


Profile of communicative and cognitive skills of children with heart disease undergoing heart surgery

 <https://doi.org/10.56238/sevned2024.012-060>

Mariana Rodrigues de Araújo¹, Joana Angélica Marques Pinheiro², Nayara Andressa Normandia Feitosa³, Antônia Amanda Souza Araújo⁴ and Cláudia Christina de Lima Silva⁵

ABSTRACT

Objective: To identify the level of communicative skills of children with congenital heart disease submitted to cardiac surgeries, corrective or not, through the behavioral observation protocol – PROC.

Methods: This is an analytical observational study with a quantitative approach. The research participants were 15 children with congenital heart disease, who had undergone some type of cardiac surgery, who were in the age group of 24 to 48 months, and were hospitalized in the pediatric unit or in outpatient medical care at the Hospital do Coração de Messejana Dr. Carlos Alberto Studart Gomes, excluding those who had any associated syndrome. For data collection, two instruments were used, the Behavioral Observation Protocol (PROC), already validated, and a questionnaire to outline the sociodemographic profile of the child and his/her guardian. Descriptive statistics were adopted for data analysis.

Results: Children with congenital heart disease submitted to surgical procedures have alterations in the language acquisition process, most of them in the initial sensorimotor phase.

Conclusion: The present study was promising as it allowed us to understand and identify the delays in linguistic development caused by heart disease, facilitating the referral for early intervention, in order to detect, prevent or minimize the impairment of linguistic aspects.

Keywords: Congenital heart disease, Language, Speech therapy, Child development.

¹ Multiprofessional Residency in Cardiopneumology – ESP. Fortaleza, Ceará, Brazil.

E-mail: marianarodrigues992@gmail.com

ORCID: <https://orcid.org/0000-0002-6594-1878>

² Dr. student in Clinical Care in Nursing- UECE. Fortaleza, Ceará, Brazil.

E-mail: joanamarquespinheiro@gmail.com

ORCID: <https://orcid.org/0000-0002-3092-3936>

³ Multiprofessional Residency in Cardiopneumology – ESP. Fortaleza, Ceará, Brazil

E-mail: nayaraandressanormandia@gmail.com

ORCID: <https://orcid.org/0000-0002-7148-911X>

⁴ Multiprofessional Residency in Cardiopneumology – ESP. Fortaleza, Ceará, Brazil.

E-mail: amandaraujo@edu.unifor.br

ORCID: <https://orcid.org/0000-0002-8506-2555>

⁵ Multiprofessional Residency in Cardiopneumology – ESP. Fortaleza Ceará.

E-mail: claudinhachristina2@gmail.com

ORCID: <https://orcid.org/0000-0002-6936-9215>



INTRODUCTION

Congenital heart disease is defined as an anomaly developed in the embryonic period that affects the anatomy and physiology of the heart (1), and may occur in the heart wall, valves or blood irrigation vessels, with or without a bluish discoloration of the skin, indicating low blood oxygenation, being classified as cyanotic or acyanotic (2)

According to the World Health Organization (WHO) (3), cardiovascular diseases are the leading causes of death worldwide and the second leading cause of infant mortality in Brazil. It is estimated that cardiac malformations affect approximately 0.9% of live births (4).

Surgical interventions, whether corrective or palliative, often occur in early childhood, requiring an early diagnosis, thus increasing the life expectancy of this population(5). However, cardiac surgery is considered a high-risk procedure, most of the time causing serious complications in the postoperative period of these children, resulting in a long period of hospitalization in intensive care units (ICU)(6), requiring specific care that requires joint action by a multidisciplinary team.

According to Ferreira et al(7), the hospitalization period is a phase that compromises the child's life in several ways; It leads to the deprivation of stimuli favorable to child development, with visual and auditory stimuli that are "threatening" and confusing for the child, where, at the time of hospital discharge, new challenges will arise in their growth and development.

Several studies point out how congenital heart disease can interfere with the motor, cognitive and language development of children. With regard to language, Nóbrega and Minervino (8) state that its development does not depend only on the innate conditions of each individual, but also on external factors such as the environment in which it is inserted and social factors, with the first year of life being fundamental for its evolution, thus, surgical interventions associated with long periods of hospitalization significantly affect child development (9).

According to Zorzi (2000) (10), language acquisition is a process of continuous evolution, whose critical period occurs in the age group of zero to six years. Throughout its development, language is divided into two major stages: prelinguistic, being considered the phase of vocalizations, which happens from birth to the first 12 months of life; and the linguistic phase, in which children begin to pronounce their first words.

