heart diseases, required by the treatment, occur in a fragile way, the management of the disease can bring losses, such as developmental delay. The emergence of clinical signs of the children with congenital heart disease, such as tiredness, the presence of cyanosis, tachycardia,[3] caused by games that require greater physical effort, are considered important information for decision-making in the health care of these Children with Special Health Care Needs (CSHCN).

CSHCN are defined as those who present or have a greater risk to manifest, whether a physical condition, in development, behavior, emotional or chronic and that, in most cases, there is a requirement of a type and quantity of health services in addition to those required by other children.[6] Their health needs are peculiar and distinct, making them special, and demanding network articulation and an organized service.[7]

The lack of nursing professionals in pediatric cardiology in the outpatient and home settings, with knowledge and expertise in the management of possible complications for this child population, can make it difficult to provide guidance on health and individualized treatment for each child, especially in relation to the feeling of powerlessness, guilt and fear,[8] in addition to the overprotection of parents, since they understand having a fragile child due to the disease,[3] which can corroborate physical inactivity, not socializing with other children, favoring a negative contribution to motor development. These barriers contribute to scarce growth and development, raising the risk of compromise and unnecessary hospitalizations.[3]

A state of the art identified only seven scientific productions on congenital heart disease, which treated mothers with feelings of guilt and strategies in coping with the pain of having a child with heart disease and the adaptation of the family to the diagnosis of congenital heart disease and its care.[9]

Another integrative review pointed to the few approaches to congenital heart disease, in addition to the authors' concern about the lack of scientific production in neonatal heart disease.[10] Thus, the research proposes the awakening of health professionals to contribute with new studies to the view of mothers and their children with congenital heart diseases in the home environment with subsidies for care in favor of maintaining their lives.

Care stands out as a life cycle in the perception of the French Nurse Marie Françoise Collière.[11-12] It is what, from the beginning, generates the maintenance of life through the health and disease process, being an ancient practice of the human race, in order to guarantee the continuity of all species.[11]

In this sense, understanding the conceptual differences of care and treatment allows nurses to have an assertive look at home care. For Collière, the disease is treated in order to prevent its progression and limit its complications. However, care is part of all the essential phases of the human being, thus reporting the conservation of the origin.[12]

Caring for these children with congenital heart defects is an act of deference, as it allows them to continue their growth and development by maintaining their health. It is also a peculiar act, since these children acquire autonomy; but it is also reciprocal, when mothers help their children to take charge of their vital needs, whether temporarily or permanently.[11]

By understanding the typologies of care brought by Collière, which involve: repair, maintenance, stimulation, compensation, opinion, appeasement and comfort,[12] the health professional, especially nurses, covers the daily challenges of mothers with children with congenital heart disease at home, favoring more assertive care.

In this sense, reparative care is intended to limit the disease by mitigating its effects; Maintenance care contributes to personal development, relating to daily, psychological, effective and social needs; Stimulation care rekindles the senses to develop motor capacity, in addition to expectations, desires and affective reactions; Compensation care fills those that are not acquired and/or compensated when one is not able to do it by oneself; Opinion care is carried out with the intention of awakening and strengthening the sense of identity; Appeasement care allows rest and release of tensions, easing turbulence and restlessness; and Comfort care provides the gain of trust, distinguishing what needs to be comforted.[12]

This research will address the stimulation, maintenance and appeasement care, and the demand for modified habitual care of these CSHCN with a view to care and special health needs. CSHCN with modified usual care demands need adaptive technologies in daily care and activities of daily living, such as getting around, eating, among others. Given this problem, the study aimed to analyze maternal care practices in the daily activities of children with congenital heart disease at home.

Method

Descriptive study, with a qualitative approach, carried out in a pediatric outpatient clinic of a university hospital located in the city of Rio de Janeiro, Brazil. The Consolidated Criteria for Reporting Qualitative Research (COREQ) criteria were observed, which were used as a guide to improve the presentation of the research report.[13]

The research institution has several specialties for care. It was the first general and university hospital in the state to receive, in 1998, the title of "Child Friendly Hospital", conferred by the United Nations Children's Fund (UNICEF) and the World Health Organization (WHO). In 2006, the perinatal center was created and today the maternity hospital is a reference in high-risk pregnancies with beds in the Neonatal Intensive Care Unit (NICU).

