

Home stimuli and characteristics at birth of children with Down syndrome

Estímulos domiciliares e características ao nascimento de crianças com síndrome de Down

Estímulos del hogar y características al nacer de los niños con síndrome de Down

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This is a quantitative and descriptive study carried out between 2018 and 2019. It aims to describe the characteristics of birth and home stimuli of children with Down syndrome. The questionnaire used to collect information about the child's home environment was the Affordances in the Home Environment for Motor Development Self-Report (18 to 36 months), through an interview, and an anamnesis questionnaire. Five mothers and their children with Down syndrome participated. The children had an average age of 31 months (\pm 3.78) and all of them underwent surgery. It was found that all children had medium and high opportunities. The interior space and the variety of stimuli were the only items in which all children received a very good score. The fine and gross motor skills of children were classified as weak. The home environment had important stimuli for children's development. The environment is important for growth and development of the child with Down, as well as participation in stimulation by parents and other adults around.

Descriptors: Environment; Down Syndrome; Play and playthings.

Este é um estudo quantitativo e descritivo realizado entre 2018 a 2019, que tem como objetivo descrever as características de nascimento e estímulos domiciliares de crianças com síndrome de Down. O questionário utilizado para coletar informações sobre o ambiente domiciliar da criança foi o *Affordances in the Home Environment for Motor Development Self-Report* (18 aos 36 meses), através de entrevista, e um questionário de anamnese. Participaram cinco mães e suas crianças com síndrome de Down. As crianças tinham média de 31 meses (±3,78) e, todas realizaram cirurgias. Verificou-se que todas as crianças apresentaram médias e altas oportunidades. O espaço interior e a variedade de estímulos foram os únicos itens em que todas as crianças receberam pontuação muito boa. A motricidade fina e grossa das crianças foi classificada como fraca. O ambiente domiciliar possuía estímulos importantes para o desenvolvimento das crianças. O ambiente é importante para o crescimento e desenvolvimento da criança com Down, assim a participação na estimulação pelos pais e outros adultos ao redor.

Descritores: Meio Ambiente; Síndrome de Down; Jogos e brinquedos.

Este es un estudio cuantitativo y descriptivo realizado entre 2018 y 2019, que tiene por objeto describir las características de nacimiento y los estímulos del hogar de los niños con síndrome de Down. El cuestionario utilizado para recoger información sobre el entorno del hogar del niño fue el Affordances in the Home Environment for Motor Development Self-Report (18 a 36 meses), a través de una entrevista, y un cuestionario de anamnesis. Participaron cinco madres y sus hijos con síndrome de Down. Los niños tenían un promedio de 31 meses (±3,78) y todos ellos realizaron cirugías. Se verificó que todos los niños tenían oportunidades medias y altas. El espacio interior y la variedad de estímulos fueron los únicos elementos en los que todos los niños recibieron una puntuación muy buena. La motricidad fina y gruesa de los niños fue clasificada como débil. El entorno del hogar tenía importantes estímulos para el desarrollo de los niños. El entorno es importante para el crecimiento y desarrollo del niño con Down, así como la participación en el estímulo de los padres y otros adultos de alrededor

Descriptores: Ambiente; Síndrome de Down; Juego e Implementos de juego.

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INTRODUCTION

The development of children suffers some social and environmental interferences during its evolution, due to the characteristics of the child's home environment in relation to the quantity and variety of stimuli, and family participation¹. The environment in which the child is inserted can act as a facilitator of their development. And the relationship of the parents with the child is important in helping them to have more freedom of movement, assisting them in standing, talking, playing and interacting with other children and adults².

The family and other adults within the context of the home environment are essential in the child's development, providing the first learning experiences through the act of playing³. The ecological theory, according to Gibson, defines as the environment's affordances that what offers a challenge to the person, that is, something that provides the first interactions with the internal and external environment of the home, such as objects, surfaces and people^{4,5}.

The birth of a child may require parental adaptation, with changes happening on a daily basis, especially after the diagnosis of a syndrome that represents delay in the baby's development⁶. Down syndrome is a genetic alteration and is characterized by slowness in motor development and clinical aspects, such as muscle hypotonia, ligament laxity, joint hypermobility, cognitive deficit and speech delay, which can be a limiting factor in exploration of environments and toys due to the parents' difficulty in providing stimuli according to the child's interest⁷.