In order to detect early alterations in language development and to systematize an assessment for young children regarding the development of communicative and cognitive skills, Hage; In 2004 Pereira and Zorzi (11) developed a behavioral observation protocol, called PROC, which allows the understanding of the typical evolution of language development, making it possible to configure the evolutionary levels and modes of cognitive and communicative functioning presented by children whose parents have complaints related to developmental delays or disorders, evaluating the aspects related to expressive communicative skills. of comprehension and symbolic scheme.



Verbal communicative skills in typical language development refer to the individual's ability to perform an interactive sequence of speech acts, i.e., to make use of language as an effectively interactive instrument with other social contexts (12). The ability to communicate effectively has been seen as a requirement for better opportunities in a productive world, where children with absences of expressive language and/or alteration in its development, when during school they have difficulties in the literacy and literacy process, with alterations in their integral development, later becoming a vulnerable adult at risk of social exclusion(13).

Thus, considering that the vast majority of children with congenital heart disease treated at a referral hospital in the North and Northeast are children who have been hospitalized for a long time, suffering social deprivation due to prolonged hospitalization, most of the time separated from their relatives, overprotection of parents due to clinical conditions and the conception of "fragility" of their children, With low-income families from different interior of Ceará, with little or almost no information regarding specialized speech-language pathology care offered by the Unified Health System (SUS), this study was carried out with the objective of identifying the level of communication skills of children with congenital heart disease submitted to cardiac surgeries, corrective or not, through the behavioral observation protocol – PROC.

METHODOLOGY

This is an analytical observational study, applied with a quantitative approach, carried out in a public hospital specialized in the diagnosis and treatment of heart and lung diseases and a reference in the North and Northeast regions for heart transplantation in adults and children.

The pediatric cardiology unit receives patients with congenital heart disease (CHD) of varying ages, from newborns referred directly from the maternity ward to adolescents and adults who return to the service for follow-up or surgical reapproach, from all over the state of Ceará and other regions of Brazil.

This study included 15 children with congenital heart disease, who underwent some type of cardiac surgery, corrective or not, in the age group of 24 to 48 months, who were hospitalized in the pediatric unit from July to November 2021, and also with children who were receiving outpatient medical care in the same period, excluding those with associated syndrome or whose parents did not show interest in participating in the research.

Initially, the project was presented to the medical team responsible for the pediatric unit and to the physicians responsible for outpatient care, and they were asked to inform when there were children who fit the inclusion criteria of the research, since both the unit and the outpatient care cover children of the most diverse age groups.

In a second moment, after medical care, a conversation was held with the parents or guardians



of the child, explaining the research, its objective and its methodology, where those who showed interest signed the Free and Informed Consent Form (ICF).

Then, the children from the outpatient clinic, together with their guardians, were referred to the speech therapy sector, where data collection was initiated, and a sociodemographic questionnaire was applied to the parents to determine the child's living conditions, and later, the behavioral observation protocol - PROC - with them. It is noteworthy that the collection with hospitalized children had the same process, but captured by active search by the researcher herself, and carried out in the bed itself.

For the application of the protocol, the child was offered a box with toys, consisting of a set of tools, a set of kitchen utensils, a set of food (size of the food proportional to the size of the kitchen set), a set of means of transport, a set of bath utensils, fitting toys, wooden blocks, dolls representing a family (a man, a woman, and 2 children) and animals.

In this way, the children were evaluated in a semi-structured context with pre-selected toys, and their behavior was observed, both from the communicative point of view and from the symbolic action.

The Behavioral Observation Protocol evaluates aspects related to expressive communicative skills, comprehension and symbolic schemes, analyzing three areas: Communicative skills (dialogic skills, communicative functions, means of communication and levels of language contextualization); Verbal comprehension and aspects of cognitive development (ways of manipulating objects, level of development of symbolism, level of organization of the toy and imitation), where each item evaluated will present a maximum score, totaling 150 points.

1. Communicative (expressive) skills – 60 points
2. Verbal language comprehension – 40 points
3. Aspects of cognitive development – 50 points

The findings of the instruments, sociodemographic profile and behavioral observation protocol were organized in tables with absolute and percentage frequencies, calculated using SPSS version 20.0, the mean statistical measures and standard deviations of the variables, age, income, number of surgical procedures, among others.

The study was designed in accordance with the guidelines and regulatory standards for research involving human beings (CNS: 466/2012) and approved by the Research Ethics Committee of the Hospital de Messejana Dr. Carlos Alberto Studart Gomes, CAAE: 47814321.9.0000.5039.

