



PERCEIVED STRESS IN MOTHERS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS, AND RELATED SOCIODEMOGRAPHIC FACTORS

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ABSTRACT

Objective: to analyze stress among mothers of children with special health care needs and identify related sociodemographic factors. **Method:** cross-sectional study with a quantitative approach and involving mothers of children with special health care needs being followed up in a medium-complexity outpatient clinic that carries out rehabilitation activities for children with conditions that affect their neuromotor and sensory development, in a city in the state of São Paulo. Data collection took place remotely, between March and July 2021, through application, via Google Forms, of a sociodemographic characterization instrument and the Perceived Stress Scale, whose score ranges from zero to 56 points. For data analysis, the following statistical tests were used: Mann-Whitney, Kruskal-Wallis, Spearman's correlation, and simple and multiple linear regression. **Results:** 57 mothers with an average age of 34.4 years participated. The average level of perceived stress stood at 30.56 – minimum 12, maximum 52. The sociodemographic factors associated with stress were: maternal age ($p < 0.001$), marital status ($p < 0.001$), and number of children ($p = 0.019$). **Conclusion:** the mothers with the highest level of perceived stress were: the youngest, those without a partner, and those with the highest number of children.

Keywords: Nursing. Children. People with disabilities. Mothers. Stress.

INTRODUCTION

Children with Special Health Care Needs (CSHCN) are those with a fragile health condition and need professional and family care, beyond what is required by children in the same age group and considered healthy⁽¹⁾. CSHCN may require adaptations in daily care, such as oxygen saturation monitoring, diet preparation for feeding via tube, regularly change of position to prevent injuries, etc.⁽²⁾

Additionally, other care demands required by these children stand out, such as the continuous use of medication, the need for neuropsychomotor rehabilitation and, in some cases, the use of technological devices to maintain life, such as enteral probe, tracheostomy, bladder catheterization, among others⁽³⁾. In general, children who use a technological device have serious chronic conditions, as well as severe functional

limitations, being called children who need continuous and complex care, a subgroup of CSHCN⁽⁴⁾.

According to a systematic review on the subject, mothers of children with chronic conditions, another nomenclature used to refer to this demographic, are more likely to experience a high level of stress⁽⁵⁾. Among the reasons, the authors highlight the accumulation of tasks related to the management of the child's illness, conflicting relationships with health professionals, uncertainty regarding the child's prognosis, financial impact, and the feeling of guilt in cases of hereditary conditions or conditions deriving from trauma⁽⁵⁾.

In the same direction, an integrative review that dealt with the psychological burden of caregivers of children diagnosed with asthma, a subgroup of CSHCN, revealed constant worry and changes in the domestic routine as factors that generate stress⁽⁶⁾. Stress triggers emotional

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and behavioral problems, in addition to physical illnesses such as depression, anxiety, fatigue, sleep disorders, and cognitive changes, negatively impacting the quality of life of these caregivers⁽⁷⁾.

However, stressful situations can be perceived differently from person to person, depending on their individual and social context. Furthermore, the same stressful event may be perceived in different ways by the same individual at different points in their life⁽⁸⁾. Thus, a Mexican study conducted with 416 family caregivers of children with chronic conditions emphasizes the importance of identifying the sociodemographic and psychosocial factors that contribute to the process of positive adaptation during the diagnosis and prolonged treatment of the child⁽⁹⁾.

In light of the foregoing, it is important to substantiate the existing literature by investigating the sociodemographic factors that influence the perception of stress in mothers of CSHCN, in order to subsidize future more specific and personalized intervention programs with potential to minimize the impact of the condition of illness among family members. To this end, the present study starts from the following research questions: how is stress perceived among mothers of CSHCN? Can sociodemographic factors influence perceived stress? Based on said questions, this study aimed to analyze stress in mothers of children with special health needs and to identify related sociodemographic factors.

METHOD

This is an observational, analytical and cross-sectional study with a quantitative approach. To guide the study methodology, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations were followed. The study was conducted in a medium-complexity outpatient clinic that performs rehabilitation activities with children who have conditions that affect their neuromotor and sensory development, in a city in the state of São Paulo. This service has carried out the physiotherapy and occupational therapy follow-up of approximately 90 children with different medical diagnoses, such as Autism Spectrum

Disorder, Cerebral Palsy, and Down Syndrome.

Data collection took place between March and July 2021. Given the social contact restrictions imposed by the Covid-19 pandemic, the entire data collection process was conducted remotely. The inclusion criteria were being mothers of children with special health care needs and over 18 years of age. The children should be aged between zero and 12 years old. In its turn, the exclusion criterion was not having access to the internet, but it was not necessary to apply it.

