

# Factors associated with stress in family caregivers of children and adolescents with Down syndrome

Fatores associados ao estresse de cuidadores familiares de crianças e adolescentes com síndrome de Down

Factores asociados al estrés en cuidadores familiares de niños y adolescentes con síndrome de Down

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## Abstract

**Objective:** To identify factors associated with stress among family caregivers of children and adolescents with Down syndrome.

**Method:** This was a cross-sectional, analytical, observational study with a quantitative approach. Data were collected in participants' homes using a sociodemographic and clinical characterization instrument, the Perceived Stress Scale, and salivary cortisol collection upon awakening. Bivariate and multivariate statistical analyses were performed to identify associations.

**Results:** A total of 30 family members participated, including 24 mothers, five fathers, and one sister. Of these, 18 (60%) reported experiencing at least one stressful event in the previous 30 days. The mean perceived stress score was 31.9 points. Mean salivary cortisol upon awakening was 0.44 µg/dL, which is within the normal range for the morning period. A statistically significant association was found between salivary cortisol levels upon awakening and occupation.

**Conclusion:** A tendency toward low salivary cortisol levels upon awakening was observed among family caregivers. Family members with paid employment had higher salivary cortisol levels than caregivers without employment.

## Resumo

**Objetivo:** identificar os fatores associados ao estresse de cuidadores familiares de crianças e adolescentes com síndrome de Down.

**Método:** estudo com delineamento observacional, analítico e transversal, de abordagem quantitativa. A coleta de dados foi realizada no domicílio, por meio da aplicação de um instrumento de caracterização, de uma escala de estresse percebido e da coleta de cortisol salivar ao despertar. Análises estatísticas bivariadas e multivariadas foram aplicadas para identificar associações.

**Resultados:** participaram 30 familiares, sendo 24 mães, cinco pais e uma irmã. Do total, 18 (60%) afirmaram ter vivenciado algum evento estressante nos últimos 30 dias. A pontuação média do estresse percebido foi de 31,9 pontos. O cortisol salivar ao despertar obteve média de 0,44 µg/dL, dentro do padrão de normalidade para o período matutino. Observou-se relação estatisticamente significativa entre nível de cortisol salivar ao despertar e ocupação.

**Conclusão:** verificou-se uma tendência a níveis baixos de cortisol salivar ao despertar entre os cuidadores familiares. Os familiares com ocupação remunerada apresentaram níveis aumentados de cortisol salivar em comparação com os cuidadores sem vínculo empregatício.

## Resumen

**Objetivo:** identificar los factores asociados al estrés entre los familiares cuidadores de niños y adolescentes con síndrome de Down.

**Método:** estudio observacional, analítico y transversal, con enfoque cuantitativo. La recolección de datos se realizó en el domicilio de los participantes, mediante la aplicación de un instrumento de caracterización sociodemográfica y clínica, una escala de estrés percibido y la recolección de cortisol salival al despertar. Se realizaron análisis estadísticos bivariados y multivariados para identificar asociaciones.

**Resultados:** participaron 30 familiares, entre ellos 24 madres, cinco padres y una hermana. De estos, 18 (60%) informaron haber experimentado al menos un evento estresante en los últimos 30 días. La puntuación media de estrés percibido fue de 31,9 puntos. La media del cortisol salival al despertar fue de 0,44 µg/dL, valor dentro del rango de normalidad para el período matutino. Se encontró una asociación estadísticamente significativa entre los niveles de cortisol salival al despertar y la ocupación.

**Conclusión:** se observó una tendencia a niveles bajos de cortisol salival al despertar entre los familiares cuidadores. Los familiares con ocupación remunerada presentaron niveles más elevados de cortisol salival en comparación con los cuidadores sin vínculo laboral.

## Keywords

Nursing; Child; Adolescent; Caregivers; Stress

## Descritores

Enfermagem; Criança; Adolescente; Cuidadores; Estresse

## Descriptoros

Enfermería; Niño; Adolescente; Cuidadores; Estrés

## Data availability:

The study data are available in this article.

