

# SUBJECTIVE ORAL HEALTH MEASURES IN CAREGIVERS OF PATIENTS WITH AUTISM SPECTRUM DISORDER AND DOWN SYNDROME: A PRELIMINARY STUDY

Juliana Vianna PEREIRA<sup>1</sup> , Tamiris Christensen BUENO<sup>2</sup> , Fernando José HERKRATH<sup>3</sup> ,  
Mirlena Mansur Dionizio DA SILVA<sup>4</sup> , Milena Cardia LEME<sup>5</sup> , Alan Roger DOS SANTOS-SILVA<sup>5</sup> ,  
Márcio Ajudarte LOPES<sup>6</sup> 

<sup>1</sup> School of Dentistry, Federal University of Amazonas – UFAM, Manaus, Amazonas, Brazil, Manaus, Amazonas, Brazil.

<sup>2</sup> Postgraduate program in Stomatopathology, University of Campinas - UNICAMP, Piracicaba Dental School, Piracicaba, São Paulo, Brazil.

<sup>3</sup> School of Health Sciences, University of the State of Amazonas - UEA, Manaus, Amazonas, Brazil.

<sup>4</sup> OROCENTRO, University of Campinas - UNICAMP, Piracicaba Dental School, Piracicaba, São Paulo, Brazil.

<sup>5</sup> Undergraduate Course in Dentistry, Piracicaba Dental School, University of Campinas - UNICAMP, Piracicaba, São Paulo, Brazil.

<sup>6</sup> Oral Diagnosis Department, University of Campinas - UNICAMP, Piracicaba Dental School, Piracicaba, São Paulo, Brazil.

## Corresponding author:

Juliana Vianna Pereira  
juvpereira@ufam.edu.br

**How to cite:** PEREIRA, J.V., et al. Subjective oral health measures in caregivers of patients with autism spectrum disorder and Down syndrome: A preliminary study. *Bioscience Journal*. 2023, **39**, e39008. <https://doi.org/10.14393/BJ-v39n0a2023-62137>

## Abstract

This study aimed to address the subjective oral health measures of caregivers of individuals with autism spectrum disorder (ASD) and Down syndrome. This cross-sectional study included 15 caregivers of individuals with ASD (n = 7) and Down syndrome (n = 8). Sociodemographic data, sense of coherence (SOC) (SOC-13 scale), social support (Social Support Scale [MOS-SSS]), oral health-related quality of life (OHRQoL) (OHIP-14), and self-rated oral health assessed on a 5-point Likert scale were collected. A descriptive analysis was performed in addition to correlation analyses (Spearman correlation coefficient). Most primary caregivers were parents of the individual (86.6%). The age of the caregivers ranged between 40 and 59 years (60%). Most caregivers have had 9 to 11 years of education (53.3%). Monthly family income was less than USD 186,28 for ASD caregivers (57.2%) and between USD 327,56 and USD 931,40 for Down syndrome caregivers (50%). Of the caregivers, 33.3% reported good oral health and 33.3% reported neither good nor bad. The average SOC score, social support and OHRQoL was 48.9, 69.3 and 10.9, respectively. The higher the family income, the better the OHRQoL ( $r_s = -0.62$ ,  $p = 0.014$ ). SOC was correlated with the score of the emotional support domain ( $r_s = 0.54$ ,  $p = 0.039$ ). It was concluded that caregivers had a strong SOC and high perceived support. Moreover, caregivers did not report a high impact on OHRQoL. A better understanding of the caregivers' protective and coping factors in caring for individuals with disabilities may better promote their quality of life.