RESULTS

In order to better understand the living conditions of children with congenital heart disease, a sociodemographic questionnaire was applied to parents and/or guardians. with data related to gender,



age, marital status, number of children, housing, level of education, profession and monthly income, in which 100% of the companions/guardians/caregivers are women, with a mean age of 33.7 years and children of 2.8. In addition, 60% are married, 53.3% own their own home, 46.7% have a high school education, 60% do not have jobs and live only for their children, and 40% have an average monthly income between 1501 and 2000 reais, as shown in table 1.

In the population studied, equivalence was observed between the sexes, with 53.3% girls and 46.7% boys, with a mean age of 33.9 months, where of these, 66.7% performed only one cardiac surgery, 20% performed three surgeries and 13.3% performed two surgeries with an average length of stay of 103.8 days divided into Intensive Care Units (ICU) and ward. In addition to these aspects, there was also no significant predominance between the different types of diagnoses, with 6.7% pulmonary artery atresia (PA), tricuspid atresia, atrial septal defect (ASD), ventricular septal defect (VSD), aortic coarctation (CoA), acute pulmonary edema (PAE), left heart hypoplasia (HLHS) and single ventricle; 20% had total atrioventricular block and 26.7% had tetralogy of fallot (FTT). Among the symptoms that presented the most, fatigue, shortness of breath and cyanosis stood out with 60%.

With regard to the children's communicative development, in dialogic or conversational skills and verbal comprehension, it was observed that 46.7% do not initiate the interaction and rarely respond to the interlocutor, 60% do not wait for their turn and only 13.3% actively participate in the dialogic activity, where 53.3% presented intentional communication with primary functions, restricted participation in dialogic activity by non-verbal and non-symbolic means and 40% demonstrated to understand only orders with an action linked to the immediate context. As for the In terms of cognitive development, 66.7% do not create symbols and 80% do not use verbal language to report what is happening, and 60% are in the initial sensorimotor phase.

Table 2 shows the mean in each aspect evaluated with its respective total, and it is possible to observe a significant difference with a mean much lower than the maximum score of each item.

Table 3 shows the score generated in each aspect evaluated, as well as the total score performed in the test.

Table 1: Sociodemographic characteristics of parents and/or guardians. Fortaleza, Ceará, December, 2021.

Variable	Total (N=15)
AGE	
N	15
Average	33.7 (8.92)
GENDER, n (%)	
F	15 (100.0%)
ESTADO CIVIL, n (%)	
MARRIED WOMAN	9 (60.0%)
SINGLE	4 (26.7%)
COMMON-LAW MARRIAGE	2 (13.3%)
OFFSPRING	
N	15
Average	2.8 (1.47)
MORADIA, n (%)	
RENTED	5 (33.3%)
OWN	8 (53.3%)
THIRD PARTY	2 (13.3%)
EDUCATION LEVEL, n (%)	
Variable	Total (N=15)
INCOMPLETE ELEMENTARY SCHOOL	4 (26.7%)
COMPLETE HIGH SCHOOL	7 (46.7%)
INCOMPLETE HIGH SCHOOL	3 (20.0%)
SPECIALIZATION	1 (6.7%)
OCCUPATION, n (%)	
FARMER	2 (13.3%)
ATTENDANT	1 (6.7%)
BUTCHER	1 (6.7%)
FROM HOME	9 (60.0%)
MANICURE	1 (6.7%)
TEACHER	1 (6.7%)
MENSAL END, n (%)	
1000 A 1500	5 (33.3%)
1501 A 2000	6 (40.0%)
2501 A 3000	1 (6.7%)
LESS THAN 1000	3 (20.0%)

Table 2: Total score in each skill and its respective items, Fortaleza, Ceará, December, 2021.

SKILLS	AVERAGE	TOTAL
CHILD'S COMMUNICATIVE SKILLS		
Dialogic or conversational	6,4	16
Communicative functions	5,9	14
Media	6,9	20
Levels of language contextualization	7	10
VERBAL COMPREHENSION	21,7	40
COGNITIVE DEVELOPMENT ASPECT		
Ways to manipulate the object	7,8	15
Level of development of symbolism	6,6	20
Level of organization of the toy	3,5	11

Table 3: Total score on assessed skills and test, Fortaleza, Ceará, December, 2021.

PUNCTUATION	AVERAGE	TOTAL
Communication skills	28,1	60
Verbal language comprehension	21,7	40
Aspect of cognitive development	17,9	50
Test Total	68,5	150

DISCUSSION

The sociodemographic profile of parents or guardians of children with congenital heart disease shows that all of them are female, a fact that is often related to sociocultural factors. The story shows and places the woman as responsible for the domestic work and care of the children, where the literature brings the woman and her role as a mother as essential to offer an adequate environment for the child's development(14).

