Original Article

Analysis of the level of burden in caregivers of children with heart disease

Análise do nível de sobrecarga em cuidadores de crianças cardiopatas

Análisis del nivel de sobrecarga de cuidadores de infantes cardiópatas

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Abstract

Objective: to correlate the characteristics of children with congenital heart disease with the level of burden of their primary caregivers.

Methods: This was a cross-sectional study with a quantitative approach. Data was collected through online interviews with 100 primary caregiver mothers of children with congenital heart disease. They answered the child characterization instrument and the Zarit Burden Interview. The data was analyzed using SPSS version 23, using descriptive statistics and analysis of variance ($p\leq0.05$).

Results: The average age of the children was 3.9 years, with a standard deviation of 3.2 years, with a prevalence of males (58.0%) and cyanotic heart disease (51.0%), under specialized cardiology care (96.0%), using regular medication (55.0%), without hospitalization in the last 12 months (56.0%) and having undergone at least one surgery (44.0%). Specialized follow-up ($p=0.003$), the presence of comorbidities ($p=0.0001$) and attending daycare or school ($p=0.001$) were associated with a higher risk of overload.

Conclusion: The correlation of the characteristics of children with heart disease indicated a slight burden on their primary caregivers. Children with specialized care, comorbidities and who attend school or daycare increased the burden on their caregivers.

Resumo

Objetivo: Correlacionar características de crianças portadoras de cardiopatia congênita com o nível de sobrecarga de seus cuidadores primários.

Métodos: Este estudo foi conduzido com delineamento transversal e abordagem quantitativa. A coleta de dados foi realizada em entrevistas *online* com 100 mães cuidadoras primárias de crianças com cardiopatia congênita. Elas responderam ao instrumento de caracterização das crianças e ao *Zarit Burden Interview*. Os dados foram analisados pelo programa SPSS versão 23, usando estatística descritiva e análise de variância ($p\leq0{,}05$).

Resultados: A média da idade das crianças foi de 3,9 anos, com desvio padrão de 3,2 anos, prevalência do sexo masculino (58,0%) e cardiopatias cianóticas (51,0%), em acompanhamento especializado em cardiologia (96,0%), uso de medicamento regular (55,0%), sem internação nos últimos 12 meses (56,0%) e realização de pelo menos uma cirurgia (44,0%). Acompanhamento especializado ($p=0{,}003$), presença de comorbidade ($p=0{,}0001$) e frequentar creche ou escola ($p=0{,}001$) foi associado a um maior risco para sobrecarga.

Conclusão: A correlação das características de crianças cardiopatas apontou sobrecarga leve em seus cuidadores primários. Crianças com acompanhamento especializado, comorbidade e que frequentam escola ou creche aumentam a sobrecarga em seus cuidadores.

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Conflicts of interest: nothing to declare.

Resumen

Objetivo: Correlacionar características de infantes portadores de cardiopatía congénita con el nivel de sobrecarga de sus cuidadores primarios.

Métodos: Este estudio se llevó a cabo con un diseño transversal y un enfoque cuantitativo. La recopilación de datos se realizó mediante entrevistas virtuales a 100 madres cuidadoras primarias de infantes con cardiopatía congénita, quienes respondieron el instrumento de caracterización de los infantes y la *Zarit Burden Interview*. Los datos fueron analizados por el programa SPSS versión 23, usando estadística descriptiva y análisis de varianza ($p \leq 0,05$).

Resultados: El promedio de edad de los infantes fue de 3,9 años, con desviación típica de 3,2 años, prevalencia de sexo masculino (58,0 %) y cardiopatías cianóticas (51,0 %), realizando seguimiento especializado en cardiología (96,0 %), con uso de medicamento regular (55,0 %), sin internación en los últimos 12 meses (56,0 %) y realización de por lo menos una cirugía (44,0 %). Los factores seguimiento especializado ($p=0,003$), presencia de comorbilidad ($p=0,0001$) y asistir a guardería o escuela ($p=0,001$) se asociaron a un mayor riesgo de sobrecarga.