**Keywords:** Disabled Persons. Family Caregivers. Quality of Life. Sense of Coherence. Social Support.

## 1. Introduction

Attention to parents and caregivers of people with disabilities has been growing in recent years (Nordahl-Hansen et al. 2018). Disability has evolved from a concept based on an individual's limitations to a more comprehensive model, that considers the influence of social and environmental factors on disability. The Convention on the Rights of Persons with Disabilities, proclaimed by the United Nations in 2006, states that persons with disabilities are those with long-term physical, mental, intellectual, or

sensory disabilities that, in interaction with various barriers, can impede their full and effective participation in society on equal terms (UN 2006). The World Health Survey conducted in 59 countries showed that the prevalence of disabilities in the adult population was 15.6%, ranging from 11.8% in higher-income countries to 18.0% in lower-income countries. For individuals under the age of 14 years, the overall prevalence was 5.1%, ranging from 2.8% in high-income countries to 6.4% in America (WHO 2011). According to the 2010 Census, approximately 24% of the Brazilian population have some degree of difficulty in at least one of the investigated skills or a mental/intellectual disability. A total of 6.7% of Brazilians have significant difficulties in these areas (IBGE 2011).

Among intellectual and behavioral alterations, conduct disorders and antisocial behaviors are the most common in children and youths (NICE 2017). Autism spectrum disorder (ASD) is characterized by the presence of restricted interests, repetitive behaviors, deficits in social interaction, and reciprocal social complications (DSM-5 2013). It is a neurodevelopmental disorder that is commonly diagnosed during childhood (Wang et al. 2012).

Down syndrome is the most prevalent genetic condition, and the most common genetic cause of intellectual disability (Kazemi et al. 2016). Individuals with this condition have characteristics such as low ears, small teeth, flattened nose, stunted, atypical growth, and hypotonia. They also have developmental delays and constitute most of the individuals with disabilities who we see in dentistry (Wang, et al. 2012).

Parents of individuals with intellectual disabilities experience greater psychological distress and lower quality of life (Staunton et al. 2020). A recent study conducted with caregivers of children and young adults with disabilities, including ASD and Down syndrome, revealed that most caregivers were unemployed married mothers with low education and health problems. Moreover, older caregivers showed a greater burden and a more significant impact on the quality of life (Barros et al. 2019). Furthermore, caregivers are often physically tired and mentally frustrated, anxious, helpless, and hopeless (Caicedo 2014). Yet, there is little information on the subjective indicators that may impact the well-being and quality of life of this population. Thus, this study aimed to address the sociodemographic characteristics, sense of coherence, social support, and oral health outcome measures of caregivers of patients with ASD and Down syndrome.

## **2. Material and Methods**

### **Ethical aspects**

The study was conducted following the Declaration of Helsinki and approved by the Ethics Committee of the Piracicaba Dental School (protocol no. 31448820.2.0000.5418). The caregivers signed an electronic informed consent before participating in the study. This cross-sectional study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (von Elm et al. 2014).

### **Study design, setting, and participants**

In total, 15 family caregivers who took care of the daily activities of individuals with ASD ( $n = 7$ ) and Down syndrome ( $n = 8$ ) were included. The study was conducted at the Service of Diagnosis and Treatment of Oral Injuries, Piracicaba Dental School, University of Campinas (UNICAMP), Brazil, for dental treatment, from October to December 2020.

This preliminary study evaluated 25% of an estimated 60 caregivers of patients with ASD and Down syndrome. This sample has a 90% power to detect differences in the 5.0 points in the scales used, considering a standard deviation of 10.0, a correlation of 0.7, and a significance level of 5% in paired samples, when compared to caregivers of individuals without disabilities.

### **Data collection and study variables**

Considering the suspension of dental care during the study period due to the coronavirus disease (COVID-19) pandemic, caregivers were selected from the scheduling system of patients with ASD and

Down syndrome who were undergoing treatment at the OROCENTRO, regardless of age. Caregivers, aged < 18 years, and those with syndromes were excluded. All caregivers of patients with ASD (n=16) and Down syndrome (n=10) attending the OROCENTRO were invited. The response rate was 57.7%.

The invitation to participate in the survey was sent via a cell phone message, together with a link to access the survey from Google Forms, as well as the study details and informed consent. The electronic survey contained questions relating to sociodemographic characteristics (sex, age, educational level, and family income), sense of coherence, social support, and self-reported oral health outcome measures (oral health-related quality of life [OHRQoL] and self-rated oral health).

