

**ORIGINAL ARTICLE**

## **Factors associated with the quality of life of caregivers of pediatric patients with congenital heart disease**

### **HIGHLIGHTS**

1. Socio-economic factors significantly affect the lives of caregivers.
2. Intrinsic religiosity had a positive impact on quality of life.
3. Negative religious coping had a negative impact on the dimensions measured.

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### **ABSTRACT**

**Objective:** To evaluate the socioeconomic impact, the health of pediatric patients, and religiosity on the quality of life of caregivers of children and adolescents with congenital heart disease at the pediatric outpatient clinic. **Method:** A cross-sectional, descriptive study with 99 caregivers from a pediatric outpatient clinic at a university hospital in the interior of Minas Gerais, Brazil. We used a Socioeconomic Questionnaire, Duke Religiosity Index, Brief Religious-Spiritual Coping Scale and World Health Organization Quality of Life - Bref for data collection. The simultaneous influence of the variables was assessed using multiple linear regression. **Results:** Factors such as negative religious-spiritual coping, self-reported color, and not having a job had a negative impact on the quality of life dimensions, while the child's age and intrinsic religiosity had a positive impact. **Conclusion:** Religiosity and spirituality influence the quality of life of caregivers, indicating the importance of considering these factors in interventions.

**KEYWORDS:** Quality of Life; Caregivers; Child; Heart Diseases; Spirituality.

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## INTRODUCTION

Congenital heart defects (CHD) are a set of structural or functional heart defects present at birth in children. The progression of the disease and symptoms depend on the severity of the anatomical alteration, among other factors, which is why some children may have limitations and others may reach adulthood and lead a normal life<sup>1-2</sup>.

In recent years, the number of children with congenital heart disease has increased considerably, with an estimate of 9 per 1000 live births<sup>3</sup>. In addition, according to the guidance manual of the Brazilian Society of Pediatrics<sup>1</sup>, the group of children with congenital heart disease represents around 30% of all congenital malformations. However, the real incidence of CHD is a question mark due to its underreporting and failure to diagnose it. This is due to the difficult access to tests, as well as the difficulty of a successful clinical approach, increasing the morbidity and mortality related to congenital heart disease<sup>4</sup>.

Faced with chronic childhood illnesses, the caregivers of these children face visible difficulties, especially in relation to the changes in routine caused by the child's condition, which results in a significant work overload<sup>5</sup>. In addition, the need for social support is essential to strengthen caregivers and mitigate the negative effects that the disease has on their lives<sup>5</sup>. Thus, it is clear that caregivers experience physical and emotional overload, making the routine stressful<sup>6</sup>.

For the World Health Organization (WHO), health-related quality of life (HRQoL) is defined as "an individual's perception of his or her position in life in the context of the culture and value systems in which he or she lives and in relation to his or her goals, expectations, standards and concerns", and is a comprehensive concept that includes physical, functional, emotional, social and cognitive domains<sup>7-8</sup>. Taking into account the special care that these children must have throughout their growth to achieve physical, social and emotional well-being, new needs will appear, which can present new adversities both in the life of the child and adolescent, as well as in the life of the parents, especially related to the school period<sup>9</sup>. For this reason, the quality of life of caregivers of children with CHD can have significant impacts.

In this context, research shows positive correlations between the dimensions of QoL and religiosity and spirituality (R/S),<sup>10</sup> demonstrating that R/S can help individuals at various times, especially in health and illness. These factors bring concepts in spirituality such as "inner peace" and "meaning of life" to people in difficult situations<sup>10</sup>.

Given these factors, this study was carried out to evaluate the socioeconomic impact, the health of pediatric patients, and religiosity on the quality of life of caregivers of children and adolescents with congenital heart disease at the pediatric outpatient clinic of a tertiary hospital.

## METHOD

### Study design and participants

This is a cross-sectional, descriptive study conducted in a university hospital in the interior of Minas Gerais - Brazil, involving caregivers of pediatric patients with congenital heart disease in a pediatric outpatient clinic. The study included caregivers of patients

aged between 0 and 13 who were waiting for a follow-up appointment. Data collection took place between November 2022 and February 2023.

