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Burden of primary caregivers of children with congenital heart disease

Sobrecarga de Cuidadores Primários de Crianças com Cardiopatia Congênita

Sobrecarga de los Cuidadores Primarios de niños con cardiopatías congénitas

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ABSTRACT
Objective: to identify the burden level on primary caregivers of children with congenital heart disease. **Method:** descriptive cross-sectional study with a quantitative approach. Data collection was carried out in a virtual environment from June 2021 to February 2022, after approval by the Research Ethics Committee. A form was used to characterize the sample and the Zarit Burden scale. Data were analyzed using the SPSS version 24 program using descriptive statistics and analysis of variance of p≤0.05. Research protocol approved by the Research Ethics Committee. **Results:** 100 mothers participated with a mean age of 34.08 years, most of them married (57%), residents of the state of São Paulo (25%), with complete secondary education (51%) It was observed that 56.0% showed moderate overload. **Conclusion:** burden is a reality in primary caregivers of children with congenital heart disease and sharing care and family support are identified as protective factors.
Descriptors: Pediatric Nursing; Child; Caregivers; Heart Defects, Congenital; Stress, Psychological.

RESUMO
Objetivo: identificar o nível de sobrecarga nos cuidadores primários de crianças com cardiopatia congênita. **Método:** estudo transversal descritivo de abordagem quantitativa. A coleta de dados foi realizada em ambiente virtual nos meses de junho de 2021 até fevereiro de 2022, após aprovação pelo Comitê de Ética em Pesquisa. Utilizou-se um formulário para caracterização da amostra e a escala Zarit *Burden*. Os dados foram analisados através do programa SPSS versão 24 utilizando a estatística descritiva e análise de variância de p≤0,05. Protocolo de pesquisa aprovado pelo Comitê de Ética em Pesquisa. **Resultados:** participaram 100 mães com média de idade entre 34,08 anos, a maioria casada (57%), residentes do estado de São Paulo (25%), com ensino médio completo (51%) Observou-se que 56,0% evidenciaram sobrecarga moderada. **Conclusão:** a sobrecarga é uma realidade em cuidadores primários de crianças com cardiopatias congênitas e o compartilhamento de cuidado e apoio familiar são identificados como fatores de proteção.
Descritores: Enfermagem Pediátrica; Criança; Cuidadores; Cardiopatias Congênitas; Estresse Psicológico.

RESUMEN
Objetivo: identificar el nivel de sobrecarga de los cuidadores principales de niños con cardiopatías congénitas. **Método:** estudio descriptivo transversal con enfoque cuantitativo. La recolección de datos se realizó en ambiente virtual de junio de 2021 a febrero de 2022, previa aprobación del Comité de Ética en Investigación. Se utilizó un formulario para caracterizar la muestra y la escala de Zarit. Los datos se analizaron con el programa SPSS versión 24 mediante estadística descriptiva y análisis de desviación de p≤0,05. El Comité de Ética en Investigación aprobó el Protocolo de investigación. **Resultados:** Participaron 100 madres con media de edad de 34,08 años, la mayoría casadas (57%), residentes en el estado de São Paulo (25%), con educación secundaria completa (51%). Se observó que el 56,0% mostró moderada sobrecarga. **Conclusión:** la sobrecarga es una realidad en los cuidadores primarios de niños con cardiopatías congénitas; el cuidado compartido y el apoyo familiar se identifican como factores de protección.
Descriptores: Enfermería Pediátrica; Niño; Cuidadores; Cardiopatías Congénitas; Estrés psicológico.

INTRODUCTION

Congenital heart disease is defined by a structural abnormality of the heart or great vessels, which can cause a significant functional impact on the individual's life. It is characterized by changes in embryonic development, with several factors capable of causing them, such as genetic or environmental factors. Congenital heart disease is responsible for approximately 40% of all birth defects, thus being considered one of the most frequent malformations[1].

Congenital heart disease is divided into cyanotic and acyanotic according to the degree of blood oxygenation[2]. The incidence ranges from 0.8% in developed countries to 1.2% in developing countries. According to data from the World Health Organization (WHO), the prevalence ranges from four to nine per thousand live births and an estimate of 1.5 million new cases per year. The estimate in Brazil is nine cases per thousand live births, with the emergence of 28,846 new cases of congenital heart disease per year[2].