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## Introduction

The term “Children with Special Health Needs” (CSHN) refers to a group of children who require greater attention from family members, healthcare professionals, and educators compared to healthy children of the same age, mainly due to physical, emotional, developmental, or behavioral conditions.<sup>(1)</sup>

Children with Down syndrome are included in this definition, as they present several associated medical conditions, such as heart disease, vision and hearing impairments, hematological disorders, among others.<sup>(2)</sup> Therefore, they require psychomotor therapies, regular visits to healthcare services, medication, and, in some cases, the use of assistive devices for feeding or breathing.<sup>(3)</sup>

Down syndrome is the most prevalent chromosomal disorder in the population. In Europe, it is estimated that 8,031 children with Down syndrome are born annually, with a prevalence of 10.1 per 10,000 live births.<sup>(4)</sup> In the United States of America, it is estimated that more than 200,000 people have the syndrome.<sup>(2)</sup> In Brazil, the estimate is one case for every 700 births, accounting for 270,000 cases.<sup>(5)</sup>

The literature highlights challenges related to parenting children and adolescents with Down syndrome, including the need to readjust family routines to meet specific therapeutic demands, financial burden, and experiences related to stigma.<sup>(6)</sup> This reality results in physical and mental overload, impaired concentration, depression, anxiety, sleep deprivation, among other conditions.<sup>(7)</sup> Furthermore, high stress levels can negatively affect the emotional bond between mother and child.<sup>(8)</sup> A North American study comparing parental stress among 36 mothers of children with Down syndrome and 47 mothers of typically developing children supports these findings, revealing significantly higher stress levels among mothers of children with Down syndrome.<sup>(9)</sup>

Furthermore, the literature highlights caregivers' concerns about the future of children and adolescents, particularly regarding dependence in daily activities and financial issues. These concerns contribute to caregiver burden and are especially relevant among caregivers of children and adolescents with disabilities.<sup>(6)</sup>

Stressful situations can negatively influence multiple biological pathways, culminating in circadian

rhythm dysregulation.<sup>(10)</sup> Cortisol has been adopted as a biomarker for analyzing chronic psychosocial stress and mental and physical health problems. It is an endogenous glucocorticoid produced by the adrenal glands following activation of the hypothalamic–pituitary–adrenal axis. Under normal conditions, it follows a circadian pattern, with cortisol levels increasing shortly after awakening and gradually decreasing throughout the day. Chronically elevated cortisol concentrations can result in immune imbalance through atrophy of lymphoid tissue in the thymus, spleen, and lymph nodes, stimulation of lymphocyte apoptosis, and inhibition of the synthesis and release of cytokines and other mediators of immune and inflammatory responses, among other biological mechanisms.<sup>(11)</sup>

In this regard, a study that examined salivary cortisol levels in 82 mothers of children with psychiatric or developmental disorders, including Down syndrome, showed that cortisol levels exhibited less pronounced daily declines in their diurnal patterns.<sup>(12)</sup> Another study found that, compared to mothers of typically developing children, mothers of children with autism spectrum disorder and other developmental disabilities exhibited a poorer antibody response to pneumococcal vaccines, indicating a reduced ability to fight infections.<sup>(13)</sup>

Although international research has analyzed salivary cortisol in caregivers of children with chronic conditions, studies that simultaneously examine biological indicators of stress, subjective measures of perceived stress, and sociodemographic factors remain limited, especially among family caregivers of children and adolescents with Down syndrome. Furthermore, most available evidence is concentrated in high-income countries, with a scarcity of research in diverse sociocultural contexts such as Brazil, where socioeconomic factors and access to healthcare services can significantly influence the caregiving experience and family members' stress levels. Therefore, generating evidence on this topic contributes to expanding international knowledge about the phenomenon and supports the planning of care interventions that are more responsive to the needs of these caregivers.

Given the above, this study was guided by the following research questions: What are the salivary cortisol levels upon awakening in family caregivers of children and adolescents with Down syndrome?

What are the perceived stress levels of these caregivers? Is there a correlation between salivary cortisol levels upon awakening, perceived stress, and sociodemographic conditions? Based on these questions, this study aimed to identify factors associated with stress in family caregivers of children and adolescents with Down syndrome.

## Methods

This is an observational, analytical, cross-sectional study with a quantitative approach.<sup>(14)</sup> This article is part of the research project (Regular FAPESP 2019/24975-7) entitled “*Ritmos circadianos de alfa amilase e cortisol salivar de cuidadores de crianças com necessidades especiais de saúde: estudo caso-controle*”. The empirical material was produced in the homes of families with children and adolescents with Down syndrome from five surrounding municipalities located in the central region of the state of São Paulo.

