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HEALTH SCIENCES

Personal and *environmental* factors and household assistance in Down syndrome: cross-sectional study

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Abstract: According to a biopsychosocial framework, personal and environmental factors might be mediators or facilitators/barriers, respectively, to functioning. However, it is not known how these factors can impact independence in household chores in children/adolescents with Down syndrome (DS). This study explored whether and how personal/environmental factors are associated with the independence level in household chores of children/adolescents with DS in Brazil. Caregivers of twenty-eight children/adolescents with DS were interviewed using the CHORES and a standardized questionnaire about personal (child's age and sex) and environmental (socioeconomic level and maternal schooling) factors. Multiple linear regression analysis identified if/how these factors are associated with level of independence. For CHORES *self-care* and CHORES *total,* sex was a significant variable explaining 21.8% and 15.8%, respectively, of the variation in the outcomes. For the outcome CHORES *family care* none of the variables was significant. Female sex was associated with a lower need for assistance. We conclude that only the personal factor assessed related to female sex in children with DS was associated with the independence level in household chores. This finding highlights the importance of health care providers and families to encourage the independence in chores regardless of sex and promote opportunities for both boys and girls.

Key words: Environment, independent living, children, adolescents, Down syndrome.

INTRODUCTION

The health framework for understanding 'functioning' has been gradually changing since the publication of the International Classification of Functioning, Disability and Health (ICF) in 2001 (WHO 2001). The ICF is an integrative biopsychosocial framework that describes functioning by considering the relationships among positive aspects of *body functions and structures*, the capacity to accomplish *activities* and ability to *participate* in different contexts (WHO 2001). In addition, the ICF recognizes the importance that *environmental* and *personal* factors play in influencing functioning.

An important and prevalent health condition is Down syndrome (DS) (Sherman et al. 2007), that is characterized by trisomy of chromosome 21 and may affect aspects of *body functions and structures*, such as cognitive, sensory and neuromotor systems (Brugnaro et al. 2022). Also, people with DS might have impaired executive functions (de Weger et al. 2021) and motor skills, which may be important predictors for adaptive ability while carrying out activities (Schworer et al. 2022). In this context, children and adolescents with DS may need more time

to learn how to perform activities of daily living when compared to their typical peers (Beqaj et al. 2018, Büyükçelik et al. 2023, Moriyama et al. 2019). Due to challenges to learn and accomplish activities, children with DS may show lower levels of independence in household chores, needing and asking for more assistance than children with typical development (Amaral et al. 2014).

Children with DS present great potential to develop autonomy (Brugnaro et al. 2024 a, b, Terrone et al. 2014). The level of care offered by the caregiver may either favor or prevent the child from performing household chores, thus affecting the acquisition and maintenance of independence (Amaral et al. 2014). Independence in household chores is a relevant factor for people with DS, since it provides opportunities to practice and improve motor skills by promoting opportunities for child-environment interactions (Huang et al. 2009), potentially leading to greater self-esteem and autonomy (Drummond et al. 2019). Autonomy can also reinforce feelings of belonging to the family context. Considering the importance of independence, and in the light of the ICF framework (WHO 2001), *personal* and *environmental* factors may be associated with independence level in household activities.

For *personal* factors, we did not find studies addressing the influence of sex in the level of independence in household chores in children with DS. Utilizing a comparative study design in children with complex physical disabilities, Law et al. (2006) reported that females participated significantly more in social and skill-based activities. Conversely, boys showed greater involvement and participation than girls in tasks involving active physical movements (Law et al. 2006). Considering age, there is no consensus about its role on the level of independence in chores, since there are only a few studies addressing the relationship between age and participation. Wuang & Su (2012) reported that older children with DS participate more consistently in activities at home and community than younger ones (Wuang & Su 2012). Conversely, Law et al. (2006) showed that children with disabilities participated less in informal activities as they got older. For children with DS, daily routine and self-care activities are very variable, and age is an important factor leading to changes in adaptive skills (Schworer et al. 2022), with reports or a substantial change over the course of life (Schworer et al. 2022).

For *environmental* factors, such as parental education and socioeconomic status of the family and children's performance, there are controversies in the literature. Some studies present these factors as facilitators of health components in different populations and ages (Brugnaro et al. 2024a, Rosenberg et al. 2013, Law et al. 2006, Milićević et al. 2020). On the other hand, other studies indicated these factors can either support or hinder it (Shabat et al. 2021, Arakelyan et al. 2019). In addition, we did not find studies addressing the association of environmental factors with household chores in children with DS, which indicates the need for further studies to fill this evidence gap.