Participants were selected using a convenience sampling approach. All caregivers approached at the outpatient clinic were invited to participate. After being informed about the study's objectives, those who agreed to take part signed an Informed Consent Form.

## **Instruments used**

The following instruments were used to assess the impact of socio-economic variables and religiosity/spirituality on quality of life: the General Social Questionnaire and History of Parents and Pediatric Patients, P-DUREL, the Brief Religious-Spiritual Coping Scale, and WHOQol-Brief.

### **General social questionnaire and history of parents and pediatric patients**

The research team developed a questionnaire to collect comprehensive information from the participants. This questionnaire included items to record socioeconomic data such as age, gender, self-reported color, marital status, occupational status, income, and schooling. Data was also collected on clinical history, such as pre-existing illnesses and psychological follow-up. The questionnaire also covered religious affiliation. Questions about pediatric patients were also included, such as age, type of delivery, prematurity, when the diagnosis of heart disease occurred, whether the child or adolescent goes to school/daycare, whether they have limitations and the need for surgical correction. Additional questions were asked to obtain information on daily habits, such as physical activity, smoking, alcohol consumption, and the presence of previous illnesses.

### **Duke Religiosity Index (P-DUREL)**

The Duke Religious Index (P-DUREL) is a five-item instrument for measuring religious attachment, which produces three dimensions of religious involvement: Organizational Religiosity (OR), Non-Organizational Religiosity (NOR), and Intrinsic Religiosity (IR)<sup>11</sup>. RO is related to participation in religious group activities, such as services, masses, and meetings (rated on a scale of 1 to 6). The RNO evaluates the individual regularity of religious practices, such as prayers, meditations, reading religious texts, among others (score from 1 to 6). While IR is about the search for the intrinsic experience of religiosity and internalization as the main individual purpose (score from 3 to 15)<sup>11</sup>.

### **Coping Scale coping spiritual-religious coping scale (CRE- brief)**

The CRE-breve scale shows how individuals use their faith to cope with stress and is associated with quality of life. It is divided into 14 items with the answers evaluated on a five-point scale (1-not at all/not applicable to 5-very much)<sup>12</sup>. The scale evaluates positive CRE, negative CRE, Total CRE and CREN/CREP, which shows the percentage of negative CRE used in relation to positive CRE by simply dividing the basic items<sup>12</sup>.

### **World Health Organization Quality of Life - Bref (WHOQOL- Bref)**

In response to the need for a synthesized instrument that maintained its psychometric quality, the WHO Quality of Life Group created an abbreviated version of the WHOQOL-100 scale, the WHOQOL-Bref<sup>13</sup>. The synthesized version has 26 questions, with two related to quality of life and 24 questions representing the 24 facets of the original instrument. In addition, unlike the original, in which each facet is assessed with 4 questions, in the WHOQOL-Bref each facet is assessed with only one

question<sup>13</sup>. A confirmatory factor analysis for the structural validation of the WHOQOL-Bref revealed the need for four domains: physical, psychological, social relationships and environment<sup>13</sup>.

## Data analysis

The data was organized in an Excel spreadsheet and the statistical analysis was conducted using the *Statistical Package for the Social Science* (SPSS), version 23.0 TM. Descriptive analyses were carried out to present the variables of interest, using frequency, percentage, mean and standard deviation for sociodemographic, clinical and quantitative data.

The simultaneous influence of the variables was assessed using multiple linear regression. The prerequisites for parametric tests were duly taken into account. Regression analyses were carried out for each of the four dimensions of quality of life (physical, psychological, social and environmental) measured by the WHOQOL. The variables included in the regression models were age, self-declared color, marital status, occupation, pre-existing illness, child's age, child's school attendance, religiosity index (RI) and negative dimension of religiosity (Negative CRE). A significance level of 5% ( $\alpha=0.05$ ) was adopted for the inferential analyses.

The dichotomous variables were categorized as follows: Color: white (reference category) or black/brown/yellow; Marital status: married (reference category) or other; Occupation: with income (reference category) or without income; Preexisting illness: no (reference category) or yes; Child goes to school: yes (reference category) or no.

