

The burden of family caregiver of children with special health needs

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ABSTRACT

The study aimed to identify the physical, emotional and social burden of caregivers of children with special health needs and to analyze the associated factors. A cross-sectional quantitative study design. A characterization instrument and a Burden Scale for Informal Caregivers – Burden Interview were answered. The Chi-Square, Fisher's Exact test, Kruskal-Wallis and simple and multiple logistic regression were calculated. One hundred caregivers participated, the majority (57%) had a moderate or severe burden. Caregivers of children requiring mixed care and those who did not have a religious belief had a higher risk for burden ($p=0.005$ and 0.035 respectively). This is a novel study because there are no investigations quantitatively measuring the burden of caregivers of children with special health needs in general, not specifying medical diagnoses. In conclusion, when recognizing the factors associated to burden, care strategies to alleviate the burden can be implemented and, consequently, qualifying the offered care.

Descriptors: Pediatric Nursing; Child; Caregivers; Family.

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INTRODUCTION

The terminology Children with Special Health Needs (CSHN) is characterized by a broad definition that includes different diseases affecting children, varying in required care complexity and demands⁽¹⁾. It includes all children requiring more attention and accompaniment from health services beyond what is required by other children of the same age group⁽²⁾.

These children represent an ascending group in the international and national population. In the United States of America, it is estimated that 11.2 million children under 18 years are classified as CSHN⁽³⁾. In Brazil, the profile of child morbidity and mortality has changed with the decrease of mortality by preventable causes and the increase of chronic conditions. However, there are no specific epidemiological data about these children. According to Brazilian researchers, CSHN represents approximately a quarter of the total Brazilian child population⁽⁴⁾. Recently, a published study validated an instrument to screen CSHN to Brazilian Portuguese, which will contribute to defining the epidemiological profile of this clientele⁽⁵⁾.

CSHN require continuing health care, resulting in the need to incorporate new knowledge and practices to the family routine⁽⁶⁾. Within the care demands there are: the medicated care when the child uses medicine continuously, except supplement and vitamins; development care when the child requires professional care such as physical therapists, occupational therapists, within others; technological care when the child uses a technological device to maintain physiological functions, for example, bladder catheterization; and modified usual care, as the use of diapers in children over three years old, use of devices to assist with mobility as a wheelchair, bracing, prosthesis and any other care that differs from the one offered to a healthy child. It is possible for the child to demand two or more care needs, classified as mixed care demand⁽⁷⁾.

A recent study investigated the time spent by the family to care for the CSHN at home, as well as, to estimate the financial cost needed to provide this care. It revealed that families spend an average of 5.1 hours per week. However, there are CSHN requiring more than 21 hours of care per week, within them: children with cystic fibrosis, with cerebral palsy and muscular dystrophy. The study also showed that the attention dedicated to CSHN care potentializes financial difficulties, social isolation, and marital dissatisfaction, generating burden⁽⁸⁾.

The caregiver's burden has been the study object coming from the main diagnoses affecting the child public. Thus, a study conducted in Goiânia with 31 caregivers of children with cerebral palsy identified approximately 705 caregivers who were moderately or moderately to severely burdened⁽⁹⁾. In 2017, researchers published an investigation comparing the overload of caregivers of children with and without Down Syndrome and they presented that approximately 90% of caregivers of children without Down Syndrome had a level "absence or little burden". On the other hand, 93% of caregivers of children with Down Syndrome had moderate to severe burden⁽¹⁰⁾.

Thus, this study was justified by the inexistence of investigations quantitatively measuring the burden of caregivers of CSHN in general, not specifying the medical diagnoses. Besides, the study becomes relevant at the measure that it directs its attention to caregivers coming from the assumption that non-burdened caregivers and with satisfactory physical and emotional health propitiate qualified care to CSHN.

Therefore, the following research questions arose: what is the level of the physical, emotional and social burden of family caregivers of CSHN?; what are the factors associated to the physical, emotional and social burden

of CSHN family caregivers? Thus, the objective of this study was to identify the level of the physical, emotional and social burden of family caregivers of CSHN and to analyze the burden-associated factors.