The following inclusion criteria were: mothers of children with congenital heart disease aged 0 to 12 years incomplete, who were not submitted to any surgical intervention and with the care provided to their children at home. Mothers whose children had other congenital anomalies associated with congenital heart disease were excluded. The monitoring of these children occurred in the cardiology consultations of which their periodicity was verified in the unit and in the consultation of the database that contained personal information, clinical history and contact of the children participating in the research.

The interviews were conducted in person during the months of March and June 2016 by the main researcher, a specialist in Neonatal Nursing, with previous training received to carry out qualitative research. The mothers were approached, for convenience, in person, at the pediatric outpatient clinic - this being the first contact with the study participants - while waiting for the consultation with the cardiologists. Those who accepted the invitation and had time available at that time were individually taken to one of the private rooms. Thus, we sought to ensure the calmest possible environment. At this time, the participant was already aware of the researcher: his profession and academic background and the interest in her maternal experience at home having a child with congenital heart disease.

In order for the interview with the mothers to take place calmly, their children were sent to the toy library, where there was a person responsible for looking at them and distracting them until the end of the interview. For those mothers who could not stay to do the interview, a new meeting was scheduled according to their availability of time. As for those who were not interested in participating, they claimed the fear of missing the appointment or, even with the option of conducting the interview after the appointment, were in a hurry to return to their homes for other appointments. It should be noted that the number of mothers invited as to those who refused to participate in the interviews was not computed due to the inexperience of the main researcher at the time of the research.

The interview had the following question: how do you care for your child who has congenital heart disease? A semi-structured questionnaire was used to search for sociodemographic data to characterize the participants' children. The interviews were concluded after the saturation criterion, apprehended as the cessation of inclusion of new participants, when the data present, in the researcher's evaluation, repetition, at which time it is no longer necessary to continue with their collection.[14]

The interviews lasted a mean of 30 minutes and were recorded in full audio. A pilot test was carried out in the first three interviews and adjustments were made in the conduct of the researcher during the interview, which allowed better clarity in obtaining the data and without inducing the answers by the researcher during the interview.

After transcribing the interviews and editing the speeches to remove grammatical errors and language defects, the methodological framework of Content Analysis, thematic modality[15] was used, applying its pre-analysis stages, with the organization of the material, followed by floating reading of the documents and systematization of the preliminary ideas, with formulation of the first hypotheses and indicators. The exploration of the material aimed to codify and categorize the text of the interviews. After this stage, the different codes generated and grouped to form the units of meaning in the text were identified. As for the treatment of the results, inference and interpretation, the researchers reflexively and critically analyzed the previously identified units, producing a logical understanding for the interpretation of the results and construction of the thematic category and its subcategories.[15] The analytical process led to the identification of the category: The care with the daily activities of the child consisting of two subcategories called: “unrestricted daily activities” and “restricted daily activities”.

This study was submitted to the Research Ethics Committee of the institution in which the research was developed, and was approved on November 17, 2014, with Opinion number 874.441, respecting the ethical issues of Resolution 466/2012, which regulate the guidelines and standards of research involving human beings. To protect the identity of the participants, they were mentioned with codenames that represent the blood vessels and the characteristics of the child. Example: (Aorta, 3-month-old child, heart murmur).

Results

The research was composed of 13 mothers of 14 children aged between one month and ten years, and one mother had two children with congenital heart disease. Regarding the age of the children, three of them were infants (1 month to 11 months and 29 days), three were infants (*Toddler*) (1 to 2 years, 11 months and 29 days), four were preschoolers (3 to 5 years, 11 months and 29 days) and four were schoolchildren (6 to 12 years incomplete).[16] The children had a predominant sociodemographic profile in males, with a clinical characteristic of the acyanotic type of disease, the most present being Intra-atrial Communication (IAC) (36%) and innocent murmur (21.4%). Regarding the Interventricular Communication (IVC), it presented (7.1%) of its totality equaling Wolff-Parkinson-White syndrome (WPW), patent ductus arteriosus (PDA) and pulmonary stenosis. However, it manifests itself associated with other heart diseases such as Intra-atrial Communication (IAC) and Anomalous Band (14.2%).

