Saúde e Pesquisa, Maringá (PR)
DOI: 10.17765/2176-9206.2020v13n4p809-819

DOWN SYNDROME: FUNCTIONALITY AND THERAPEUTIC HISTORY OF THE CHILD, ADAPTATION AND OCCUPATIONAL PERFORMANCE OF PARENTS

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ABSTRACT: The aim of this study is to analyze the functionality of children with DS in the areas of mobility, self-care and social function in relation to the child's therapeutic history, parental adaptation, child's disability, socioeconomic aspects and parents' occupational performance. The Pediatric Disability Assessment Inventory, Canadian Occupational Performance Measure, the Parental Adaptation Scale for child's disability and an interview constructed by the researchers were used. Thirty parents of children with DS from 10 months to seven years old participated. Children have mobility performance within the normal range and a significant delay in the area of self-care. The most therapies are structural in nature, focused on family and child. The parents' occupational performance presents problems, mainly in the area of productivity. These have difficulty in dealing with the diagnosis. The socioeconomic level, schooling and leisure activities of the parents influence child's development.

KEY WORDS: Child; Down's syndrome; Functionality; Parents.

SÍNDROME DE *DOWN*: FUNCIONALIDADE E HISTÓRICO TERAPÊUTICO DA CRIANÇA, ADAPTAÇÃO E DESEMPENHO OCUPACIONAL DOS PAIS

RESUMO: O objetivo deste estudo é analisar a funcionalidade de crianças com Síndrome de *Down* (SD) nas áreas de mobilidade, autocuidado e função social em relação ao histórico terapêutico da criança, à adaptação parental, à deficiência do filho, aos aspectos socioeconômicos e ao desempenho ocupacional dos pais. Foram utilizados o Inventário de Avaliação Pediátrica de Incapacidade, a Medida Canadense de Desempenho Ocupacional, a Escala de adaptação parental à deficiência do filho e uma entrevista construída pelas pesquisadoras. Participaram 30 genitores de crianças com SD de 10 meses a sete anos de idade. As crianças apresentam desempenho em mobilidade dentro dos padrões de normalidade e atraso significativo na área de autocuidado. Grande parte das terapias é de cunho estrutural, focada na família e na criança. O desempenho ocupacional dos pais apresenta problemas, principalmente na área de produtividade. Estes possuem dificuldade em lidar com o diagnóstico. O nível socioeconômico, de escolaridade e o exercício do lazer dos pais influenciam o desenvolvimento da criança.

PALAVRAS-CHAVE: Criança; Funcionalidade; Pais; Síndrome de *Down*.

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Received in: 12/09/2019
Accepted on: 07/07/2020

INTRODUCTION

Down's syndrome (DS) also known as trisomy 21 manifests itself in three cytogenetic ways: simple or free trisomy, Mosaicism and Robertsonian translocation[1]. Worldwide, DS affects one child for every 800 births. In Brazil, eight thousand children with DS are born each year. The most frequently diagnosed genetic alteration in the pediatric area [2].

Subjects with DS manifest intellectual disability and unique characteristics regarding physical and motor issues. Others factors associated with DS may also affect these subjects, such as delayed neuropsychomotor and language development, heart disease, respiratory problems, tendency to obesity, short stature, neurological and stomatognathic changes[4].

The arrival of a disabled child can be a stressor for the family, since, in addition to the natural changes generated by the arrival of a new family member, it may also require acquisition of a series of more specific skills and competences due to characteristics of the family disability[4].

The one of areas that may be affected by the child's arrival in the family is parents' occupational performance. This is conceptualized as execution of an occupation that is the result of the association between the individual, the activity, the environment and the context[5], which demands subject's skills in playing roles and activities with regard to their self-care, productivity and leisure[6].

The family of the child with DS needs to make changes regarding the reorganization of roles, structuring and family dynamics. In view of this, it seeks to reestablish the balance, facing an extensive process of the adapting to child's disability and difficulties. The moment of developing, is the more appropriate environment to incorporate the child as a member of the family[7].

The most important is that after the discovery of disability, the child starts therapies early and the family receives support to promote the acceptance of this subject within family[8]. The professional who cares for children needs to have a global view as a psychological, biological, cognitive and social being. And the family should be called upon to take this same look at their child, so that they can see qualities beyond pathology[9].

