



Functional Performance in Children with Down Syndrome: Correlations between Social Support and the Quality of Life of Caregivers

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Authors' contributions

This work was carried out in collaboration between all authors. Author LKR developed the study. Author SMBDA oriented the study. Authors FAC and SGDC participated in the defense of the thesis banking. Author LFB performed the statistical analysis. Authors WCAM and SPCS reviewed and contributed to the manuscript draft. All authors read and approved the final manuscript.

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ABSTRACT

Children with Down syndrome (DS) have neuro-sensorimotor disorders that limit their functionality and social participation. The aim of the study was to investigate the relationship between functional performance of children with DS and the perception of social support, quality of life and socioeconomic status of their caregivers. To develop the proposed objectives, we opted for a clinical study of character, quantitative analysis, exploratory and descriptive cross-sectional. Fifty caregivers of both genders, caregivers of children with DS, aged between six months and seven and a half years, were divided into two subgroups homogeneous for ages 6 months to 4 years (n = 24) and over 4 years to 7 years (n = 26), regulars of specialized institutions. The instruments used were WHOQOL Bref, social support scale, Inventory Ordered evaluation. The results obtained from the application inventory Pedi were different for children of different age groups. For children under 4 years there is a significant correlation between the indexes Cuidador- Assistance Self-care and quality of life, negative correlation that can be considered moderate and among the indices caregiver assistance - Social Function and Social Support, positive correlation that can be considered moderate. For children older than four years, there is no significant correlation between the indicators of Pedi and indicators Social Support, Quality of Life and Economic Partner Level. We conclude that there is relationship between functional performance, perceived social support, quality of life and socio-economic status of their caregivers in SD with the group of children under 4 years old. Work to identify ways of intervention for this group should be the subject of future investigations mainly favoring social support for families, assuming that social support integrates the policies on inclusive education.

Keywords: Functional performance; down syndrome; social support; caregivers; quality of life.

1. INTRODUCTION

This study evaluates a relevant theme in public health, which is the role of caregivers in the rehabilitation and social inclusion of children with Down syndrome in order to understand their performance based on activities, developmental potential, and social environmental relations.

Some theoretical implications can be addressed as relevant when considering the conceptual bases of authors with expertise on the functional performance of children with Down syndrome. Among them, is the idea of inclusion described in the Brazilian legislation, which values inclusion as a mainspring of actions and yet, is extremely punitive and non-inclusive.

The idea of inclusion of children with disabilities in the Brazilian educational system is contained in the Brazilian legislation as the 1st Law of Directives and Bases (LDB, Law No. 4024/61). However, it is known that the placement of these children in the Brazilian educational system is still conducted according to European models of special schools, which are based on their separation from society and their right to development among other same age children [1].

Another conceptual base is related to the concept developed in the 8th National Health Conference

states that "health is the result of conditions related to feeding, housing, education, income, environment, work, transportation, employment, leisure, freedom, access and land tenure, and access to health services." This definition involves recognizing human beings as whole, and health as the indicator of the quality of life (QOL). The concept of citizenship that the Constitution guarantees must be translated into the living conditions of a population. However, the divergence between economic development and human and social development is historical and structural in Brazil [2]. Children who need special care are those with congenital neuro-sensory-motor dysfunctions or dysfunctions acquired very early during their development [3]. These are children with motor, behavioral, and learning impairments that limit their functional performance in carrying out activities of daily living (ADLs) as well as their participation in their social environment and make them dependent on specific care, usually performed by caregivers. Hence the importance of associating the functional performance of the child with Down syndrome with social support of their caregivers because rehabilitation is essential in these cases.

The atypical development of this population has raised, and continues to raise, interest in the scientific community in various areas of knowledge; understanding their intellectual,

motor, personal, social, and relational abilities and demystifying the misconceptions of disability, including the Intellectual Disability (ID) and Down Syndrome (DS) [4]. According to Wehmeyer et al. [5], the concept of ID appeared in 1992 with the *American Association of Mental Retardation* terminology (AAMR), now called *American Association on Intellectual and Developmental Disabilities* (AAIDD). This designation goes on to consider the existing dynamic interaction between the individual's functional abilities and social environment [6].