Caregivers completed a structured questionnaire to collect data on their educational level and monthly family income. The former was assessed based on the years of schooling. Monthly family income was categorized as follows: (1)  $\leq 1$  Brazilian minimum wage (BMW), (2)  $> 1 \leq 2$  BMW, (3)  $> 2 \leq 5$  BMW, (4)  $> 5 \leq 10$  BMW, and (6)  $> 10$  BMW. The currency conversion was approximately 1 BMW = 186.28 USD.

To assess the sense of coherence (SOC), a version of the SOC 13-item scale (Antonovsky 1987) adapted cross-culturally to the Portuguese language (Bonanato et al. 2009) was used. The SOC-13 consists of 13 questions that are answered using a five-point Likert scale. When the score for a question was negative for the sense of coherence, it was inverted for the final score composition. The final score was obtained by adding the scores on each of the 13 items. The higher the score, the greater the SOC.

Social support was assessed using an adaptation from the Sherbourne and Stewart questionnaire (Sherbourne and Stewart 1991), specific to Brazil (Chor et al. 2001). The questionnaire had 19 items in five dimensions: material support, affective support, emotional support, positive social interaction, and information support. The total score is calculated as the average of the total score of all the dimensions, which are calculated by adding the value of each item (Griep et al. 2003).

To assess the OHRQoL, the short version of the Oral Health Impact Profile questionnaire (OHIP-14) was used. The OHIP-14 version used in this study was translated and validated for Brazil (Oliveira and Nadanovsky 2005). Through individual self-perception, the instrument assesses the biopsychosocial consequences of oral problems in seven dimensions: functional limitation, physical pain, psychological discomfort, physical, psychological, social, and disability. Higher scores indicate a worse OHRQoL (Oliveira and Nadanovsky 2005).

Self-rated oral health was assessed on a 5-point Likert scale in response to the question: "In general, how do you consider your oral health status (teeth and gums)?" (Atchison et al. 1998). The response options include "very good", "good", "neither good nor bad", "bad", and "very bad".

## Data analysis

Data were tabulated using Microsoft Excel, version 16.45 (Microsoft Excel, Microsoft Inc., Redmond, WA, USA). The data were then imported and analyzed using SPSS, version 25.0 (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp). Descriptive analysis was performed. Categorical variables were presented as absolute frequencies and percentages. The numerical variables are presented as means and standard deviations. Exploratory nonparametric correlation analyses were also performed between subjective oral health outcomes and other variables using Spearman's correlation coefficient.

## 3. Results

Fifteen caregivers of individuals with disabilities were evaluated: 7 with ASD and 8 with Down syndrome. In general, most patients with special needs had their mother or father as their primary caregiver (86.6%). Most caregivers were female (93.3%), aged between 40 and 59 years (60%), with 9 to 11 years of education (53.3%). The monthly family income was less than 1 BMW (USD 186,28) for ASD caregivers (57.2%) and between 2 and 5 BMW (USD 327,56 and USD 931,40) for Down syndrome caregivers (50%). Most caregivers reported good oral health (33.3%), or "neither good nor bad" (33.3%). The average score for the sense of coherence was 48.9. The average score for social support was 69.3. For OHRQoL the mean score was 10.9. A descriptive analysis of the caregivers' data is shown in Table 1.

**Table 1.** Sociodemographic characteristics, psychosocial factors, social support, oral health-related quality of life, and self-perceived oral health of caregivers of patients with ASD and Down syndrome.