Regarding treatments, there are two main lines of intervention, these being the early stimulation named in this study as instrumental therapy centered on the child and the early intervention called structural therapy centered on the family and the child. Child-centered instrumental therapy offers child's maturation stimuli, aiming to stimulate and facilitate postures for good motor and cognitive development[10]. The structural therapy centered on family and the child is a set of integrated support actions focused on the child and the family, encompassing prevention and rehabilitation actions in the social, health and education areas[11]. However, the efficacy of different types of therapies is not known, with regard to aspects of child development and family setting.

The due to importance of the theme and family relationships with child 's development. The objective of this research was to analyze the functionality of children with DS in the areas of mobility, self-care and social function in relation to the child's therapeutic history, to the parental adaptation to child's disability, socioeconomic aspects and parents' occupational performance.

METHODOLOGY

This research is configured as a cross-sectional, descriptive study with a quantitative approach. It was held between the months of December 2018 and April 2019, in institutions that serve children with intellectual disabilities. The participants were parents of children diagnosed with DS in three municipalities in the interior of the state of the Rio Grande do Sul.

Inclusion criteria were parents of children from six months to seven years of age with a medical diagnosis of DS, who are undergoing therapeutic follow-up or who have received any health intervention before the age of three. Exclusion criteria were parents of children with associated pathologies, such as the clinical picture of Autistic Spectrum Disorder and non-progressive motor encephalopathy, children who have not received therapeutic follow-up.

The researcher went to the municipalities to carry out the data collection, being performed in a room available at the collection sites. The participants were contacted, via telephone or in person at the institution, in order to explain the study. In case the responsible person accepted to participate in the research, the objectives and procedures of the research were explained, the possible risks and discomforts, and the informed consent form was signed and the collection time was scheduled. The researcher signed confidentiality agreement.

At the scheduled time, the person responsible for the child responded to an interview with socioeconomic data, information on therapies and the three instruments used in the assessment: the Canadian Occupational Performance Measure (COPM), the Parental Disability Adaptation Scale (EPAD) and the Pediatric Evaluation of Disability Inventory (PEDI), the latter on the child's development in the areas of self-care, mobility and social function.

The interview with the relative covered open and closed questions with the data of the child and his family, about the socioeconomic, obstetric aspects, birth information and the details of treatments that the child was submitted to. Since, in the treatment history, questions were asked about the professional area, treatment time and the child's age at the beginning of the intervention. From the interview, each treatment area was classified according to its focus, which could be centered on the most instrumental child or be focused on the child and his family in a joint way, considering structural aspects.

The therapy was classified as instrumental for the development of the child's skills when there was no continuous conversation with the family, when the parents did not participate within the session and when there were rarely games between parents and child in care. It was classified as structural centered on the child with the participation of the family, when the professionals held continuous conversations with the family, when the parents participated in the session and when there was the presence of games between parents and child in care. We also investigated which professions participated or participated at the time of collection in the therapeutic process, among them Speech Therapy, Occupational Therapy, Physiotherapy, Psychology, among others.

Considering the different professions in each case and the fact that they could adopt a more structural or instrumental view centered on the child, with or without insertion of the family, the structural classification centered on the child with insertion of the family was considered if at least one of the professionals attending the case took such an approach. If, on the contrary, none of the professionals who attended the child included the family in therapy, and performed the work with the child in a more instrumental way, especially behavioral, the therapeutic type assignment was identified as instrumental.

PEDI is a standardized North American instrument that quantitatively assesses the child's functional capacity and independence to perform self-care, mobility and social function activities. Applied through an interview with the family member or guardian of the child. It covers the age of six months to seven years and six months. The instrument is divided into three parts, the first part evaluates the child's functional skills, regarding self-care (73 items), mobility (59 items) and social function (65 items). Each item is scored with a score of 0 (zero) if the child is not able to perform the functional activity, or 1 (one) if the child is able to perform[12].

The second part identifies the amount of help that is needed for the child to perform the activity and is scored on an ordinal scale that varies from 5 (if the child is independent to perform the task, requiring no assistance from the caregiver to perform it) it) to 0 (if the child is totally dependent on the caregiver to perform the task). The intermediate scores describe different amounts of assistance provided by the caregiver (supervision: minimum, moderate or maximum). The third part identifies changes in the environment for the performance of functional tasks12, and this part was not used in this study. Then, in this research, the three scales of the functional activities of part I and part II of caregiver assistance were evaluated.