Conclusión: La correlación de las características de infantes cardiópatas indicó sobrecarga leve en sus cuidadores primarios. Infantes con seguimiento especializado, comorbilidad y que asisten a la escuela o guardería aumentan la sobrecarga en sus cuidadores.

Introduction

Congenital heart diseases are defects in the structure of the heart and great vessels that usually develop during the embryonic period. There is no clear etiology. However, heart defects can be associated with genetic factors, chromosomal alterations, maternal age, use of medication during pregnancy, etc. They are among the most common malformations at birth and affect eight out of every thousand live births in Brazil and 94 out of every ten thousand live births worldwide.(1,2)

In Brazil, 28,900 children with congenital heart disease (CHD) are born every year, corresponding to 1% of all births. Of these, around 23,800 (80.0%) children require surgical intervention, half of them in the first twelve months of life. Congenital heart disease is the malformation with the highest infant mortality rate and is the second leading cause of death up to 30 days of age.(3)

Congenital heart defects can be identified in utero and prenatal care, delivery and birth should take place in more technologically dense locations, with birth planned in units with adequate infrastructure to provide intensive neonatal and surgical care. In this way, transporting the newborn after birth is avoided and surgical and intensive neonatal care is promoted, with a positive impact on quality indicators through access to a specialized and experienced multi-professional team. These care strategies increase the possibility of survival, reduce complications, increase safety and quality, thus improving the prognosis of these newborns.(4)

These children have special health needs during pregnancy, birth and the postpartum period. These needs are characterized by the continuous use of medication, dependence on life-sustaining technologies (due to examinations and surgical interventions), more restricted monitoring of their growth and development, as well as changes in daily habits. In international literature, they are identified and classified as Children with Health Special Care Needs. In Brazil, this expression has been translated and adapted to Children with Special Health Care Needs (CRIANES), as the use of health services and multi-professional care (including nursing) by such children is broader than that of other children.(5-7)

Children with congenital heart disease have different care demands to be met by health professionals and family members. In the context of family care, the health complexity imposed by congenital heart disease places a heavy burden on the primary caregiver. The primary caregiver is the person with the main, total or greatest responsibility for caring for the child, without remuneration for doing so, and may or may not be a family member.(8)

In the literature, the primary caregiver's burden is approached from the objective and subjective aspects. The former is related to changes in routine, impacts on social, professional and financial life, performing different tasks, as well as the need to monitor behavior in order to prevent health problems for the person being cared for. The subjective aspects are related to the caregiver's perception of their situation, including guilt, anger, expectations and positive and negative thoughts.(9)

In general, the physical and mental health of primary caregivers (most of whom are mothers) of children with special health needs is strongly related to the behavior and time demands of caring for the child.(10) Recent national and international studies have looked at the burden on primary caregivers of children with special health needs (including children with genetic syndromes, chronic illnesses and neurodevelopmental delays) who are dependent on complex and continuous care etc.(11-13)

However, there is a need for research measuring the burden on family caregivers of children with special needs (especially those with congenital heart disease), as the demand for care for these children has an impact on the physical, emotional and social health of caregivers who also need care. In this sense, knowing their burden will help to better organize and optimize the portfolio of services available in the Health Care Network (HCN) in order to reduce the burden on caregivers (including articulating strategies to meet the needs of children and family members).(9-12)

Therefore, the aim of this study was to correlate the characteristics of children with congenital heart disease with the level of burden of their primary caregivers.

Methods

This is a cross-sectional, descriptive and exploratory study with a quantitative approach. To write the manuscript, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines were followed. Data was collected in Brazil in the form of an online interview, carried out in an environment of the participant's choice between June 2021 and February 2022.

For the selection of participants, the following items were considered as eligibility criteria: being the primary caregiver of children, from zero to less than 12 years of age, with congenital heart disease and being over 18 years of age. The exclusion criterion was: being a caregiver without an electronic device with a camera available.