The adoption of the ID term implies a consistent understanding of disability with an ecological base and a multidimensional perspective, which requires that society responds with interventions that focus on the individual strengths and emphasizes the roles of support to improve personal and social functioning. The American Association on Intellectual and Developmental Disabilities (AAIDD) recognizes that the manifestation of ID involves the engagement between intellectual ability, adaptive behavior, health, participation, and individualized context and support [6].

It is noteworthy that the following decrees or ordinances use the concept of ID: the International Convention on the Rights of Persons with Disabilities, ratified by the Brazilian government through the Decree 6949/2009, National Policy for Special Education in the Perspective of Inclusive Education, which directs their actions to meet the specific characteristics of students in the educational process, and ultimately the Ordinance GM/MS No. 793 of 24/04/2012, which established the Care Network for Persons with Disabilities under the National Health System with emphasis on basic attention, specialized care on issues related to hearing, physical, intellectual, visual, ostomy, multiple disabilities, oral health, and hospital/emergency care.

The committee of the Unified Health System of Minas Gerais CIB-SUS/MG established the advanced early intervention program through Resolution No. 1404 of March 19, 2013. This program performs early diagnosis, encourages monitoring of risky newborns, promotes early intervention in users with intellectual disabilities (ID), and attempts to prevent injuries, and improve the prognosis and the quality of life (QOL) of people with disabilities. It develops early intervention actions in children 0 to 6 years old ensuring a timely rehabilitation process.

This study evaluated the functional performance of children with DS, perceived social support (SS), quality of life (QOL), and socioeconomic status (SES) of their caregivers.

The practical implications are serious if caregivers of children with Down syndrome do not receive social support and do not have an adequate quality of life because the functional performance of these children depends on the activities performed, how much they are motivated in their potential for development, and their social and environmental relations. These activities are performed in their daily lives along with their caregivers.

1.1 Objective

Investigate the relationship between functional performance of children with DS and the perception of social support, quality of life and socioeconomic status of their caregivers.

2. METHODS

To develop the proposed objectives, we opted for a clinical study of character, quantitative analysis, exploratory and descriptive cross-sectional.

This was an exploratory cross-sectional study with a quantitative analysis. The study population consisted of 50 adults of both genders who were caregivers of children with DS and fifty children (23 male and 27 female). These children were between six months and seven and a half years old at the time of data collection and regularly attended specialized institutions. The children were divided into two subgroups: G1 (n = 24) included children from 6 months to 4 years old, and G2 (n = 26) included children from over 4 years to 7 and a half years old. This division was based on the characteristics of functional performance, which shifts toward independence with increasing age. The sample size was not calculated a priori. Thus, for the chosen confidence levels, the deviations (errors) in each of the statistics calculated for the sample according to their sizes (number of degrees of freedom) were considered in the tests used. The deviations (uncertainties) in the calculated statistics were appropriate for the purposes of this study and did not require a larger sample.

The inclusion criteria for caregivers were: To be literate, be the primary caregiver of a DS child attending a care institution for people with special needs, to be a caregiver for at least six months,

to be available, and to consent to participate in the study by signing the consent form. The exclusion criteria were: Caregivers whose DS children had other associated diagnoses such as autism and chronic encephalopathy.

The study was conducted in special education institutions in the southern region of Minas Gerais State in the cities of Itajubá, Caxambu, Pouso Alegre, Poços de Caldas, Santa Rita do Sapucaí, Três Corações, Campanha, Ouro Fino, and Lambari.

The Research Ethics Committee of Mackenzie Presbyterian University approved this research project under the process CEP/UPM No. 1297/11/2010 and CAAE No. 0105.0.272.000-10, (FR-381607).

The following instruments were used for data collection:

1. WHOQOL *Bref* World Health Organization *Quality of Life* questionnaire in the original version was developed by the World Health Organization (WHO) and contains 100 questions. The Portuguese summarized version of the WHOQOL-Bref was used as the evaluation instrument. This instrument consists of 26 questions divided into four domains: physical, psychological, and social and environmental relations.
2. The Social Support Scale, the *Social Support Questionnaire* (SSQ), which provides scores for the number of supporting persons perceived by respondents and satisfaction with the social support received. The SSQ is composed of 27 questions, and each question requires an answer in two parts. In the first part, the number of sources of perceived social support (SSQ-P) must be indicated; the respondent can list up to nine possibilities (in addition to any option); in the second part, the respondent indicates their satisfaction with this support (SSQ-S) choosing a score on a 6-point scale (ranging from very satisfied to very dissatisfied).
3. The *Pediatric Evaluation of Disability Inventory* (PEDI) is an American standardized instrument to quantitatively evaluate functional performance of children with respect to mobility, ability to independently perform self-care activities, and social function.