The availability of stimuli, such as toys, are the support of many games that engourage the acquisition of fine and coarse motor coordination⁸. Essential toys for child development are, for example, plush toys, cars, animals, puzzles games, construction toys of various sizes, sandbox, coloring pencils, books, song boxes, musical instruments, tricycles, bicycles and swings.

The outcomes of child growth are influenced by biological and social risk factors, such as housing (characteristics of the place), family relationships, parents' education and family income⁹. Families with better financial conditions, a higher level of education, in which the head of the family has a well-paid profession, are more likely to have a greater variety of goods and services that will privilege their children¹⁰. Thus, children who are in a more favorable situation have better stimulation. In this sense, this study aims to describe the characteristics of birth and home stimuli of children with Down syndrome.

METHOD

This is a quantitative and descriptive study that was approved by the UFTM Research Ethics Committee (*Comitê de Ética em Pesquisa - CEP*) (opinion number 2,695,020). Data collection was carried out through an interview from December of 2018 to March of 2019 at the Universidade Federal do Triângulo Mineiro in Uberaba, in the state of Minas Gerais.

The mothers were asked the questionnaire *Affordances in the Home Environment for Motor Development Self-Report* (AHEMD-SR - 18 to 36 months) through interviews, for 20 minutes.

The scores were generated from the program (AHEMD-SR Calculator VPbeta 1.5.xls) according to five subscales, which are: indoor space (space to play and walk freely, more than one type of soil, furniture for the child to climb, descend and jumping, toy room and chests to store toys), outdoor space (a garden or yard and can have more than one type of soil such as: grass, cement, wood; sloping surfaces, toys for the child to hang on, stairs, place for the child to play).

The variety of stimulation (if the child plays with other children, if the parents play with them, the children play with other adults besides the parents, also on freedom of movement that the child's allows, how long they stay in a specific region of the home, in a park, free to walk throughout the residence), fine motor skills (the number of toys a child will have will be observed, ranging from zero to more than 5, of which are: puppets, toys that imitate phones, kitchen supplies, tools, games, stacking and nesting toys, trays with nesting pieces, lego, colored pencils, crayons, paper, paints, clay or molding clay, round tipped scissors; musical toys, such as: rattles, tambourines and pianos) and gross motor skills (balls of different sizes, colors and materials, sticks and bats, targets, baskets, cones, wooden horses, scooters, slides, tunnels, tricycles, bicycles, cars and swings) that receive independent scores according to their quality: very good (4), good (3), poor (2), very poor (1) and bad (0). In the end, the total AHEMD-SR classifies the opportunities to stimulate the home environment as "low" (environment offers little opportunity), "average" (reasonable environment) or "high" (excellent environment)¹¹.

RESULTS

Five children participated, four of whom were girls, with an average gestational age of 35 weeks (\pm 2.28), an average age of 31 months (\pm 3.78), an average birth weight of 2.278 kg (\pm 416), mean length at birth of 42.3 cm (\pm 5.21) and mean Apgar score in the fifth minute of 9 (\pm 1.14).

All children underwent some type of surgery, three of whom underwent cardiac surgery and two had surgery of the gastrointestinal tract (Table 1).

Children	Gestational age	Apgar	Weight	Lenght	Surgery	Lenght of Hospitalization	Chronological Age
А	38 weeks	10	2.600kg	48 cm	Cholecystectomy	2 days	36 months
В	33 weeks	9	1.800kg	42 cm	Heart	180 days	32 months
С	35 weeks	7	2.200kg	42,5 cm	Gastroesophageal	14 days	33 months
D	33 weeks	8	1.990kg	45 cm	Heart	210 days	29 months
E	37 weeks	9	2.800kg	34 cm	Heart	21 days	26 months

Table 1. Characterization of children with Down syndrome. Uberaba-MG, 2019.

Key: kg - kilograms, cm - centimeters.

Family characteristics are shown in Table 2 according to the AHEMD-SR questionnaire. The most common type of residence were houses, parental education level prevailed in high school, the monthly income in most families was over R\$ 2,500.00.

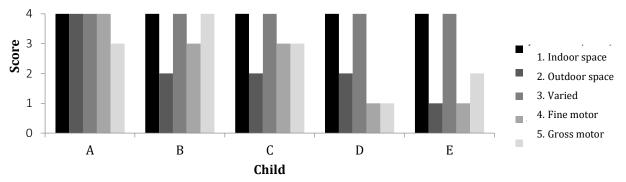
Table 2. Family characteristics of children with Down syndrome, according to AHEMD-SR. Uberaba - MG, 2019.