METHODS

This is a study with a cross-sectional design and a quantitative approach⁽¹¹⁾. The data collection occurred in an inner city of São Paulo state, from May 2017 to March 2018, in four specialized services attending CSHN. One hundred family caregivers participated in the study. The eligibility criteria were: to be a family caregiver, older than 18 years, of CSHN between zero and 12 incomplete years registered in the research institutions. The exclusion criterion was to be a family caregiver with less than three months of experience of caring for CSHN.

Initially, contact was established with the institutions composing the research context to explain the project and to request authorization to develop the research. The first contact with participants occurred at the moment that CSHN and their family caregiver were in the institution to continue the follow-up. The eligible candidates who accepted to participate in the study answered an online form in their service, in a reserved space. It is important to note that, there was no rejection to participate; all eligible participants accepted the invitation. The online form application was intermediated by a researcher with an approximate duration of 20 minutes.

The online form was composed by a characterization instrument and by the Burden Scale for Informal Caregivers – Burden Interview (BI). The Burden Scale for Informal Caregivers contains 22 questions that were answered using a Likert-type scale varying from 0-4 points. The final score was obtained by adding all answers, varying from zero to 88. The higher the final score, the higher the burden. Thus, an overload of zero to 20 points was defined as small burden; 21 to 40 as moderate burden; 41 to 60 as moderate to severe burden and, 61 to 88 points as severe burden⁽¹²⁾.

The dependable or answer variable was the physical, emotional and social burden of informal caregivers of CSHN, categorically classified (small, moderate, moderate to severe and severe burden). The variables from the characterization instrument were considered as independent variables, and they were: a) variables related to the family context as the number of residents in the house, caregiver's age and education level, religious belief, marital status, occupation and family income; b) variables related to CSHN as age, if they attend a daycare or school and care demand.

After finishing the production of the empirical material, the database was exported to the SAS System for Windows (Statistical Analysis System), version 9.2, where analyses were performed. In the descriptive statistical analysis phase, the categorical variables were described using absolute and relative frequency measures, while for the description of the numerical variables, measures of central tendency, variability and position were used. After the descriptive analysis, the comparison of overload between the categories of independent variables was conducted using the Chi-Square and Fisher's Exact tests. The comparison between numerical and outcome variables used the Kruskal-Wallis's test due to lack of normal distribution. At last, a simple and multiple polytomous logistic regression analyses were conducted, with Stepwise selection criteria. For the tests, a significance level of 5% was adopted.

The study development met the national and international ethical norms for research involving human beings, and the Ethics in Research Committee of São Carlos Federal University approved the study (CAAE: 63061716.2.0000.5504).

RESULTS

One hundred family caregivers of CSHN participated in the study, with a mean age of 35.9 years. Regarding marital status, 83 (83%) affirmed to have a partner. Regarding their occupation and source of income, 56 had some paid job, and the others had non-paid activities. About their education level, they had an average of 11.7 years of study, equivalent to the complete high school. In general, the families were composed of three members, with additional statistical data in Table 1.

Table 1: Characterization of family caregivers of CSHN and analysis of their physical, social and emotional burden according to numerical variables. São Carlos, SP, Brazil, 2017-2018.

Variables	Mean	Standard Deviation	Median	Minimum	Maximum	p
CSHN age (years)	3.33	3.52	2.00	0.00	12.0	0.792*
Family income (reals)	2821.4	1880.3	2500.0	256.0	10000	0.705*
Caregiver's education (years)	11.6	3.5	11.0	2.0	24.0	0.908*
Caregiver's age (years)	35.9	9.6	36.5	18.0	6.0	0.205*
Residents at home	3.1	1.1	3.0	1.0	8.0	0.154*

* Kruskal-Wallis's test.

The mean age of CSHN was approximately 3.3 years. Regarding the care demand required by CSHN, six had medicated demand; seven with modified habitual care; 29 had development care demand and, 58 had mixed care demand. It is important to highlight that there were no children with technological care demand. Within the most common diagnosis, there were cerebral palsy, myelomeningocele, asthma, autism, Down Syndrome and prematurity sequelae.

About physical, social and emotional burden of caregivers, 27 (27%) had scores between 21-40, corresponding to a moderate burden, 57 (57%) scored between 41-60, presenting a moderate to severe burden and 16 (16%) were classified as severe burden. The participants' characteristics and analysis of physical, social and emotional burdens of caregivers, according to numerical variables are presented in Table 1.