A study conducted in São Paulo with caregivers of children or adolescents with congenital heart disease showed a mean age of 34 years, of which 52.4% did not work, dedicating themselves exclusively to children (1). Leal et al (2016), in their study on the motor development of heart disease patients, also presenting socioeconomic characteristics of caregivers, showed that 53.4% had elementary school as their highest level of education, and 43.3% had a family income with an average of 1 minimum wage (15). On the other hand, Cesario, Carneiro and Dolabela, in a study conducted with mothers of heart disease patients in 2020, showed that 64.3% had completed high school, corroborating the data found in this study (16).

Several studies in the field of child development correlate the socioeconomic conditions and the level of education of parents with the stimuli attributed to their children, since for an adequate



development it is important to offer spaces that favor the exploration of the environment, providing motor, cognitive and social stimulation(15).

In relation to children with congenital heart disease, Belo, Oselame and Neves(2) investigated the clinical-hospital profile of these children and brought results similar to those described in this study, finding a mean age of two years and three months, with no prevalence of gender and a maximum hospitalization time of 4 months, with respiratory distress as the main symptom of heart disease(17). Freire et al, with 21 participants, brought in their studies, a maximum hospitalization time of 387 days for a child with readmissions throughout childhood for the performance of three cardiac surgical procedures, and also presented another participant who had a shorter hospitalization time of 39 days (18).

The prolonged length of hospital stay has been discussed by several authors and highlighted as one of the main factors causing alterations/delays in neuropsychomotor development(19). Children with severe heart disease need to undergo a series of surgeries in order to correct or minimize the effects caused by the pathology, immediately entering the risk group for alterations in their general development, due to their various hospitalizations, especially in the ICU, making it difficult to live and interact with their families and/or other children of the same age(17).

In the first years of life, more specifically in the first three years, the brain is in its full development, being formed and strengthened through stimuli and bonding (20). Linguistic and cognitive skills develop in an integrated way and depend on a neurobiological and social apparatus, with social interaction and the quality of stimuli being essential for language acquisition. (21).

In order to evaluate the influence of congenital heart disease on the neuropsychomotor development (NPMD) of infants, by applying a protocol that evaluates linguistic aspects, Paula et al showed that heart disease negatively influences NPMD, affecting several aspects, including linguistic skills(17).

It is noteworthy that more than half of the studied population have restricted dialogic skills, presenting communication by non-verbal and non-symbolic means, data that are similar to the research carried out by Freire et al, who, by also applying the behavioral observation protocol at the Heart Hospital of the Municipality of São Paulo, obtained as a result 50% of the children evaluated. were non-verbal and had difficulty in communicative intention, oral language comprehension, and sound and gestural imitation (18). On the other hand, Castro, when applying the same protocol in the same institution, obtained divergent data, resulting in satisfactory answers, where all the subjects evaluated presented multifunctional intentional communication with wide participation in dialogic activity, presenting alterations only in phonology, however, it is worth mentioning that when selecting the participants, the researcher involved a larger age group, including children from 3 to 7 years of age(22).



Alterations in speech and language development have significant repercussions in different contexts present in the child's daily life, including social, educational and family environment(23). Learning and learning disabilities socialization, are directly related to a history of delayed language acquisition, thus demonstrating the need for early identification and diagnosis, avoiding subsequent psychosocial consequences(24).

CONCLUSION

The present study was promising as it allowed us to understand and identify the delays in linguistic development experienced among the repercussions of heart disease in children, enabling referral to early intervention services, as well as guidance to parents on how to stimulate and assist in the development of speech and language, in order to detect, to be able to act in order to prevent and minimise the impairment of linguistic aspects.