## Ethical aspects

The research was authorized by the Research Ethics Committee, under number CAAE: 57294022.7.0000.5152, approval opinion: 5.074.577.

## RESULTS

In the study, 99 caregivers were interviewed, all of whom were mothers (Table 1). Self-reported color black/brown ( $n=61$ , 61.6%), were not married ( $n= 53$ , 53.5%) and had an average age of 33.96 years ( $SD=9.55$ ). Of the total, 53 (53.5%) had a job with no income and an average income of R\$2,315.80 (US\$398.44). As for schooling, the majority did not answer ( $n=53$ , 53.5%) and of those who did, 29 (29.3%) had completed high school or less. With regard to lifestyle habits, 36 (36.4%) reported practicing physical activity, two (2%) reported being smokers and 13 (13.1%) consumed alcoholic beverages. In addition, 30 (30.3 %) reported having pre-existing illnesses. With regard to psychological counseling, 23 (23.2%) reported having it, and seven (7.1%) had psychiatric counseling. About religiosity, 90 (90.9%) reported having a religion, the majority ( $n=42$ , 42.4%) being evangelicals, 33 (33.3%) Catholics, nine (9.1%) Spiritists, and three (3%) Umbandists.

As for the pediatric patients, 63 (63.6%) were between 0 and 5 years old, 71 (71.7%) were born vaginally and 72 (72.7%) had a full-term pregnancy. Regarding the diagnosis of heart disease, 77 (77.8%) were diagnosed after birth, with 46 (46.5%) reporting the need for surgical correction. At the outpatient clinic, most of the follow-ups were quarterly or more ( $n=71$ ; 71%). In addition, 54 (54.5%) of the children attended school

or nursery, and the majority (=4n7; 47.5%) had no limitations such as running or not being able to go to school (Table 1).

**Table 1.** Frequency and percentage of sociodemographic and clinical characteristics of caregivers of pediatric patients at the pediatric outpatient clinic of a university hospital (n=99). Uberlandia, MG, Brazil, 2024

(continued)

Caregiver Variable	(n)	%
<b>Sex</b>		
Female	99	100
Male	0	0
<b>Self-reported color</b>		
Black/Brown/Yellow	61	61.6
White	35	35.4
No answer	3	3.0
<b>Marital status</b>		
Single/separated/widowed	53	53.5
Married	42	42.4
No answer	4	4.0
<b>Occupational status</b>		
Occupation without income	53	53.5
Occupation with income	41	41.4
No answer	5	5.1
<b>Education</b>		
High school or less	29	29.3
Higher education or more	17	17.2
No answer	53	53.5
<b>Age (years - mean/standard deviation)</b>	33.96	9.55
<b>Income (R\$ - mean/standard deviation)</b>	2325.80	2155.20
<b>Physical activity</b>		
Yes	36	36.4
No	57	57.6
No answer	6	6.1
<b>Smoking</b>		
Yes	2	2.0
No	96	97.0
No answer	1	1.0
<b>Consume alcoholic beverages</b>		
Yes	13	13.1
No	81	81.8
No answer	5	5.1
<b>Pre-existing illness</b>		
Yes	30	30.3
No	66	66.7
No answer	3	3.0

**Table 1.** Frequency and percentage of sociodemographic and clinical characteristics of caregivers of pediatric patients at the pediatric outpatient clinic of a university hospital (n=99). Uberlandia, MG, Brazil, 2024

(continued)

Caregiver Variable	(n)	%
<b>Psychological support</b>		
Yes	23	23.2
No	76	76.8
<b>Psychiatric follow-up</b>		
Yes	7	7.1
No	92	92.9
<b>Has a religion</b>		
Yes	90	90.9
No	9	9.1
<b>Religion</b>		
Catholic	33	33.3
Protestant	42	42.4
Spiritist	9	9.1
Umbanda	3	3.0
No answer	12	12.1
<b>Pediatric Patient Variables</b>		
<b>Age</b>		
0-5 years	63	63.6
6-10 years	25	25.3
More than 10	8	8.1
No answer	3	3.0
<b>Type of delivery</b>		
Cesarean section	25	25.3
Vaginal delivery	71	71.7
No answer	3	3.0
<b>Premature Birth?</b>		
Yes	24	24.2
No	72	72.7
No answer	3	3.0
<b>Diagnosis of heart disease</b>		
Before birth	20	20.2
After birth	77	77.8
No answer	2	2.0
<b>Outpatient follow-up</b>		
Quarterly or more	71	71.7
Monthly/Weekly	21	21.2
No answer	7	7.1
<b>Do you go to school?</b>		
Yes	54	54.5
No	39	39.4
No answer	6	6.1