Therefore, the aim of this cross-sectional study was to investigate whether and how *personal* (age and sex) and *environmental* (socioeconomic level and maternal schooling) factors are associated with the level of independence in household chores in children and adolescents with DS. Considering the results of previous studies addressing the theme, we expected to find that for children with DS female sex and older age would be predictors of higher levels of independence in household chores. Also, we expected that higher socioeconomic level and maternal age would also be associated with higher independence in household chores, since they may be factors that favor greater

opportunities for home activities (Arakelyan et al. 2019).

This is an exploratory study that might help to clarify determinants of independence in household activities in children with DS. These results might support therapeutic strategies to improve the performance of the household chores more independently since childhood and adolescence favoring independence also during future adulthood.

MATERIALS AND METHODS

Study design

This was an observational cross-sectional design, carried out between October and November 2018.

Participants

Participants were a sample of convenience of caregivers of children and adolescents with DS recruited from regular schools, rehabilitation centers, and associations that provide care for children and families with DS. Data collection occurred in three towns (São Carlos, Mogi das Cruzes and Limeira) in São Paulo state, Brazil. The cities were chosen because the researchers had contact with schools and rehabilitation centers in these cities, making it easier to contact them to disseminate the research. The inclusion criteria were caregivers of children and adolescents with a diagnosis of DS whose children were aged 7-14 years, had no uncorrected heart defects, uncorrected sensory impairments, or neurodevelopmental conditions other than DS (such as autism) that might independently affect the outcomes of interest. Exclusion criteria were children and adolescents with other diagnoses besides DS. The age range was established considering the same age group used in research that translated and validated the CHORES measure to Brazilian Portuguese (Amaral et al. 2012); this instrument assesses the level of assistance in household chores, and was the main outcome of this study.

The sample size was determined a priori using G-Power Software 3.1.9.7. The effect size used was that found in the study carried out by Amaral et al. (2014), using the CHORES in a correlation between children with DS and those with typical development. Therefore, for running linear multiple regression, with the following parameters: effect size 0.6, power 0.85, number of factors 4, and level of significance 0.05, the sample size should be 28 individuals.

Twenty-nine caregivers were invited, but one was not included because the child did not fully meet the inclusion criteria (cerebral palsy associated with DS). Therefore, twenty-eight caregivers completed the evaluation. Half of the sample consisted of girls.

Procedures

Caregiver interviews were carried out in a single session using the CHORES scale and a standardized sociodemographic questionnaire, created by the researchers, about personal and environmental factors. Two examiners were previously trained and had reached an inter-observer agreement index [matching items/total number of items*100] of 94% for the CHORES scale. For this agreement, the two examiners assess two children with Down syndrome (one boy and one girl, aged 7 and 8 years respectively), with the same inclusion criteria established in this study. For this agreement, the two examiners assess two children with Down syndrome (one boy and one girl, aged 7 and 8 years respectively), chosen by the same inclusion criteria established in this study. These two children were only used to calculate agreement, and were not part of the sample analyzed in the results of this study. All assessments were made through interviews

by these two examiners, in order to improve reliability and ensure the standardization of all assessments. The local Ethics Committee for Human Research approved the study (CAAE: 62685316.2.0000.5504). Caregivers of children were admitted to the study following informed written consent.

Measures

A)Personal factors

Data on the *personal* factors of age (completed years) and sex (male or female) of the participants were collected through interviews with the participant's caregivers. The age groups were categorized in percentage of occurrence and were described by mean and standard deviation. As sex is a qualitative variable, it was categorized as follows: 1 = female; 2 = male.

B)Environmental factors

B1)Socioeconomic level

Socioeconomic level was obtained through the standardized questionnaire 'Criteria for Economic Classification Brazil' (see: < https://www.abep.org/>), according to the Brazilian Association of Research Companies (ABEP). This socioeconomic segmentation instrument uses a survey of household characteristics (presence and quantity of specific household items of comfort and education level of the head of the family) to differentiate the population, and is widely used in the country where the study was developed. The criterion assigns points according to each household characteristic and makes the sum of these points into a score. A correspondence is made between the scoring ranges of the criterion and strata of socioeconomic classification defined by D-E, C2, C1, B2, B1 and A, from lowest to highest socioeconomic level, respectively. For statistical analysis, these values were numerically categorized as a discrete quantitative (D-E = 1, C2 = 2, C1 = 3, B2 = 4, B1 = 5, A = 6) with higher values indicating greater socioeconomic level.