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These children present special healthcare needs since birth, such as the use of medication and technology to maintain life through examinations and surgical interventions. They are then identified and classified in the international literature as Children with health special care needs (CHSCN)[3].

The term was then translated into Portuguese as *Crianças com necessidade de saúde especial* (*CRIANES*), and they are so called because they present clinical frailties due to chronic, physical, developmental, behavioral or emotional conditions. Therefore, they require greater use of health services and care by a multidisciplinary team, including nursing[4].

CHSCN are classified according to seven healthcare demands. The first is developmental and includes children with developmental delay and in need of rehabilitation. The second demand is technological care, which are children who use life-sustaining devices such as the use of pacemakers and stents, and others[4].

Medication care constitutes the third demand, and includes those who use daily medication, beta-blockers, antihypertensive or anticoagulant medications, etc. Next, modified habits are the fourth demand, in which children need adaptations in routine activities such as eating, aid in locomotion due to muscle hypertrophy in the postoperative period, as well as limitations related to physical activities such as running and crying, as this can cause a cyanotic crisis[4].

The fifth demand is that of mixed care when the child has one or more previous demands, except for technology. The sixth demand is called clinically complex care, which groups all the previous ones, including the management of life support technologies[4].

There is a recently incorporated demand in CHSCN care, which is the social educational demand and is related to learning how to perform care during the transition from hospital to home, which is still a challenge for the family caregiver of a child with congenital heart disease[5].

The news of the birth of a child with cardiac malformation generates physical and psychological overload on parents, as they will have to adapt to special healthcare needs such as greater frequency of health services, surgeries, monitoring of vital conditions, continuous use of medication, limitation of daily activities to avoid burden, among others[6].

The primary caregiver is defined as a person who assumes full or main responsibility for the care provided to the person in need of care, and who is not financially remunerated for this task. In the case of primary caregivers of children with congenital heart disease, mothers are usually the ones who assume this role in the family nucleus, suffering burden in their financial, social and physical life, abdicating paid work and leisure activities[7].

There are already studies in the scientific literature presenting the burden of the primary caregiver in children with Down syndrome, autism spectrum disorder, cerebral palsy, etc[7-9]. However, there is a need for studies which assess the burden on primary caregivers of children with congenital heart disease, since they also need special healthcare.

This study is justified in view of this scenario, which aims to identify the level of burden on primary caregivers of children with congenital heart disease.

METHOD

This is a cross-sectional, exploratory and descriptive study developed using the online interview technique carried out in the participant's chosen environment. The recommendations of Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) were followed in preparing this article. The sample was composed by convenience and consisted of 100 primary caregivers of children with congenital heart disease who were members of interest groups in an online social network.

The groups of interest were identified by searching the social network's magnifying glass tool with keywords (congenital heart disease and children with congenital heart diseases) and selected through the title. The researcher then made contact with their administrator requesting access to participate in closed groups. The first contact was via dissemination of the study with prior authorization of the group administrator.

Potential participants who expressed interest in the study and identified themselves as the primary caregiver of the child filled out a link released by the researcher in Google Forms® format and provided their email address and telephone number for the initial contact. The chosen technique was a virtual interview through the Google Meet® platform with audio and video authorization by the participants.

The study included primary caregivers aged over 18 years of children aged between zero and 12 years, both genders, with congenital heart disease, who were undergoing outpatient treatment, meaning who were not hospitalized during the data collection period. Caregivers who refused to participate via video call, did not have an electronic device with a camera available, or those who did not respond to the researcher's contact were excluded.

Next, the day, time and platform (Google Meet®) for the virtual interview were agreed on for primary caregivers who agreed to participate in the study. The participants then received the Informed Consent Form in Google Forms® format for electronic acceptance, followed by the agreement term to use image and voice recording on the day of the interview, before starting the recording.

The study was developed after approval by the Research Ethics Committee and the interviews took place between June 2021 and February 2022, with an average duration of 20 minutes. The researcher filled in the research instruments during data collection according to the participants' responses and this was accompanied through screen projection, namely: Primary caregiver characterization instrument and application of the Zarit Burden Interview/Caregiver Burden Scale. This scale was translated into Portuguese in 2002.

The Zarit Burden Interview scale consists of 22 items involving the 'health', 'social and personal life', 'financial situation', 'emotional well-being' and 'interpersonal relationship' domains. Each item on the scale is scored from 0 to 4, with: 0=never, 1=rarely, 2=sometimes, 3=often and 4=always, in a total score which can vary from 0 to 88 points. After summing the points, it is considered that a score from 0 to 21 corresponds to little or no burden, from 21 to 40 corresponds to mild to moderate burden, from 41 to 60 to moderate to severe burden, and from 61 to 88 severe burden/overload[10].