Box 1 shows the characteristics of the children of the mothers participating in the research.

Box 1 - Characterization of the children of the study participants and their respective congenital heart diseases. Rio de Janeiro – RJ, Brazil, 2015

Identification of mothers of children with congenital heart diseases	Diagnosis of heart disease	Type of heart disease	Age of child with heart disease at time of interview		Total children by Diagnosis presented	
					(n = 14)	%
Pericardium.	IAC	Acyanotic	6 years		5	36
Vena Cava			5 years			
Tricuspid			2 years and 8 months*			
Coronary			1 year and 2 months			
Bicuspid			3 months			
Aorta	Innocent murmur		8 years		3	21.4
			6 years			
Ventriculus			4 years			
Lobby	IVC		3 years		1	7.1
Cardiac muscle	WPW syndrome		10 years		1	7.1
Sinus node	PDA		4 years		1	7.1
Pulmonary Trunk	Pulmonary valve stenosis		10 months		1	7.1
Mitral	IAC and IVC		1 year and 5 months	Associated heart diseases	2	14.2
HIS bundle	Anomalous Band + IVC	Cyanotic	1 month			

Key: Intra-atrial Communication (IAC); Interventricular Communication (IVC); Patent ductus arteriosus (PDA)
Note: Survey carried out in August 2015

From the analysis, the following category emerged: care for the child's daily activities and its subcategories: unrestricted daily activities and restricted daily activities.

In non-restricted daily activities, mothers reveal socialization as an important, continuous care and perceive interactions in the school environment, in daycare and with their peers as essential for their children.

> *I put him in kindergarten, he did well, and he's there to this day. (Mitral, 1 year and 5 months old son, IAC + IVC)*
> *He is much better, he does activities at school, with his classmates; he is interacting very well. (Aorta, 8-year-old son, innocent murmur)*

In addition, for mothers, their children with congenital heart diseases perform some leisure activities of the games common to any child:

> *Normal child, running, playing, a child who didn't get sick. (Mitral, 1 year and 5 months old son, IAC + IVC)*
> *I let her play normally, [...] some activities at home. She plays normal [...] in the playground, playing up and down, playing slip (Ventriculus, 4-year-old daughter, innocent murmur)*
> *In the past he didn't run, he didn't jump [...] now he runs, he jumps [...] [from there, to here, he] improved 100%! [...] he does sports at school, plays naturally. [...]He can do everything [...] Now he is normal. He does capoeira at school [...]. Now that he's starting to play, to go out, to fly a kite. He came to learn how to fly a kite, [...], it's been about 15 days. [...] Today he runs normally [...], flies kites, plays ball, rides a bicycle; he knows how to swim [...]. Play, run, jump. Just like a normal child does, before I wouldn't let him. (Aorta, 8-year-old son, innocent murmur)*

Regarding restricted daily activities, mothers are cautious about the presence of physical effort, playing in the bounce house, playing time and going up and down stairs. There is a greater vigilance of mothers towards these activities, making it impossible for their children to play with them.

> *I talk to you because you can't [play ball] and you insist on doing it! [mother refers to talk to the child] then, he already stops [...]. I think it's better to teach, to talk, so he knows what he can and can't do. I explain, "you can't because you know, it feels bad. He can't play ball, he can't make [effort] [...] in bouncing I give a gift on Children's Day, a game. I guide calmer games [...] And what he can't do is run, [play] football at school, with his classmates on the football field. [...]. This is very difficult for me, having to say "you can't play ball!" "Mom, I want to, but I want to!". [...] Music class, he likes wind instrument. Limiting him from things, for me, is the worst. (Myocardium, 10-year-old son, WPW syndrome)*
> *I try to control it a little. Just like the bouncing; If you let her, she'll be straight into the pogo stick. But then I control. (Ventriculus, 4-year-old daughter, innocent murmur)*

In addition, mothers understand as dangerous, for their children, certain games that require greater effort, thus determining the child's play time.