Following, Table 2 presents the distribution of physical, social and emotional burden according to categorical variables.

The simple logistic regression analysis was used to study the relationship of the variables of interest with the three overload categories, as presented in Table 3.

Following, the variables "care demand" and "religious belief" entered the multiple logistic regression model. As presented in Table 4, the caregivers of CSHN who demand mixed care had 26.22 times more chance for overload than caregivers of children who demand medicated care. The results also indicated that family caregivers without a religious belief had 2.7 times higher chances for high levels of burden when compared to those who affirmed to have a religious belief.

Table 2: Distribution of physical, emotional and social burden of caregivers of CSHN according to categorical variables. São Carlos, SP, Brazil, 2017-2018.

Variables	Moderate n (%)	Moderate to Severe n (%)	Severe n (%)	p
Frequency daycare/school				0.845*
Yes	15(55.5)	31(54.3)	10(62.5)	
No	12(44.4)	26(45.6)	6(37.5)	
Marital Status				0.706**
With partner	24(88.8)	46(80.7)	13(81.2)	
Without partner	3(11.1)	11(19.3)	3(18.75)	
Religious belief				0.202*
Yes	22(81.4)	39(68.4)	9(56.2)	
No	5(18.5)	18(31.5)	7(43.75)	
Caregiver occupation				0.266*
Paid	16(59.2)	34(59.6)	6(37.5)	
Unpaid	11(40.7)	23(40.3)	10(62.5)	
Care demand				0.010**
Medicated care	5(18.5)	1(1.7)	0(0.0)	
Modified habitual care	3(11.1)	2(3.51)	2(12.5)	
Development care	10(37.0)	15(26.3)	4(25.0)	
Mixed care	9(33.3)	39(68.4)	10(62.5)	

* Chi-Square Test;

**Fisher's Exact test.

Table 3: Effect of independent variables in the physical, social and emotional burden of caregivers, according to a simple logistic regression model. São Carlos, SP, Brazil, 2017.

Variable	P- value	O.R.*	CI 95% O.R.**
CSHN age	0.839	1.011	0.907 – 1.128
CSHN home residents	0.198	0.804	0.576 – 1.121
Caregiver's age	0.296	1.022	0.981 – 1.064
Caregiver's education	0.995	1	0.898 – 1.113
Family income	0.541	1	0.999 – 1.001
CSHN School			
No (ref.)	---	1	---
Yes	0.737	1.14	0.53 – 2.46
Care demand			
Medicated (ref.)	---	1	---
Modified habitual	0.062	12.02	0.89 – 163.02
Development	0.042	10.64	1.09 – 103.53
Mixed	0.007	22.18	2.36 – 208.17
Religious belief			
Yes (ref.)	---	1	---
No	0.076	2.18	0.92 – 5.13
Marital status			
With partner (ref.)	---	1	---
Without partner	0.439	1.5	0.54 – 4.17
Occupation			
Paid work (ref.)	---	1	---
Unpaid work	0.252	1.58	0.72 – 3.43

* OR (Odds Ratio) = odds ratio for greater burden; (n=27 moderate, n=57 moderate to severe and n=16 severe);

** CI 95% OR = 95% confidence interval for the odds ratio.

Table 4: Effect of independent variables in the physical, social and emotional burden of caregivers, according to the multiple logistic regression model. São Carlos, SP, Brazil, 2017.

Selected variables	P- value	O.R.*	CI 95% O.R.**
Care demand			
Medicated (ref.)	---	1	---
Modified habitual	0.1	10.55	0.64 – 175.48
Development	0.064	8.92	0.88 – 90.36
Mixed	0.005	26.22	2.67 – 257.40
Religious belief			
Yes (ref.)	---	1	---
No	0.035	2.68	1.07 – 6.71

* OR (Odds Ratio) = Odds ratio for higher overload; (n=25 moderate, n=57 moderate and severe and n=15 severe);

** CI 95% OR = 95% confidence interval for odds ratio.

DISCUSSION

Regarding the burden, the results demonstrated that 73% of caregivers had moderate to severe and severe burden; none caregiver had light burden. A study conducted in England to determine predictors for caregivers' burden among parents of children with chronic conditions from the same scale used in this investigation found a mean burden score of 52.55 and standard deviation of 16.8, which corresponds to moderate to severe burden⁽¹³⁾. According to a study with quantitative approach conducted with primary caregivers of children with an asthma diagnosis, a CSHN subgroup, the burden is common among caregivers and results from different factors such as inadequate sleep, concern and constant monitoring of children's clinical conditions and unequal division of care between family members⁽¹⁴⁾.

