

## Educational strategies for the anxiety reduction of caregivers of children with congenital heart disease

Estratégias educativas para redução da ansiedade dos cuidadores de crianças com cardiopatia congênita

Estrategias educativas para reducir la ansiedad de los cuidadores de niños con cardiopatía congénita

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### ABSTRACT

**Objective:** to evaluate the performance of educational interventions for caregivers of children with congenital heart disease as a strategy to reduce the level of anxiety. **Methods:** Interventional group study, performed at a referral hospital in Pernambuco, from June to September, 2014. **Results:** 32 caregivers of children with congenital heart disease participated in the study. It was observed that caregivers of children with congenital heart disease presented a lower level of anxiety after the educational interventions performed by the nurse in the preoperative period when compared to those who did not participate ( $12.47 \pm 8.98$  versus  $17.12 \pm 10.46$ ). **Conclusion:** It is concluded that strategies of educational intervention have positive effects on the improvement of anxiety level in caregivers of children with congenital heart disease.

**Keywords:** Anxiety; Caregivers; Congenital Heart Disease; Nursing.

### RESUMO

**Objetivo:** avaliar a realização de intervenções educativas para os cuidadores de crianças com cardiopatia congênita como estratégia para redução do nível de ansiedade. **Métodos:** Estudo do tipo grupo intervencionista, realizada em um hospital de referência de Pernambuco, no período de junho a setembro de 2014. **Resultados:** Participaram do estudo 32 cuidadores de crianças com cardiopatia congênita. Observou-se que os cuidadores de crianças com cardiopatia congênita apresentaram-se com nível de ansiedade menor após as intervenções educativas realizadas pelo enfermeiro no pré-operatório quando comparados com os que não receberam ( $12,47 \pm 8,98$  versus  $17,12 \pm 10,46$ ). **Conclusão:** Conclui-se que as estratégias de intervenção educativa produzem efeitos positivos na melhoria do grau de ansiedade em cuidadores de crianças com cardiopatia congênita.

**Descritores:** Ansiedade; Cuidadores; Cardiopatias Congênitas; Enfermagem.

### RESUMEN

**Objetivo:** Evaluar el rendimiento de las intervenciones educativas para los cuidadores de niños con cardiopatía congénita como una estrategia para reducir el nivel de ansiedad. **Métodos:** Estudio de grupo intervencionista, realizado en un hospital de referencia en Pernambuco, de junio

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a septiembre de 2014. **Resultados:** Los participantes fueron 32 cuidadores de niños con cardiopatía congénita. Se observó que los cuidadores de niños con cardiopatía congénita presentaron un menor nivel de ansiedad después de las intervenciones educativas realizadas por la enfermera en el período preoperatorio en comparación con los que no recibieron ( $12.47 \pm 8.98$  versus  $17.12 \pm 10.46$ ). **Conclusión:** Se concluye que las estrategias de intervención educativa tienen efectos positivos en la mejora del nivel de ansiedad en cuidadores de niños con cardiopatía congénita.

**Descriptores:** Ansiedad, Cuidadores, Enfermedad cardíaca congénita, Enfermería.

## INTRODUCTION

Congenital heart defects are defined by structural defects of the heart and represent the most frequent serious malformations that manifest in the newborn, contributing significantly to perinatal mortality.<sup>1</sup>

The prevalence of congenital heart disease in Europe showed a general index of 8: 1000 live births. It is estimated that 36,000 children are born in the European Union each year with congenital heart disease and 3,000 are diagnosed with the same conditions, but they result in intrauterine death due to the presence of fetal anomaly.<sup>2</sup> Brazil has shown a prevalence of approximately 6 : 1,000 live births with congenital heart disease. In the last years, there was a decrease in deaths in the first year of life from 11.5% in 2000 to 8.7% in 2004, due to improved health care and early diagnosis, as well as the results of neonatal cardiac surgery, allowing an increasing number of children born with congenital heart disease to live with physical conditions that make possible a good quality of life.<sup>3</sup>