REFERENCES

1. Silva, G. V. D., Moraes, D. E. B., Konstantyner, T., & Leite, H. P. (2020). Apoio social e qualidade de vida de família de crianças com cardiopatia congênita. *Ciência & Saúde Coletiva, 25*(8).
2. Belo, W. A., Oselame, G. B., & Neves, E. B. (2016). Perfil clínico hospitalar de crianças com cardiopatia congênita. *Cadernos de Saúde Coletiva, 24*(2).
3. Organização Mundial da Saúde. (2019, 4 de outubro). [Inserir título se houver]. Recuperado de [URL]
4. Souza, P. C. D., Gigoski, V. S., Etges, C. L., & Barbosa, L. R. (2018). Achados da avaliação clínica da deglutição em lactentes cardiopatas pós-cirúrgicos. *CoDAS, 30*(1).
5. Doná, T. C. K., Lawin, B., Maturana, C. S., & Felcar, J. M. (2015). Características e prevalência de cardiopatias congênitas em crianças com síndrome de Down submetidas a cirurgia cardíaca em um hospital na região Norte do Paraná. *Revista Equilíbrio Corporal e Saúde, 7*(1).
6. Santana, G. R. D., et al. (2013). Avaliação da qualidade de vida de pacientes submetidos à cirurgia cardíaca no estado de Sergipe. *Cadernos de Graduação Ciências Biológicas e da Saúde, 17*(1), 113-124.
7. Ferreira, A. N., et al. (2020). Hospitalização infantil: impacto emocional indexado à figura dos pais. *Revista Interfaces, 8*(1).
8. Nóbrega, J. D. N., & Minervino, C. A. D. S. M. (2017). Análise do nível de desenvolvimento da linguagem em crianças abrigadas. *Psicologia Argumento, 29*(65).
9. Ribeiro, P. I., et al. (2020). Influência da cardiopatia congênita no desenvolvimento neuropsicomotor de lactentes. *Fisioterapia e Pesquisa, 27*(1).
10. Zorzi, J. L. (2000). Aspectos básicos para compreensão, diagnóstico e prevenção dos distúrbios de linguagem na infância. *CEFAC, São Paulo*.
11. Hage, S. R. D. V., Pereira, T. C., & Zorzi, J. L. (2012). Protocolo de observação comportamental – PROC: valores de referência para uma análise quantitativa. *CEFAC, 14*(4), 677-690.
12. Mayumi, C. A., Bretanha, A. C., Bozza, A., Ferraro, G. J. K., & Lopes-Herrera, A. S. (2013). Habilidades comunicativas verbais no desenvolvimento típico da linguagem – relato de caso. *CoDAS, 25*(1), 76-83.
13. Lamego, D. T. D. C., Moreira, M. C. N., & Bastos, O. M. (2018). Diretrizes para a saúde da criança: o desenvolvimento da linguagem em foco. *Ciência & Saúde Coletiva, 23*(9), 3095-3106.
14. Borsa, J. C., & Nunes, M. L. T. (2011). Aspectos psicossociais da parentalidade: O papel de homens e mulheres na família nuclear. *Psicologia Argumento, 29*(64), 31-39.
15. Leal, L. S., Silva, R. L. M., Aita, K. M. S. C., Monteiro, R. P. A., & Montalvão, T. C. (2016). Assessment of motor development of children with congenital heart disease. *International Journal of Cardiovascular Sciences, 29*(2), 103-109.
16. Cesario, M. S. A., Carneiro, A. M. F., & Dolabela, M. F. (2019). Mães de crianças com cardiopatia congênita: dúvidas e estratégias de intervenção. *Revista Eletrônica Acervo Saúde, 12*(5).



17. Paula, I. R., et al. (2020). Influência da cardiopatia congênita no desenvolvimento neuropsicomotor de lactentes. *Fisioterapia e Pesquisa, 27*(1), 41-47.
18. Freire, R. M. A. C., et al. (2021). Possíveis fatores de risco para o desenvolvimento em crianças com cardiopatia congênita. *Research, Society and Development, 10*(11).
19. Rocha, H. A. L., et al. (2021). Maternal and neonatal factors associated with child development in Ceará, Brazil: A population-based study. *BMC Pediatrics, 21*, 163.
20. Venancio, S. I., Bortoli, M. C., Frias, P. G., Giugliani, E. R. J., Alves, C. L. R., & Santos, M. O. (2020). Development and validation of an instrument for monitoring child development indicators. *Journal of Pediatrics, 96*(6), 778-789.
21. Soare, A. C. C., Silva, K., & Zuanetti, P. A. (2017). Variáveis de risco para o desenvolvimento da linguagem associadas à prematuridade. *Audiology - Communication Research, 22*, 745.
22. Castro, B. M. (2020). Relações entre desenvolvimento de linguagem oral e ocorrência de hospitalizações e cirurgias precoces em crianças portadoras de cardiopatia congênita. *PUC-SP. Pontifícia Universidade de São Paulo, 72 p*.
23. Ostroschi, D. T., Zanolli, M. L., & Chun, R. Y. S. (2017). Percepção de familiares de crianças e adolescentes com alteração de linguagem utilizando a classificação internacional de funcionalidade, incapacidade e saúde (CIF-CJ). *CoDAS, 29*(3).
24. Schirmer, C. R., Fontoura, D. R., & Nunes, M. L. (2004). Distúrbios da aquisição da linguagem e da aprendizagem. *Jornal de Pediatria, 80*(2).