Participants were selected through non-probabilistic convenience sampling and included family caregivers of children and adolescents with Down syndrome aged over 18 years. A family caregiver was defined as the individual responsible for most of the care of the child or adolescent. According to the Statute of the Child and Adolescent, children and adolescents are defined as individuals up to 18 years of age.<sup>(15)</sup> An incomplete COVID-19 vaccination schedule was adopted as an exclusion criterion due to saliva sample handling; however, this criterion was not applied.

Data collection took place between March and October 2023. Participants were recruited through advertisements on social media platforms, such as WhatsApp® and Facebook® groups. Additionally, some participants referred other potential participants, characterizing the snowball sampling technique.<sup>(16)</sup> After expressing interest, family caregivers received the Informed Consent Form (ICF) via WhatsApp® or email, according to their preference. After providing consent, a home visit was scheduled to collect saliva samples and administer the research instruments.

The Perceived Stress Scale, composed of 14 items with response options ranging from 0 to 4 (0 = never; 1 = almost never; 2 = sometimes; 3 = almost always; 4 = always), was used. Positively worded items were re-

verse scored. The total score is obtained by summing the responses to the 14 items, ranging from 0 to 56 points. According to the authors, higher scores indicate higher perceived stress levels. The scale demonstrates high internal consistency, with Cronbach’s  $\alpha$  values above 0.80.<sup>(17)</sup> The total score may also be categorized as follows: scores below 18 indicate low stress; 19–24, normal stress; 25–29, moderate stress; 30–35, high stress; and above 35, very high stress.<sup>(17)</sup>

A sociodemographic questionnaire was also administered to caregivers, including questions on age, skin color, education, marital status, occupation, family income, use of anxiolytic or antidepressant medications, and stressful events in the previous 30 days.

Regarding the saliva collection procedure, the day before the appointment, the researcher provided a leaflet containing written and illustrated instructions. Participants were instructed not to consume alcoholic beverages within the previous 24 hours, and to refrain from eating or drinking (including coffee), brushing their teeth, using mouthwash, smoking, or exercising for at least one hour before sample collection.

On the scheduled day, the researcher arrived at the participant’s home at 8:00 a.m., when the saliva sample was collected. For salivary cortisol collection, Salivette® was used, consisting of an absorbent swab that participants were instructed to gently chew for two minutes to obtain a minimum of 500  $\mu$ L of saliva. The biological material was then refrigerated until delivery to a contracted third-party laboratory for processing. Salivary cortisol concentrations were determined using the electrochemiluminescence method (Elecsys 1010/1020, Roche Diagnostics, Laval, Quebec). For result interpretation, the reference values provided by the laboratory were adopted, considering concentrations below 0.736  $\mu$ g/dL as within the normal range for the time of collection. Values equal to or greater than this cut-off point were interpreted as indicative of greater activation of the hypothalamic–pituitary–adrenal axis, possibly reflecting higher stress levels among caregivers.

In this study, salivary cortisol levels upon awakening and perceived stress scores were considered dependent variables. The independent variables were derived from the sociodemographic questionnaire. Regarding the organization of these variables, “skin color” was categorized as white or non-white, in-

cluding individuals who identified as mixed-race or black. The variable “occupation” was categorized into paid work (including formally employed and self-employed individuals) and unpaid work (including domestic work). Education level was categorized as primary/secondary education or higher education.

In relation to data analysis, descriptive analyses were initially performed using absolute and relative frequencies, mean, median, standard deviation, quartiles, and minimum and maximum values. Subsequently, the relationships between dependent and independent variables were examined using bivariate and multivariate analyses.<sup>(18)</sup> To analyze the association between salivary cortisol levels upon awakening and sociodemographic variables, simple and multiple linear regression models were used. These models assume that residuals follow a normal distribution with a mean of zero and constant variance ( $\sigma^2$ ).<sup>(18)</sup>

To analyze the association between perceived stress scores and sociodemographic variables, a regression model with a negative binomial distribution and crude and adjusted log link functions was used, as this outcome is a discrete variable rather than continuous, such as cortisol. Tukey’s post hoc test was used for multiple comparisons involving categorical variables with more than two levels. Differences were considered statistically significant when  $p < 0.05$ .<sup>(18)</sup> All statistical analyses were performed using the Statistical Analysis System for Windows version 9.4 under the supervision of a statistician.

