

# Profile of independence in the self-care of the child with Down's Syndrome and congenic cardiopaties<sup>1</sup>

Irmara Gêssica Santos Amaral<sup>a</sup> , Victor Augusto Cavaleiro Corrêa<sup>b</sup> ,  
Karla Maria Siqueira Coelho Aita<sup>a</sup> 

<sup>a</sup>Universidade do Estado do Pará – UEPA, Belém, PA, Brasil.

<sup>b</sup>Instituto de Ciências da Saúde, Universidade Federal do Pará – UFPA, Belém, PA, Brasil.

**Abstract:** Introduction: The work to be performed on the child Down Syndrome (DS) with Congenital Heart Disease (CHD) must be carried out by qualified professionals and provide these conditions to expand their capacities, helping them to achieve independence in the activities of self-care. Objective: To delineate the independence profile in the self-care activities of DS children who present CHD in the age group of 3 to 7 years and 6 months old and who receive outpatient follow-up at a cardiology reference unit in the city of Belém, Pará, Brazil. Method: This is a quantitative study, in which 18 children, male and female, were followed up at the reference outpatient clinic in cardiology in the state of Pará. To collect data, a personal information interview was conducted with the parents/caregiver and part I of the Pediatric Invalidation Assessment Inventory (PEDI) regarding the child's abilities for self-care activities. Results: The study showed that children with DS and CHD presented impairment in the area of fine motor skills, which interferes with activities such as handling of locks, opening, and closing of faucets, use of utensils, among others. Conclusion: Both DS and CHD are conditions that interfere in the development of skills necessary for independence in self-care activities. Thus, the study demonstrated that the functional performance in the self-care activities of children studied is lower than in children with typical development.

**Keywords:** *Down Syndrome, Heart Diseases, Personal Autonomy, Self-Care, Ambulatory Care.*

## Perfil de independência no autocuidado da criança com Síndrome de Down e com cardiopatia congênita

**Resumo:** Introdução: O trabalho a ser realizado junto à criança Síndrome de Down (SD) com Cardiopatia Congênita (CC) deve ser efetivado por profissionais qualificados e deve proporcionar à criança condições para expandir suas capacidades, auxiliando-as a alcançar a independência nas atividades de autocuidado. Objetivo: Delimitar o perfil de independência nas atividades de autocuidado da criança SD que apresente CC na faixa etária de 3 a 7 anos e 6 meses e que receba acompanhamento ambulatorial em unidade de referência cardiológica na cidade de Belém, Pará, Brasil. Método: Trata-se de um estudo quantitativo, do qual participaram 18 crianças, de gênero masculino e feminino, em acompanhamento no ambulatório de referência em cardiologia do estado do Pará. Para coleta de dados foram realizadas, junto aos pais/cuidadores, uma entrevista de informações pessoais e a parte I do Inventário de Avaliação Pediátrica de Incapacidade (PEDI) referente às habilidades da criança para as atividades de autocuidado. Resultados: O estudo mostrou que as crianças com SD e CC apresentaram prejuízo na área de motricidade fina, o que interfere na realização de atividades como manuseio de fechos, abrir e fechar torneira, utilização de utensílios, entre outros. Conclusão: Tanto a SD quanto a CC são condições que interferem no desenvolvimento de habilidades necessárias para a independência nas atividades de autocuidado. Dessa forma, o estudo demonstrou que o desempenho funcional nas atividades de autocuidado das crianças estudadas é inferior ao de crianças com desenvolvimento típico.

**Palavras-chave:** *Síndrome de Down, Cardiopatias, Autonomia, Autocuidado, Ambulatório.*

**Corresponding author:** Karla Maria Siqueira Coelho Aita, Centro de Ciências Biológicas e da Saúde, Universidade do Estado do Pará, Tv. Perebebuí, 2623, Marco, CEP 66087-662, Belém, PA, Brasil, e-mail: km.aita@uol.com.br

Received on Feb. 19, 2018; 1<sup>st</sup> Revision on Sept. 2, 2018; 2<sup>nd</sup> Revision on Nov. 23, 2018; Accepted on Feb. 6, 2019.