From the gross scores (EB) and the chronological age of the children, the normative scores (EN) were obtained, which inform about the expected performance of children of the same age range. In each age group, the normal range comprises an EN between 30 and 70, so that EN, less than 30, represents significantly less delay or development and EN, greater than 70, identifies a performance significantly superior to children of the same age group[13].

COPM was applied considering the difficulties in the family member's daily life after the child's arrival in the family. This instrument is an individual measure of the individual's self-perception about the problems found in his own occupational performance. This evaluation allows the subject to identify occupations that he wants to have, needs or expects to perform in daily life, considering whether he is able to perform those occupations or if he is satisfied with the way he performs them. Therefore, the first questions refer to the needs perceived by the subject and the others are related to performance and satisfaction when performing them. Then, after the subject identifies his problems in the area of self-care, productivity and leisure, he is asked to score the activity from 1 to 10, regarding importance, performance and satisfaction. The scores in each category are added, and the result is divided by the number of problems in each category, generating a final score for performance and satisfaction, with a score closer to 0 meaning inability to perform the activity and / or dissatisfaction in carrying it out, already the score closer to 10, means greater capacity and satisfaction in carrying out the activity[14]. To collect the data for this research, all the steps of the COPM were used, except for step 2, which refers to the importance note of the problems.

EPAD is an instrument for individual assessment and identifies at what point in the process of development and adaptation to disability the father and mother[15]. This scale consists of 60 items with a choice for marking the results on a five-point Likert scale. These items are grouped into 10 dimensions, each consisting of six items.

The aesthetic dimension deals with the way in which parents show pride in their child, are happy to present it and that other people feel affection for the child. The capacities dimension refers to the way in which parents identify qualities and abilities in their child, seeing them in a positive way. The future dimension encompasses how parents have positive expectations for the future and are able to relate it to what is happening today.

The resilience dimension refers to the parents' internal resources to adapt to reality. The dimension of social support refers to the support received by parents, who help them to respond to daily demands. The idealization dimension deals with the parents' connection with the child's initial idealization, maintaining the initial expectations. The diagnostic dimension refers to how the parents are immersed in the news of the diagnosis and the suffering generated by the fact.

The depression dimension refers to the negative feelings that affect the parents' thoughts and behavior. The guilt dimension refers to the way in which parents blame the disability on themselves, others or social entities. The functionality dimension refers to the way in which parents are immersed by the practical dimensions and the effort they have to spend to do them.

There are positive issues in the dimensions and there are negative issues. Therefore, when evaluating each dimension, a mirror value is assigned between positive and negative questions on the Likert scale used in the answers. Thus, a positive item, which indicates re-realization, will have a value of 5 for the answer I totally agree and a negative item that indicates difficulties in re-realization will have a value of 1. In general, the better the re-realization process, the higher the overall EPAD score. This is especially positive in items related to the development of parents towards adaptation such as re-realization occurring in the aesthetic, capacity and future dimensions, and as support for such development through internal resources such as resilience and external resources such as social support.

The statistical analysis consisted of descriptive and inferential analysis, with the non-parametric U-tests of Mann-Whitney and Spearman's correlation being performed with the aid of the computational application STATISTICA 9.1., Using a significance level of 5%.

This research followed the ethical precepts contemplated in Resolution nº 466/2012, of the National Health Council[16], in which it is inserted in a larger project under the title Child Development and its relationship with parental adaptation to the child's disability: analysis of the association with sociodemographic aspects and clinical and educational opportunities, approved under CAAE number 02235218.9.0000.5346, and opinion number 3.054.755.

RESULTS

Thirty parents (28 mothers and three fathers) of children with DS aged between 10 months and seven years (average = 3.6 years; standard deviation = 2.0 years) participated in this study. Of the total children, 50% are female, with white skin color 80%, black 13.3% and brown 6.6%.

Regarding the age of the parents, the mothers' average age was 38.3 years (minimum = 18.0 years;

maximum = 48.0 years), the parents had an average of 43.5 years (minimum = 24.0 years) years; maximum = 64.0 years).