The study complied with national and international ethical standards for research involving human subjects. The parent project was submitted to the *Universidade Federal de São Carlos* Institutional Review Board, in accordance with Resolution 466/2012 of the Brazilian National Research Ethics Commission of the Brazilian National Health Council, and was approved under Opinion 5,261,942 on February 24, 2022.

## Results

Thirty family caregivers of children and adolescents with Down syndrome participated in the study, most of whom were mothers, with a mean age of approximately 40 years. Table 1 presents the sociodemographic characteristics of participants.

**Table 1.** Sociodemographic characterization of family members of children/adolescents with Down syndrome (n=30)

Variables	n (%)	
Skin color		
White	24 (80)	
Non-white	6 (20)	
Education		
Elementary school/high school	13 (43.33)	
Higher education	17 (56.67)	
Occupation		
Paid work	22 (73.33)	
Unpaid work	8 (26.67)	
Anxiolytics or antidepressants		
No	20 (66.67)	
Yes	10 (33.33)	
	<b>Mean (standard deviation)</b>	<b>Minimum-Maximum</b>
Age	39.7 (7.37)	22-55
Family income	8,713.33	1,200-30,000

Regarding salivary cortisol upon awakening, the mean value was 0.44  $\mu\text{g/dL}$ , which is within the expected range for that time. The mean perceived stress score was 31.9 points, ranging from 21 points (indicative of low stress) to 43 points (very high stress). Of the participants, 18 (60%) reported experiencing at least one stressful event in the previous 30 days. However, as shown in Table 2, salivary cortisol levels upon awakening and perceived stress scores were similar to those of participants who did not report recent stressful events.

Another noteworthy finding concerns salivary cortisol concentrations among different family members. Mothers and fathers presented values below 0.736  $\mu\text{g/dL}$ , therefore within the normal range. In contrast, the sibling caregiver presented a concentration of 0.98  $\mu\text{g/dL}$ , suggesting greater activation of the hypothalamic–pituitary–adrenal axis and possibly higher physiological stress levels. A difference was also observed in salivary cortisol concentrations between caregivers with paid work and those without paid work (0.49  $\mu\text{g/dL}$  versus 0.29  $\mu\text{g/dL}$ , respectively), although both values remain within the expected range for the time of awakening.

The following tables present the regression models used to analyze the association between the variables of interest, salivary cortisol levels (Table 3) and perceived stress scores (Table 4). In the unadjusted model, that is, without adjustment for potential confounding variables, a statistically significant association was observed between degree of kinship and salivary cortisol concentration ( $p = 0.019$ ). Specifically, it is

**Table 2.** Cortisol levels upon waking and perceived stress levels of family caregivers of children/adolescents with Down syndrome (n=30) according to categorical sociodemographic variables

	Cortisol levels upon waking		Perceived stress	
	Mean (standard deviation)	Median (Minimum-Maximum)	Mean (standard deviation)	Median (Minimum-Maximum)
Kinship				
Sibling	0.98 (-)	0.98 (0.98 - 0.98)	30 (-)	30 (30 - 30)
Mother	0.45 (0.23)	0.41 (0.05 - 0.83)	32.08 (5.41)	32 (21 - 43)
Father	0.26 (0.18)	0.21 (0.07 - 0.52)	31.25 (4.35)	32.5 (25 - 35)
Skin color				
White	0.45 (0.24)	0.40 (0.05 - 0.98)	31.7 (5.25)	32 (21 - 43)
Non-white	0.40 (0.30)	0.31 (0.08 - 0.79)	32.67 (5.01)	33.5 (25 - 39)
Education				
Elementary school/high school	0.43 (0.28)	0.41 (0.05 - 0.98)	33.46 (4.37)	34 (25 - 43)
Higher education	0.44 (0.23)	0.39 (0.07 - 0.83)	30.63 (5.48)	31.5 (21 - 40)
Marital status				
With partner	0.43 (0.24)	0.39 (0.05 - 0.83)	31.96 (5.39)	32 (21 - 43)
Without partner	0.52 (0.42)	0.41 (0.16 - 0.98)	31.33 (2.31)	30 (30 - 34)
Occupation				
Paid work	0.49 (0.26)	0.45 (0.07 - 0.98)	31.86 (4.86)	32 (21 - 40)
Unpaid work	0.29 (0.18)	0.34 (0.05 - 0.57)	32 (6.14)	31.5 (22 - 43)
Anxiolytics or antidepressants				
No	0.46 (0.26)	0.42 (0.07 - 0.98)	32.15 (4.33)	32 (23 - 43)
Yes	0.39 (0.24)	0.34 (0.05 - 0.80)	31.33 (6.86)	33 (21 - 40)
Stressful event				
No	0.51 (0.18)	0.51 (0.21 - 0.80)	31.83 (6.38)	31.5 (21 - 43)
Yes	0.39 (0.28)	0.32 (0.05 - 0.98)	31.94 (4.25)	32 (22 - 40)