## 1 Introduction

In recent years, Down Syndrome (DS) has received more attention due to being the most common chromosomal anomaly among neonates, with an approximate incidence of 1 in 700 live births (MOURATO; VILLACHAN; MATTOS, 2014). Some of the physical characteristics of the child with DS after birth are: delayed mental and motor development, associated with signs such as muscular hypotonia (90.9%), single transverse palmar crease (59.0%), single crease on the fifth finger (18.1%), sulcus between the hallux and the second toe (77.2%), excess skin on the neck (82%), oblique palpebral cleft (100%), flat face (86.3%) (SALVIO et al., 2007; ANTUNES, 2004).

Most children with DS will have generalized hypotonia and delay in neuropsychomotor development. Pazin and Martins (2007) affirm that the impairment of the functional and cognitive abilities is influenced by the pathologies associated with DS that affect the diverse systems of the child, and the specific demands of the task and the characteristics of the environment in which the child is inserted.

According to Bonomo and Rossetti (2010), hypotonia and generalized muscle weakness commonly interfere in obtaining the child's motor skills with DS and in interaction with the environment, reducing the exploration of this space, generating deficits in sensations and experiences, hindering the selection and sensory integration of the information received. In the fine motor skills, there is a decrease in grip strength and anatomical modifications (such as small hands and a single palmar crease), which may interfere with the manipulation, the exploration of objects and the performance of the function related to the upper limbs.

In addition to the phenotypic characteristics, individuals with DS have a variety of malformations, which may be isolated or associated with thyroid, gastrointestinal, bone, cardiologic, and other abnormalities (BOAS; ALBERNAZ; COSTA, 2009). When considering the population of children with heart disease with DS, the incidence is 40-60%, especially in their morbidity and mortality (MOURATO; VILLACHAN; MATTOS, 2014). Boas, Albernaz and Costa (2009) state that in the last years, a significant improvement in the life expectancy of patients with DS who have congenital heart disease (CHD) has been observed, either by early detection or by effective surgical treatments.

Congenital heart disease causes several changes, causing significant impacts on the child's life and compromising her occupational performance (ROCHA; ZAGONEL, 2009). Aita and Souza (2016) states that when children are not operated on in their first year of birth, they evolve with successive hospitalizations due to pulmonary complications and other complications related to heart disease. The child with CHD will have fatigue to the minimum physical effort, difficulty or impossibility to run short distances in flat terrain, and low suction threshold as some of the limitations to perform daily activities.

Thus, when CHD is associated with any other condition that impairs adequate neuropsychomotor development, such as DS, the support of a multi-professional team becomes necessary, able to develop the child's potentialities, promoting independence in self-care.

In childhood, most of the motor skills are obtained and provide greater body control in different movements and postures, used in activities of daily living, practical life and leisure (BONOMO, 2010).

Monteiro et al. (2012) explain that as rich as the genetic inheritance, the child receives, the experience of greater autonomy in the daily life of the caregiver, and the social environment interference from their parents. The emotional history of the child determines how development occurs.

According to Bonomo (2010), human development is a dynamic, multidimensional process related to the major areas of development (motor, cognitive and psycho-emotional) that operate on the individual and also on the environment.

Therefore, the interaction of the child with the context in which he lives is fundamental to achieve motor, cognitive and social skills, and the set of these things allows the child to explore the environment in a more organized way. Thus, any element that may directly interfere with the way the children relate to the environment in which they live and, consequently, the child development may lead to difficulties in acquiring independence for carrying out activities of daily living, practical life and recreation.

According to the International Classification of Functioning, Disability and Health for Children and Young People (CIF-CJ), all pathologies, as well as resulting in compromises to body structure and function, can cause changes in the execution of activities and in the level of participation of the individual (ORGANIZAÇÃO..., 2003). When

considering these aspects, it is observed that DS directly interferes with the way the child interacts with the environment in which he lives and, consequently, causes difficulties for the acquisition of independence in activities of daily living.

Many research suggests that children with DS aged two to five years old have low functional performance in the areas of mobility, self-care and social function (MANCINI et al., 2003; COPPEDE et al., 2012).

The child with DS has limitations, especially in the intellectual aspect. However, when stimulated, he can be independent, participating in everyday activities in all aspects, according to his potentialities (PAZIN; MARTINS, 2007). Therefore, it is necessary to use resources that enable to assess the level of independence that the children with DS with a diagnosis of CHD, which is applicable and appropriate to this profile, considering their physical limitations to guide professional practices and favor child development.