Variables	ASD N=7	Down syndrome N=8	Total N=15
	7 (100.0)	7 (87.5)	14 (93.3)
Male	-	1 (12.5)	1 (6.7)
Caregiver-patient relationship N (%)			
Father or mother	7 (100.0)	6 (75.0)	13 (86.6)
Brother or sister	-	1 (12.5)	1 (6.7)
Uncle or aunt	-	1 (12.5)	1 (6.7)
Age, N (%)			
Between 18 and 25 years	1 (14.2)	-	1 (6.7)
Between 26 and 39 years	3 (42.9)	2 (25.0)	5 (33.3)
Between 40 and 59 years	3 (42.9)	6 (75.0)	9 (60.0)
Socioeconomic level			
Years of schooling, N (%)			
1 - 8 years	2 (28.6)	1 (12.5)	5 (33.3)
9 - 11 years	4 (57.2)	2 (25.0)	8 (53.3)
> 12 years	1 (14.3)	5 (62.5)	2 (13.4)
Family income/month, N (%)			
< 1 BMW	4 (57.2)	1 (12.5)	5 (33.3)
>1 BMW ≤ 2 BMW	1 (14.3)	3 (37.5)	4 (26.7)
>2 BMW ≤ 5 BMW	1 (14.3)	4 (50.0)	5 (33.3)
>5 BMW ≤ 10 BMW	1 (14.3)	-	1 (6.7)
Psychosocial factors, mean (SD)			
Sense of coherence	48.9 (5.7)	49.4 (6.0)	48.9 (6.0)
Social support, mean (SD)			
Total	68.8 (20.4)	70.9 (20.5)	69.3 (20.7)
Material Support	14.6 (4.7)	15.0 (4.7)	14.7 (4.7)
Affective Support	11.9 (3.6)	12.1 (3.2)	11.9 (3.2)
Emotional Support	13.8 (4.1)	14.3 (4.2)	14.0 (4.7)
Information support	14.2 (4.7)	14.8 (4.5)	14.3 (4.7)
Social interaction support	14.4 (5.0)	14.6 (5.1)	14.5 (5.0)
OHRQoL - OHIP-14, mean (SD)			
Functional limitations	0.9 (1.1)	1.0 (1.4)	0.9 (1.2)
Physical pain	2.9 (2.2)	2.1 (1.6)	2.5 (1.9)
Psychological discomfort	3.7 (2.9)	3.0 (2.1)	3.3 (2.4)
Physical disability	0.9 (1.6)	0.6 (0.9)	0.7 (1.2)
Psychological disability	2.3 (3.4)	1.0 (0.9)	1.6 (2.4)
Social disability	1.4 (2.5)	1.1 (1.5)	1.3 (1.9)
Handicap	1.1 (1.3)	0.1 (0.4)	0.6 (1.4)
Self-rated oral health, N (%)			
Very good	2 (28.6)	1 (12.5)	3 (20.0)
Good	1 (14.3)	4 (50.0)	5 (33.3)
Neither good nor bad	3 (42.8)	2 (25.0)	5 (33.3)
Bad	1 (14.3)	-	1 (6.7)
Very bad	-	1 (12.5)	1 (6.7)

ASD= Autism Spectrum Syndrome, SD=Standard Deviation, BMW= Brazilian Minimal Wage (One BMW was USD 186.28 in the study period).

Correlation analyses showed that the higher the family income, the better the OHRQoL ( $r_s = -0.62$ ,  $p = 0.014$ ). SOC was also correlated with the score of the emotional support domain of the social support scale ( $r_s = 0.54$ ,  $p = 0.039$ ). In contrast, there were no correlations between the other domains. The OHIP

score was not associated with SOC ( $r_s = -0.44$ ,  $p = 0.097$ ) or social support ( $r_s = 0.09$ ,  $p = 0.737$ ). SOC and social support were not associated with any of the seven OHIP dimensions.

#### 4. Discussion

Social determinants of health include factors that influence, affect, or determine the health of individuals (WHO 2008). The literature has demonstrated the influence of social factors on health, with evidence suggesting that they are powerful determinants of health (Braveman and Gottlieb 2014). In other words, income, education, and employment can influence health-related behaviors (Stringhini et al. 2010).

The population of caregivers of people with disabilities, especially ASD and Down syndrome, has been characterized by mothers with limited education (Barros, et al. 2019). The finding is consistent with the results of this study. We observed that the families of individuals with ASD had a mensal income of less than one BMW (USD 186,28), and the caregivers had between 9 and 11 years of education. These factors may reflect the access to health services, as reported previously. It has been reported that socioeconomic factors can be stressors that lead to delayed access to care among caregivers of individuals with disabilities (Donley et al. 2018).