B2)Maternal schooling

Maternal schooling was obtained through interviews with participants, with questions categorized on a 6-point scale for statistical analysis: Incomplete elementary school = 1; Complete elementary school = 2; Incomplete high school = 3; Complete high school = 4; Incomplete college = 5; Complete college = 6. These values were used in the statistical analysis as a discrete quantitative variable, with higher values indicating greater schooling.

C)Level of independence in household chores: Children Helping Out-Responsibilities, Expectations and Supports scale (CHORES)

The CHORES scale, a questionnaire that measures the level of independence in household chores through activities taking place in the home, was developed by Dunn in 2004, then translated and validated for use in Brazil in 2012 by Amaral et al. (2012). CHORES can be used for children with and without disabilities. The Brazilian version showed strong consistency within a 7-14-day interval. CHORES scale can be used by interview or to be self-responses with the caregivers. In order to standardize the assessments and eliminate possible biases of understanding, we applied the CHORES through an interview. The evaluations were carried out by two trained and concordant examiners, one of them a master's student in physiotherapy and the other a graduate student in physiotherapy, both with experience in pediatric rehabilitation. The questionnaire includes 34 items that evaluate functional tasks subdivided into two subscales: *self-care* (13 tasks) and *family-care* (21 tasks) (Dunn 2004). The former items evaluate tasks

related to the child's own needs in their particular space (self-care activities), and the latter assess tasks of caring for other family members (family-care activities), as well as for the common household space (Dunn 2004). Each task is scored on a 6-point Likert-based scale on how it is accomplished: 6 (on own initiative), 5 (with a verbal prompt), 4 (with supervision), 3 (with some help), 2 (with lots of help), 1 (cannot do task), and 0 (not expected to do task). Scores between 0 and 1 indicate that the child does not do the task; scores between 2 and 4 indicate that the child does the task with some level of assistance; and scores between 5 and 6 indicate that the child does it independently. Scores in each subscale are summed to produce assistance scores (CHORES *total* score: i.e., the sum of the subscales (*family-care* and *self-care*), ranging from 0 to 204); *self-care* scores range from 0 to 78, and *family-care* scores range from 0 to 126). Higher scores indicate higher independence in household chores.

Statistical analyses

Descriptive analyses (means, standard deviations and frequency of occurrence) were performed. A multivariate linear regression analysis was performed on 3 models using a backward stepwise method, which inserts all variables into the model and tests the elimination of each variable. The statistical analysis was chosen based on the Mishra et al. (2019) recommendation. The assumptions for specific analyses were satisfied (linear relationship; normality; no multicollinearity; no auto-correlation and homoscedasticity). The dependent variables in each of the analyzed models were CHORES *total score*, the CHORES *self-care* score and the CHORES *family-care* score, using the sum of the raw scores. For each of these models, the potentially associated factors tested (independent variables) were: *personal* factors (child's age [completed years] and sex [male or female]) and *environmental* factors (socioeconomic level [categorized in 6 groups] and maternal schooling [categorized in 6 groups]). Statistical analyses used SPSS (version 24.0). The level of statistical significance was set at $p < 0.05$. We used only cases with valid data. Missing values were treated as missing and no values were imputed.

RESULTS

All caregivers participated were mothers. Table I describes the children's mean age (mean age:10.3±2.1 years) and sex (50% male and 50% female) and the environmental factors of socioeconomic level and maternal schooling classification. Half the families were in socioeconomic level B2 (n = 8) and B1 (n = 6), representing middle level and the majority of mothers had complete college (n = 11) followed by incomplete college (n = 4).

Table II describes the means and the standard deviations of assistance levels in household chores. For the total score, the mean was 98.5, representing 48.2% of the maximum possible. For self-care the mean was 46.7 and family-care was 51.7, representing 59.9% and 42.7% of the maximum possible, respectively.