**Table 1.** Frequency and percentage of sociodemographic and clinical characteristics of caregivers of pediatric patients at the pediatric outpatient clinic of a university hospital (n=99). Uberlandia, MG, Brazil, 2024

Caregiver Variable	(n)	(conclusion)	
		%	
<b>It has limitations</b>			
Yes	25	25.2	
No	47	47.5	
No answer	27	27.3	
<b>Requires surgery</b>			
Yes	46	46.5	
No	42	42.4	
No answer	11	11.1	

Source: The authors (2024).

Table 2 shows the measures of central tendency and variability for the Religiosity and Quality of Life scales. In general, the table shows that, for all the dimensions measured, the participants' scores were above 50% of the total possible value on each scale, indicating moderate to high levels of religiosity and perceived quality of life in the various dimensions assessed.

**Table 2.** Measures of centrality and dispersion of the P-DUREL, religious-spiritual coping and Quality of Life Scale scores. Uberlandia, MG, Brazil, 2024 (n=99)

	Minimum	Maximum	Average	Standard Deviation
<b>Religiosity</b>				
Intrinsic	7	15	13.85	1.63
Organizational	1	6	4.31	1.38
Non-Organizational	1	6	4.67	1.27
<b>Religious-spiritual coping</b>				
Positive	3.00	5.00	4.34	0.5
Negative	1.00	4.57	1.84	0.98
<b>Quality of life</b>				
Physics	17.86	96.43	68.13	17.22
Psychological	20.83	95.83	69.03	15.72
Social	0	100	65.03	19.49
Environmental	18.75	93.75	62.46	14.37

Source: The authors (2024).

The multiple linear regression showed that negative religious-spiritual coping had a significant negative impact on all dimensions of Quality of Life (Table 3).

In addition, for the physical dimension of quality of life, being self-declared black/brown ( $\beta = -0.251$ ,  $p = 0.034$ ), not having a job ( $\beta = -0.247$ ,  $p = 0.042$ ) also had a negative and significant impact. The variable Age of the child ( $\beta = 0.280$ ,  $p = 0.048$ ) showed a positive impact, meaning that the older the pediatric patient, the higher the QoL scores (Table 3).

In the psychological dimension of quality of life, the results indicated that being self-declared black/brown ( $\beta = -0.208$ ,  $p = 0.036$ ) had a negative and significant impact. Intrinsic Religiosity ( $\beta = 0.189$ ,  $p = 0.069$ ) tended towards a positive impact but did not reach statistical significance. As for the social dimension of quality of life, the Intrinsic Religiosity variable ( $\beta = 0.322$ ,  $p = 0.007$ ) had a positive and significant impact (Table 3).

Being self-declared black/brown ( $\beta = -0.274$ ,  $p = 0.010$ ) negatively and significantly impacted the environmental dimension. The "child's age" variable ( $\beta = 0.364$ ,  $p = 0.005$ ) had a positive and significant impact (Table 3).

**Table 3.** Linear regression analysis, with Beta and p-values for each predictor in the four dimensions of quality of life (QoL). Uberlandia, MG, Brazil, 2024