Aside from the impact of social determinants on health, interest in the effect of psychosocial factors on an individual's health and the consequent impact on quality of life is also growing. The perception that strict physiological measures are insufficient to determine the health status of individuals is not new (Guyatt and Cook 1994). Currently, health is also a reflection of the lived experiences of each individual, including social determinants, psychosocial factors, social support, and behaviors (Braveman and Gottlieb 2014; Guyatt and Cook 1994).

Although the literature suggests that caregivers are impacted (Barros, et al. 2019; Caicedo 2014), psychosocial factors (Batool and Khurshid 2015) and social support (Ong et al. 2018) have been shown to protect health. However, the mediators or modifying factors of impact need to be studied further. Antonovsky's salutogenic theory focuses on factors that support human health and well-being but not the etiological factors. As such, Antonovsky's theory seeks reasons that keep an individual healthy, and considers stressors as inherent to the human condition. In this context, the idea of a sense of coherence, defined as the individual's ability to adapt to a situation of adversity, arises (Antonovsky 1987). Sense of coherence has been presented as an important determinant of caregivers' well-being and can protect caregivers from high levels of psychological distress and burden (Del-Pino-Casado et al. 2019). The current study showed that the caregivers of patients with ASD and Down syndrome had a strong SOC, ranging from 39 to 57, with an average of 48.9 for caregivers of patients with ASD and 49.4 for caregivers of patients with Down syndrome (scores ranged from 13 to 65). The higher scores indicate a better SOC (Antonovsky 1987). This may reflect an improvement in coping with a stressful situation, and consequently, better well-being (Antonovsky 1987; Eriksson and Lindström 2006), as observed in the present study. This correlation may explain how parents of children with ASD in similar contexts often have different outcomes due to the different processes they use to develop skills to manage their stress (Bonis and Sawin 2016). The ability, competence, and confidence of parents of children with ASD in the care they provide for their child and in challenging situations, can reduce their stress because of the protective effect of a strong SOC (Batool and Khurshid 2015). In contrast, parents of children with developmental disabilities who demonstrate a low SOC are likely to be impacted negatively (Oelofsen and Richardson 2006). Although there is literature regarding the protective effect of SOC in caregiving, data on caregivers of individuals with ASD and Down syndrome are scarce. In this study, a correlation between SOC and social support (emotional domain) was established. Similar data have not been obtained in this population before. The literature suggests that greater perceived social support and SOC are directly related to a better quality of life. Moreover, social support has a mediating role in the quality of life (Gomes et al. 2020). The current scientific evidence supports that sense of coherence influences oral health-related quality of life (Gomes et al. 2018).

Another important aspect that can have a favorable impact on an individual's health and emotional well-being is social support. The social support scale assesses the extent to which a person has the support of others to face different situations in their lives (Sherbourne and Stewart 1991). Consequently, social support is beneficial to the caregivers who are raising children with disabilities (Mantri-Langeveldt et al.

2019). A study of caregivers of elderly people diagnosed with physical and/or mental illness showed that perceived social support mediates the association between resilience and caregiver burden among the caregivers (Ong, et al. 2018). Among the caregivers of children with ASD, social support plays a mediating role in the discrimination perceived by parents and the self-esteem of these caregivers, with positive implications for the quality of life of these parents. This, in turn, results in an improvement in the quality of life of their children (Recio et al. 2020). In the current study, the social support received by caregivers varied widely, showing that some had material support, affective support, emotional support, positive social interaction, and information support, while others did not. In particular, the emotional support received was related to SOC. This highlights the importance of strengthening psychosocial variables in healthcare.