4. The SELquestionnaire - ABEP - Brazilian Association of Research Corporation was used to determine the socioeconomic status of families and characterize the sample. It is based on the accumulation of material goods, income, and education of the household head. It groups the data into five socioeconomic levels ranging from A (highest) to E (lowest).
5. Participant identification questionnaire: this was applied to obtain data from caregivers such as age, gender, education level, marital status, and data from the children such as age, gender, and diagnosis.

All participants were interviewed individually in the room assigned by the home institution. The application of all instruments occurred during this interview and lasted an average of 90 minutes.

3. RESULTS

Among the 50 participants, the highest SEL concentration evaluated by the ABEP instrument occurred in the C1, C2, and D (80%) classes, with only 20% being distributed between levels A2, B1, B2, and E.

The mother was the main caregiver in 92% of cases followed by grandparents (4%), father (2%), and aunt (2%). The age of caregivers varied between 16 and 72 years (mean = 40 years) and the level of education was Complete Elementary Education (46%), Middle School (28%), High School (18%), and College (8%). Among caregivers, 20% had a job outside the home environment and 80% did not. The marital status was distributed as 70% married, 18% in a stable relationship, 4% separated, and 8% single. Among the 50 caregivers, only one was male, a father. The study group was divided into two subgroups homogeneous for ages 6 months to 4 years ($n = 24$) and over 4 years to 7 years ($n = 26$). Opting for this division was given the characteristics of functional performance, which changes toward independence with increasing age of the child.

As for the two general questions about QOL, the answers to:

"How would you rate your quality of life?" They indicated that of the total of 50 caregivers of children with DS from 6 months to 7 years and a half, 58% ($n = 29$) the evaluated as "good", 28% ($n = 14$) rated as

"neither good nor bad," 8% (n = 4) rated as "very good" and the other 6% (n = 3) rated as "bad".

On the question "How satisfied are you with your health?", 60% (n = 30) of caregivers reported being "satisfied", 20% (n = 10) felt "neither satisfied nor dissatisfied", 16% (n = 8) said they felt "dissatisfied" and 4% (n = 2) "very satisfied".

Statistical tests were performed including mean, variance, median, quartiles, and parameters associated with the distribution; the Anderson-Darling normality test was conducted. Except for the distributions of the continuous scores of "Self-care - Functional Skills - G1" with P-value = 0.206 and "Self-care - Functional Skills - G2" with P-value = 0.093 considering 0.05% as the confidence level, the hypothesis of samples normality was rejected.

Therefore, the use of parametric tests such as the Student t test for the comparison of samples or the calculation of Pearson's correlation coefficients was not convenient. The analysis used non-parametric tests such as the Mann-Whitney test for the comparison between groups, Wilcoxon on for paired samples, and Spearman for the analysis of the correlation between variables.

Samples from the two age groups, G1 and G2, were compared to evaluate if both belong to the same population average. The adjusted P-value showed that the samples are significantly different in all studied variables (P-value < 0.05). Thus, the results obtained from the application of the PEDI inventory were different for children indifferent age ranges (groups) for the continuous scores.

Cronbach's alpha values were calculated to analyze the reliability of the questionnaires used in the evaluation of quality of life and social support. This value can be related to consistency of responses. Generally, if the alpha is less than 0.70, the use of the questionnaire should be avoided or its structure should be revised. If the alpha value is close to or greater than 0.90, the questionnaire is very reliable (coherent).

The Cronbach's alpha value for each group was calculated from the answers synthesized in Table 1.

The evaluation of the obtained Cronbach's alpha values shows that the questionnaires are reliable and coherent.