The regression model for the dependent variable *CHORES self-care* demonstrated that only sex showed a significant association, explaining 21.8% of the *CHORES self-care* scores. None of the other variables (maternal schooling [τ statistics = 0.831; $p = 0.415$], socioeconomic level [τ statistics = -1.671; $p = 0.109$], and sex [τ statistics = -3.037; $p = 0.006$]) were significant.

For *CHORES family-care scores*, none of the variables were significant in the model.

For *CHORES total scores* the regression analysis showed that the sex was the only

Table I. Descriptive results of *personal* and *environmental* factors in the sample.

Mean age	**10.3 ± 2.1 years**	
Sex	**Number of participants**	**%**
Male	14	50%
Female	14	50%
Socioeconomic level	**Number of participants**	**% of participants in each category**
D-E	2	7.1%
C2	1	3.6%
C1	5	17.9%
B2	8	28.6%
B1	6	21.4%
A	4	14.3%
Did not answer	2	7.1%
Maternal schooling	**Number of participants**	**% of participants in each category**
Incomplete elementary school	3	10.7%
Complete elementary school	3	10.7%
Incomplete High School	2	7.1%
Complete high School	3	10.7%
Incomplete college	4	14.3%
Complete college	11	39.3%
Did not answer	2	7.1%

variable significantly associated in the model and explained 15.8% of the variation.

In both analyses, female sex values were associated with higher CHORES values. The results are represented in Table III, and are expressed from lower to higher association status on each dependent variable.

DISCUSSION

Our findings partially confirmed our initial hypothesis, since we found that only female sex was associated with lower levels of assistance in household chores and total chores. No associations were found for other independent variables.

As expected, female participants presented higher independence in household chores in activities related to child's self-care (CHORES *self-care*) and the total of activities at the home environment (CHORES *total).* Thus, we can infer that females with DS probably perform more household chores related to their own space, instead of activities directed to another family member. This is an interesting finding that deserves attention. Since we did not evaluate the reason that a child did not perform the activity, we do not know if this result is because families do not ask the child to do activities

Table II. Measures obtained on the CHORES *total* score, CHORES *self-care* score and CHORES *family-care* in participation at home for children with Down syndrome.

CHORES score	Mean (Me)	Standard Deviation (SD)	Score Range (minimum -maximum)	Score Variation	Percentage of score obtained (considering the mean score)
Total	98.5	33.9	35-168	0-204	48.2%
Self-care	46.7	15.7	72-16	0-78	59.9%
Family-care	51.7	20.2	96-19	0-126	42.7%

towards another person, or because they do not want to do so, or do not understand the meaning of doing so. Therefore, this particular feature should be explored in further studies. Previous findings suggested that females perform more self-care activities (Dolva et al. 2004) and present greater diversity of activities than boys (Dolva et al. 2004, Law et al. 2006). In contrast, King et al. (2010) have shown different results according to the type of activity, i.e., males with physical disabilities performed more in recreational and sport participation than girls, and girls performed self-improvement activities more frequently than boys. Furthermore, it is important to highlight the social and cultural determinants for participation in chores for girls/women with disabilities, and also without disabilities. This is an important aspect that could impact the results of our study, since girls are more likely to participate in these activities, and may have more activities aimed at them just because they are girls/women. Thus, due to mistaken perceptions of the extent to which the child or adolescent can participate in activities, or due to the influence of contextual aspects, this may result in lower participation in household activities (McGarty & Melville 2018). Therefore, regardless of sex, these individuals should be encouraged to participate in activities related to home routines, in order to promote better functioning as well as the sense of belonging to the family environment, increasing their potential autonomy in these activities.

We did not find significant associations for any other variables. Considering age, previous findings in the literature are controversial. Since we did not find studies addressing the level of independence related to the child's age, we looked at some general participation literature, as participation might indicate a way to initiate independence at home. One study has shown lower participation levels in informal activities for children with disabilities as they get older (majority with cerebral palsy, and others with a range of developmental disorders) (Law et al. 2006), and that young children were more likely to have a greater diversity of participation overall than older children (Shields et al. 2015). Conversely, Wuang & Su (2012) reported that older children with DS more consistently participate in activities in general than younger ones. Because our findings did not reveal any associations of age with independence level, we suggest that further studies explore this topic. We also highlight that specific characteristics in DS may be related to the level of independence, such as delays in perception and adaptive behavior development and motor coordination (Alesi et al. 2022). These difficulties could also impact the results according to the age group studied, since they might be less motivated to do household activities or receive less opportunities to be active during chores and

Table III. Regression analysis for each outcome: CHORES *self-care*, CHORES *family-care* and CHORES *total*.