The family's quality of life has recently emerged, both to improve the living conditions of families of people with disabilities and to evaluate the results of the services and support they receive (Balcells-Balcells et al. 2019). The OHRQoL represents the subjective experience of symptoms related to oral conditions that affect psychosocial well-being (Sischo and Broder 2011). The literature suggests that caregivers of people with disabilities have lower HRQoL (Faria Carrada et al. 2020; Wall et al. 2020). However, little attention has been paid to caregivers' self-rated oral health and OHRQoL. Limited evidence is available. A recent study reported that the OHRQoL of most caregivers of children with disabilities is negatively impacted (Cancio et al. 2018). Interestingly, the current study did not report a high impact on the OHRQoL. Caregivers, particularly patients with Down syndrome, reported good oral health. Although data on OHRQL are sparse, those on health-related quality of life are available. It has been observed that parents/caregivers of people with Down syndrome have a good quality of life and are satisfied with their health (Oliveira Ede and Limongi 2011). To understand these results, we need to understand that social factors are powerful determinants of health (Braveman and Gottlieb 2014), and should be considered together with protective and coping factors, such as social support (Cobb 1976) and SOC (Antonovsky 1987). Further investigations in these areas are needed.

This study has limitations. The data presented must be analyzed with caution, as this is a preliminary study. We could not assess the degree of impairment in individuals with ASD, in addition to correlating the data obtained according to the different age groups of individuals with disabilities. Future investigations with a larger sample are needed to verify the results. Study designs to include caregivers of individuals with ASD and Down syndrome from multiple centers, with age stratification, and consideration for the different severity of health impairment are also warranted. Furthermore, to identify possible modifying factors and associations between the variables, improving our knowledge relating to psychosocial, protective, and coping factors, and applying theoretical models and structural equation modeling should be considered.

## 5. Conclusions

In summary, this preliminary study showed that the caregivers of patients with ASD and Down syndrome had a strong SOC. Most of them reported high perceived support and their OHRQoL was not impacted. The importance of understanding the caregiver's protection and coping factors in caring for patients with special needs was highlighted.

**Authors' Contributions:** PEREIRA, J.V.: conception and design, acquisition of data, analysis and interpretation of data, drafting the article, critical review of important intellectual content ; BUENO, T.C.: conception and design, acquisition of data, critical review of important intellectual content, final approval of the version to be published; HERKRATH, F.J.: conception and design, analysis and interpretation of data, critical review of important intellectual content; DA SILVA, M.M.D.: critical review of important intellectual content; LEME, M.C.: critical review of important intellectual content; DOS SANTOS-SILVA, A.R.: critical review of important intellectual content; LOPES, M.A.: conception and design, critical review of important intellectual content. All authors have read and approved the final version of the manuscript.

**Conflicts of Interest:** The authors declare no conflicts of interest.

**Ethics Approval:** The research was carried out in accordance with the Declaration of Helsinki and approved by the Ethics Committee of the Piracicaba Dental School (protocol nº 31448820.2.0000.5418).

**Acknowledgments:** The authors thank the public funding agency, Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - CAPES, Brazil, in the scope of the National Program for Academic Cooperation in the Amazon - PROCAD (Process No. 88887.200486 / 2018-00) for their funding support. Juliana Vianna Pereira received a postdoctoral scholarship (process no. 88887.473222 / 2020-00).

