


Caregiving of children with Down syndrome: impact on quality of life, stress, mental and oral health

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Abstract

Aim: Parental caregivers of children with Down Syndrome (DS) have a greater burden of daily activities that may affect their health. The aim of this exploratory study was to evaluate the impact of caregiving of children with Down syndrome on parenting quality of life, stress, mental and oral health.

Methods: Fifty-four parental caregivers of children with DS and 51 parents of children without physical or mental disabilities participated of this study. All participants were clinically examined to evaluate the presence of dental caries, gingival conditions and answered a sociodemographic questionnaire. Depression, anxiety, quality of life and coping strategies were assessed using specific instruments. Hair cortisol level was assessed as biological marker of chronic stress.

Results: Psychological and quality of life parameters were similar between the groups of caregivers ($p > .05$). Caregivers of children with DS were older (48.6 vs. 41.5, $p < .001$), had longer caregiving period (> 10 vs < 10 years, $p = .003$), presented higher gingival bleeding index (6.1 vs. 4.7, $p = .014$) and higher cortisol levels (55.9 vs. 38.4, $p = .07$) as compared with parents of children without disabilities. Sociodemographic data has no influence on cortisol levels ($p > .05$).

Conclusions: These findings suggest that the caregiving of children with DS has an impact on parenting oral health and stress.

KEYWORDS

caregiver, Down syndrome, oral health, quality of life, stress

1 | INTRODUCTION

Caregiving has been often associated with worsen physical and mental health activities, poorer economic conditions, lack of emotional support and poor quality of life. The caregiver of a disabled person is usually a family member who does not have specific training, knowledge, or psychological skills for the daily duties.^{1–6} Caregivers of children with Down syndrome (DS) present a high burden,

as they are deeply engaged in their child's education and care. Parental caregivers of these children may develop chronic disorders that are often stress-related, including depression and anxiety disorders.^{2,3,6,7}

Previous studies have indicated that chronic stress could be related to tooth decay due to lifestyle changes, such as excessive sugar intake and poor oral hygiene, or stress-induced changes in salivary flow and composition.^{6,8–10}

Although several studies have reported the general and oral health of individuals with DS,^{11–15} there are no studies reporting the oral health of parental caregivers of individuals with Down syndrome. Therefore, the objective of this exploratory study was to evaluate the impact of caregiving of children with Down syndrome on parenting quality of life, stress, mental and oral health.

2 | MATERIAL AND METHODS

2.1 | Participants

Fifty-four parental caregivers of children with DS were recruited from local educational institutions for disabled persons and were also selected from the Pediatric Dentistry Clinic of the Faculty of Dentistry of the Federal University of Rio Grande do Sul. Fifty-one parents of children without physical or mental disabilities were recruited from local community (controls). This research study was approved by the Research Ethics Committee of the Federal University of Rio Grande do Sul (#1.967.497). All participants were previously informed of the objectives of this study and signed an informed consent.

2.2 | Intraoral clinical examinations

Intraoral clinical examinations were performed in a dental office by a single trained and experienced examiner. The kappa coefficient for intra-examiner reproducibility for dental caries assessments was 0.97. The same examiner recorded the participants' gingival bleeding before the dental examination, using the gingival bleeding index (GBI).¹⁶ After this examination, each participant received professional prophylaxis. Dental caries was diagnosed according to the criteria of the World Health Organization and registered using the Decayed, Missing and Filled Surfaces (DMFS) index.¹⁷

2.3 | Sociodemographic questionnaire

Participants answered a structured questionnaire addressing sex, age, ethnicity, caregivers' schooling, household income, degree of relatedness and caregiving period, based on previous studies.^{14,18,19} Ethnic group was defined based on skin color (white, brown, or black) and subsequently dichotomized as white or non-white. Caregiver's schooling was based on a statistical criterion (median), recorded in number of complete years of study and was categorized as 8 years, it means that 8 years of schooling means that a person finished elementary school. Household income was defined in Brazilian currency (real) of all residents

in the home and subsequently was categorized based in a statistical criterion (median) since the variable did not have pre specified values in terms of Brazilian minimum wage ($< \$722.00$, $\geq \$722$ per month). Degree of relatedness was classified as mother and other family member. Caregiving period was categorized as <5 years, ≥ 5 and <10 years, ≥ 10 years.^{14,18,19}