In the present study, the sample size was not calculated, and the participants were selected by convenience; thus, support was requested from the service's professionals in disseminating the research among the mothers of the CSHCN under follow-up; then, by telephone, the researchers presented the objectives of the study and invited them to participate. All potential participants who were invited accepted to join in the research; no one declined. Three unsuccessful phone calls, on different days and times, were set as maximum for ceasing the attempts. Upon acceptance, a virtual meeting was scheduled via Google Hangout®, a freely accessible online communication platform, in accordance with the participants' availability.

During the virtual meeting, first, the Free and Informed Consent Form (FICF) was presented for reading and discussion with the researchers, on "screenshare" mode. Next, two research instruments, duly organized in Google Forms®, were applied. The time between the initial interaction and the application of the instruments was approximately 20 minutes.

The first instrument was a characterization questionnaire organized from sociodemographic and clinical variables: mother's and CSHCN's age, education, marital status, number of children, occupation, income, CSHCN's medical diagnosis and care demands (drug care, developmental care, modified usual care, and technological care). It is important to mention that the present study did not aim to analyze the relationship between perceived stress and the clinical variables of the CSHCN, but such variables were collected and presented in the results with the intention of characterizing the study population.

The second was a generic stress assessment

instrument called Perceived Stress Scale (PSS), consisting of 14 questions with five response options (0=never; 1=almost never; 2=sometimes; 3=almost always; 4=always). The scale total is the sum of the scores of these 14 questions, ranging from zero to 56, and the higher the score, the greater the perceived stress⁽¹⁰⁾. The score obtained through the application of the PSS also provided a categorical indicator in which scores below 18 indicate low stress, between 19 and 24, normal stress, between 25 and 29, moderate stress, between 30 and 35, high stress, and greater than 35, very high stress.

It is worth noting that the PSS is considered a generic instrument because it can be used in different age groups, from teenagers to the elderly, as it does not contain context-specific questions. In this direction, some national and international investigations stand out for having adopted the PSS to measure stress in caregivers of children, along the lines of the present study⁽¹¹⁻¹³⁾. Also, at the end of data collection, Cronbach's alpha coefficient was calculated to analyze the internal consistency of the PSS among the mothers of CSHCN, obtaining $\alpha=0.857$, a value indicative of good internal consistency.

As for data organization and analysis, the database was exported to The SAS System for Windows, version 9.2, where statistical analyses were run. Initially, the Shapiro-Wilk and Kolmogorov-Smirnov normality tests were performed and the absence of normal distribution of the variables was verified. Categorical variables were described based on absolute and relative frequency measurements, while numeric variables were expressed using mean values, standard deviation, minimum and maximum values, median and quartiles. To compare numerical variables between two groups, the Mann-Whitney test was used, and the Kruskal-Wallis test was used for comparison involving three or more groups. Spearman's correlation coefficient was also calculated to assess the influence of numerical sociodemographic variables on stress scores. Finally, simple and multiple linear regression analysis was used with Stepwise selection criteria, with transformation by ranks of variables without normal distribution. A significance level of 5% was adopted. In the

multivariate regression, the absence of multicollinearity was verified from the calculation of the Variance Inflation Factor (VIF) of each variable. The values were close to 1.0, confirming the non-collinearity between the independent variables.

The development of the study complied with national and international standards on ethics in research involving human beings and was approved by the Research Ethics Committee of the Federal University of São Carlos, on February 24, 2021, under opinion number 4.555.413.

RESULTS

The study included 57 mothers of CSHCN, with an average age of 34.37 years. With regard to occupation, 40 (70.17%) had a paid job, either through formal contract or self-employment. The average family income was 4,115.30 BRL. As for education, 29 (50.9%) mothers had a college degree, and three (5.2%) did not complete high school. The average number of children was 1.75, with a minimum of one and a maximum of five children. The presence of a partner was mentioned by 48 (84.2%) mothers.

The average age of the CSHCN was 3.2 years. With regard to the presented health problems, 23 (40.5%) children had neurological disorders such as cerebral palsy, hydrocephalus, and epilepsy. The consequences of prematurity affected another 16 children (28%); the others had some type of congenital malformation or genetic syndrome. As it is an outpatient clinic specializing in the rehabilitation of children with conditions that affect their neuromotor and sensory development, all of them had a demand for developmental care. In total, six (10.5%) were classified as children in need of continuous and complex care, that is, they used technological devices to maintain life, needed continuous medication and required modified routine care.