The work to be carried out with the DS children with CHD must be carried out by qualified professionals and provide these children with the conditions to expand their capacities, helping them to reach the later stages of human development. In this sense, the objective of this research was to characterize self-care performance of independence in the self-care activities of children with DS and diagnosis of CHD in the age group of 3 to 7 years and 6 months old in outpatient follow-up at a cardiology reference unit in the city of Belém.

## 2 Method

This is a study with a quantitative, observational and cross-sectional approach. It was approved by the Research Ethics Committee involving human beings (CEP) of the State Public Foundation Hospital das Clínicas Gaspar Vianna, according to the resolution nº 466/2012 (BRASIL, 2012), with the approval opinion number 029858/2017.

### 2.1 Research place

The research was developed at the outpatient clinic of the State Public Foundation Gaspar Vianna Hospital (FPEHCGV), which is characterized as an institution of medium and high complexity that provides care to patients of the Unified Health System (SUS), coming from several specialties, being a reference in cardiology, nephrology and psychiatry, and offering multidisciplinary care.

### 2.2 Process of sampling and selection of research participants

The sampling process of the research was characterized as a non-probabilistic sample for convenience. The sample had 18 male and female children aged 3 to 7 years and 6 months old with Down's Syndrome, who presented a diagnosis of congenital heart disease, in a regular follow-up at the reference outpatient clinic in cardiology, with the pediatricians and/or cardio-pediatricians of the FPEHCGV, in the morning, between June and August of 2017.

### 2.3 Data collection

The data collection process was carried out in a single meeting with the caregivers/parents, in which the Pediatric Disability Inventory (PEDI) (Part I) (functional abilities of the child) was answered through an interview (MANCINI, 2005).

### 2.4 Research instrument

The inventory was developed to provide a detailed description of the child's functional performance, predicting their future performance and documenting longitudinal changes in their functional performance. Thus, it contributes to the targeting of the treatment plan in the specific area where the children have their greatest difficulty (SANTOS; PRUDENTE, 2014).

It is an evaluation instrument that shows the functional performance of children in the age groups of 6 months to 7 years and 6 months old, within their domestic environment, adapted and validated to the Brazilian sociocultural reality (MELLO; MANCINI, 2007). It provides quantitative information on the children development and the achievement of functional skills and independence that are important for the performance of the children's daily activities at home, and it can be applied by an interview method with parents, clinical judgment or direct observation (MELLO; MANCINI, 2007).

The PEDI is divided into three parts that assess: the children's abilities to perform daily tasks; the independence of the children to perform their daily activities and tasks; the necessary changes in the environment to promote the performance of the children. In these three parts, self-care, mobility and social function performance activities are considered. The analysis of the information obtained through the protocol is a basis for the treatment (COELHO; REZENDE, 2011).

## 2.5 Data analysis

The data analysis was performed by a quantitative methodology to better interpret reality and to reach the objectives of the study. These data were entered in a database to perform the statistical analysis. According to the nature of the variables, a descriptive analysis was carried out, and the percentage values of the results of the categorical variables were reported, as well as the measurements of the mean, median and standard deviation of the numerical variables. The information was stored in Excel 2010™ software (Microsoft Corporation, Redmond, USA) and analyzed using BioEstat™ software 5.0 software (software, Inc., Belém, Brazil).

The Brazilian Version Manual Adapted of PEDI states that the normative score allows the researchers to reflect the expected performance of the children. The normative score is considered normal when it is 30-70 and, when less than 30, it is characterized by a delay or performance that is significantly lower than the children of the same age group (MANCINI, 2005).

The total gross scores were transformed into normative standard scores using the appropriate table, presented in the PEDI manual.

## 3 Results and Discussion

Table 1 shows the distribution of the children surveyed and the normative scores reached in part I of the PEDI in the self-care area.

In this study, only one child (C13) had a score above 30, which corresponds to the expected functional performance for age in self-care activities. Five children had a normative score <10, that is, they had a very low score so they could not be converted into a normative score. The remaining ten children had a normative score below 30, thus, they had a significant delay in self-care activities.