2.4 | Assessment of depression, anxiety, coping strategies and quality of life

Validated instruments for assessing depression (Beck's Depression Inventory), anxiety (Beck's Anxiety Inventory), coping strategies (Coping Health Inventory for Parents) and general quality of life (WHOQOL-BREF) were applied to all study participants.^{17,20–22}

2.5 | Analysis of hair cortisol level

Hair cortisol is a long-term retrospective measure of systemic cortisol exposure, and it was used here as biological marker of chronic stress. Samples of 3 cm of hair were collected from the participants, as previously described.²³ Based on an average hair growth rate of 1 cm per month, the capillary segment reflected the cumulative cortisol secretion of the last 3 months, on average.²⁴

Hair strands with a 3 mm diameter were cut from the vertex posterior of participants, properly identified, and stored at room temperature for further analysis. Hair cortisol extraction followed the protocol described in the literature.^{23,25} The hair cortisol levels were quantified by a commercially available immunoenzymatic assay for assessing salivary cortisol (ELISA cortisol kit, Enzo Life Sciences, Inc., Farmingdale, USA), following the manufacturer's instructions. Dyed hair color has no effects on cortisol concentrations. All analyzes were performed in duplicates.

2.6 | Statistical analysis

The distribution of the analyzed variables was assessed using the Shapiro-Wilk test. Descriptive measures were summarized by means and standard deviations (SD), or medians and interquartile ranges (IQR), as appropriate. To test differences between study groups, the Chi-squared test and Fisher's exact test were used for categorical variables. For continuous variables, Student's *t*-test or Mann-Whitney test were used. Analysis of covariance (ANCOVA) was performed to investigate between group main differences in cortisol controlling for age. Linear regression models were developed to investigate the association

TABLE 1 Characteristics of parental caregivers of children with DS and controls

	DS-caregivers n (%)	Controls n (%)	<i>p</i> value
Sex			
Male	9 (16.7%)	12 (23.5%)	
Female	45 (83.3%)	39 (76.5)	.38 ^a
Age (years) – mean (± SD)	48.6 (11.1)	41.5 (9.4)	<.001 ^b
Household income/ month (US\$)			
≤722	39 (49.4)	40 (50.6)	
>722	15 (51.7)	14 (48.3)	1.00 ^a
Caregiver's schooling (years)			
<8	12 (60.0)	8 (40.0)	
≥8	42 (47.2)	47 (52.8)	.431 ^a
Caregiving period (years)			
<5	10 (18.9)	5 (0.09)	
5 to 10	8 (15.0)	24 (43.6)	
>10	35 (66.0)	26 (47.3)	.003 ^c

Abbreviation: DS-caregivers, parental caregivers of children with Down syndrome;

^aQui-square test.

^bStudent's *t* test.

^cFisher test.

between sociodemographic variables and hair cortisol concentrations. The analyses were performed using the software R 4.0.2 (R Core Team, Vienna, Austria). Two-tailed *p* values less than .05 were considered statistically significant.

3 | RESULTS

Table 1 shows the characteristics of the studied populations. Forty-five caregivers of DS-children and 49 controls were females ($\chi^2 = 0.77$, $p = .38$). Parental caregivers of children with DS were slightly older (48.6 years) than controls (41.5 years, $p < .001$). Around 66% of caregivers of DS-children had taken care of the children for more than 10 years, as compared to 47% of controls ($p < .05$). No differences were observed for sex, household income, and caregiver's schooling between groups.

Table 2 shows the assessments of oral health, mental health, quality of life and coping strategies of the subjects. Caregivers of children with DS had higher values of GBI when compared to controls ($p = .01$). No differences were observed for the DMFS index between groups. Both groups were similar concerning the quality of life assessments, psychological scores and coping strategies.