Participants were recruited from interest groups on a virtual social network aimed at family members and caregivers of children with congenital heart disease. Seven groups were identified. They were selected by title, searching in a social network tool (magnifying glass) with two keywords: congenital heart disease and children with congenital heart disease. In the closed groups, the researcher contacted the administrator and asked for access to participate. After gaining access, the first contact was made by publicizing the research using a standard text introducing the researcher and a summary (objectives and eligibility criteria) of the research.

Caregivers who expressed an interest in the research and met the inclusion criteria identified themselves as the child's primary caregiver, filled in a link (Google Forms®) sent by the researcher and provided their e-mail address and telephone number. During the initial contact with the participants, the researcher introduced herself and explained the objectives and development of the research. She then invited the primary caregivers to take part in the research and informed them that the interview would be recorded.

The study population comprised primary caregivers of children with congenital heart disease, with non-randomized convenience sampling. After the invitation, 130 people showed interest in taking part in the study. These included people who refused to take part via video call (5), did not get back to the researcher (10), did not have access to the camera for the video call (2), were not primary caregivers (1), and whose children were over twelve years old (4), were hospitalized at the time (7), died during the week of the interview (1). Thus, the total sample consisted of 100 participants.

During data collection, the main researcher filled in the two research instruments, Characterization of the child and the Caregiver Burden Scale (Zarit Burden Interview), according to the participants' answers, which were followed up by screen projection.

In the pediatric field, the caregiver burden scale has been used in studies to assess the burden of caregivers of children and/or adolescents with chronic conditions such as Down syndrome, cancer, cerebral palsy and autism spectrum disorder.(11-13)

This scale was translated into Portuguese in 2002 and consists of 22 items covering the domains of health, social and personal life, financial situation, emotional well-being and interpersonal relationships. Each item on the scale is scored (0: never, 1: rarely, 2: sometimes, 3: often and 4: always) and the total score can vary from 0 to 88 points. After adding up the points, the bands correspond to the following overloads: none (0-21), mild (21-40), moderate (41-60) and severe (61-88).(14) The internal consistency of the overload scale was assessed by comparing the alpha values (Cronbach) estimated for the dimensions of its items (α: 0.83).(15)

Data was collected online on days and times previously agreed for the interview (Google Meet®). On the day of the interview, before starting the recording, the participants were given the Informed Consent Form(ICF) for electronic acceptance (Google Forms®) and the Assignment of Use of image and voice.

The data collected was exported to the Statistical Package for Social Sciences (SPSS; v. 23), where it was analyzed. At this stage, the means of the dependent variable (ZBI) were calculated in relation to each level of exposure to the independent variables.

The dependent variables in the study were as follows: physical, emotional and social overload of primary caregivers of children with congenital heart disease, classified as categorical; absent, moderate, moderate-severe and severe overload. The variables in the characterization tool were the independent variables related to the children: age (in years or months), gender, name of congenital heart disease, follow-up in a health unit specializing in cardiology, use of continuous medication, cardiac surgery, hospitalization in the last 12 months of life, time since diagnosis of heart disease, association with another disease, attendance at nursery or school and receipt of some social benefit.

The analyses were carried out using descriptive statistics. Mean, median and standard deviation (SD) were calculated for the quantitative variables. The qualitative variables were described using absolute (n) and relative (%) frequencies. To carry out the bivariate and multivariate analyses, the normality of the data distribution was first tested (Shapiro-Wilk test). After confirming that the study variables followed a normal distribution, parametric statistics were used. The bivariate analyses were based on analysis of variance (one-way ANOVA) applied to categorical variables.

Multivariate analysis was carried out using multiple linear regression. The multivariate model included all the variables that showed statistical significance ($p \leq 0.10$) in the bivariate analysis. All variables that showed an association with the outcome remained in the multivariate model (significance level: 5%; $p \leq 0.05$). The quality of fit of the multivariate models was assessed by the R-squared (R2) and F-statistic measures.

The research was approved by the Research Ethics Committee of the institution that proposed the study, Opinion 4.733.602; CAAEE 39358620.5.0000.5238. It also met the ethical criteria for research involving human beings according to the National Health Council (Brazilian Resolution 466/2012; Circular Letter 2/2021/CONEP/SECNS/MS).(16,17) All participants read and agreed to the Informed Consent Form (ICF), which was sent as a hidden copy to all e-mail addresses provided.