> *I control her going up the stairs, because going up she knows, but going down is complicated. In physiotherapy, when she was doing it, she had a ladder to teach her to go up and down, she thinks that the ladder at home is the same ladder as physiotherapy, which is a joke, this joke I restrict, the ones that are dangerous. (Tricuspid, daughter of 2 years and 8 months, IAC)*
>
> *I don't leave much either! Up to half an hour, nothing of an hour like that, [...] Control [time]. I say that later we come back again [on the playground to play bouncing], it will be the same there in the little room [mother refers to the outpatient toy library], later or tomorrow we come back, [to the bouncing/toy library] then she calms down. (Ventriculus, 4-year-old daughter, innocent murmur)*

Another important point observed was the overprotection of these mothers with their children during play.

> *I didn't let the boy play alone, run, I thought he was going to get hurt. I wanted to protect him too much! [...]. And I didn't want him to feel pain. I protected him from his brother, from the other children. Running, jumping, playing. [...] He turned purple, tired. He kept to himself. He didn't talk, he stood by the corners. I'd put it on to watch television and play with puzzles. He really likes puzzles, [...] he has a lot! (Aorta, 8-year-old son, innocent murmur)*

The care of the child's activities carried out by mothers of children with congenital heart diseases involves socialization, leisure, physical effort, types of play, time to play and overprotection when inserted in their home environment.

Discussion

Children with congenital heart diseases whose mothers were interviewed were aged between one month and ten years and the mothers demonstrated various maternal care practices in the daily activities of the children with congenital heart disease at home.

Regarding sex and type of heart disease, this profile of children has been identified in Brazil, demonstrating that the male sex is a predominant factor as well as its acyanotic type, the most common, as demonstrated by secondary data from the Live Birth Information System (SINASC), in five Brazilian regions, in which 52.9% were male and 47% female.[17] However, researchers in a pediatric clinic in Pará revealed that there was no statistically significant difference between children of both sexes, but that acyanotic congenital heart disease, as well as this study was also the most recurrent (54.5%).[18]

As for the results of the category "unrestricted daily activities", they revealed in the subcategory, through the mothers' testimonies, socialization as an important care in the lives of their children with congenital heart disease. It can be seen, in their speeches, the good adaptation of the children in the environments of daycare and school. These places together with the family have a positive impact on the well-being of children.[19]

The interaction of the children with the environment in which they live is necessary for their growth and development. Interacting with other children of the same age allow them to recognize their space and the other; they learn to socialize and deal with their confrontations in the face of unexpected situations. The children provide exchange through socialization, relating in their own way to knowledge. This interaction allows the construction of cognitive, psychomotor, language and play skills, revealing their individual characteristics compounded in their own identity.[19-21]

By inserting their children in daycare and school, mothers Mitral, a one-year-old and five-month-old son, IAC + IVC, and Aorta, an eight-year-old son, innocent murmur, ensure the right to education for their children, according to the Child and Adolescent Statute,[22] at the same time, perform stimulation care with them. In this way, contact with the other awakens the senses, creates affective relationships, and stimulates interest and psychomotor development. A great promotion for the construction of thought.[12]

Some leisure activities performed by children with heart disease, such as: jumping, running, playing in the up and down square, playing sports at school, flying kites, cycling, playing ball and swimming, for their mothers, are normal activities, the same practiced by a child without cardiac impairment. For them, the fact that their children were born with an acyanotic congenital heart disease, but with cyanogenic repercussions, does not prevent them from playing like healthy children. It is known that children with congenital heart disease perform physical activities below the recommended, which makes them more sedentary. This is because most parents consider it to be less important to their children.[23]

It is understood that playing is a childhood need, as it is part of its daily lives. It should always be encouraged the children expressing their feelings and desires.[24] Studies on physical activity point to its health benefits that are transversal to all children, even those with chronic disease, such as congenital heart disease, for example. It is essential for the good development and general well-being of the children, prevents comorbidities and improves the quality of life. Its absence has been marked as a risk factor for other diseases.[23-25]