**Table 3.** Analysis of the relationship between variables of interest and salivary cortisol levels in family caregivers of children/adolescents with Down syndrome

Variable	Unadjusted model				Adjusted model (n=30)			
	Estimated effect	P-value	Confidence Interval (95%)		Estimated effect	P-value	Confidence Interval (95%)	
Family member age <sup>1</sup>	-0.007	0.267	-0.020	0.006	0.002	0.775	-0.014	0.018
Kinship								
Sibling versus mother	0.530	0.072	-0.040	1.100	0.574	0.266	-0.333	1.482
Sibling versus father	0.718	0.019	0.106	1.330	0.831	0.079	-0.083	1.745
Mother versus father	0.188	0.224	-0.087	0.463	0.257	0.096	-0.039	0.553
Skin color								
White versus non-white	0.052	0.659	-0.186	0.290	0.035	0.754	-0.194	0.264
Education								
Elementary school/high school versus higher education	-0.018	0.852	-0.210	0.175	0.118	0.340	-0.134	0.370
Marital status								
With partner versus without partner	-0.089	0.568	-0.405	0.227	0.093	0.639	-0.315	0.501
Occupation								
Paid work versus unpaid work	0.196	0.057	-0.006	0.398	0.263	0.030	0.029	0.498
Family income <sup>2</sup>	0.001	0.827	-0.012	0.015	0.010	0.271	-0.009	0.029
Anxiolytics or antidepressants								
No versus yes	0.063	0.525	-0.138	0.264	0.065	0.525	-0.144	0.273
Stressful event								
No versus yes	0.128	0.175	-0.060	0.317	0.147	0.135	-0.050	0.344

<sup>1</sup> An increase/decrease in cortisol was estimated for each one-unit increase in the family member's age<sup>2</sup> It was estimated that cortisol levels increased/decreased with each R\$1,000.00 increase in income

estimated that, on average, the sibling caregiver's cortisol level is 0.718 µg/dL higher than that of the father.

However, in the adjusted model, in which the effect was controlled for other variables included in the

**Table 4.** Analysis of the relationship between variables of interest and the perceived stress score of family caregivers of children/adolescents with Down syndrome

Variable	Unadjusted model				Adjusted model (n=30)			
	Estimated effect	P-value	Confidence Interval (95%)		Estimated effect	P-value	Confidence Interval (95%)	
Family member age <sup>1</sup>	1.002	0.675	0.993	1.011	1.004	0.550	0.991	1.017
Kinship								
Sibling versus mother	0.935	0.931	0.605	1.446	1.014	0.999	0.500	2.055
Sibling versus father	0.960	0.978	0.596	1.546	1.076	0.968	0.530	2.187
Mother versus father	1.027	0.960	0.819	1.287	1.062	0.841	0.827	1.364
Skin color								
White versus non-white	0.970	0.708	0.829	1.136	1.021	0.817	0.855	1.219
Education								
Elementary school/high school versus higher education	1.093	0.179	0.960	1.243	1.108	0.308	0.910	1.349
Marital status								
With partner versus without partner	1.020	0.855	0.824	1.263	1.156	0.369	0.843	1.586
Occupation								
Paid work versus unpaid work	0.996	0.952	0.862	1.150	1.093	0.340	0.910	1.313
Family income <sup>2</sup>	0.994	0.228	0.985	1.004	0.993	0.377	0.978	1.008
Anxiolytics or antidepressants								
No versus yes	0.994	0.228	0.985	1.004	0.993	0.377	0.978	1.008
Stressful event								
No versus yes	0.997	0.960	0.874	1.136	0.949	0.506	0.814	1.107

<sup>1</sup> An increase/decrease in cortisol was estimated for each one-unit increase in the family member's age

<sup>2</sup> It was estimated that cortisol levels increased/decreased with each R\$1,000.00 increase in income

analysis, the variable “degree of kinship” lost statistical significance. In contrast, the variable “paid work” showed a significant association. According to the adjusted model, it is estimated that, on average, family members with paid work have cortisol levels 0.263 µg/dL higher than those without paid work. Finally, no factors associated with perceived stress were identified.