Results

A total of 100 mothers caring for children with congenital heart disease took part in the study. The burden of these caregiver mothers was assessed for mean score (34.5), standard deviation (12.5) and minimum (8.0) and maximum (63.0) scores. Table 1 shows the bivariate analysis between the characteristics of affected children and the caregiver burden scores of children with heart disease. After categorical analysis, the majority of primary caregivers had a mild burden (Table 2).

In terms of gender, the children with congenital heart disease were divided into boys (58%) and girls (42%). The average age of the children was 47.2 months, or 3.9 years (SD: 3.2), most of whom (59%) were between pre-school age and infants (1-5 years) and more than half did not attend school or nursery (60%). Congenital heart diseases were classified according to blood flow, as cyanotic and acyanotic, and may be associated with more than one heart disease in the same child. In the children in this study, the most frequent were cyanotic (51%). In terms of time since diagnosis, 86% of the

Table 1. Bivariate analysis between the characteristics of children with heart disease and the mean burden scores of caregivers

Variables	n(%)	Mean (SD)	p-value*
Gender			
Male	58(58)	34.1 (13.0)	0.715
Female	42(42)	35.0 (11.9)	
Age (years)			
<1	13(13)	29.1 (13.8)	0.078
1-5	59(59)	33.9 (12.6)	
≥6	28(28)	38.2 (10.9)	
Classification			
Acyanotic	49(49)	34.5 (11.4)	0.994
Cyanotic	51(51)	34.5 (13.6)	
Time since diagnosis (years)			
<1	14(14)	28.6 (13.6)	0.057
>1	86(86)	35.4 (12.1)	
Specialized follow-up			
No	6(6)	22.5 (12.2)	0.015
Yes	94(94)	35.2 (12.2)	
Use of medication for heart disease			
No	45(45)	35.0 (13.2)	0.710
Yes	55(55)	34.0 (11.9)	
Number of heart surgeries performed			
0	21(21)	29.9 (12.8)	0.118
1	49(49)	36.7 (12.6)	
≤ 2	30(30)	34.0 (11.6)	
At least 1 heart surgery			
No	21(21)	29.9 (12.8)	0.063
Yes	79(79)	37.5 (12.2)	
Number of hospitalizations			
0	56(56)	35.4 (13.4)	0.692
1	25(25)	33.7 (9.2)	
≤ 2	19(19)	32.7 (13.9)	
At least 1 hospitalization			
No	56(56)	35.4 (13.4)	0.412
Yes	44(44)	33.3 (11.4)	
Presence of comorbidities			
No	57(57)	31.1 (12.1)	0.001
Yes	43(43)	39.0 (11.7)	
Attends nursery or school			
No	60(60)	31.6 (12.1)	0.004
Yes	40(40)	38.8 (12.1)	

*ANOVA; SD - Standard Deviation

children had been diagnosed for more than a year. It was observed that 96% of the children were under specialized follow-up in a cardiology unit (or with a cardiologist) and 55% of them were taking continuous medication specifically for the treatment of congenital heart disease. As for heart surgery, 49% had at least one and 30% had two or more. With regard to hospital admissions in the last 12 months, more than half (56%) did not require hospitalization. Children with comorbidities made up 47% of the sample, i.e. 47 children were diagnosed with a disease other than congenital heart disease. The assessment of the level of burden of primary caregivers of children with congenital heart disease, considering the total score of the scale, showed an average value of 34.5, standard deviation: 12.5; minimum and maximum scores of 9 and 63 points, respectively. Thus, 17% of the caregivers were classified as having no burden, while others were classified as having mild (54%), moderate (26%) and severe (3%) burdens (Table 2).