Table 1. Shows the sociodemographic results of fathers and mothers (n = 60)

	Parents	
Marital status	**Mother**	**Father**
Married	80,0	80,0
Single	13,3	10,0
Divorced	6,6	6,6
Education		
Incomplete elementary school	13,3	13,3
Complete elementary school	13,3	6,6
Incomplete high school	3,3	20,0
Complete high school	13,3	6,6
Incomplete higher education	6,6	0
Complete higher education	26,6	0
Occupational situation		
Household	33,3	0
With activity	46,6	100,0
No activity	20,1	0

Regarding income, 13.3% of families receive up to 1000 reais a month, 36.6% up to 2000 reais, 13.3% up to 3000 reais, 6.6% up to 4000 reais, 13.3% up to 5000 reais , 3.3% up to 6000 reais, 10% up to 7000 reais and 3.3% more than 7000. Regarding the situation of the family residence, 80% have their own house, 13.3% rented and 6.6% borrowed.

Regarding the children's daily lives, the vast majority (90%) spent most of the day under the care of the mother. In 83.3% of families, the father participates in the daily care of the child, 10% does not participate and 6.6% participates sporadically. Of the total number of fathers and mothers, only 20% received any psychological and / or psychiatric monitoring for themselves, after the child's arrival in the family.

Data on the child's therapeutic history are shown in Table 2.

Table 2. Description of care received by children, age at onset and treatment time in months (n = 30)

		Average (months)		**Standard Deviation**
Profession	% access	Age at the beginning of the intervention	Intervention time	Intervention time
Speech therapy	93,3	17,1	24,8	20,55
Physiotherapy	90,0	8,4	29,9	27,7
Occupational Therapy	63,3	26,3	11,3	7,4

Regarding parallel therapies, 50.0% of the children had access to the three consultations, 33.3% had follow-up with speech therapists and physiotherapists, 6.7% had access to speech therapists and occupational therapists, 6.7% had access only intervention with physical therapists and 3.3% only with speech therapists. No child had psychological counseling.

Regarding the general classification of therapies, based on the reports of the parents, it was observed that 76.7% (n = 23) of the therapies were centered on the family with a structural focus and 23.3% (n = 7) centered on the child with an instrumental focus. Regarding the classification of therapies by group of professions, the predominant area classified as structural centered on the family was the speech therapy intervention with 95.7% (n = 22), followed by physiotherapy with 87.0% (n = 20) and occupational therapy with 73.9% (n = 17). On the other hand, when the classification is child-centered, 100.0% (n = 7) underwent intervention with physical therapists, 85.7% (n = 6) with speech therapists and 28.6% (n = 2) with occupational therapists.

Table 3 presents the descriptive measures of the PEDI normative scores, which assess the areas of self-care, mobility and social function of children. Scores between 30 to 70 represent a normal range for each age, below 30 mean a significant delay in development.

Table 3. Descriptive measures of the normative scores of the Pediatric Evaluation of Disability Inventory (n = 30)

Normative scores	Average (minimum-maximum)	Standard deviation	CV %	ChildDelay (%)	CA (%)
Self-care	22,4 (10,0 - 58,4)	13,8	61,6	73,3	
Mobility	31,1 (10,0 – 56,3)	16,8	54,0	50,0	
Social Function	26,8 (10,0 – 63,1)	18,6	69,4	63,3	
CA for self-care	27,6 (10,0 – 68,1)	16,5	59,8		56,7
CA for mobility	29,3 (10,0 – 67,7)	20,6	70,3		56,7
CA for social function	26,5 (10,0 – 90,0)	20,5	77,4		73,3

CA = Caregiver assistance; CV% = Coefficient of percentage variation

Regarding the parents' occupational performance, it was found that 9 parents reported difficulty in self-care, several problems were mentioned, such as eating, sleeping, personal care, physical activity and shopping. In the area of productivity, 16 parents reported having problems, with 33.3% reporting it as a difficulty not to be working at the moment. As for the leisure area, 9 parents said they were having difficulties, of which 23.3% mentioned not walking as a daily problem.