The burden of the primary caregivers was considered as dependent variables or response variable, called categorical (absence of burden, little or no burden, mild to moderate, moderate to severe and severe). The independent variables were considered those obtained in the characterization instrument of the primary caregivers, which were: age, gender, marital status, Brazilian state of residence, number of residents in the house, education, profession, work situation, if someone helps in the care of the child, health problem(s), continuous use of medication, religious belief and housing situation.

The means of the dependent variable (ZBI) were calculated in relation to each exposure level of the independent variables. One-way analyzes of variance were performed for categorical exposure variables, while simple linear regression was used for ordered and continuous variables. In addition, 95% confidence intervals were estimated for the means.

Multivariate analysis was performed using multiple linear regression. A value of $p<0.25$ was used in the univariate analysis for the choice of variables to be tested in the model. The variable had to have $p<0.05$ to remain in the final model, as obtained through the likelihood test. The Scale's Cronbach's alpha coefficient was 0.83% and was measured in order to estimate its application reliability in this research. A Cronbach's α value from 0.60 was considered acceptable[11].

RESULTS

A total of 100 primary caregivers of children with congenital heart disease were interviewed. The results of the profile of primary caregivers and the mean burden scale are shown in Table 1 and the categorical results of the Caregiver Burden Scale (Zarit Burden Interview) are shown in Table 1. 1.

The average age of the mothers was 34.08 years with a standard deviation of 6.19 years, with a minimum age of 19 and a maximum of 49 years. Among the interviewees, 81% claimed to have a religion, with Catholic being the most prevalent (38%), followed by the evangelical religion with 33 participants (33% of the sample), in addition to two who claimed to be Catholic and spiritists and 6 spiritists. Furthermore, 19 participants declared having no religion.

According to marital relationships, it appears that the most frequent are stable relationships, as 57% of caregivers claimed to be married and 19% live with partners. For the type of housing, 57% of those surveyed claimed to have their own house/apartment.

Most caregivers (54.84%) declared to be employed at the time of the interview, and the majority said they did not receive social benefit/government assistance (78%); for those who receive it, they specifically referred to the Benefit of Continuous Provision (*Benefício da Prestação continuada - BPC*)/Organic Law of Social Assistance (*Lei Orgânica da Assistência Social - LOAS*), 4 declared receiving a family allowance, one child received assistance through the National Institute of Social Security (*Instituto Nacional do Seguro Social - INSS*) and another received a government assistance program (*auxílio Brasil*).

The mean number of children that caregivers had in addition to the child with heart disease was 1.0 with a standard deviation of 0.9. The largest number of children was four more and the smallest was one more child in addition to the child with congenital heart disease. Of the participants, 36% do not have children other than the child with heart disease. The Brazilian states most featured in the study were: São Paulo, with 25% of the participants, followed by Rio de Janeiro, with 15%.

TABLE 1: Bivariate analysis between the characteristics of the primary caregiver and the mean burden scale of primary caregivers of children with heart disease (n=100). Brazil, 2022.

Variables	n	Mean score of the Burden scale (SD)	*p*-value*
Region of residence			
North	7	32.9 (13.6)	0.829
Northeast	15	35.8 (9.2)	
South	17	32.3 (10.4)	
Southeast	56	34.5 (14.1)	
Central West	5	39.2 (8.5)	
Education level			
Higher education	40	34.5 (11.4)	0.914
High school	51	34.2 (13.8)	
Elementary	9	36.1 (10.8)	
Age			
≤ 34 years	49	34.6 (12.9)	0.931
≥ 35 years	51	34.4 (12.1)	
Live with partner			
No	22	40.5 (13.7)	**0.010**
Yes	78	32.8 (11.7)	
Share care with another person			
No	35	36.7 (12.9)	0.193
Yes	65	33.3 (12.3)	
Own residence/housing			
No	43	36.7 (13.7)	**0.095**
Yes	57	32.7 (11.3)	
Currently working			
No	56	35.6 (11.3)	0.310
Yes	44	33.0 (13.9)	
Follow a religion			
No	19	34.9 (11.6)	0.867
Yes	81	34.4 (12.8)	
Have other children			
No	36	33.5 (12.6)	0.578
Yes	64	35.0 (12.5)	
Take care of other children			
No	49	34.9 (12.8)	0.709
Yes	51	34.0 (12.3)	
Have any illness/disease			
No	69	32.8 (12.9)	**0.053**
Yes	31	38.1 (10.9)	
Use medication for this illness/disease			
No	69	34.5 (12.8)	0.961
Yes	31	34.4 (12.0)	
Receive any government assistance			
No	78	33.9 (12.5)	0.421
Yes	22	36.4 (12.5)	
Number of residents in home			
1 to 3	71	33.8 (12.4)	0.403
4 residents	29	36.1 (12.7)	