CHORES SELF-CARE						
PREDICTORS	***B***	***p***	***τ statistics***	***R² variable***	***R² model***	***Model effect size***
Maternal schooling	0.209	0.415	0.831	0.021	0.313	0.38
Socioeconomic level	-0.434	0.109	-1.671	0.074		
Child's sex	-0.561	**0.006***	-3.037	0.218		
CHORES FAMILY CARE						
PREDICTORS	***B***	***p***	***τ statistics***	***R² variable***	***R² model***	***Model effect size***
Maternal schooling	-0.042	0.885	0.147	0.01	0.152	0.15
Child's age	0.153	0.540	0.624	0.016		
Socioeconomic level	-0.270	0.371	-0.915	0.05		
Child's sex	-0.445	0.096	-1.746	0.085		
CHORES TOTAL						
PREDICTORS	***B***	***p***	***τ statistics***	***R² variable***	***R² model***	***Model effect size***
Child's sex	-0.397	**0.045***	-2.120	0.158	0.158	0.45

Legend: * = p<0.05.

consequently, be less independent. In addition, the age range studied was not so wide (7-14 years old), which may explain the results found. These other factors should be explored by future studies. However, research has shown the importance of epigenetic regulation (Ghosh et al. 2023), i.e., the relevance of the environment for people with DS to develop to their maximum potential, including on chores independence, regardless of the deficiencies they may present.

Regarding *environmental* factors, previous studies reported variable findings (Arakelyan et al. 2019, Brugnaro et al. 2024a, Taheri et al. 2017). The required assistance in household chores depends not only on maternal schooling, but also on other factors in the home routine, which may stimulate participation and therefore minimize possible barriers arising from low maternal educational level. In relation to a family's socioeconomic status, current findings in the literature addressing this issue are controversial, showing positive (Law et al. 2006), negative (Law et al. 2006, Marques et al. 2021) or no influence (Bult et al. 2013, Brugnaro et al. 2024a, Palisano et al. 2011) of this variable on level of independence in household chores. Our study showed no association between these factors and the level of independence in household chores, corroborating previous findings (Bult et al. 2013, Brugnaro et al. 2024b, Palisano et al. 2011). Therefore, socioeconomic level is not the main environmental factor, as opportunities to participate are available in all households regardless of income.

Limitations

We acknowledge some limitations in this study. First, this study did not include a control group of typically developing children, which could (and likely would) have illustrated

potential differences between them and the DS population. Since the measure CHORES does not have cutoff points or normative data that indicate expected values as adequate, we suggest to consider what is expected by age group in a typical developmental child. Second, considering the complexity of existing *personal* and *environmental* factors that can impact functioning, there is a possibility that other factors that were not evaluated may play a role in the outcomes assessed in this study. For example, other relevant demographic variables not assessed, e.g., presence of siblings or other adult family members, availability of paid help in the home (e.g., maids), different habits and cultural values of families, might impact, and possibly change, the relationship between family and child. In the same way, the cognitive level of the children was not assessed, but could have been important as a control. Third, the sample was obtained by a convenience, which may influence the recruiting process, with a bias to sample selection. Last, other factors should be investigated in longitudinal studies including, for example, the children's and adolescents' preferences, the availability of the caregivers to support their need for assistance in household chores, cultural aspects in expectations of chores, paternal education level, and availability of therapies that focus on household chores and participation, to investigate potential associations.

CONCLUSION

The results illustrate that, of the *personal* and *environmental* factors investigated, only the personal factor female sex in children with DS was associated with higher levels of independence in household chores. The other factors investigated (child's age, maternal schooling and socioeconomic levels) were not associated with the independence level in household chores in children with SD in the age range assessed. Based on our results, we reinforce the need to promote opportunities for both boys and girls with DS to perform activities at the home environment according to the potential and the personal interest of each child, regardless of sex. This will enable them to develop a sense of independence at home in activities either related to themselves or to other family members, as well as a sense of competence and accomplishment. Other factors such as environmental facilitators/barriers and family dynamics, should be explored in future studies, taking into consideration the relationship among health components.

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