TABLE 2 Oral health, quality of life, mental health and coping strategies of parental caregivers of children with DS and controls

	DS-caregivers	Controls	<i>p</i> -value
<i>Oral Health</i> ^a			
DMFS – median (IQR)	49.0 (44.2)	40 (25.0)	.148
GBI – median (IQR)	6.1 (4.6)	4.7 (6.5)	.014
<i>Quality of life</i> ^b			
Quality of life – mean (± SD)	3.7 (0.8)	3.5 (0.9)	.100
Satisfaction with health – mean (± SD)	3.5 (0.8)	3.4 (0.9)	.626
Physical domain – mean (± SD)	52.8 (10.1)	55.9 (10.5)	.116
Psychological domain – mean (± SD)	57.8 (9.6)	59.1 (10.7)	.506
Social domain – mean (± SD)	61.6 (15.9)	58.3 (17.6)	.316
Environmental domain – mean (± SD)	53.6 (11.9)	53.8 (10.9)	.962
<i>Psychological variables</i> ^a			
Depression – median (IQR)	10.0 (9.2)	8.0 (7.0)	.124
Anxiety – median (IQR)	9.0 (7.0)	8.0 (9.5)	.629
Coping strategies – median (IQR)	1.5 (0.7)	1.5 (0.5)	.762

Abbreviations: DS-caregivers, parental caregivers of children with Down syndrome; DMFS, decayed, missing and filled surfaces; GBI, Gingival Bleeding Index; IQR, interquartile range.

^aMann-Whitney-Wilcoxon test.

^bStudent *t* test.

Hair cortisol was determined as a biological marker of chronic stress (Figure 1). caregivers of children with DS had higher cortisol levels (median = 55.95, IQR = 49.76) than controls (median = 38.42, IQR = 49.77), however this only approached statistical significance (Mann-Whitney $U = 969$, $p = .07$). Because aging is associated with increasing cortisol levels,²⁵ ANCOVA was applied to adjust for this confounder ($F [2, 1] = 2.07$, $p = .13$). In addition, hair cortisol levels were not associated with sociodemographic data ($p > .05$, Table 3).

4 | DISCUSSION

Caregivers of disabled person face additional burden in their daily activities due to the peculiarities of the type of individual being cared for.^{1,4} This burden could lead to poorer health conditions in parental caregivers of individuals with Down syndrome. However no studies were found about this topic. This pioneer study evaluated the impact of

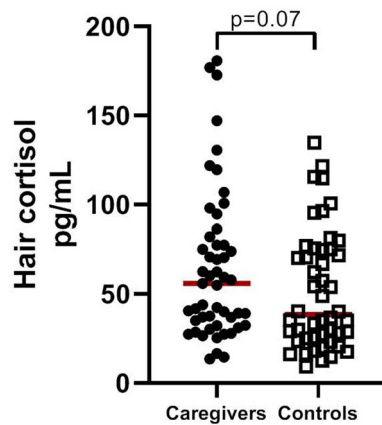


FIGURE 1 Hair cortisol levels of parental caregivers of children with DS and controls. Data shown as individual values and medians. Mann-Whitney *U* test, $p = .07$

TABLE 3 Univariable estimates of the association between sociodemographic variables and hair cortisol levels

Independent variable	Group	Beta	<i>p</i> -value
Sex	DS-caregivers	-0.130	.357
	Controls	0.103	.476
Age	DS-caregivers	0.060	.674
	Controls	0.180	.211
Household income	DS-caregivers	0.196	.163
	Controls	-0.188	.196
Caregiver's schooling	DS-caregivers	0.233	.148
	Controls	0.038	.813
Caregiving period	DS-caregivers	-0.103	.474
	Controls	0.275	.054

Abbreviation: DS-caregivers: parental caregivers of children with Down syndrome.

caregiving of children with Down syndrome on parenting quality of life, stress, mental and oral health.