The adjusted P-value was 0.0748 for the quality of life and 0.1526 for social support. Considering these values and the 5% confidence level, the hypothesis that the scores are equivalent for both age groups was not rejected. Thus, with respect to quality of life and social support, the data were analyzed independently of age through the normality test for two scores considering all mothers in one single sample. It was verified that the distribution of quality of life scores was considered normal, and the normality hypothesis was rejected (at 5%) in the case of social support scores.

The Spearman test was used to analyze the correlation between social support and quality of life. The correlation coefficient was equal to $r = 0.43$, which is significant at the level of 0.05%, i. e., there is a weak to moderate correlation between the scores of quality of life and social support.

An analysis to determine whether the entire group of caregivers could be considered homogeneous, disregarding the age group of children with DS, was first performed to analyze the relationship between the number of supporting people and perceived social support.

Thus, a comparison between the averages of indexes for samples of caregivers of children in both groups was required. The normality test of the distributions of the number of supporting people and perceived social support was first conducted in each group of caregivers (G1 and G2). The hypothesis of samples normality was rejected based on the Anderson-Darling test at a significance level of 5%; a nonparametric test was used to compare samples.

Medians were compared using the Mann-Whitney test. The median of the number of supporting people is not different between the two groups (G1 and G2) at the 5% significance level; the test P-value was 0.236.

Similarly, the comparison of medians of social support between the two groups (G1 and G2) showed that they are not statistically different at the significance level of 5%; the test P-value was 0.105.

Thus, caregivers were grouped in one single sample in the analysis of the relationship between numbers of supporting people and perceived social support. The normality of the sample was also rejected in this analysis (P -value < 0.05), and a nonparametric test was used in this comparison. The Spearman correlation coefficient was 0.41, which indicates a weak and moderate correlation, however, statistically significant at the 0.05 level (P -value = 0.003).

The analysis based on the SSQ-P and SSQ-S showed that most caregivers are not satisfied with the social support received.

Table 2 shows the correlation matrix for G1 patients. There is a significant correlation only between the Caregiver Assistance-Self-care and Quality of Life indexes (Spearman correlation coefficient = -0.47: negative correlation considered moderate) and between the Caregiver Assistance-Social Function and Social Support indexes (Spearman correlation coefficient = 0.449: positive correlation considered moderate). The analysis of the correlation matrix in the G1 patients at a significance level of 5% showed a significant correlation only between the Caregiver Assistance-Self-care and Quality of Life indexes and between the Caregiver Assistance - Social Function and Social Support indexes.

Table 3 shows the correlation matrix for G2 patients. No significant correlation between the indicators of PEDI and Social Support, Quality of Life, and Social Economic Level was observed at the significance level of 5%.

Comparisons between the means of domains that make up the indicators of Quality of Life (Physical, Psychological, Social, and Environmental), socioeconomic level, and level of education were performed. The Spearman correlation coefficient was calculated for the analysis of the correlation between indicators (Table 4).

The observed statistically significant correlations ($p = 0.05$) were moderate in most cases. Among the indicators of domains that make up the quality of life index, the highest correlation was found between the social and psychological indicators of quality of life.

A negative correlation was observed between most indicators of quality of life and socioeconomic level and level of education. Thus, it is suggested that low quality of life was

observed in the lowest socioeconomic levels, especially considering the environmental domain. Low socioeconomic levels were also associated with low level of education.

The results obtained from the application inventory Pedi were different for children of different age groups. For children under 4 years there is a significant correlation between the indexes Cuidador- Assistance Self-care and quality of life, negative correlation that can be considered moderate and among the indices caregiver assistance - Social Function and Social Support, positive correlation that can be considered moderate. For children older than four years, there is no significant correlation between the indicators of Pedi and indicators Social Support, Quality of Life and Economic Partner Level.

The results obtained from the application inventory Pedi were different for children of different age groups.

Children under 4 years: For children under 4 years there is a significant correlation between the indexes Cuidador- Assistance Self-care and quality of life, negative correlation that can be considered moderate and among the indices caregiver assistance - Social Function and Social Support, positive correlation that can be considered moderate.

Children older 4 years: For patients older than four years, there is no significant correlation between the indicators of Pedi and indicators Social Support, Quality of Life and Economic Partner Level.