According to Coelho and Rezende (2011), the occupational performance of a typical child can be specified by three areas of occupation: To play, education and ADL. To play is described as a complex behavior that reflects reality. Activities related to education include the activities necessary to play the role of student and participation in the school environment. On the other hand, ADLs are characterized as activities aimed at the care of the individuals with their body, including in these activities: bathing, sphincter control, dressing up, eating, feeding, functional mobility, personal equipment care, personal hygiene and self-care, use of the toilet, sleep/rest (ASSOCIAÇÃO..., 2015).

Self-care activities are occupational tasks of great importance for the overall development of the children, fundamental to the achievement of motor skills, functional independence, and autonomy, contributing to the self-esteem and self-confidence of the children (SILVA et al., 2013). As the children are able to independently perform the activities of their daily life, they become able to participate in different social contexts, experiencing the

**Table 1.** Distribution of children with DS and CHD in gender (M = male and F = Female), chronological age and their respective normative scores in the self-care area of part I of PEDI (functional skills).

Identification	Gender	Chronological age	Normative score
C1	M	7y 6m	27.8
C2	M	7y 2m	21.1
C3	M	6y 11m	26.5
C4	M	4y 11m	27.5
C5	M	6y 11m	<10
C6	F	7y 6m	20.7
C7	M	7y 1m	24.4
C8	M	4y 6m	<10
C9	F	5y 10m	11
C10	M	3y 2m	<10
C11	M	3y 3m	14.4
C12	M	6y 9m	<10
C13	M	6y 11m	30.9
C14	F	7y 4m	21.9
C15	M	3y 8m	18.1
C16	F	3y 6m	24.5
C17	M	7y 6m	25
C18	M	4y 2m	<10

Source: Field research.

privileges of these interactions (CHRISTIANSEN; OTTENBACHER, 2002).

Bronfenbrenner (1996) states that the person develops from his engagement in activities and interactions that builds in and with the environment in which he lives, understanding that it is in the interaction with people, objects and symbols that through activities, relationships and roles, the children become capable of giving meaning to the environment in which they participate.

Functional development in childhood begins with the acquisition of motor skills that enable the children to control their body in static or dynamic postures. The combination of these achievements determines the mobility function, relating to cognitive development (VICARI, 2006).

The first three years of life are characterized by sensorial-neural maturation, responsible for the motor acquisition and language acquisition. In the interval between three and seven years, the postural motor modifications become less intense, to get cognitive expressions, encompassing logical arguments, socio-emotional aspects, and graphic communication (FERREIRA et al., 2009).

Regarding these aspects (PEDREMÔNICO, 2003), the early stimulation of performance components provides independence in child performance. However, children with DS can show the ability to learn a small number of new things, needing repetitions to learn, with a difficulty in expanding their abilities and to maintain them, and the repertoire of limited responses because they have a degree of intellectual deficiency (LOTT; DIERSSEN, 2010; OPERMANN, 2014).

The physical changes presented by children with DS are shown functionally, influencing their ability to independently perform the activities and tasks of the daily routine. The lack of evidence about the functional performance of this people restricts the intervention of professionals who collaborate in the development of these children, in setting goals and expectations with possibilities of being reached (MANCINI et al., 2003).

The achievement of self-care skills and social function are related to the capacity of mobility for exploration of the environment and the understanding of perceptive-motor skills, fine coordination, communication, and social coexistence. The anatomical changes, characteristic of the syndrome, such as small hands with short fingers, the presence of a palmar crease and absence of some carpal bones hinder to grip and may influence the performance of self-care tasks (VICARI, 2006).

A study comparing the level of independence of children with DS and children with typical development using PEDI revealed that in the area of self-care, children with DS are less independent than children with typical development. This fact can be justified because parents and caregivers of children with DS have a tendency to limit their participation in feeding, bathing, personal hygiene, dressing, and bathroom use, suggesting the overprotection of children by them. Another factor was reduced availability time to allow children to participate in self-care activities (MANCINI et al., 2003).