## References

- ANTONOVSKY, A. Unraveling the mystery of health: how people manage stress and stay well / Aaron Antonovsky. Edtion ed. San Francisco: Jossey-Bass, 1987.
- ATCHISON, K.A., DER-MARTIROSIAN, C. and GIFT, H.C. Components of self-reported oral health and general health in racial and ethnic groups. *Journal of public health dentistry*. 1998, **58**(4), 301-308. <http://dx.doi.org/10.1111/j.1752-7325.1998.tb03013.x>
- BALCELLS-BALCELLS, A., et al. Impact of supports and partnership on family quality of life. *Research in Developmental Disabilities*. 2019, **85**, 50-60. <http://dx.doi.org/10.1016/j.ridd.2018.10.006>
- BARROS, A.L.O., et al. Quality of life and burden of caregivers of children and adolescents with disabilities. *Special Care in Dentistry*. 2019, **39**(4), 380-388. <http://dx.doi.org/10.1111/scd.12400>
- BATOOL, S.S. and KHURSHID, S. Factors Associated with Stress Among Parents of Children with Autism. *Journal of Colleague Physicians and Surgeries*. 2015, **25**(10), 752-756. <http://dx.doi.org/10.2015/jcsp.752756>
- BONANATO, K., et al. Trans-cultural adaptation and psychometric properties of the 'Sense of Coherence Scale' in mothers of preschool children. *Interamerican Journal of Psychology*. 2009, **43**, 144-153.
- BONIS, S.A. and SAWIN, K.J. Risks and Protective Factors for Stress Self-Management in Parents of Children With Autism Spectrum Disorder: An Integrated Review of the Literature. *Journal of Pediatric Nursing*. 2016, **31**(6), 567-579. <http://dx.doi.org/10.1016/j.pedn.2016.08.006>
- BRAVEMAN, P. and GOTTLIEB, L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Reports*. 2014, **129**(2), 19-31. <http://dx.doi.org/10.1177/00333549141291s206>
- CAICEDO, C. Families with special needs children: family health, functioning, and care burden. *Journal of the American Psychiatric Nurses Association*. 2014, **20**(6), 398-407. <http://dx.doi.org/10.1177/1078390314561326>
- CANCIO, V., et al. Individuals with special needs and their families' oral health-related quality of life. *Brazilian Oral Research*. 2018, **32**, e39. <http://dx.doi.org/10.1590/1807-3107bor-2018.vol32.0039>
- CHOR, D., et al. Medidas de rede e apoio social no Estudo Pró-Saúde: pré-testes e estudo piloto. *Cadernos de Saúde Pública*. 2001, **17**, 887-896.
- COBB, S. Social support as a moderator of life stress. *Psychosomatic Medicine*. 1976, **38**(5), 300-314. <http://dx.doi.org/10.1097/00006842-197609000-00003>
- DEL-PINO-CASADO, R., et al. Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. *Journal of Affective Disorders*. 2019, **242**, 14-21. <http://dx.doi.org/10.1016/j.jad.2018.08.002>
- DONLEY, T., et al. Socioeconomic Status, Family Functioning and Delayed Care Among Children With Special Needs. *Social Work in Public Health*. 2018, **33**(6), 366-381. <http://dx.doi.org/10.1080/19371918.2018.1504703>
- DSM-5 American Psychiatric Association. DSM-5 Edtion ed. Arlington, VA, US: American Psychiatric Publishing, Inc., 2013. 947 p.
- ERIKSSON, M. and LINDSTRÖM, B. Antonovsky's sense of coherence scale and the relation with health: a systematic review. *Journal of Epidemiology and Community Health*. 2006, **60**(5), 376-381. <http://dx.doi.org/10.1136/jech.2005.041616>
- FARIA CARRADA, C., et al. Caregivers' Perception of Oral Health-Related Quality of Life of Individuals with Down Syndrome. *Journal of dentistry for children*. 2020, **87**(3), 132-140.
- GOMES, M.C., et al. Influence of sense of coherence on oral health-related quality of life: a systematic review. *Quality of Life Research*. 2018, **27**(8), 1973-1983. <http://dx.doi.org/10.1007/s11136-018-1832-5>
- GOMES, A.C., et al. Socioeconomic status, social support, oral health beliefs, psychosocial factors, health behaviours and health-related quality of life in adolescents. *Quality of Life Research*. 2020, **29**(1), 141-151. <http://dx.doi.org/10.1007/s11136-019-02279-6>
- GRIEP, R.H., et al. Test-retest reliability of measures of social network in the "Pró -Saúde" Study. *Revista de saude publica*. 2003, **37**(3), 379-385. <http://dx.doi.org/10.1590/s0034-89102003000300018>
- GUYATT, G.H. and COOK, D.J. Health status, quality of life, and the individual. *Journal of the American Medical Association*. 1994, **272**(8), 630-631.
- IBGE. CENSO DEMOGRÁFICO 2010: características da população e dos domicílios: resultados do universo. In. Rio de Janeiro: Sidra: sistema IBGE de recuperação automática. 2011.