With regard to the level of perceived stress, the mothers presented a mean score of 30.56, standard deviation of 8.53, minimum of 12, 1st quartile of 26, median of 31, 3rd quartile of 35, and maximum of 52. Analyzing stress as a categorical indicator: 14 (25%) mothers had low or normal stress, 12 (21%), moderate stress, 17

(29%) had high stress, and 14 (25%), very high stress. Below, Table 1 presents the level of perceived stress according to the categorical sociodemographic variables; it is possible to

observe a higher level of perceived stress among mothers who stated not having a partner ($p=0.034$).

Table 1. Level of perceived stress in mothers of CSHCN ($n=57$), according to categorical sociodemographic variables. São Carlos - SP, Brazil, 2021.

Variables	Mean (SD)	Minimum	Q1	Median	Q3	Maximum	p-value
Education							0.068**
Elementary	34.33(5.77)	31	31	31	41	41	
High School	33.00 (9.02)	12	29	33	40	52	
Higher Education	28.07 (7.75)	13	23	28	34	41	
Occupation							0.069**
Self-employed	28.86 (9.90)	12	21	28.50	34	46	
Unemployed	36.82 (7.70)	24	31	37	42	52	
Stay-at-home mother	30.67(4.50)	23	28	32	34	35	
Formal employment	28.81(7.88)	13	24	30	34	42	
Marital status							0.034*
Partner	29.67(8.81)	12	24	28.50	34.50	52	
No partner	35.33(4.72)	30	32	34	40	42	

*Mann-Whitney Test ** Kruskal-Wallis Test

Table 2 presents the correlation between the level of perceived stress and numerical sociodemographic variables, indicating a negative correlation between the level of perceived stress and the “maternal age” and “family income” variables, that is, the mothers who had a higher level of perceived stress were

those of a younger age and with a lower family income ($p=0.0018$ and 0.0284 , respectively). Furthermore, it reveals a positive correlation between stress and number of children, which means that the more children the mother had, the greater her level of perceived stress ($p=0.0159$).

Table 2. Correlation between the level of perceived stress in mothers of CSHCN ($n=57$) and numeric sociodemographic variables. São Carlos - SP, Brazil, 2021.

Variables	Maternal age	Family income	Number of children
Stress	r	-0.41491	-0.29037
	p	0.0018	0.0284
			0.31803
			0.0159

r= Spearman's correlation coefficient; P= p-value; n=number of subjects.

Next, simple linear regression analysis was used, as shown in Table 3. It is important to highlight that all sociodemographic variables that were statistically significant in the previous tests remained statistically significant in the linear regression analysis, reinforcing that maternal age, family income, marital status, and number of children were predictive variables for the level of perceived stress. Unlike the result presented by the Kruskal-Wallis test, the occupation variable, in simple linear regression, was associated with the level of perceived stress, indicating that mothers who claimed to be unemployed had higher levels of perceived stress compared to those who had a formal job or were dedicated to domestic work (stay-at-home mothers), with $p=0.024$.

In the multiple linear regression analysis, the “family income” and “occupation” variables lost significance and were not included in the model. According to the results presented in Table 4, maternal age explains approximately 17.5% of the variation in the level of perceived stress and presents a negative association with stress ($\beta=-0.52$). The marital status variable, in its turn, is responsible for 18.3% of the total variation in the level of perceived stress and presents a positive association with the outcome ($\beta=20.97$). Number of children explains approximately 7% of the variation, from a positive association with the level of perceived stress ($\beta=0.29$). Finally, the three variables inserted in the final model explained a variance of 42.5% (R^2 Total= 0.4253) in the level of perceived stress.

Table 3. Prediction of sociodemographic variables in the level of perceived stress of mothers of CSHCN (n=57), according to a simple linear regression model. São Carlos, SP, Brazil, 2021.

Variable	Categories	Beta (SE)*	p-Value	R ²
Maternal age (years)	Continuous variable	-0.45 (0.14)	0.002	0.1745
Education	Elementary (ref.)	---		
	High School	-2.43 (9.81)	0.805	
	Higher Education	-12.32 (9.73)	0.211	0.0963
Occupation	Self-employed (ref.)	---		
	Unemployed	14.97 (6.42)	0.024	
	Stay-at-home mother	4.04 (7.77)	0.606	
Marital status	Formal	-0.06 (5.28)	0.991	0.1265
	Partner (ref.)	---		
	No partner	12.80 (5.83)	0.032	0.0807
Family income	Continuous variable	-0.29 (0.13)	0.028	0.0843
Number of children	Continuous variable	0.35 (0.14)	0.016	0.1011

* Beta: value of the estimate or angular coefficient (slope) on the regression line; SE: standard error of beta. R²: coefficient of determination (% of variability of the response variable explained by the independent variable). Variables without normal distribution were transformed into ranks.