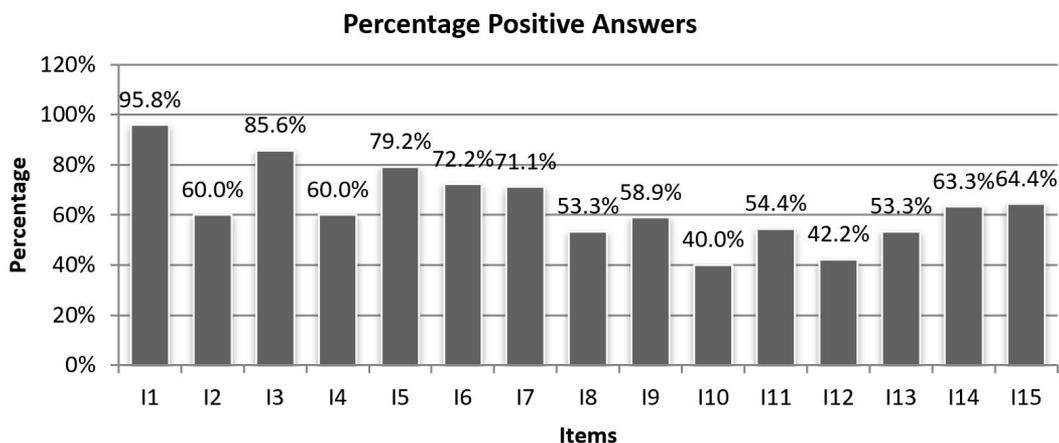
According to Sampaio et al. (2013), tracing the profile of the children with Down's syndrome is of great importance for their neuropsychomotor development, showing aspects related to their development, showing their difficulties and potentialities.

In Figure 1, the self-care activities investigated in the research are shown by sub-items. The quantitative was counted from the frequency of positive responses (if the child is able to independently perform the task) in the interviews.

The self-care activities that the children analyzed are able to perform independently are those related to food texture (95.8%), use of drinking containers (85.6%), (79.2%), nose care (72.2%) and hand washing (71.1%). The activities that represented the greatest difficulties to be performed independently were those related to clasps (40.0%), shoes and socks (42.2%), body and face washings (53.3%) and toilet tasks (53.3%). Based on the occurrence and the contrast between the evaluated items, the fine motor skills are the most delayed in the research participants. These children have great difficulty in adequately performing tasks that require skills such as opening and closing a faucet, opening and closing zippers, holding pencils, buttoning and unbuttoning. Also, tasks related to the handling of shoes and socks, body and face wash and toilet tasks are difficult to perform by them.

Silva et al. (2013) in their studies showed that the items with the greatest level of difficulty found by them were related to the use of clasps and clothing due to the need for greater fine motor skills for their execution, as well as the item related to the toilet tasks that they obtained lower score.

However, Coppede et al. (2012), in their studies on the functionality of the children with Down syndrome affirm that one of the areas of the greatest damage to the independence of these children is the fine motor. They emphasize that, in general, it is expected that at the end of the first year of age



**Figure 1.** Descriptive data on the number of positive answers in each self-care task in part I of the PEDI, corresponding to the Functional Skills of the Self-Care Area of children with Down syndrome and congenital heart disease. I1 = Texture of Foods; I2 = Use of Utensils; I3 = Use of Drinking Containers; I4 = Oral Hygiene; I5 = Hair Care; I6 = Nose Care; I7 = Washing Hands; I8 = Washing the Body and the Face; I9 = Coat/Front Open Clothes; I10 = Clasp; I11 = Pants; I12 = Shoes/Socks; I13 = Toilet Tasks; I14 = Urinary Control; I15 = Intestinal Control.

the development of precision gripping is initiated, which requires control of the intrinsic musculature of the hand and independent finger movement, skills needed to manipulate small and delicate objects. In their results, these authors state that even after this phase, children with DS remain with difficulties in performing activities that require fine motor coordination.

In this sense, it is necessary to emphasize that anatomical differences in hand and finger size plus clinical characteristics such as hypotonia, ligament laxity, and central nervous dysfunctions influence the acquisition and execution of fine motor skills in the grasping of objects, in the development of the writing ability, and in the definition of the laterality (SOUZA et al., 2012). These aspects should be considered for the development of the therapeutic plan when the stimulation of these skills is compromised.