Regarding the total score given by the parents to quantify their performance in the problems pointed out, an average of 5.52 (minimum = 2.0; maximum = 8.0) with a standard deviation of 2.04 was obtained. As for the satisfaction score, the average was 4.95 (minimum = 0.0; maximum = 9.0) with a standard deviation of 2.96.

Table 4 shows the scores of the dimensions of the EPAD, answered by the parents in relation to the parental adaptation to the child's disability. The higher the score, the better the adaptation in this item. It is important to note that the parents of this study had greater difficulty in dealing with the diagnosis and easier to see the child's abilities.

Table 4. Descriptive measures of the sum of the scores of the dimensions of the Parental Scale for Acceptance of Disability answered by the parents (n = 30)

Dimensions of EPAD	Average (minimum- maximum)	Standard deviation	CV %
Aesthetics	25,6 (21,0 – 29,0)	2,1	8,4
Capacities	27,6 (23,0 – 30,0)	2,2	8,0
Future	25,5 (21,0- 30,0)	2,8	11,0
Depression	24,2 (14,0 – 30,0)	4,7	19,4
Diagnostic	19,3 (12,0 – 24,0)	3,1	16,1
Resilience	25,8 (18,0 – 30,0)	2,9	11,2
Idealization	25,0 (16,0 – 30,0)	3,5	14,0
Functional	21,2 (14,0 – 26,0)	3,0	14,2
Blame	23,8 (19,0 – 30,0)	2,7	11,3
Social Support	24,9 (12,0 – 30,0)	4,1	16,5
Total	243,0 (205,0 – 278,0)	20,4	8,4

CV% = coefficient of percentage variation

Table 5 shows the significant correlations ($p \leq 0.05$) between the dimensions of the EPAD and the PEDI scores. Parents identify more capacities in the child, as the child expresses greater independence in self-care and social function. Another important result was the significant correlation between social support and the child's level of independence in self-care, that is, the greater the social support that the family receives, the greater independence the child manifests in the area of self-care.

Table 5. Significant correlations between dimensions of the Parental Disability Acceptance Scale and normative scores from the Pediatric Evaluation of Disability Inventory (n = 30)

Variables	Correlation coefficient (r)	p
Capacities x NE of self-care	0,61	< 0,01
Capacities x NE of social function	0,45	0,012
Capacities x CA of self-care	0,44	0,014
Capacities x CA of social function	0,58	< 0,01
Social support x NE of self-care	0,45	0,013

NE = Normative score; CA = Caregiver assistance.

Considering the comparisons between PEDI and EPAD as a function of COPM, it was observed that there was no significant difference ($p > 0.05$) in the PEDI and EPAD scores in relation to the areas of self-care (no problem; with problem) and productivity (none problem; with problem) of COPM.

However, it was found that parents who do not identify problems in the leisure area, have children significantly ($p = 0.01$) with greater independence in social function. In addition, these parents without leisure problems are able to identify significantly ($p = 0.04$) greater capacities in their children, in relation to those who reported a problem in this area.

When comparing the scores of the dimensions of the EPAD according to the classification of therapy, there was no significant difference. When the association between COPM and the therapies that the child was submitted to was evaluated, there was also no significant association ($p > 0.05$) between the type of therapy (structural centered on the child with insertion of the family or instrumental centered on the child) and problems in parents' occupational performance.

It was found that when the therapy is of a child-centered instrumental type, the scores for self-care assistance are significantly higher ($p = 0.005$) than when the therapy is structurally family-centered. When comparing the children's PEDI normative scores according to the type of therapy (structural centered on the child with family insertion or instrumental centered on the child), there was no significant difference for functional mobility skills ($p = 0.227$), self-care ($p = 0.147$) and social function ($p = 0.100$), as well as caregiver assistance in mobility (0.432) and social function ($p = 0.175$). For the caregiver's assistance in self-care, the PEDI normative scores were significantly lower for the child whose therapy was structurally centered on the child with family insertion ($p = 0.006$).

When correlating family income and PEDI, it was found that there is a significant correlation between income and assistance for social function ($r = 0.57$; $p = 0.001$), that is, the higher the family income, the more independent it is the child to exercise social function. With the other PEDI areas, there was no significant correlation with income.

When comparing family income according to the areas of the COPM, it was found that there were parents who did not report a problem in leisure has significantly higher income in relation to those who reported problems in leisure ($p = 0.032$). Comparisons of family income with other areas of COPM for self-care ($p = 0.529$) and productivity ($p = 0.207$) did not show significant differences.