- KAZEMI, M., SALEHI, M. and KHEIRROLLAHI, M. Down Syndrome: Current Status, Challenges and Future Perspectives. *International Journal of Molecular and Cellular Medicine*. 2016, **5**(3), 125-133.
- MANTRI-LANGEVELDT, A., DADA, S. and BOSHOFF, K. Measures for social support in raising a child with a disability: A scoping review. *Child: Care, Health and Development*. 2019, **45**(2), 159-174. <http://dx.doi.org/10.1111/cch.12646>
- NICE. National Institute for Health and Care Excellence: Clinical Guidelines. In Antisocial behaviour and conduct disorders in children and young people: recognition and management. London: National Institute for Health and Care Excellence (UK) Copyright © NICE 2020. 2017.
- NORDAHL-HANSEN, A., HART, L. and ØIEN, R.A. The Scientific Study of Parents and Caregivers of Children with ASD: A Flourishing Field but Still Work to be Done. *Journal of Autism and Developmental Disorders*. 2018, **48**(4), 976-979. <http://dx.doi.org/10.1007/s10803-018-3526-9>
- OELOFSEN, N. and RICHARDSON, P. Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability*. 2006, **31**(1), 1-12. <http://dx.doi.org/10.1080/13668250500349367>
- OLIVEIRA, B.H. and NADANOVSKY, P. Psychometric properties of the Brazilian version of the Oral Health Impact Profile-short form. *Community Dentistry and Oral Epidemiology*. 2005, **33**(4), 307-314. <http://dx.doi.org/10.1111/j.1600-0528.2005.00225.x>
- OLIVEIRA EDE, F. and LIMONGI, S.C. Quality of life of parents/caregivers of children and adolescents with Down syndrome. *Jornal da Sociedade Brasileira de Fonoaudiologia*. 2011, **23**(4), 321-327. <http://dx.doi.org/10.1590/s2179-64912011000400006>
- ONG, H.L., et al. Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. *BMC Psychiatry*. 2018, **18**(1), 27. <http://dx.doi.org/10.1186/s12888-018-1616-z>
- RECIO, P., et al. Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: The mediational role of affiliate stigma and social support. *Research in Developmental Disabilities*. 2020, **105**, 103737. <http://dx.doi.org/10.1016/j.ridd.2020.103737>
- SHERBOURNE, C.D. and STEWART, A.L. The MOS social support survey. *Social science & medicine*. 1991, **32**(6), 705-714. [http://dx.doi.org/10.1016/0277-9536\(91\)90150-b](http://dx.doi.org/10.1016/0277-9536(91)90150-b)
- SISCHO, L. and BRODER, H.L. Oral health-related quality of life: what, why, how, and future implications. *Journal of Dental Research*. 2011, **90**(11), 1264-1270. <http://dx.doi.org/10.1177/0022034511399918>
- STAUNTON, E., KEHOE, C. and SHARKEY, L. Families under pressure: stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine*. 2020, **28**, 1-8. <http://dx.doi.org/10.1017/ipm.2020.4>
- STRINGHINI, S., et al. Association of socioeconomic position with health behaviors and mortality. *Journal of the American Medical Association*. 2010, **303**(12), 1159-1166. <http://dx.doi.org/10.1001/jama.2010.297>
- UN 2006. Convention on the Rights of Persons with Disabilities (CRPD). In Proceedings of the United Nations, USA2006 ONU.
- VON ELM, E., et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. *Int J Surg*, Dec 2014, **12**(12), 1495-1499, <http://dx.doi.org/10.1016/j.ijsu.2014.07.013>.
- WALL, R., et al. Oral Health-Related Quality of Life of Children: An Assessment of the Relationship between Child and Caregiver Reporting. *Journal of Dental Hygiene*. 2020, **94**(2), 18-26.
- WANG, Y.C., et al. Dental anesthesia for patients with special needs. *Acta Anaesthesiologica Taiwanica*. 2012, **50**(3), 122-125. <http://dx.doi.org/10.1016/j.aat.2012.08.009>
- WHO. Commission on Social Determinants of Health final report: closing the gap in a generation: health equity through action on the social determinants of health. In. Geneva: World Health Organization, 2008.
- WHO. World report on disability 2011. In. Geneva: World Health Organization, 2011.

Received: 3 July 2021 | Accepted: 24 April 2022 | Published: 20 January 2023



This is an Open Access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.