Evaluations performed with DS children to stipulate their motor development showed that they presented developmental delays in all areas, with better results in the area corresponding to global motor skills. For these authors, the findings are associated with different ways of moving the body, a fundamental aspect in the improvement of nervous commands and in the refinement of body sensations and perceptions (REIS FILHO; SCHULLER, 2010; SILVA; DOUNIS, 2014).

It is important to highlight that children's experiences in different contexts require the authorization of

their parents. In this sense, when analyzing the development of the patient with congenital heart disease, Aita and Souza (2016, p. 143) add that:

These children have impaired motor performance in their daily activities, partly because they have the low cardiopulmonary performance to perform tasks; and in other situations due to poor nutritional status, they are always monitored by caregivers who fear hypoxemic attacks or even accidents such as falls and bruises. In children who have cyanotic heart disease, there is a certain "impediment", even in manifesting their pain or sorrow through crying. This is denied because crying greatly increases their respiratory discomfort, which, if it persists for a few minutes, may progress to cardiorespiratory arrest. However, this behavior of the caregiver generates a delay in the acquisition of autonomy to carry out their activities of daily living and independence from family members.

When analyzing the behavior of parents and caregivers, and the perception of fragility on which the concept about their children is constructed, as reality or myth, the manifested overprotection affects the constitution of the subjectivities of these children and can sometimes come to be more disabling than the DS or the symptoms of heart disease.

Regarding CHD and children development, when investigating children in the cardiovascular preoperative and postoperative, Mari (2015) identified

that these people have developmental delay, with more significant difficulties related to fine motor, gross motricity, and language. In general, congenital heart diseases, together with the proposed therapeutics, imply changes in the children's life, with a constant presence of dyspnea, tiredness, a history of long or recurrent hospitalizations in the hospital context, special daily care, temporary or definitive physical limitations that may influence the independent performance of activities of daily living, practical life and leisure.

No other studies were found to relate the level of independence of children with Down's Syndrome with the presence of Congenital Heart Disease.

The findings suggest that the work carried out by the multidisciplinary team of the outpatient clinic should expand its intervention strategies to involve the caregivers of these children, sensitizing them for the possibilities and potential that the exploitation of the domestic environment offers, and the social aspects for the acquisition of new motor skills.

## 4 Conclusion

In the context of childhood, pathologies and/or genetic conditions that imply difficulties in acquiring the basic skills that contribute to the overall development and independence of the child are highly relevant to study and analyze. In this research, the functional performance in the self-care activities of children with DS and CHD is lower than in children with typical development, which tends to reinforce the concept of fragility in the decisions of their parents and to make it more difficult to acquire the autonomy of the children in the different contexts of life.

Self-care activities provide the studied people with a universe of motor, sensory, cognitive and social experiences that contribute to the acquisition of more complex abilities, providing their integral development.

PEDI has proved to be an effective instrument, since it identifies the exact area where the children are at a disadvantage and allow the delineation of the information in a strategic way in the specific difficulties of each of them, through a holistic view at their needs, providing assertive elements for therapeutic planning. Therefore, it is recommended to use it for health professionals.

The small sample of this study related to the access of the target population to specialized services is a limitation of this study, especially when the geographic characteristic aspects in the northern

region of the country is taken as the basis for analysis. Therefore, due to the impact on the health of this population and the scarcity of research directed to these people, new studies with similar groups are suggested.

The need to stimulate the development of the child and actions directed at the parents to highlight the relevance of the experiments in the domestic and social environment as an important and low-cost strategy in the acquisition of these skills is also reaffirmed. Other studies are recommended for discussion of inclusive interventions and actions.