Notes: *Spearman's Correlation Coefficient; SD = Standard deviation

Regarding the education level, 51% of the participants had completed high school, 20% had a higher education and 21% had a postgraduate degree. Only three participants had incomplete elementary school.

In addition, 31 of the participants answered yes for having a health problem. There was a prevalence of illnesses/diseases related to: metabolism, cardiovascular system, non-transmissible chronic disease, hormonal, reproductive system, visual, rare syndrome, musculoskeletal and psychological.

Of the interviewees, 30% reported using medication regularly, namely: anticoagulants, antidepressants, antihypertensives, regular and neutral protamine Hagedorn (NPH) insulin, contraceptives, thyroid hormone, analgesics and muscle relaxants.

Moreover, 35% of the caregivers shared the child's care with another person. The people who shared care were: the child's father, husband, child's grandmother, child's aunt, child's sister, child's great-grandmother, nanny, and one child had home care provided by a nursing technician on a timely basis, with the mother still as the main caregiver. There is a higher prevalence of males assisting the caregivers, with 45% represented by the child's father and/or the caregiver's husband.

Table 2 shows the burden level of primary caregivers.

TABLE 2: Burden level of primary caregivers of children with congenital heart disease (n=100). Brazil, 2022.

Variable	n	(%)
Absence of burden	17	17%
Moderate burden	54	54%
Moderate to severe burden	26	26%
Severe burden/overload	3	3%

The evaluation using the Brazilian version of the Zarit Burden Interview Scale showed that the average value considering the total score of the scale was 34.46, with a standard deviation of 12.49, a minimum score of 9 and a maximum score of 63 points. Thus, it was observed that 17% were stratified as no burden, while 54% were classified as moderate burden, 26% were classified as moderate to severe burden, and only three participants (3%) as severe burden/overload.

DISCUSSION

There is a predominance of females among the primary caregivers of children with congenital heart disease, more specifically the mother. This is similar to most international studies, in which most caregivers of children with chronic conditions are mothers[12,13].

Regarding the level of burden presented by the primary caregivers in the present study, there is a predominance of moderate burden, with most responses of burden perception being "very", "moderately" and "extremely", showing that there is a burden perceived by the caregiver themselves.

In a Brazilian study[7] with children and adolescents with Down syndrome, the burden of primary caregivers was similar to that of this study, with the majority at a moderate level; therefore, this reinforces that chronic diseases in childhood are causes of burden in their caregivers. The caregivers in this study were mostly also the mothers, they had health problems, were Catholic and had stable relationships.

Similarly, the sample in a study carried out in Nigeria[13] with caregivers of children with cerebral palsy also consisted of mothers and a third had a high level of caregiver burden through the use of the Modified Caregiver Strain Index (MCSI) scale, which is also an instrument used to measure burden on caregivers.

Studies carried out in Iraq[14] and Saudi Arabia[15] with caregivers of children with autism spectrum disorder and attention deficit hyperactivity disorder revealed that they also had a moderate level of burden, corroborating that caring for children with chronic diseases favors burden on their caregivers.

Stable union was the most prevalent with regard to marital status, as more than half of the participants reported being married, as was also observed in other studies carried out with families of children with chronic conditions where more than half of the caregivers were married[16-18].

Health problems were found in 31 participants and were mostly related to metabolism diseases, heart diseases, non-transmissible chronic disease, hormones, reproductive system disease, vision problems, rare syndrome, musculoskeletal and psychological problems/diseases. According to an Australian survey of mothers of children with chronic illnesses, 50% of the sample had been diagnosed with health problems and another 50% with mental health problems. The same study showed that when mothers reported improvement in their mental health condition, the children's quality of life also improved[19].