Most healthy children receive encouragement from family members to play sports, whether at school or in clubs and many become amateur athletes reaching the professional level in some cases. Children with congenital heart disease, such as healthy ones, need to stay active, avoiding risks of anxiety, depression or other cardiovascular and metabolic impairments.[23-25]

From this perspective, it is possible to perceive that mothers exercise the care of maintaining life, inserted in playing, facing the needs of the children in their daily lives.[11] Without playing, it is not possible to be a child, nor a child with good development.

In the subcategory “restricted daily activities”, there is resistance to games that require more physical effort or that they consider being dangerous, preventing their children from doing so. For a cardiopathic CSHCN, playing in the bounce house for a time longer than 30 minutes can mean the manifestation of the symptomatology of the disease. A systematic review of rehabilitation points to the benefits associated with physical exercise practices, but there are difficulties in their execution due to the insecurity of family members due to the appearance of symptoms that cause hemodynamic instability.[26] Thus, mothers demand modified usual care, creating means for their children to interrupt play by indicating to them the time to stop playing.

Although the health benefits of physical activity are recognized, some children with congenital heart diseases do not practice them enough to reach the indicated levels, as it is understood that their levels of physical activity are below those of healthy children.[23] However, it is important that mothers, as well as their children with heart disease, in school, have knowledge and understanding about the disease, being a factor for their self-care, expanding the information about the diagnosis to the most relevant clinical sequences.[27]

Measures to restrict the time of play or agreements between mothers and children for the return to recreational activities at another time demonstrate the usual care modified during the child's play. For CSHCN with heart diseases, this type of care requires modifications in their usual way so that their physical integrity, well-being and comfort are preserved, thus avoiding the clinical signs of the disease and possible cardiac decompensation.[28-29]

Since mothers choose to replace the activities of greater effort with those of less physical effort, it is understood that strategies are used to adapt daily recreational activities, while meeting the psychological, affective and social needs, which contribute to the personal development of their children. This maintenance care happens when the children alone can do it, even if in an adapted way, they remain playing before their daily needs,[12,27] strengthening their development.

Authors highlight in the cross-sectional study, carried out with children and adolescents with Congenital Heart Disease and aged between 8 and 13 years, under monitoring at the Pediatric Outpatient Clinic of the Institute of Cardiology of Rio Grande do Sul, that most of the participants of the interviews did not know how to verbalize the name of their disease, much less explain it in their own words. In this sense, identifying how much is known by the children about their heart disease will reflect on the planning of programs for their health directed by the nurses and instructional for mothers, contributing to the reduction of doubts and uncertainties regarding recreational practices.[23]

It is still possible to observe that in the same way that mothers restrict their children's recreational practices, they act with overprotective care, avoid playing in order to prevent damage, such as getting hurt, or the manifestation of symptoms of the disease, such as cyanosis and fatigue, for example. It is known that children with congenital heart diseases have risks for delayed motor development and one of the factors is physical disability.[3] This also affects the conflict of allowing or not the children to interact with the sibling or with other children, avoiding interaction with their peers as a strategy to protect them from running, jumping, that is, playing with activities of greater physical effort. In this way, mothers naturally exercise the usual modifications of their children, directing them to other activities or imposing limits that are a risk to their children.

This excessive care occurs due to the parents' perception of fragility in relation to the child's disease. In these cases, the external stimuli and socialization of the children are impaired and contribute negatively to their development.[3]

Children with heart disease tend to play differently; their usual play is modified for recreational activities that require less physical effort. More dangerous games or classes that require respiratory effort (wind instrument) are desired by their children, such as living with family members or other children. However, in order to ensure the maintenance of their lives, mothers strive to explain the non-practice of such activities desired by them.

In addition, limiting the children from everyday practices is not an easy task. The children are reluctant to accept restrictions, especially when these are the most pleasurable. Mothers need to be inserted in this care and be appeased by the nurses, expressing their feelings and pains in order to relieve their tensions in the face of the possible limitations of their children.