Predictors	Physical QoL		Psychological QoL		Social QoL		QV Ambiental	
	Beta	p	Beta	p	Beta	p	Beta	p
<b>Age</b>	0.027	0.841	-0.152	0.184	-0.079	0.543	-0.061	0.621
<b>Self-declared color</b>	<b>-0.251</b>	<b>0.034</b>	<b>-0.208</b>	<b>0.036</b>	-0.098	0.373	<b>-0.274</b>	<b>0.010</b>
<b>Marital status</b>	0.027	0.809	-0.140	0.143	-0.146	0.177	-0.192	0.063
<b>Occupation</b>	<b>-0.247</b>	<b>0.042</b>	-0.058	0.565	-0.118	0.304	-0.138	0.206
<b>Preexisting illness</b>	-0.129	0.267	0.166	0.093	-0.124	0.261	-0.199	0.061
<b>Age of the child</b>	<b>0.280</b>	<b>0.048</b>	0.190	0.107	0.015	0.911	<b>0.364</b>	<b>0.005</b>
<b>Go to school</b>	0.043	0.757	-0.024	0.839	-0.041	0.763	0.196	0.127
<b>RI</b>	0.070	0.568	0.189	0.069	<b>0.322</b>	<b>0.007</b>	0.201	0.070
<b>CRE Negative</b>	<b>-0.397</b>	<b>0.004</b>	<b>-0.541</b>	<b>0.000</b>	<b>-0.394</b>	<b>0.003</b>	<b>-0.453</b>	<b>0.000</b>

Caption: Dichotomous variables - Color: white (reference category) or black/brown/yellow; Marital status: married (reference category) or other; Occupation: with income (reference category) or without income; Pre-existing illness: no (reference category) or yes; Child goes to school: yes (reference category) or no; RI: intrinsic religiosity; CRE: negative religious and spiritual coping.

Source: The authors (2024).

## DISCUSSION

This study refines our ideas about the influence of religiosity and socioeconomic factors on the quality of life of caregivers of children with congenital heart disease. It took place in a University Hospital in the interior of Minas Gerais, limiting itself to this region, taking into account the socio-economic and cultural characteristics of the area, which may have influenced the results.

The profile of the participants showed that all the caregivers were women, which is in line with other studies that also investigated the difficulties experienced by families in coping with their child's chronic condition<sup>5,14</sup>. This data reinforces the trend that women often take on the role of primary caregiver, especially in situations of chronic illness<sup>14</sup>. Most of the participants in the study declared themselves to be black or brown and unmarried. Other factors, such as lack of a paid job and pre-existing illnesses, were also observed in other studies<sup>14</sup>.

Most of the pediatric patients were up to 5 years old, and more than half attended school or nursery school. Most had no significant limitations, such as difficulty running or attending school, which aligns with previous findings<sup>14</sup> in which most children with chronic conditions attended school.

Among the characteristics of the caregivers, the majority reported having a religion, with evangelicals predominating. This survey indicated that levels of religiosity and quality of life were classified as moderate to high, with scores above 50%. These findings align with an integrative literature review, which identified a strong and positive relationship between religiosity, spirituality, and quality of life, reinforcing the importance of these factors in the well-being of individuals<sup>10</sup>.

In this study, a relevant factor that negatively impacted the lower scores on the quality of life scale was self-declaration as black or brown, affecting the physical, psychological, and environmental domains. Similarly, other studies have also shown that self-declaration as a black person has a significant influence on the burden of caregivers, as evidenced in a study with caregivers of children and adolescents with cancer, where this variable was associated with greater burden and poorer quality of life<sup>15</sup>.

In addition to the negative impact on the physical, psychological, and environmental domains, self-declaration as black or brown may be related to structural and social factors that aggravate the vulnerability of these caregivers<sup>16</sup>. Today's societies still carry prejudice and inequality in their foundations, which in Latin America generates societies with extreme conditions of inequality and poverty in the social structure.<sup>16</sup>. Thus, it is clear that caregivers often face additional barriers, such as less access to quality health services, racial discrimination and economic difficulties, which contribute to increased burden and further compromise quality of life<sup>17</sup>. These factors can intensify stress, reduce social support, and make it difficult to manage the demands of care, highlighting the intersection between race, social class, and health. Highlighting these issues can help better understand the inequalities faced by this group of caregivers and the importance of public policies to reduce these disparities<sup>17</sup>.

In the physical dimension of quality of life, which includes factors such as activities of daily living, ability to work, discomfort, rest, dependence on substances and medical help, the variable "not having a job" had a negative impact. This finding is consistent with other studies, which show that caregivers with financial limitations after the illness of pediatric patients are twice as likely to have a low quality of life<sup>14</sup>. Similarly, it was observed that, even though they were of working age, the majority of caregivers of children and adolescents with Down syndrome did not work, which highlights the exhausting workload of these caregivers, often leading them to give up their professional activities<sup>18</sup>.