Family characteristics	Child A	Child B	Child C	Child D	Child E
Type of housing	Apartment	House	House	House	House
Quantity of adults	2	2	1	2	2
Quantity of children	2	1	2	2	1
Educational level - Father	University	University	High school	High school	High school
Educational level - Mother	University	High school	High school	High school	High school
Monthly income (reais)	R\$5.000 or more	R\$5.000 or more	R\$2.500 to R\$3.500	R\$2.500 to R\$3.500	R\$1.000 to R\$1.500

Figure 1 shows the scores obtained by the children in each of the AHEMD-SR subscales. The interior space and the variety of stimuli were the only items in which all children received a score of 4 (very good). In the outer space, only one child had a score of 4. In gross motor skills, four children had a low score.

Children D and E had the lowest scores in the characterization of their home environment (poor and/or very poor) in the items external environment, fine and gross motor skills. However, in the total score of the AHEMD-SR they were classified with reasonable opportunities. This shows the importance of analyzing each item, so that the cause of the difficulties can be identified and readjusted according to the financial conditions of the families.

Figure 1. Characterization of the child's profile in the home environment according to AHEMD-SR. Uberaba-MG, 2019.



Keys: The letters A, B, C, D and E represent the five children of the study.

Table 3 shows that all children had a high amount of fine motor toys, being greater than the number of gross motor toys.

AHEMD-SR	Child A	Child B	Child C	Child D	Child E
		FIN	NE MOTOR SKI	LLS	
Playing dolls	≥5	≥5	≥5	≥5	≥5
Puzzles	≥5	≥5	≥5	3 or 4	≥5
Games	≥5	≥5	≥5	1 or 2	3 or 4
Building materials	≥5	1 or 2	3 or 4	1 or 2	1 or 2
Educational toys	≥5	≥5	≥5	1 or 2	≥5
Others	3 or 4	≥5	≥5	1 or 2	1 or 2
		GRO	DSS MOTOR SK	ILLS	
Musical materials	≥5	≥5	≥5	3 or 4	≥5
Manipulative materials	3 or 4	≥5	3 or 4	1 or 2	1 or 2
Locomotive materials	≥5	≥5	≥5	1 or 2	3 or 4
Global exploration materials	1 or 2	1 or 2	3 or 4	1 or 2	1 or 2

Table 3. Quantity of fine and gross motricity materials (AHEMD-SR). Uberaba - MG, 2019.

Table 4 shows the total AHEMD score for each child, showing that the score varied from average to high and the environment was classified as reasonable to excellent.

Children	ChildrenTallyScoreA19High		Classification of stimulus opportunities
А			Excellent environment
В	17	High	Excellent environment
С	16	Average	Reasonable environment
D	12	Average	Reasonable environment
Е	12	Average	Reasonable environment

Table 4. Classification of each child in the total score of the AHEMD-SR. Uberaba- MG, 2019.

DISCUSSION

It is understood that factors such as type of housing in which the child lives can influence stimuli offered to them, from existing spaces such as: internal and external environment, the presence of siblings or not, adults and children living in the child's environment, parents' educational level, socioeconomic level, among other factors that intervene in opportunities in order to give challenges to the developing individual¹².

Child A was born with adequate weight for gestational age (AGA) and term. On the outside space, that being a terrace, the child has contact with inclined surfaces to descend, climb or jump and stairs, and has the opportunity to play in the playground of their condominium. The internal space proved to be enough to play, has furniture to hang safely and a room for toys and games. On daily activities, child A does not play every day with other children, however, they regularly play with other adults besides the parents. Parents allow the child to choose their own games, teaching them to recognize different parts of the body. The mother reports that the

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residence is very small. In relation to gross motor toys, the child had a small amount of global exploration materials, the child had a total AHEMD-SR score of 19 points. The variety of stimulation (play with other children, choice of toys, encouragement to play by parents, comfortable clothes to play with and time spent in certain environments) can be a significant predictor of growth¹³.

Child B was born preterm with adequate weight for gestational age. Regarding the outdoor space, it has ramps of varying inclinations and a place for children to play, such as a playground. The interior space is sufficient for playing and walking, there is no more than one type of floor being tiled in all environments, and there is also no toy room, but the toys are kept inside chests or drawers. About daily activities, child B almost always plays with other children and other adults in addition to the parents, parents play with the child, teaching and stimulating the child with a commanding voice for the child to run, walk, crawl and stop, the child does not always choose the toys they want to play with. About strolling in the playground, the child goes almost always and the house is considered to be of reasonable size. The child had a small amount of fine motor toys, which are building materials and gross motor skill toys of global exploration. The total AHEMD-SR was 17 points. A study that took place in the state of Rio Grande do Sul (SINPRO), in the city of Santa Maria, carried out with parents of typical children between 18 and 42 months, shows how the home environments are poor in relation to materials offered to children, and how much this directly affects motor skills in childhood³.