It is important to emphasize that children with congenital heart disease need to play, talk and socialize, explore the environment through play and recreational activities according to the specificities of each case. Thus, the contribution of this knowledge is ratified not only for mothers and their children, but also for the care practice of nurses who, together with mothers, must develop safe care plans aimed at the home environment according to the degree of complexity required, with the intention of contemplating the psychosocial development of these children.

As a limitation of the study, in order to favor other research proposals, the study was carried out in a single institution. It is inferred that, for care practice, the study may bring improvements in the quality of life of children with congenital heart disease, since it offers the possibility of implementing more effective care strategies, meeting the real care needs of these children at home, contextualized by their socio-historical-cultural reality.

Conclusion

Maternal care practices performed during the daily activities of CSHCN, with congenital heart disease, are activities that do not require greater physical effort from the children, as they understand that playing actively can have repercussions for cardiac decompensation. Although mothers perform stimulation care, by revealing their children's socialization in daycare and school, and practicing recreational activities in a normal way, they interrupt the games that require more physical effort, convincing the children to return at another time, which characterizes a modified habitual care applied by mothers. In order to meet the special needs of their children, they also offer other means of playing such as watching television and putting together puzzles, exercising compensatory care, since these playful activities do not require physical effort.

The attempt to prevent the performance of more dangerous actions or games is possibly to avoid excessive tiredness and, consequently, to be guaranteed the maintenance the life of their children. On the other hand, mothers express that it is not an easy task to limit the children from playing, as they are usually reluctant to accept these limitations in the way they play. In this sense, by explaining their discomfort in having to deny the possibility that the children experience games considered more pleasurable, it means that the health professional also needs to develop, with the mothers, the care of the type of appeasement, so that they can express their feelings and pains in the face of the possible limitations of their children.

Thus, the points of support identified have pertinent repercussions for children with congenital heart disease, in their growth and development, in the social and recreational (leisure) sphere, requiring the creation of groups of mothers, inside and outside the hospital context, in which they can be heard, with the possibility of sharing maternal care practices in their daily activities. The experience of each one of them can show what is necessary and fundamental with regard to caring for a CSHCN with congenital heart disease in the home context.

References

1. Leite GCP. Dicas de saúde (Enfrentamento ao Covid-19): cardiopatia congênita [Internet]. Natal (RN): HUOL-UFRN; EBSERH; 2021 [acesso em 2023 jul 29]. Disponível em: https://www.gov.br/ebserh/pt-br/hospitais-universitarios/regiao-nordeste/huol-ufrn/saude/coronavirus-covid-19/cartilha-dicas-de-saude/cardiopatia-congenita-2.pdf

2. Mota CS, Araújo TA, Conceição LFC, Veiga IN. O impacto das cardiopatias congênitas no desenvolvimento neuropsicomotor: uma revisão sistemática. Rev Inspir Mov Saúde. 2021;21(1):1-15. [acesso em 2023 jul 20]. Disponível em: http://revistams.inspirar.com.br/wp-content/uploads/2021/04/869.pdf

3. Moraes BR, Bassi D, Santos PHM, Santos-de-Araújo AD, Matias PHVAS, Calles ACN. Desenvolvimento neuropsicomotor de crianças com cardiopatias congênitas. Rev Pesqui Fisioter. 2019;9(3):316-20. doi: 10.17267/2238-2704rpf.v9i3.2386

4. Soares AM. Mortalidade em doenças cardíacas congênitas no Brasil: o que sabemos? Minieditorial. Arq Bras Cardiol; 2020;115(6):1174-5. doi: 10.36660/abc.20200589

5. Jornal da USP. Conscientização é essencial para identificar casos de cardiopatia congênita [Internet]. São Paulo (SP): Universidade de São Paulo; 2023 [acesso em 2023 Jul 29]. Disponível em: https://jornal.usp.br/radio-usp/conscientizacao-e-essencial-para-identificar-casos-de-cardiopatia-congenita/