4. DISCUSSION

It is important that the caregiver receives support from family members because a prolonged exposure to a stressful situation contributes to the individual's depletion and consequent feeling of overload from the psychosocial effects of the syndrome.

The results of this study show that the alterations displayed by children with Down syndrome are manifested functionally, influencing their ability to independently perform various activities and tasks of daily routine.

Such information can be useful to professionals who work with this population, suggesting specific areas of assessment and intervention at different ages and support to family members.

Table 1. Cronbach's alpha values for each questionnaire distribute by age groups

Questionnaire	Number of questions	Number of respondents	Cronbach's alpha values
Quality of life – older than 4 years old	26	26	0.865
Quality of life – younger than 4 years old	26	24	0.880
Social support – older than 4 years old	27	26	0.967
Social support – younger than 4 years old	27	24	0.964

Table 2. Correlation matrix for patients younger than 4 years old (G1)

		Functional skills – self-care	Functional skills - mobility	Functional skills–social function	Caregiver assistance - self-care	Caregiver assistance - self-care- mobility	Caregiver assistance - social function
Quality of life	Correlation coefficient	-0.16	-0.274	-0.267	-0.47	-0.344	-0.081
	P-value	0.455	0.195	0.208	0.02	0.1	0.707
Social support	Correlation coefficient	-0.052	-0.062	-0.148	-0.06	-0.197	0.449
	P-value	0.81	0.774	0.49	0.78	0.355	0.028
Socioeconomic level	Correlation coefficient	0.298	0.104	0.145	-0.08	0.296	0.344
	P-value	0.157	0.628	0.498	0.71	0.16	0.1

Table 3. Correlation matrix for patients older than 4 years old (G2)

		Functional skills – self-care	Functional skills - mobility	Functional skills–social function	Caregiver assistance - self-care	Caregiver assistance - self-care- mobility	Caregiver assistance - social function
Quality of life	Correlation coefficient	-0.049	0.081	0.302	-0.091	0.223	0.195
	P-value	0.813	0.693	0.134	0.659	0.273	0.339
Social support	Correlation coefficient	0.043	0.068	0.266	-0.125	0.066	0.14
	P-value	0.833	0.741	0.19	0.543	0.75	0.496
Socioeconomic Level	Correlation coefficient	0.065	0.02	0.211	-0.255	-1.08	-0.093
	P-value	0.751	0.922	0.3	0.208	0.599	0.652

Table 4. Spearman correlation coefficient values

Domain	Physical	Psychological	Social	Environmental	SEL	Age	Education
Physical	1.00	0.42	0.35	0.32	-0.23	-0.11	0.02
Psychological	0.42	1.00	0.63	0.56	-0.35	0.11	0.43
Social	0.35	0.63	1.00	0.35	-0.44	-0.20	0.20
Environmental	0.32	0.56	0.35	1.00	-0.51	-0.12	0.39
SEL	-0.23	-0.35	-0.44	-0.51	1.00	0.33	-0.52
Age	-0.11	0.11	-0.20	-0.12	0.33	1.00	-0.03
Education	0.02	0.43	0.20	0.39	-0.52	-0.03	1.00

Values in **bold** indicate a significant correlation at the $p = 0.05$ level

Both intrinsic and extrinsic (environmental factors) characteristics involving the lives of these individuals should be considered in a treatment designed to stimulate them to develop because these characteristics can limit or expand the possibilities of their performance in their daily routine.

This research correlates the SD with children engine performance with social support and quality of life of their caregivers, confirming the importance of investigating the interaction between individuals and their environments. The emphasis on disability can damage the individual abilities to meet the challenges that arise from all components of their environments. The first evidence of mental development are manifestations because engine throughout early childhood and up to three years of age, intelligence and motor skills are separated, however, their symbiosis reappears after that age, in cases of disability. Thus, this psychomotor parallel reveals a decreased intelligence quotient corresponding to a motor behavior that is also deficient [7].

It was observed that despite the difference between the performances, there is a change in these throughout development. The results of the functional performance showed that the G2, has superior performance in the evaluated functions, which was expected, since there is a consensus in the literature indicating that while there is a general delay in the development of children with DS, they evolve in their motor and functional abilities as increases your age [8].