## References

- AITA, K. M. S. C.; SOUZA, A. M. Cenas sobre a morte, reveladas pela criança cardiopata, por abrir o coração. *Revista NUFEN*, Belém, v. 8, n. 1, p. 141-162, 2016.
- ANTUNES, G. A. A. *O enfrentamento da Síndrome de Down: uma abordagem do comportamento materno e do tratamento fisioterapêutico*. 2004. 36 f. Monografia (Graduação em Fisioterapia) – Universidade Federal de Goiás, Goiânia, 2004.
- ASSOCIAÇÃO AMERICANA DE TERAPIA OCUPACIONAL – AOTA. Estrutura da prática da terapia ocupacional: domínio e processo. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 26, p. 1-49, 2015.
- BOAS, L. T. V.; ALBERNAZ, E. P.; COSTA, R. G. Prevalência de cardiopatias congênitas em portadores da síndrome de Down na cidade de Pelotas (RS). *Jornal de Pediatria*, Porto Alegre, v. 85, n. 5, p. 403-407, 2009.
- BONOMO, L. M. M. *Aspectos percepto-motores e cognitivos do desenvolvimento de crianças com Síndrome de Down do município de Vitória/ES*. 2010. 167 f. Dissertação (Mestrado em Psicologia) – Universidade Federal do Espírito Santo, Vitória, 2010.
- BONOMO, L. M. M.; ROSSETTI, C. B. Aspectos percepto-motores e cognitivos do desenvolvimento de crianças com Síndrome de Down. *Revista Brasileira de Crescimento e Desenvolvimento Humano*, São Paulo, v. 20, n. 3, p. 723-734, 2010. <http://dx.doi.org/10.7322/jhgd.19980>.
- BRASIL. Resolução nº 466/12, de 12 de dezembro de 2012. Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 12 dez. 2012.
- BRONFENBRENNER, U. *A ecologia do desenvolvimento humano: experimentos naturais e planejados*. Porto Alegre: Artmed, 1996.
- CHRISTIANSEN, C. H.; OTTENBACHER, K. J. Avaliação e gerenciamento das necessidades de cuidados