Table 2. Levels of burden of primary caregivers of children with congenital heart disease

Variables	n(%)
None	17(17)
Mild	54(54)
Moderate	26(26)
Severe	3(3)

Multivariate linear regression showed that children's age (p=0.881), time since diagnosis (p=0.708) and having had heart surgery (p=0.116) were not significantly associated with the caregiver burden scale. In other words, they cannot be considered predictors of the burden assessed. On the other hand, specialized care (p=0.003), the presence of comorbidities (p=0.0001) and attending daycare or school (p=0.001) were significantly associated and could be considered predictors of caregiver burden (Table 3). Specialized health care increases the chances of caregiver burden by 14.2 times (95%CI=4.94-23.33) compared to children who do not receive it. A similar analysis can be made in relation to the presence of comorbidities, as children who have other comorbidities can increase the chances of caregiver burden by 8.23 times (95%CI=3.83-12.63) when compared to children without comorbidities. Finally, attending school or daycare increases the odds of primary caregiver burden by 7.61 times (95%CI=3.17-12.06). With regard to the quality of the model's fit, it is worth mentioning that the F-statistic proved to be more robust to testing the overall significance of the regression model (F=10.9; p<0.001) in model 2 when compared to model 1 (F=5.94; p<0.001). The R2 values ranged from 0.25 (in the full model) to 0.28 (in the final model), showing that the reduction in the number of variables for a simpler model was pertinent.

Table 3. Multivariate linear regression models of the association between the characteristics of affected children and the burden of care scores for children with heart disease

Linear regression models	OR*	95%CI**	p-value*
Model 1			
Age	-0.01	-0.08-0.07	0.881
Time since diagnosis	1.30	-5.58-8.18	0.708
Special follow-up	13.40	3.84-22.70	0.007
At least 1 surgery	4.40	-1.10-9.91	0.116
Presence of comorbidity	8.40	3.98-12.81	<0.0001
Attendance at nursery or school	7.17	0.95-13.38	0.024
Model 2			
Special monitoring	14.15	4.94-23.33	0.003
Presence of comorbidity	8.23	3.83-12.63	<0.0001
Attendance at nursery or school	7.61	3.17-12.06	0.001

* t-test; *OR - Odds Ratio; **95%CI - 95% confidence interval for the odds ratio; B - Regression coefficient

Discussion

Male children with congenital heart disease predominated, as in a study carried out in Buenos Aires (Argentina) and in Brazilian studies.(18-23) As for the clinical characteristics of children with congenital heart disease, cyanotic congenital heart disease showed a slight prevalence. However, acyanotic congenital heart disease is among the most prevalent characteristics in epidemiological studies of Brazilian reference hospitals.(24,25)

One study evaluated congenital heart disease in Germany and found that its prevalence was higher in females, while complex lesions were more prevalent in males. The main diseases found were: ventricular septal defect (19.2%), atrial septal defect (13.0%), tetralogy of Fallot (9.3%), univentricular heart (9.4%) and coarctation of the aorta (7.0%). Acyanotic heart diseases are the ones that require corrective surgery most often, with greater severity and clinical impairment for the children (in addition to the correlation with Down's syndrome), thus contributing to a greater burden on the primary caregiver.(26)

With regard to surgical correction, 79% of the children had already undergone a surgical procedure at some point in their lives, with specialized cardiology care. This assistance is ensured in Brazilian specialized cardiology treatment centers (National Plan for Assistance to Children with Congenital Heart Disease; Ordinance 1.727; 11/07/2017).(27)

Emergency or elective cardiac surgery for children generates stress in children and primary caregivers, which can lead to overload. Caregivers may feel fear due to the possibility of death and a sense of helplessness in the face of the complexity of the situation. It is therefore important for the nursing team to be attentive during the pre-, intra- and post-operative periods and to offer the necessary support and information to reduce caregivers' distress, as a lack of information and appropriate professional guidance can be the cause of this distress.(28)

In this study, most of the children had undergone at least one surgical intervention to correct a congenital heart defect. Of these, 43% had an associated comorbidity, which contributes to increasing the burden on the caregiver and making pre-surgical preparation more difficult, including blood sampling, electrocardiograms, invasive tests and imaging tests such as cardiac catheterization, chest X-rays, transthoracic or transesophageal ultrasound, etc. These are carried out to study the heart disease, define the intervention to be carried out and the therapeutic possibilities.(20)