In short, perceived stress levels are higher among mothers without a partner, compared to those with a partner. Regarding maternal age, as it increases, there is a decline in perceived stress

levels. As for number of children, a rise in perceived stress levels is observed as the number of children increases.

Table 4. Prediction of sociodemographic variables in the level of perceived stress of mothers of CSHCN (n=57), according to a multiple linear regression model. São Carlos, SP, Brazil, 2021.

Selected variables	Categories	Beta (SE)*	p-Value	Partial R ²
Maternal age (years)	Continuous variable	-0.52 (0.12)	<0.001	0.1745
Marital status	Partner (ref.)	---		
	No partner	20.97 (5.20)	<0.001	0.1832
Number of children	Continuous variable	0.29 (0.12)	0.019	0.0676

* Beta: value of the estimate or angular coefficient (slope) on the regression line; SE: standard error of beta. R²: coefficient of determination.

Stepwise criterion for selecting variables. Total R²: 0.4253. Intercept (SE): 31.88 (5.37); P<0.001. Variables without normal distribution were transformed into ranks.

DISCUSSION

In the present study, the average family income was 4,115.30 BRL, 70.17% of the mothers stated that they had some type of paid work, and most had higher education. According to research carried out with families of children with multiple, complex and continuous care, education allows access to well-paid jobs, consequently improving family income and reducing the social vulnerability of these families⁽¹⁴⁾. However, the sociodemographic characteristics of the mothers in the present study differ from the common findings for this population, generally characterized by social vulnerability, with the majority having elementary education, being stay-at-home mothers, and having low income^(4,9).

According to the results presented, the

average level of perceived stress was 30.56, and 54% of the mothers had high or very high stress, corroborating a study carried out with family caregivers of children and adolescents hospitalized for cancer treatment, where the percentage of family caregivers with a high level of perceived stress was 41%⁽¹¹⁾. In the same direction, research conducted in Iran with 250 parents of children with disabilities reinforces that parents experience a high level of stress and mental pressure, with an increased risk of psychological problems and family functioning disruption⁽¹⁵⁾. On the other hand, the average level of perceived stress identified in a study carried out in Turkey with 181 mothers of children with physical and/or mental disabilities was 24.99, with a standard deviation of 4.32⁽¹²⁾.

It is relevant to recall that the data collection for the present study took place during

the pandemic period, and such a context may have aggravated the stress level of these mothers. However, a North-American study that compared the stress level of parents of children with and without chronic conditions during the Covid-19 pandemic, based on the PSS, identified an average stress score of 16.41 among parents of healthy children, and 19.69 among those with children with chronic conditions such as Asthma, Diabetes, and Autistic Spectrum Disorder⁽¹⁶⁾, a result that is inferior to that of the present investigation, which weakens the hypothesis of worsening stress due to the pandemic.

A positive correlation was observed between number of children and stress, that is, stress was greater among those who had more children, corroborating the testimonies of mothers of children and adolescents with Type 1 Diabetes Mellitus (DM1), which revealed that the challenges to reconcile work, household chores, care for other family members, and frequent visits to health services expose them to high levels of stress⁽¹⁷⁾.

Another important finding was that mothers who reported not having a partner presented a higher level of stress. In the same direction, a meta-analysis study that assessed the relationship between parental stress and marital status showed that married or cohabiting parents reported less parental stress ($p < 0.001$), and so did those who positively evaluated the quality of their marriage ($p < 0.001$)⁽⁵⁾. The study also suggests that married parents tend to share care responsibilities, reducing care demands on the maternal figure⁽⁵⁾.

A similar result was also evidenced in a study carried out in Egypt with 94 mothers of children with ASD, where mothers who declared themselves divorced or single reported an average perceived stress level of 52.5, while married ones had an average level of 29.9 ($p < 0.001$)⁽¹³⁾. On the other hand, disharmony is common among couples who have CSHCN⁽¹⁸⁾.