In addition, an intriguing result was that the age of the patients positively impacted physical and environmental QoL, with the older the child, the higher the levels of quality of life. Similarly, using a qualitative approach, a study that sought to analyze the quality of life of caregivers of visually impaired children in Catalonia found that as time passed, there was a greater understanding of the child's condition and the factors that were caused by the disability<sup>19</sup>. In addition, they had greater internal control in the care process through acquired coping strategies<sup>19</sup>.

Intrinsic religiosity had a significant and positive impact on the social domain of quality of life, reflecting the personal experience of religiosity and its internalization as an individual purpose. Studies suggest that there is a correlation between the intensity of the religiosity of caregivers and those with the disease, indicating that families tend to share similar religious experiences<sup>20</sup>. In addition, caregivers with greater religiosity participate more frequently in religious activities, which may explain the influence of intrinsic religiosity on the improvement in social quality of life observed in this study<sup>20</sup>.

Religious-spiritual coping is using religion or spirituality to deal with stressful situations or the negative consequences of day-to-day adversity<sup>21</sup>. In this study, the results indicated a negative impact between negative religious-spiritual coping and quality of life. This suggests that interpreting their children's illness as a spiritual punishment for their mistakes or sins can generate additional suffering when searching for the reason for this condition. In a study of caregivers of Alzheimer's patients, it was observed that although they had high levels of intrinsic religiosity, the progression of the disease and the increase in care responsibilities often led to the development of negative patterns of religiosity and spirituality, such as negative religious coping<sup>20</sup>.

The education variable was not added to the multiple linear regression because most (53.5%) did not answer the question, which could have affected the results. The reason for the lack of answers was not questioned for ethical reasons. However, several studies have demonstrated the impact of this variable<sup>15,22-23</sup>.

Thus, this study has made important contributions to understanding the factors that affect the quality of life of caregivers of pediatric patients with congenital heart disease. The results showed that being black or brown negatively influenced the quality of life of these caregivers, showing that in Brazilian society, skin color still has a significant impact, even in the current century. It is, therefore, crucial that public policies promoting racial equality are expanded and better implemented. Another relevant socio-economic factor was the lack of employment, which also contributed to the worsening quality of life, suggesting that many of these caregivers are overburdened and face difficulties getting a formal job.

On the other hand, religiosity and spirituality are beneficial to quality of life, except in the case of negative religious-spiritual coping, which tends to interpret illness as a spiritual punishment for past sins. These findings reinforce the need for a multidimensional approach to caring for caregivers, including emotional, socioeconomic, and spiritual support.

Some factors can be pointed out as limitations in this work, such as the fact that the research was carried out in only one collection center, which excludes geographical and cultural variables, given that Brazil is a diverse country. Furthermore, although multiple linear regression was useful for identifying associations and controlling confounding variables, the study's cross-sectional nature prevents causal relationships from being determined.

With this in mind, future studies could address a multicenter study considering the factors discussed and propose interventions related to the quality of life domains. Finally, considering including qualitative data would be of great value so that individual experiences complement quantitative data.

## CONCLUSION

The results of this study indicate that socioeconomic factors, the age of pediatric patients, and religiosity significantly affect the quality of life of caregivers. Factors such as self-declared black/brown color and lack of employment among caregivers were associated with lower quality of life scores, especially in the physical and environmental dimensions.

Religiosity proved to be a relevant factor, with negative religious coping hurting all dimensions of quality of life. On the other hand, intrinsic religiosity showed a positive trend, especially in the social dimension, highlighting its potentially protective role. These findings highlight the importance of support strategies that integrate socio-economic aspects, the patients' state of health and the strengthening of emotional and spiritual resources, such as religiosity, to understand and improve the quality of life of these caregivers.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Merino AS, Guerra VCM, Oliveira LS, Scalia LAM.** Drafting the work or revising it critically for important intellectual content

- **Merino AS, Scalia LAM.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Merino AS, Scalia LAM.** All authors approved the final version of the text.

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