- peçoais diários. In: DELISA, J. A. *Tratado de medicina de reabilitação: princípios e prática*. São Paulo: Manole, 2002. p. 145-172.
- COELHO, Z. A. C.; REZENDE, M. B. Atraso no desenvolvimento. In: CAVALCANTI, A.; GALVÃO, C. *Terapia ocupacional: fundamentação e prática*. Rio de Janeiro: Guanabara Koogan, 2011. p. 299-307.
- COPPEDE, A. C. et al. Desempenho motor fino e funcionalidade em crianças com síndrome de Down. *Fisioterapia e Pesquisa*, São Paulo, v. 19, n. 4, p. 363-368, 2012.
- FERREIRA, D. M. et al. Funcionalidade de crianças com e sem Síndrome de Down. *Revista Neurociências*, São Paulo, v. 17, n. 3, p. 231-238, 2009.
- LOTT, I. T.; DIERSSEN, M. Cognitive deficits and associated neurological complications in individuals with Down's syndrome. *Lancet Neurology*, London, v. 9, n. 6, p. 623-633, 2010. [http://dx.doi.org/10.1016/S1474-4422\(10\)70112-5](http://dx.doi.org/10.1016/S1474-4422(10)70112-5). PMID:20494326.
- MANCINI, M. C. *Inventário de Avaliação Pediátrica de Incapacidade (PEDI): manual da versão brasileira adaptada*. Belo Horizonte: UFMG, 2005.
- MANCINI, M. C. et al. Comparação do desempenho funcional de crianças portadoras de Síndrome de Down e crianças com desenvolvimento normal aos 2 e 5 anos de idade. *Arquivos de Neuro-Psiquiatria*, São Paulo, v. 61, n. 2B, p. 409-415, 2003. <http://dx.doi.org/10.1590/S0004-282X2003000300016>. PMID:12894276.
- MARI, M. A. *Avaliação do desenvolvimento infantil e a influência dos fatores biopsicossociais em crianças com cardiopatia congênita*. 2015. 100 f. Dissertação (Mestrado em Psicologia) – Universidade Federal do Rio Grande do Norte, Natal, 2015.
- MELLO, M. A.; MANCINI, M. C. Métodos e técnicas de avaliação nas áreas de desempenho ocupacional. In: CAVALCANTI, A.; GALVÃO, C. *Terapia Ocupacional: fundamentação e prática*. Rio de Janeiro: Guanabara Koogan, 2007. p. 49-54.
- MONTEIRO, J. A. et al. Avaliação do nível de independência nas atividades de vida diária da criança com paralisia cerebral: um estudo de caso. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 20, n. 1, p. 129-141, 2012. <http://dx.doi.org/10.4322/cto.2012.014>.
- LOURATO, F. A.; VILLACHAN, L. R. R.; MATTOS, S. S. Prevalência e perfil das cardiopatias congênitas e hipertensão pulmonar na Síndrome de Down em serviço de cardiologia pediátrica. *Revista Paulista de Pediatria*, São Paulo, v. 32, n. 2, p. 159-163, 2014. <http://dx.doi.org/10.1590/0103-0582201432218913>.
- OPERMANN, C. Z. *Comparação entre o desempenho funcional de crianças com síndrome de Down e crianças com desenvolvimento típico dos 2 aos 7 anos de idade*. 2014. 127 f. Dissertação (Mestrado em Saúde da Criança e do Adolescente) – Universidade Federal do Rio Grande do Sul, Porto Alegre, 2014.
- ORGANIZAÇÃO MUNDIAL DE SAÚDE – OMS. *Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF)*. São Paulo: EdUSP, 2003.
- PAZIN, A. C.; MARTINS, M. R. I. Desempenho funcional de crianças com Síndrome de Down e a qualidade de vida de seus cuidadores. *Revista Neurociências*, São Paulo, v. 15, n. 4, p. 297-303, 2007.
- PEDREMÔNICO, M. R. M. Problemas de desenvolvimento da criança: prevenção e intervenção. *Temas sobre Desenvolvimento*, São Paulo, v. 12, p. 7-9, 2003. Suplemento Especial.
- REIS FILHO, A. D.; SCHULLER, J. A. P. A capoeira como instrumento pedagógico no aprimoramento da coordenação motora de pessoas com Síndrome de Down. *Pensar a Prática*, Goiânia, v. 13, n. 2, p. 1-21, 2010.
- ROCHA, D. L. B.; ZAGONEL, I. P. S. Modelo de cuidado transicional à mãe da criança com cardiopatia congênita. *Acta Paulista de Enfermagem*, São Paulo, v. 22, n. 3, p. 243-249, 2009. <http://dx.doi.org/10.1590/S0103-21002009000300002>.
- SALVIO, C. C. et al. Congenital epiphora in patients with Down syndrome. *Arquivos Brasileiros de Oftalmologia*, São Paulo, v. 70, n. 3, p. 423-427, 2007. <http://dx.doi.org/10.1590/S0004-27492007000300007>. PMID:17768547.
- SAMPAIO, P. L. G. et al. Perfil motor de crianças com Síndrome de Down entre 08 e 11 anos de idade na APAE de Santarém/PA. *Apae Ciência*, Brasília, v. 1, n. 2, p. 37-54, 2013.
- SANTOS, J. O.; PRUDENTE, C. O. M. Síndrome de Down: desempenho funcional de crianças de dois a quatro anos de idade. *Revista Neurociências*, São Paulo, v. 22, n. 2, p. 271- 277, 2014.
- SILVA, M. N. S.; DOUNIS, A. B. Perfil do desenvolvimento motor de crianças entre 9 e 11 anos com baixo rendimento escolar da rede municipal de Maceió, AL. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 22, n. 1, p. 63-70, 2014. <http://dx.doi.org/10.4322/cto.2014.007>.
- SILVA, V. F. et al. Análise do desempenho de autocuidado em crianças com Síndrome de Down. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 21, n. 1, p. 83-90, 2013.
- SOUZA, A. B. et al. Síndrome de Down: correlação entre o desempenho funcional com a força da preensão palmar e a destreza manual. *Fisioterapia Brasil*, Rio de Janeiro, v. 13, n. 3, p. 211-215, 2012.
- VICARI, S. Motor development and neuropsychological patterns in persons with Down Syndrome. *Behavior Genetics*, Westport, v. 36, n. 3, p. 355-364, 2006. <http://dx.doi.org/10.1007/s10519-006-9057-8>. PMID:16505965.

---

## Author's Contributions

Irmara Gécica Santos Amaral participated in the elaboration of the project, obtaining, analyzing and discussing the data, besides the preparation and review of the version to be published. Victor Augusto Cavaleiro Corrêa participated in the preparation and review of the text. Karla Maria Siqueira Coelho Aita coordinated and guided the research, participating in the analysis, discussion, and interpretation of the data, and the preparation and final review of the text. All authors approved the final version of the text.

## Notes

<sup>1</sup> This article was submitted to the Research Ethics Committee and approved with a favorable opinion, Protocol nº 029858/2017.