Child C was born preterm with adequate weight for gestational age. The child underwent gastroesophageal surgery and was hospitalized for 14 days. On the outer space of the house, there is more than one type of soil (grass and cement), it does not have inclined surfaces, with a toy to hang on and no stairs. In the interior space, the house does not have enough space, it has a carpet on the floor for the child to fall safely, and there is also furniture to climb, descend and jump. It does not have a toy room, but chests to store them. For daily activities, the child plays with other adults and other children, and can choose toys to play with; the parents encourage and stimulate the child to play. The child spends a long time in the playground, and almost always is free to walk around the house, which is considered small. The child had an average amount of toy in both fine and gross motor skills, the total AHEMD-SR was 16 points, which is classified as average. One study describes that a residence classified as average provides reasonable opportunities for the child's motor development¹⁴.

When child D was born prematurely, their weight was adequate for gestational age (AGA) and the child underwent cardiac surgery. The length of hospital stay was 210 days. In relation to outdoor space, there is no staircase, no different floors and no toys in an area simulating a playground, and the space does not have ramps. In the house interior, there is enough space to play and walk, furniture to hang and a toy room and toy chests. In daily activities, child D plays with other children and adults, in addition to the parents. Parents play with the child, allow them to choose their toys and teach about parts of the human body. In a playground, the child stays for a short time and is free to walk around the house, which is considered large, for a long time.

Child C had a small amount of toys in the fine motor skills subscale in the items games, construction materials, educational toys and others. In the gross motor subscale, there was little amount of manipulative materials, locomotive materials, global exploration materials, AHEMD-SR total of 12 points. A study conducted in Juazeiro do Norte, a municipality located in the southern region of the state of Ceará, shows that when using the same AHEMD-SR questionnaire (18 and 36 months) with guardians of children aged (as in this report), it showed that the situation of scarcity of opportunity for environmental stimuli may compromise children's motor development, since the availability of stimulating materials and objects are important in development¹⁵.

Child E was born preterm, with adequate weight for gestational age and underwent cardiac surgery with a hospital stay of 21 days. The house does not have an external environment. In

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the indoor environment it is sufficient for the child to play and walk. Inside the house, there are no different types of soil, furniture to hang safely and no stairs. It has a room only with toys, chests and drawers. Regarding daily activities, the child does not play every day with other children and plays regularly with adults other than the parents. The child chooses toys to play with, and parents play and stimulate the child.

The child E almost never goes to the park, and is free to walk at home. The child had a small amount of toys with fine motor skills, in the items of construction materials and others, and gross motor skills, in the items of manipulative materials, global exploration materials, AHEMD-SR total was 12 points. The external space was the variable that showed the greatest inadequacy. The same was observed in the study which evaluated the home environment of typical children aged 32 to 48 months in a municipal school in Campina Grande do Sul, in the state of Paraná, verifying that the outdoor space of most of the households analyzed did not offer sufficient opportunities for children's development¹³.

In a survey with infants with Down syndrome, aged between 3 and 18 months, living in the Triângulo Mineiro region, in the state of Minas Gerais, it showed that the syndrome's limitations interfere with motor performance and that there are precarious home opportunities for these infants. Even with the limitations, children with Down syndrome with more affordances provided by their parents can present an easier socialization with the environment and a better interaction with toys, as long as they are stimulated and have these opportunities².

CONCLUSION

The home environment and characteristics at the birth of children are fundamental for development, children were born with some limitations, such as prematurity, and then they underwent surgery, so stimulation is very important.

The environment will provide good growth, as will parents and other adults who have an important role in their lives. With that, it is important that new studies are done, to always help in the lives of children and parents who need help so much, aiming to improve their development, since they have Down syndrome, and have certain limiting characteristics.

The study is limited by the small number of children surveyed, but it shows the reality of children with Down that may be identical to other locations.

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CONTRIBUTIONS

Monise Fernandes de Carvalho contributed to collection and interpretation of data and writing. **Janaine Brandão Lage** collaborated on data interpretation and writing. **Karina Pereira** worked on data interpretation and revision.

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