6. Favaro LC, Marcon SS, Nass EMA, Reis P, Ichisato SMT, Bega AG, et al. Percepção do enfermeiro sobre assistência às crianças com necessidades especiais de saúde na atenção primária. REME Rev Min Enferm. 2020;24:e-1277. doi: 10.5935/1415-2762.20200006

7. Bastos MPC, Santos AST, Ledo BC, Moraes JRMM, Cabral IE, Góes FGB. Crianças com necessidades de saúde especiais em um serviço de pronto atendimento pediátrico: estudo transversal Rev Enferm UFSM. 2022;12(e24):1-19. doi: 10.5902/2179769269299

8. Souza BFR, Buck ECS, Souza IVB, Souza CR, Oliveira RC, Morais CAC. Cardiopatias congênitas: desafios e perspectivas para o cuidado de enfermagem. Saúde Colet (Barueri). 2021;11(64):5570-81. doi: 10.36489/saudecoletiva.2021v11i64p5570-5581

9. Castro FM. Vivências maternas de cuidados à criança portadora de cardiopatia congênita no domicílio [tese]. Rio de Janeiro: Universidade Estadual do Rio de Janeiro; 2016. 89 f.

10. Santos EKA, Lins IVG, Santos TS. Assistência de enfermagem ao neonato com cardiopatia congênita: uma revisão integrativa. Braz J Health Rev [Internet]. 2022 Oct 28 [acesso em 2024 Jun 22];5(5):21455-6. doi: 10.34119/bjhrv5n5-288

11. Colliére MF. Promover a vida: da prática das mulheres de virtude aos cuidados de enfermagem. Lisboa: Lidel; 1999.

12. Colliére MF. Cuidar: a primeira arte da vida. 2ª ed. Loures: Lusociência; 2003.

13. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-57. doi: 10.1093/intqhc/mzm042

14. Nascimento LCN, Souza TV, Oliveira ICS, Moraes JRMM, Aguiar RCB, Silva LF. Theoretical saturation in qualitative research: an experience report in interview with schoolchildren. Rev Bras Enferm. 2018;71(1):228-33. doi: 10.1590/0034-7167-2016-0616

15. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.

16. Wilson D. Wong: fundamentos de enfermagem pediátrica. Rio de Janeiro: Guanabara Koogan; 2018.

17. Barros EB, Yamada LS, Paiva AO, Soares AER, Albuquerque MA, Souza GM, et. al. Perfil epidemiológico de nascidos vivos com cardiopatia congênita nas regiões brasileiras. Braz J Implantol Health Sci [Internet]. 2023 [acesso 2023 set 02];5(5):2316-28. Disponível em: https://bjihs.emnuvens.com.br/bjihs/article/view/792

18. Gallon M, Carvalhal MML, Gomes DL, Garces DCP, Guterres AS, Barbosa SNA. Cardiopatias congênitas cianóticas e acianóticas: aspectos clínicos e nutricionais em crianças internadas, em Belém-PA. RBONE [Internet]. 2020 [acesso em 2023 nov 28];16(101):303-12. Disponível em: http://www.rbone.com.br/index.php/rbone/article/view/1993

19. Sudario MVB, Moreno GL. Criança, escola e acolhimento institucional: a escola como espaço de socialização. Teias**.** 2022;23(68):29-41. doi: 10.12957/teias.2022.60916

20. Rodrigues ICS, Lima JS, Aita KMSC, Folha DRSC, Rodrigues RM. Impactos da pandemia da covid-19 na participação do brincar de crianças com cardiopatia: percepção de mães e crianças. Rev Interinst Bras Ter Ocup. 2024;8(2):2527-40. doi: 10.47222/2526-3544.rbto59114

21. Pimentel CM, Freire CS, Barros DMD, Pinheiro FV, Costa IS, Almeida MSC, et al. A socialização na educação infantil. REASE. 2021;7(10):2623-15. doi: 10.51891/rease.v7i10.2904

22. BRASIL. Lei n° 8.069 de julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. Brasília, DF: Presidência da República, 1990. Disponível em: https://www.planalto.gov.br/ccivil_03/leis/l8069.htm. Acesso em: 15 out. 2023.