In the present study, when evaluating oral health conditions, parental caregivers of children with DS had a higher rate of gingival bleeding compared to controls. This observation suggests that oral health care may be deficient in these caregivers, in agreement with previous studies that have indicated that caregivers of individuals with intellectual disabilities have little time for themselves and their own care.^{6,26} Caregivers often neglect their own health in favor of prioritizing the person being cared for, leading to the deterioration of their health and quality of life.^{5,6,27}

Family caregivers perceive problems in their health only when they become unable to perform their daily activities, as the focus of their attention is on the cared for, making it difficult to perceive themselves as individuals who also suf-

fer and require attention and care.^{28,29} It has been shown that parental caregivers may develop fibromyalgia, hypertension, and gastritis, among other health problems, associated with heavy caring demands.^{30,31}

Parents are major contributors to the development of their children. There is a need to address the burden and psychiatric co-morbidity in caregivers to enhance their caregiving ability.²⁸ Parental caregivers often experience high levels of anxiety, depression, stress, morbidity, physical problems, and poor quality of life.^{28,32–36} However, no differences in psychological variables of depression and anxiety were found between the participants of the present study.

A recent study reported that symptoms of depression, anxiety and stress were associated with higher levels of dental caries experience for caregivers of people with intellectual disabilities.⁶ With regard to dental caries experience, the present study showed similar results for the two groups of caregivers.

General quality of life and coping strategies were similar between parental caregivers of children with DS and controls in the present study. Previous studies have also shown that most caregivers of individuals with DS show increasing friendliness and ease to adapt to situations, which may facilitate social interaction of parents/caregivers in their daily life.^{37,38}

Previous studies have also indicated the caregiving stress may be experienced at different intensities.^{11,39,40} In the present study, although similar scores of anxiety and depression were found in the groups, parental caregivers of children with DS had higher cortisol levels as compared to controls (although this only approached statistical significance). As hair cortisol represents cumulative stress exposure over the last three months, it could be better informative than questionnaires assessing short-term perceptions. Differences in coping strategies developed by the parental caregivers of children with DS as compared to controls may explain the stress-related differences between groups.

Sex plays an important role where female caregivers experience more burden and psychiatric morbidity.²⁸ The present study observed that the majority of caregivers were female. This is in line with previous studies showing that mothers usually fulfill this full-time role. When different areas of stress were considered, mothers were more stressed compared with fathers in daily care, emotions and social stress.²⁸ The maternal figure usually displays feelings of selflessness, donation, altruism, closeness, submission and even guilt for the disabled children and their living conditions, reinforcing the real need for support of these individuals. In general, women often take on the role of care, due to traditional conceptions that females present great skill and knowledge regarding caring for their families.^{34,35,41–44} With regard to the coping

strategies adopted by parental caregivers, studies suggest that women are more likely to adopt more positive coping strategies than men.^{1,45-47} This could be explained due to family resilience, which is not problem-related, but rather to its ability to deal with and resolve such problems.^{41,48}

Although no differences were found in the psychological variables of mental health and quality of life between caregivers and controls, it should be noted that the act of caring for an individual is burden that generates an overload. Furthermore caregiving burden and depression may vary depending on the characteristics of disabled person.⁵ Stress-related issues, emotional problems and worsen quality of life are reported frequently, but parental caregivers may remain resilient due to the different coping strategies that they adopt.

Limited samples sizes may have influenced the study's lack of power. This study obtained a convenience sample which resulted in a selection bias. As parental caregivers of children with DS were recruited through educational and health services, the results represent the views of parents who accessed these services. Parents who visit these services may have different views and perceptions in relation quality of life compared to parents who do not access these services.⁴⁸ Therefore, the results of the present study should be interpreted with caution and cannot be generalized. Future studies should be carried out using a larger number of participants to assess stress-reactivity, such as realistic exposure to acute stressors, differences in coping strategies and different stress-related hormones.

5 | CONCLUSION

The results of the present study indicate that caregiving of children with DS has an impact on parenting oral health and stress.

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CONFLICTS OF INTEREST

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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