Maternal age remained in the explanatory model, revealing a negative association with levels of perceived stress, that is, younger

mothers had higher levels of stress. This result differs from the findings presented in a study that aimed to identify the sociodemographic and psychosocial variables associated with the overburden of family caregivers of children with chronic diseases such as cancer, asthma, nephrotic syndrome, and kidney failure⁽⁹⁾. According to the authors, the "caregiver's age" variable was not considered a predictor of caregiver overburden⁽⁹⁾. Maternal age was not directly analyzed in the meta-analysis described above; however, a longer duration of the child's condition and parenting older children were associated with lower levels of health-related parental stress ($p < 0.05$), indicating an indirect relationship with maternal age⁽⁵⁾.

As for the limitations of the study, it is worth highlighting the adoption of non-probabilistic sampling and a lack of control for possible confounding factors, such as the age and clinical conditions of the CSHCN, for instance. Another limitation concerns the reduced number of participants, since mothers from a single health service were recruited. Thus, investments in new studies with increased participation of mothers of CSHCN and inclusion of children's clinical variables in statistical analyses are recommended.

Regarding the practical implications of the present study, its potential to support future more specific and personalized intervention programs is highlighted, with special attention to mothers who fit into the sociodemographic factors associated with the level of perceived stress.

CONCLUSION

The results presented met the objective and answered the research questions. The average level of perceived stress stood at 30.56, and 54% of the mothers had high and very high levels of stress. Some sociodemographic factors can influence perceived stress; thus, mothers with a higher level of perceived stress were younger, had no partner, and had a greater number of children.

ESTRESSE PERCEBIDO DE MÃES DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE E FATORES SOCIODEMOGRÁFICOS RELACIONADOS

RESUMO

Objetivo: analisar o estresse entre mães de crianças com necessidades especiais de saúde e identificar os fatores sociodemográficos relacionados. **Método:** estudo transversal e de abordagem quantitativa realizado junto a mães de crianças com necessidades especiais de saúde em seguimento em um ambulatório de média complexidade que desenvolve atividades de reabilitação a crianças com condições que afetam o desenvolvimento neuromotor e sensorial de um município do interior do estado de São Paulo. A coleta de dados ocorreu remotamente, entre março e julho de 2021, mediante aplicação via *Google Forms* do instrumento de caracterização sociodemográfica e da *Perceived Stress Scale*, cuja pontuação varia de zero a 56 pontos. Para análise dos dados, utilizaram-se os seguintes testes estatísticos: Mann-Whitney, Kruskal-Wallis, correlação de Spearman e regressão linear simples e múltipla. **Resultados:** participaram 57 mães com idade média de 34,4 anos. O nível médio de estresse percebido foi de 30,56, mínima 12 e máxima 52. Os fatores sociodemográficos associados com o estresse foram: idade materna ($p < 0,001$), situação conjugal ($p < 0,001$) e número de filhos ($p = 0,019$). **Conclusão:** as mães com maior nível de estresse percebido foram: as com menor idade, sem companheiro e com maior número de filhos.

Palavras-chave: Enfermagem. Criança. Pessoas com deficiência. Mães. Estresse.

ESTRÉS PERCIBIDO DE MADRES DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD Y FACTORES SOCIODEMOGRÁFICOS RELACIONADOS

RESUMEN

Objetivo: analizar el estrés entre madres de niños con necesidades especiales de salud e identificar los factores sociodemográficos relacionados. **Método:** estudio transversal y de enfoque cuantitativo realizado junto a madres de niños con necesidades especiales de salud en seguimiento ambulatorio de mediana complejidad que desarrolla actividades de rehabilitación a niños con condiciones que afectan el desarrollo neuromotor y sensorial de un municipio del interior del estado de São Paulo-Brasil. La recolección de datos ocurrió remotamente, entre marzo y julio de 2021, a través de la implementación, vía *Google Forms*, del instrumento de caracterización sociodemográfica y de la *Perceived Stress Scale*, cuya puntuación varía de cero a 56 puntos. Para el análisis de los datos, se utilizaron las siguientes pruebas estadísticas: Mann-Whitney, Kruskal-Wallis, correlación de Spearman y regresión lineal simple y múltiple. **Resultados:** participaron 57 madres con edad media de 34,4 años. El nivel promedio de estrés percibido fue de 30,56, mínima 12 y máxima 52. Los factores sociodemográficos asociados con el estrés fueron: edad materna ($p < 0,001$), situación conjugal ($p < 0,001$) y número de hijos ($p = 0,019$). **Conclusión:** las madres con mayor nivel de estrés percibido fueron: las con menor edad, sin compañero y con mayor número de hijos.

Palabras clave: Enfermería. Niño. Personas con discapacidad. Madres. Estrés.

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