The complexity of the treatment and the special care imposed by CHD changes the family routine and directly impacts the personal and professional lives of primary caregivers. In this study, most of the children (96%) had been diagnosed with congenital heart disease for more than a year, with the need for specialized health monitoring and the use of heart disease medication. This has an impact on the routine of primary caregivers, who may find it difficult to keep their jobs while caring for and attending to the schedule of appointments, exams, hospitalization and ensuring medication care, as they need to accompany the children to medical appointments and exams.(20)

With primary caregivers leaving the job market, financial resources in the family are restricted. Even for CCCs who receive social benefits, the money is used only for treating the children, reducing family income and impacting on quality of life. This hinders access to good food and better health, housing and leisure conditions, leading families into a critical financial situation, thus contributing to a moderate burden on primary caregivers.(20)

The mild overload of caregivers found in this study can be aggravated without professional help to manage care activities for the children, such as encouraging them to go to school and daycare, planning special care, strengthening their support network, etc. The consequences of these changes are limitations on primary caregivers' leisure time and on caring for their own health, which can evolve into increasing levels of moderate to severe overload. Studies show that the absence or failure of a support network is reflected in the need for psychological support for mothers. Part (10%) of the requests made to the Psychology Service of a Brazilian hospital were due to the family context of vulnerability, little support network and probable caregiver overload.(20,29)

As for CCC, care should be provided at the most complex hospital level in the SUS, with guaranteed and effective access to the healthcare network. According to the data from this study, 79 of the children with congenital heart disease required surgery and specialized follow-up, contributing to a moderate level of burden on their primary caregivers.(30)

The low school or nursery attendance observed in this study may be related to the average age of the children. Most of them were pre-schoolers and infants and therefore did not yet attend nursery school or school. In Brazil, the enrollment of children from the age of four in basic education is compulsory (Law 12.796 of 2013).(31) In addition, we understand that this data can be justified by the pandemic situation. During this period, many schools were not operating or mothers were afraid to send their children to face-to-face education. This, coupled with social distancing and isolation (including restricted access to hospitals and bed reservations for COVID-19 cases), may have contributed to a moderate burden on these caregivers.

As most of the children in this study had special health needs, which can impose physical and educational limitations, such as not using stairs, not running, not doing sports, regular use of medication, absence from classes due to the need for medical monitoring, we also thought about the need for inclusion and school adaptation. Thus, with regard to the rights of children with disabilities, special health needs and CCC, the state must ensure comprehensive protection, planning and development of actions. In addition, intersectorality is a guideline that should guide health, education, professional qualification and inclusion, culture, sport and leisure services, as recommended by the National Council for Children and Adolescents (2018).(32)

Public health, education and social assistance policies have specific guidelines for caring for this public. They require intersectoral coordination and interdisciplinary work in the planning and operationalization processes (among other intersections), as well as family participation in the placement of children with congenital heart disease in daycare or school.

The same was shown in a Brazilian study that assessed the burden of caregivers of children with cerebral palsy in relation to school attendance. The lower level of motor impairment seems to indicate greater school participation by these children. A counterpoint was presented in relation to the burden of these caregivers, as the burden of caregivers of children with milder motor impairments was greater than that of caregivers of children with more severe motor impairments. One possible explanation was the fact that children with milder impairments have greater independence and participation in social life. Thus, it is possible to infer that these factors can generate frustration and anguish in family members, increasing their emotional burden.(14)

With regard to the use of specific drugs for heart disease, most children use them, which is common for treating symptoms and avoiding complications of heart disease. However, the choice of medication to treat congenital heart disease depends on the type of heart disease and its hemodynamic changes. They can be platelet antiaggregant (for the pre- and postoperative periods), antiarrhythmics (to control arrhythmia), diuretics, antihypertensives, etc.(33)

A European study found that among children with congenital heart disease, the use of cardiovascular medication indicates greater cardiac and circulatory impairment; when medication needs to be prescribed, it happens in the first few years of life. Diuretics and antihypertensive drugs are the most commonly used.(34)