The etiology of congenital heart disease is still not fully defined. In most cases, multifactorial origins can be considered, taking into account hereditary predisposition and environmental factors. It was observed that, in about 60% of the occurrences, the causes are still unknown. A little more than 30% are included in the set of genetic abnormalities. Congenital heart disease may also be related to external factors (maternal rubella, teratogenic drugs and alcoholism) that can cause damage to the fetus development, increasing the risk of heart disease.<sup>4</sup>

The birth of the baby with congenital heart disease can be a serious situation for the caregivers, both for the clinical situation and for the “death” of the healthy child that, symbolically, existed prior to diagnosis. Another aggravating factor is the treatment, usually long and complex. Therefore, support and guidance to caregivers during child care are of fundamental importance.<sup>5</sup>

It is understood that the hospitalization of the child generates several feelings in the caregiver. She may experience a sense of incapacity, dependence, insecurity and lack of control over the condition of illness that the child bears. In the hospital, the family tends to depersonalize itself as it needs to conform to the norms and routines imposed by the hospital institution, and may have its identity and autonomy affected.<sup>6</sup>

Health education has been valued as a possibility of transforming the current practice of health care. This practice is a resource used by health professionals to act in the daily lives of people through the scientific knowledge produced in the health field. However, in order for this process to take place in an effective and non-taxing manner, it must be preceded by practices that respect the differences of the actors involved, rendering health education a real tool for the empowerment of the individual.<sup>7</sup>

Nursing can work with caregivers in the prevention of illness, in relieving suffering, in protecting, promoting and restoring health. In the case of children with heart disease, nursing promotes, together with caregivers, the most satisfactory health conditions, as well as the best possible environment for its growth and development. Such interventions can be therapeutic, supportive and counseling, or even in health education.<sup>1</sup> Nowadays “both health and education seek ways to construct a subject in a state of permanent learning, learning to learn, learning to teach and teaching to learn”, conspiring to the context of the qualification of the Unified Health System (UHS) health practices.<sup>8</sup>

Education for health care is an important work object of nurses, and it is possible, through this action, to reduce anxiety and the responses to stress before surgery, providing the physical and emotional preparation, fundamental for rehabilitation.<sup>9</sup>

Considering health education as a pedagogical practice of improvement of care that allows a greater autonomy in the decision-making of caregivers of children with congenital heart disease, it is necessary to understand the importance of health education in relation to the role of the caregiver of children with congenital heart disease, with a view to reduce anxiety, promote effective knowledge and transform attitudes and life habits, enabling caregivers to critically analyze reality and favoring the improvement of the living conditions of these children.

Health education is a practice focused on the development of individual and collective skills in order to improve the quality of life, structured from a pedagogical tendency.<sup>7</sup> In this perspective, the objective was to evaluate the performance of educational interventions for caregivers of children with congenital heart disease as a strategy for reducing anxiety and improving knowledge.

## METHODS

This is an exploratory, descriptive, intervention-type study with a quantitative approach. This type of study is based on an intervention of the researcher in the reality studied, with the intention of modifying it or solving a problem.<sup>10</sup>

The research was carried out in the Congenital Heart Disease Infirmary of the Pernambuco Cardiovascular Emergency Department Prof. Luiz Tavares (PROCAPE), from June to September 2014. The unit has 20 beds for the accommodation of children and adolescents with cardiopathy who are under the responsibility of the caregiver and the multidisciplinary team during the entire

hospitalization period. The average number of surgeries performed at the hospital unit is one per week. However, during the period of hospitalization, the unit has a diagnostic support service and examinations for clinical decision on the conduct of the cases. The choice of said hospital was given as a unit of reference in cardiology in the state of Pernambuco, also attending the north and northeast of the country.