Therefore, a relationship between the caregiver's health and the children's quality of life is perceived, as it is understood that the caregiver provides better quality care when he or she is in good health.

One study pointed out that the average age of caregivers of children with chronic illness and special health needs was 39.8 years, and the authors did not associate the caregiver's age with their quality of life[9]. Likewise, in another study with caregivers of children with microcephaly, their mean age was similar to that of the present study, and there was no association between age and burden[20].

The Catholic religion prevailed among those most cited by primary caregivers, followed by Evangelical. This data is in line with data from the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística - IBGE*) obtained in 2010, as Brazil is considered the largest country in the world in number of Catholics and the evangelical church is in second place as a religious group on the rise in the country, growing considerably[21]. In a study conducted in Mexico[22], it was shown that caregivers of children with chronic diseases in a hospital were Catholic in 80.9% of the sample, followed by non-Catholic Christians with 11.7%.

Religion is considered a support form for caregivers of children with chronic conditions, as in a Brazilian study[17] with CHSCN caregivers, families seek hope and strength in spirituality and use faith as an aid in the child's better prognosis. A study carried out in Turkey[23] showed that spirituality is also used as a way of coping and managing stress when caring for a child with a disability.

Another factor revealed was that the financial expenses due to the disease impact the monthly budget due to the purchase of medications, health exams which are not covered by the Unified Health System (*Sistema único de Saúde - SUS*) or have a long waiting list, as well as transportation to the hospital, as many families live far from the specialized treatment center.

As observed in a study on the impact of the chronic condition on the family from the economic perspective in Egypt in relation to the financial situation, a change in the family scenario is inevitable[24].

Regarding care support, a significant part of the caregivers in the present study did not share the child's care with someone else. It is known that caregivers who have a support network tend to have low anxiety, parental stress, depression and care burden levels, as evidenced in a Mexican study[22]. Similarly, in a study conducted with family members of children with congenital heart disease[25] they reported seeking family support to deal with the demands of care.

Regarding education level, half of the participants in this study had completed high school, as in a study[26] conducted in Mexico, where 63% of caregivers of children with chronic diseases had completed high school. In a North American study[27], 96% of caregivers of children with type 1 diabetes mellitus had graduated from high school.

Of the women interviewed, just over half said they were employed, in contrast to a study conducted in Mexico[22] in which 80.9% of female caregivers of children with chronic illnesses had unpaid work, while 75% of men had paid work. It is known that mothers of children with chronic conditions leave their jobs in some situations to dedicate themselves to child care.

Another study showed that caregivers of children who moved frequently were more likely to have poor health and maternal depressive symptoms. In the same study, it was analyzed that families with late rent payments experienced a greater chance of domestic difficulties such as food insecurity and reduced child care[28]. However, most of the mothers interviewed in this study have their own housing.

According to a study carried out with relatives of children with chronic conditions, an average of 4.59 family members was found, and there was a negative correlation between the number of family members with care burden, as well as isolation and disappointment, so that the greater the number of family members, the greater the total burden of care, isolation and lessened disappointment[12]. The average number of people living with the interviewees in this study was 2.89 people.

Study limitations

The results were obtained during the COVID-19 pandemic, which may have influenced the burden on the research participants.

Another possible limitation of the study would be selection bias, since the collection only took place with caregivers of children with congenital heart disease who were members of an interest group in an online social network, and may not have included caregivers so overloaded that they were unable to maintain access to the internet or those who even have economic or geographic conditions which make access impossible.

CONCLUSION

Burden is a reality in primary caregivers of children with congenital heart disease, as more than half of the caregiver mothers interviewed had moderate burden. Mothers commonly play the role of primary caregiver in society, as in the present study as well as in other national and international studies. It is worth emphasizing the importance of sharing care and family support for primary caregivers, otherwise they have no one to share their concerns with and may feel lonely, thus favoring isolation, sadness, anxiety and overload.

It is important for the family to be involved in the nursing care actions provided to children with congenital heart disease in health services, especially in outpatient consultations. The nurse must be able to solve doubts and offer support to the family in the face of the difficulties they may encounter in caring for a child with heart disease.

A strategy which may be useful is to create groups of primary caregivers of children with congenital heart disease in healthcare settings for these children, thus enabling conversation circles with other caregivers and multidisciplinary health professionals, where it would be possible to share experiences, providing social and emotional support for caregivers, thus contributing to alleviate the burden of care.

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