In a study of mothers of children with attention deficit disorder, some reported feeling guilty for medicating their children without being able to help them in any other way. Medication care can generate doubts in caregivers. The attention required contributes to their overload, especially when children use more than one medication.(35,36)

In this study, most of the caregivers had a mild burden. However, a study of caregivers of children with heart disease in Iran showed that 47.2% of them suffered from moderate overload.(37) Similarly, studies on caregivers of children with special health needs (chronic non-progressive encephalopathy) have shown that they go through critical phases. These begin with the diagnosis, last throughout the care process and bring future fears about the prognosis of the clinical condition, social acceptance, schooling, the job market and death.(38,39)

After hematopoietic cell transplantation in children and adolescents, the burden on caregivers was focused on pain and emotional distress during treatment. This emotional experience produced changes not only in their personal lives but also in the lives of the children, generating feelings of flight, fear, despair and uncertainty about the future.(40)

Thus, the overload expressed in the form of suffering, as reported in the literature, can lead to a significant deterioration in the emotional state, resulting in depression, stress and anxiety, as well as a reduction in personal care, quality of life and health.(40)

In a study of caregivers of children with heart disease in China, they also showed excessive mental burden, guilt and remorse. They felt guilt about their child's illness, fear of other people finding out about the illness and the child suffering discrimination, economic impact related to cost, surgery and frequent trips to hospital, and family conflicts due to the excessive burden of caring for the children.(41)

In this study, three relevant factors were associated with the outcome of caregiver burden. These were: the presence of comorbidities, specialized monitoring and attending daycare or school.

The presence of comorbidities was likely to increase caregiver burden by 8.23 points. We understand that care demands are greater in the presence of comorbidities. In a study carried out in Sao Paulo on children with special health needs with different chronic conditions, caregivers were 26.2% more likely to be overburdened when the children had mixed care demands.(10)

According to a study on the experience of mothers of children with congenital heart disease and Down syndrome, the two conditions caused cumulative impacts on the mothers. The children had more than one chronic condition and required specialized care, thus bringing challenges to daily life due to the need to care for both health conditions.(42)

Children with heart disease who are undergoing specialized health care often require long hospital stays, including intensive care units, specific tests and surgical procedures. This factor is closely related to stress and psychological damage for parents. During the treatment process, mothers feel vulnerable and alone, with fear, anxiety and depression. Studies show that families of CRIANES are financially overburdened, as many families live far away from the treatment unit and have to pay for travel and food on the days of consultations and examinations needed by the children. The need to reshape daily life can increase the burden.(43,44)

In relation to school or daycare attendance, the literature states that it is common for children with special conditions and physical limitations to have difficulty in school performance and independence to carry out daily activities, and that they should be included in inclusion classes. These limitations generate stress, anguish and worry in their caregivers, leading them to overload.(45)

The contribution of this study is that it is necessary to know the factors associated with the burden of caregivers of children with congenital heart disease. They should therefore be added to the planning of care and intervention for this population.

Such data can be useful for strategies to protect, monitor and assist children with special health needs and their primary caregivers. Thus, this research could contribute to changes in care through shared, longitudinal and articulated care with families and health services.

The limitations of this study are related to the sample size due to changes in the data collection strategy during the COVID-19 pandemic, which forced online interviews to be conducted. Another possible limitation would be selection bias, as the data was only collected from caregivers of children with congenital heart disease who belonged to a specific group on an online social network. This may have excluded other overburdened caregivers who were unable to access the internet, including economic or geographical conditions. Given the limitations of this study in establishing cause and effect relationships, it is important to develop new studies with a longitudinal design.

Conclusion

In the correlation between the characteristics of children with congenital heart disease and the level of burden of their primary caregivers, being under specialized care, having comorbidities and attending school or daycare are characteristics that increase the burden of their caregivers, although it is identified as mild.

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Collaborations

Guimarães GRR, Moraes JRMM, Silva LF, Góes FGB, Ciuffo LL and Souza TV contributed to the conception of the project, analysis and interpretation of the data, writing of the article, relevant critical review of the intellectual content and approval of the final version to be published.

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