The trend in the area of motor behavior is to investigate the interaction between the individual and environment, contributing to clarify the process of adjustment to each individual or disability. Individuals may have unique ways to solve problems. Freedom to exercise unorthodox

solutions may result in workable resolutions to the problems and demonstrate competency [9].

In this study, the primary caregiver was the mother in 92% of cases, followed by grandparents (4%), father (2%), and aunt (2%). In studies on the topic of QOL performed with children with SD, authors intend to present findings involving parents/caregivers and, in general, their population is composed mainly of mothers. In rare cases, the objective is to study the male element as the caregiver, that is, the father or the affected individual. In the study by Oliveira and Limongi [10], the target was caregivers as defined in the method, mostly composed of mothers, however, including seven father sand two grandmothers.

In our study, the majority of caregivers had a socioeconomic level with monthly family income ranging from R\$ 1,459.00 to R\$ 680.00 reais (units of Brazilian currency), characterizing medium to low income families. A relationship between family socioeconomic level, child's functional performance, quality of life, and social support forthe caregiver was observed in this study, which is opposed to the results reported by Gonçalves et al. [11], Makiyama et al. [12], and Amendola, Oliveira, and Alvarenga [13] indicating thatthe socioeconomic level did not affect the dynamics of families with DS individuals.

In this study, low quality of life was correlated with the lowest socioeconomic levels especially considering the environmental domain. It was also observed that the level of education is lowin the lowest socioeconomic levels.

Regarding marital status, 70% of caregivers who participated in this study were married, which corroborate the results reported by Braccialli et al. [14], Roig, Abengózar, and Serra [15], Kluthcovsky and Takayanagui [16].

In this study, most caregivers (80%) did not have a job outside the home environment. According to these authors, caregivers do not exercise a formal professional occupation; this would be a way for families to fit the care needs in this population of patients with disabilities.

In this study, we observed that caregivers are satisfied with their quality of life; conformism and acceptance were noticeable features in the interviewed caregivers, which also influenced their perception of quality of life.

However, most caregivers state that they do not receive outside support which corroborates the observation of other studies that mothers/families of children with diseases/chronic deficiencies have a social network smaller than that of comparable samples [17,18]. And differs from others found no difference in support social [19,20]. Regarding social support, the obtained results indicate that the participants in the group of mothers of children with special needs (MSN) have a smaller number of support people than the group of mothers of children without disabilities [19,20].

In this study, a significant correlation is only observed between Caregiver Assistance - Self-care and Quality of Life indexes in children in the G1 group; we observe that the greater the assistance provided by the caregiver in feeding, bathing, personal hygiene, dressing, and bathroom use (i.e., self-care) the more precarious is the caregiver's quality of life suggesting an overprotective behavior that results in less independent children [21]. However, although the quality of life of caregivers is precarious in this study, caregivers reported being satisfied with it.

Mancini et al. [22] believe that a good performance in functional skills is an important objective in the rehabilitation process because lesions in the central nervous system (CNS) limit the performance of activities and daily tasks, especially in the area of self-care. Likewise, the use of functional activities is recommended to increase the degree of independence in children.

In fact, studies indicate that technological and scientific advances in the field of rehabilitation and new child development stimulation techniques contribute to approximately similar developmental rates of children with DS and children without disabilities [23]. Authors

advocate the importance of searching for interventions to increase the degree of independence of DS children in an attempt to mitigate the functional constraints they find in society [23-24].

We observed that there is a positive correlation between Caregiver Assistance - Social Function and Social Support in the G1 group, i.e., the greater the caregiver assistance toward the child's social function, the greater is the social support to the caregiver.

According to Lynch and Hanson [25], Brazilians parents of special needs children have a historical stance of super protection that ends up masking the child's abilities and impairing their motor development.

In this study, we observed that the highest correlation was between the social and psychological domains among indicators of the quality of life index. The Environment domain, which is related to leisure, access to health services, transportation, and housing conditions showed the lowest average compared to other domains.

5. CONCLUSION

We conclude that there is relationship between functional performance, perceived social support, quality of life and socio-economic status of their caregivers in SD with the group of children under 4 years old. Work to identify ways of intervention for this group should be the subject of future investigations mainly favoring social support for families, assuming that social support integrates the policies on inclusive education.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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