23. Marques A, Gouveia B. Conhecimento sobre atividade física e seus níveis em crianças com cardiopatia congênita. Arq Bras Cardiol. 2020;114(5):793-4. doi: 10.36660/abc.20200286

24. Oliveira LM, Meggiolaro TH, Ceccato AC, Marchesan C. Projeto pedagógico: o poder do brincar no desenvolvimento das crianças [Internet]. MoEduCiTec: Mostra Interativa da Produção Estudantil em Educação Científica e Tecnológica: o protagonismo estudantil em foco. Ijuí (RS): Unijuí; 2022 [acesso em 2023 jul 31]. Disponível em: https://publicacoeseventos.unijui.edu.br/index.php/moeducitec/article/view/22646

25. Department of Health & Human Services USA. 2018 physical activity guidelines advisory committee scientific report [Internet]. Washington, DC: U.S. Department of Health & Human Services USA; 2018 [cited 2023 Aug 12]. Available from: https://health.gov/sites/default/files/2019-09/PAG_Advisory_Committee_Report.pdf

26. Sharma KMF, Correa DFP, Maciel FLS, Gomes J, Maciel ML. Os efeitos de programas de reabilitação em crianças e adolescentes com cardiopatia congênita e a segurança de aplicabilidade à domicílio: uma revisão sistemática. Rev CPAQV. 2023;15(1). doi: 10.36692/v15n1-06R

27. Campos EFL, Perin L, Assmann M, Lucchese F, Pellanda LC. Knowledge about the disease and the practice of physical activity in children and adolescents with congenital heart disease. Arq Bras Cardiol. 2020;114(5):786-92. doi: 10.36660/abc.20180417

28. Precce ML, Moraes JRMM. Educative process with relatives of children with special health needs in the hospital-home transition. Texto Contexto Enferm. 2020 [cited 2023 jul 20];29:e20190075. Available from: https://www.scielo.br/j/tce/a/fsNqCVqtcVzwPPSMb48PC7q/?format=pdf&lang=en

29. Depianti JR, Cabral IE. Crianças hospitalizadas com necessidades de saúde especiais complexas: estudo de casos múltiplos. Acta Paul Enferm. 2023;36:eAPE012732. doi: 10.37689/acta-ape/2023AO012732

Authorship contribution

1 – Flavia Melo de Castro
Corresponding Autor
Nurse, Master – flaviadoutorado@outlook.com
Conception and/or development of the research and/or writing of the manuscript; Review and approval of the final version

2 – Sandra Teixeira de Araujo Pacheco
Teacher; Nurse; Doctor – stapacheco@yahoo.com.br
Conception and/or development of the research and/or writing of the manuscript; Review and approval of the final version

3 – Marialda Moreira Christoffel
Teacher; Nurse; Doctor – marialda.ufrj@gmail.com
Conception and/or development of the research and/or writing of the manuscript; Review and approval of the final version

4 – Emília Gallindo Cursino
Teacher; Nurse; Doctor - egcursino@gmail.com
Conception and/or development of the research and/or writing of the manuscript; Review and approval of the final version

5 – Elisa da Conceição Rodrigues
Teacher; Nurse; Doctor - elisadaconceicao@gmail.com
Conception and/or development of the research and/or writing of the manuscript; Review and approval of the final version

6 – Juliana Rezende Montenegro Medeiros de Moraes
Teacher; Nurse; Doctor - jumoraes333@gmail.com
Conception and/or development of the research and/or writing of the manuscript; Review and approval of the final version

Chief Scientific Editor: Cristiane Cardoso de Paula
Associate Editor: Aline Cammarano Ribeiro

How to cite this article

Castro FM, Pacheco STA, Christoffel MM, Cursino EG, Rodrigues EC, Moraes JRMM. Maternal daily care practices for children with congenital heart disease at home. Rev. Enferm. UFSM. 2024 [Access at: Year Month Day]; vol.14, e12:1-18. DOI: https://doi.org/10.5902/2179769285955