When correlating parents' education with PEDI, it was found that there is a significant correlation between mother's education ($r = 0.55$; $p = 0.002$) and father's ($r = 0.45$; $p = 0.015$) with assistance for social function. That is, the higher the parental education level, the greater child's independence for social function. With the other parts of the PEDI, there was no significant correlation with education.

When comparing the education of the mother and father with the COPM problems, there was no statistically significant difference in the areas of self-care (mother: $p = 0.906$ / father $p = 0.820$), productivity (mother: $p = 0.983$ / father $p = 0.572$) and leisure (mother: $p = 0.063$ / father: $p = 0.150$).

DISCUSSION

The results of this research on the functionality of the mobility child may be related to the early instrumental work, centered on the child, performed by physiotherapists, since 90% of the sample presented the intervention, with early onset and longer duration of this therapy.

Marinho[17], in his bibliographic review on the performance of physiotherapy in DS, concluded that physical therapy intervention for this audience is primarily a motor one and this professional must understand about the performance of other professions and alternative treatments for children with DS in order to meet the needs subject's needs.

Speech therapy presented itself as the predominant profession in relation to access (93.3%), that is, families identify the child's insertion in this therapy as a priority. Perhaps this fact occurs due to the biological and functional characteristics of children with DS, which can impact on eating, hearing and language functions, all of which are the object of the speech therapist's performance.

It is important to consider that most of the speech therapy interventions in this research were, predominantly, structural with insertion of the family, demonstrating that the professionals focused on playing and dialogue for child development, as well as considering the importance of the family environment for such development.

Regarding occupational therapeutic intervention, a lower percentage of access for children with DS was observed, in addition to having a later onset. This result may explain the difficulty of children in self-care, whereas this profession acts directly on autonomy and independence, in addition to neuropsychomotor development. It is important to mention that independence in mobility does not guarantee that the child has independence in self-care, that is, physical therapy with a focus on motor issues, although it has shown gains in neuromotor aspects, does not ensure independence of children in their daily lives.

A result similar to that of the present study, in relation to self-care and social function, found Gomes et al.[18], who conducted a survey in Goiânia in which evaluated the functional performance of 28 children aged five and six years, 14 with DS and 14 with typical motor development. They used PEDI to assess children. Children with DS had a lower functional performance than children with typical development of the same age, mainly in social function (functional skills) and self-care (caregiver assistance).

It is important to mention that most therapies from different professions are centered on the child with the insertion of the family (76.7%), that is, they use games as the main form of intervention, include parents in session and ongoing conversations are held with caregivers. This strategy is emphasized by Nunes and Garcia[19:13] when they emphasize that "playing within the therapeutic setting cannot be considered as something devoid of meaning, since, when playing, it makes a journey in search of its constitution as a human being". These authors carried out a study using fragments of care at a school clinic in the interior of Rio Grande do Sul, evaluating the importance of playing in conducting treatment. As a result, playing is an important ally and an essential therapeutic resource for the child's psychic constitution, making the child able to go through the transition that involves the real world and the imaginary world, and the therapist will provide the support so that the child is able to overcome his anxieties. Thus, playing will help the child to assign meaning to what is being expressed, in addition to serving as a means of communicating matters that need to be said and heard. Therefore, the authors conclude that the therapeutic setting should continue to be the construction of a space where playing, in all its diversity, is par excellence the resource for listening to the child.

Continued conversations with parents inside and outside the session with the child are also crucial for families, with regard to the exercise of their parenting functions, the reorganization in the face of the difficulties of caring for the child, allowing the therapist to identify the difficulties and can include as demands for your intervention. According to Siquier and Salzberg[20], when the therapist listens to the family's apprehensions about the child, it is possible to discover the place occupied by the child in the life of these parents. Listening allows us to know the needs they bring and that can be covered in words and go beyond them. In addition, listening can enable parents' insights, that is, when verbalizing, they listen to themselves and manage to deal with their questions.