## Discussion

First, it is important to highlight the inclusion of family caregivers other than the maternal figure in this study. In general, studies involving caregivers of children and adolescents with special health needs tend to include exclusively mothers.<sup>(19–20)</sup> Although, historically and culturally, women are primarily responsible for childcare, this perspective should be reconsidered, as paternal involvement is beneficial for the development and strengthening of family bonds, as well as for mitigating adverse effects associated with its absence in child development.<sup>(21)</sup> Another distinctive aspect of this study is the inclusion of family caregivers of

children and adolescents diagnosed with Down syndrome, whereas most studies include various conditions grouped under the term “children with neurodevelopmental disorders”.

Participants' salivary cortisol levels upon awakening averaged 0.44 µg/dL (12.1 nmol/L). This value is lower than that reported in a cross-sectional study that investigated cortisol levels upon awakening in parents of children with various chronic conditions, such as Down syndrome, autism spectrum disorder, cerebral palsy, and type 1 diabetes mellitus. In that study, the mean cortisol level upon awakening among 31 family caregivers of children with Down syndrome was 19.0 nmol/L.<sup>(11)</sup> Furthermore, another study assessing salivary cortisol levels upon awakening in mothers and primary caregivers of children with cerebral palsy reported a mean of 0.70 µg/dL, which is higher than that observed in the present study.<sup>(12)</sup>

Lower cortisol levels among family caregivers of children with chronic conditions have been identified in studies comparing this biomarker with that of parents of healthy children.<sup>(22,11,24)</sup> The hypothesis of reduced cortisol activity is consistent with the concept of a protective physiological response among individ-

uals experiencing chronic stress. Furthermore, low cortisol levels have also been reported in individuals with post-traumatic stress disorder.<sup>(25)</sup>

According to the results, the mean perceived stress score was 31.9 points, supporting findings from a quantitative study conducted with 57 mothers of children receiving care at a medium-complexity outpatient clinic providing rehabilitation for neuromotor and sensory conditions in a municipality in the countryside of the state of São Paulo. The mean score obtained using the Perceived Stress Scale in that study was 30.56 points.<sup>(19)</sup> In contrast, a study conducted in Turkey with 181 mothers of children with physical and/or mental disabilities reported a lower mean perceived stress score of 24.99.

The regression models applied to analyze the association between the variables of interest and salivary cortisol levels and perceived stress did not show statistically significant associations with most socio-demographic variables, except for occupation. In contrast, the previously cited study identified a negative correlation between perceived stress levels and the variables “maternal age” and “family income”; that is, mothers with higher perceived stress levels were younger and had lower family income ( $p = 0.0018$  and  $p = 0.0284$ , respectively).<sup>(19)</sup> Furthermore, contrary to the present findings, a meta-analysis examining the relationship between parental stress and marital status showed that married or cohabiting parents reported lower parental stress ( $p < 0.001$ ).

According to the analyses performed, it is estimated that, on average, family members with paid employment have cortisol levels 0.263  $\mu\text{g/dL}$  higher than those without paid employment. No studies were identified reporting a statistically significant association between occupation and cortisol levels among family caregivers. Although it does not directly address occupation, a 2011 study involving mothers of children with cerebral palsy reported an association between family income and cortisol concentration. According to the authors, mothers living in precarious socioeconomic conditions while caring for a child with disabilities presented higher stress levels.<sup>(12)</sup>

The main limitations of this study include the use of convenience sampling and the absence of a prior sample size calculation, which may limit the generalizability of the findings to other caregiver populations.

Additionally, low participation of family members other than mothers was observed. Therefore, future studies should include broader family participation and adopt probabilistic sampling methods to strengthen the robustness and external validity of results.

As for practical implications, this study contributes to the existing literature on the challenges faced by family caregivers of children and adolescents with Down syndrome. In addition, it reinforces the importance of incorporating objective measures in nursing research to complement the self-reported stress measures commonly used in studies on family care.

## Conclusion

The results indicated scores consistent with moderate perceived stress levels among family caregivers of children and adolescents with Down syndrome, with no factors identified as associated with this outcome. Mean salivary cortisol concentrations upon awakening remained within normal limits. In the adjusted regression model, the variable “occupation” was the only factor that remained statistically associated with cortisol levels.

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