According to the results, most family caregivers of CSHN affirmed to have a partner. However, marital status did not have a significant statistical relationship with burden. An investigation conducted with caregivers of children and adolescents with Down Syndrome corroborates when presenting that 53.6% of participants were married or were in a stable relationship, but also did not identify a statistical significance with burden⁽¹⁰⁾. On the other hand, an international study aimed to analyze the factors associated with the stress of caregivers of children with cancer during their first year since diagnosis identified that the stress was higher among single caregivers⁽¹⁵⁾. Although children under cancer treatment are CSHN, this divergence can be justified at the measure that the child cancer requires continuous management of adverse effects from treatment⁽¹⁵⁾, a factor that certainly potentializes the burden of caregivers who do not have the support of a partner.

The average family income in this study was of approximately 2,800 reais, and 56% of caregivers had some type of paid job, formal or informal. Additionally, the tests did not identify a statistically significant relationship between burden and the variables family income and occupation. Differently, a study conducted with 231 parents of children with mitochondrial disease that aimed to determine the relationships between parental stress, coping and demographic variables, identified significant correlations between parental stress and parental income⁽¹⁶⁾.

The variable care demand presented a significant association ($p < 0.05$) with the burden of family caregivers. The results showed that family caregivers who had CSHN with mixed care demands had 26.22 higher chance for burden than the ones responsible for CSHN who exclusively required medicated care. From the perspective that mixed care demand commonly corresponds to a fragile clinical condition of CSHN, it was possible to identify a study corroborating with the present finding at the measure that significant correlations were also found between

parental stress and the presence of development delays, number of hospitalizations, number of medical visits, number of organs involved and number of specialists conducting the follow-up⁽¹⁶⁾.

In this study, the demand for medicated care was not statistically relevant. However, another study that aimed to comprehend the experience of mothers of children dependent of technology in comparison to medicated care indicated that the need to regularly administrate medicines is imposed as a factor that potentializes burden⁽¹⁷⁾. In the same direction, linear regression analyses of an international study determined that the number of medicines administered orally and via parenteral were associated with caregiver's burden⁽¹³⁾.

Regarding religious belief, the literature is broad when pointing to the benefits of spirituality and religiosity when facing the illness of a family member, being a child or not⁽¹⁸⁻¹⁹⁾. A quantitative study conducted with 175 mothers of children with congenital cardiopathies found that higher trust in spirituality contributed to an effective family coping⁽¹⁸⁾. Thus, an investigation that analyzed the comprehension of the nurse relating to spiritual care reinforces the importance of interventions related to the spiritual dimension to guarantee care integrity⁽¹⁹⁾.

CONCLUSION

In this study, the objective was to identify the level of the physical, emotional and social burden of family caregivers of CSHN and to analyze the associated overload factors and, the results presented met the proposed objectives. Thus, the conclusion is that more caregivers of CSHN have moderate to severe physical, emotional and social burden and, caregivers of children who demanded mixed care and those who did not have a religious belief had higher chances to be burdened. Thus, when identifying the factors associated with burden, it is possible to implement new care strategies to caregivers aiming to alleviate their burden and consequently, to qualify the care offered to CSHN.

It is also important to reinforce the novelty of the study. There are no investigations in the literature quantitatively measuring the burden of caregivers of children with special health needs in general, not specifying the medical diagnoses. About the implications of this study to the nursing team, more attention to caregivers of CSHN with mixed demands is required from the frequent and systematized appointments through home visits or nursing consultations. It is also recommended to offer broad care considering the spiritual dimension. However, the practical relevance of this study is extended to all health professionals working with this clientele.

At last, the development of new longitudinal studies is important considering the limitation of the present investigation in establishing cause-effect relationships.

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