In this research, one of the difficulties of the parents was in aspects related to the diagnosis of their child. A result similar to that of Silva and Ramos[21] who carried out a study on the reactions and feelings that were and are present in the lives of four mothers and three fathers of children with disabilities and aged between two and seven years. As a result, the parents 'emotional fragility in relation to the theme and the health professionals' lack of preparation to explain the diagnosis, failing to provide the necessary support and explanations for the family, which aggravated the negative feelings regarding the disability of the child, causing difficulty in the process of understanding by the parents. Feelings, such as shock, denial, guilt and sadness, stood out as the most frequent reactions to the diagnosis.

It is important to mention that the child is already part of the family before birth, through the miparents' thinking and imagination, being constituted through aesthetic, competence and future components[22], being the basis for relations with the newborn.

In the present study, it was found that the mothers of this research, for the most part, do not have a professional occupation and are the main caregiver of children with DS. In addition, there was a relationship of social support received by families, with greater independence of the child in self-care, demonstrating the importance of this support for the families of children with DS.

Costa[23] points out that the mother is often responsible for the care of the child and this demands a social support network so that she can support the daily burden of the responsibility of taking care of the child. This support network can take place through a system of diverse functions offering emotional, financial and division of responsibilities in care.

Stort et al.[24] found similar results on social support, in which they investigated 14 relatives of children with DS to know and analyze the parenting of parents of children who are cared for in a specialized institution in a city in the interior of São Paulo. They found that there is significant influence and importance of the parents' support network, providing the necessary support so that they feel capable of taking care of their children.

Another important aspect for re-realization, family organization and adaptation to the new situation is psychological assistance. However, the present study also revealed that the vast majority of parents have not received psychological counseling since the child's arrival.

Jesus[25] carried out a longitudinal study with two primiparous families of babies with DS, in which the participants were filmed at the child's three and eight months of age, at the family residence. The verbal and non-verbal interactions of the mother-baby and father-baby relationship were analyzed. They obtained as a result that the parents understood crying as the child's physiological needs and not as interactions for more affective contact, showing a significant fear of holding the child, maintaining the same relationship in the third and eighth month. It was clear that parents find it difficult to assume a subject in the child, manipulating the child according to their own wishes. Thus, it is necessary for parents to be assisted in the exercise of their parenting functions and to be able to sustain a common language between parents and child. The results of Jesus[25] exemplify the importance of the role of psychology in cases of the discovery of disability.

In this research, it can be seen that the children's parents have low socioeconomic and educational levels, and that this result is related to the child's performance in the exercise of their social functions. Nascimento, Carvalho and Blascovi-assis[26] conducted a study with 20 family caregivers of children with DS aged between two and five years old from Teresina / PI, using PEDI as an assessment. They concluded that children with financially deprived caregivers are imminently more vulnerable to stressful events and the scarcity of stimuli. The researchers emphasized that the socioeconomic level can influence the functional performance of children with DS and the quality of their caregivers, being a risk condition for development.

The main problems in occupational performance reported by the parents participating in this research were not exercising work and leisure. The results showed that access to leisure is related to greater independence in the area of social function of the child. It is important to consider the possible contribution of low socioeconomic status as an obstacle to full participation to citizenship, in addition to being able to negatively influence the involvement in work and leisure occupations.

Ferraz[27:196] mentions that "work is in almost all cultures a central activity in social and economic organization". It contributes for the subjects to affirm for themselves and for others, what they are, playing a central role in the subject's identity and in the composition of the collectivity, being a fundamental occupation in society[28]. Another occupation mentioned as a difficulty for the families of this research was leisure. This is performed spontaneously and differently from work, it is performed according to the desire to perform it[29]. For Marcellino[30], leisure is the time spent for living values that collaborate in the exercise of citizenship, popular participation, being one of the bases for social change.

CONCLUSION

It is concluded that children present adequate performance for their age in the mobility area. In the areas of self-care and social function, they are significantly delayed. The physical therapy intervention started early, had a longer duration and was classified mainly as instrumental in the child-centered nature. The attendance of speech therapists was predominant in relation to access. The occupational therapeutic intervention was the least accessible and started later. No child had access to psychological intervention.

In general, families have low socioeconomic and educational levels as characteristics, with mothers being the main caregivers. The parents presented as main problems of occupational performance issues related to the non-exercise of work and leisure occupations. The parents had an important difficulty in dealing with the diagnosis. In addition, they show ease in identifying their children's abilities.

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