Thirty-two caregivers of children with congenital heart disease participated in the study. To carry out the research, the following requirements were chosen to be filled out by the participants: caregivers of children up to 12 incomplete years of age; the consent of the caregiver to participate in the interviews, with the signing of the Term of Free and Informed Consent (TFIC); child hospitalized in the PROCAPE Pediatric Cardiopathy sector in the perioperative period with diagnosis of congenital heart disease and; not making use of anxiolytic and antidepressant. The exclusion criteria were: the caregivers of children who are in the transoperative period, considering

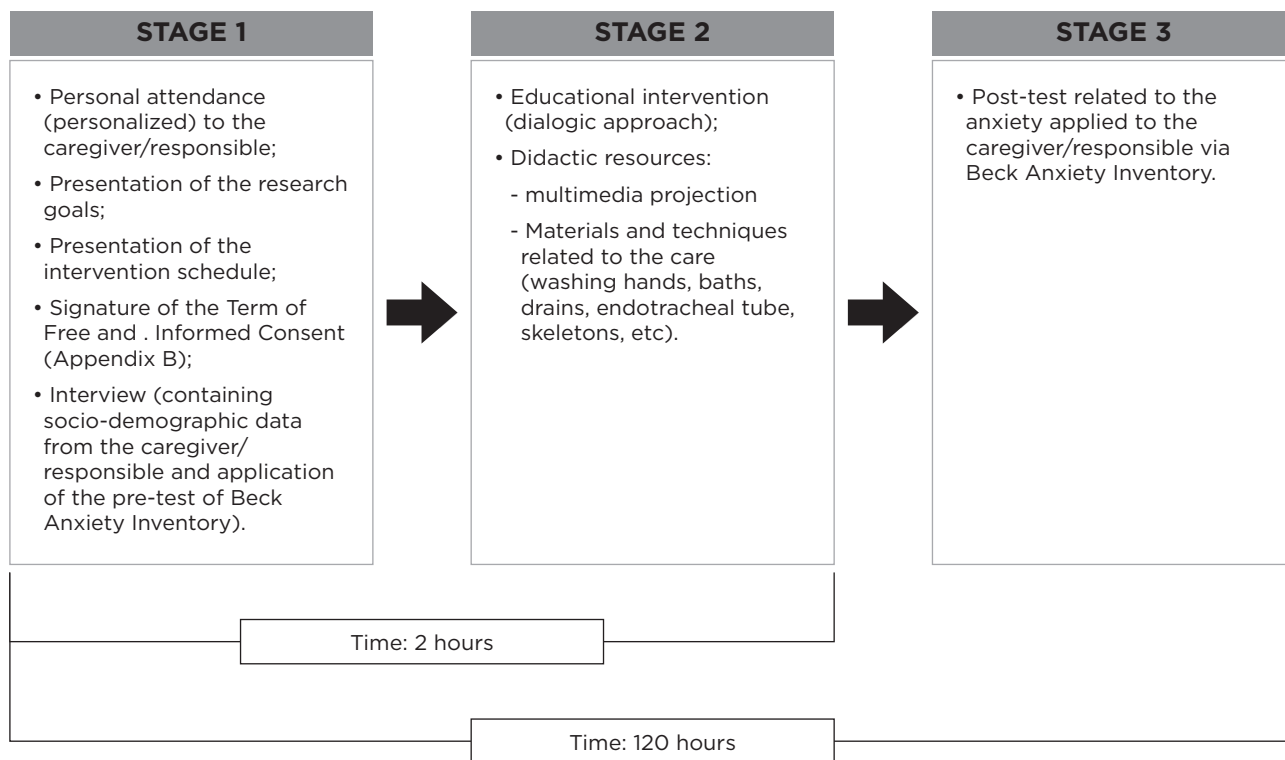
the increase of anxiety by the result of the surgery; and caregivers of children with acquired heart disease. There were losses during the research: child death (1), previous surgical accomplishment (5) and hospital discharge (2).

It was considered child, a person with up to 12 years of age, as set out in article 2 of the Statute of the Child and Adolescent (SCA), inspired by the International Human Rights Instruments of the United Nations (UN) in the Declaration of the Rights of the Child, in the "Principles of the United Nations".<sup>11</sup>

For the assessment of anxiety, a worldwide free use scale was used: the Beck Anxiety Inventory, which is a symptomatic scale of anxiety screening. The inventory is composed of 21 items, each of which reflects on the gradual levels of each symptom, with the anxiety being graded as minimal with values ranging from 0-10, mild (11-19), moderate (20-30) and severe anxiety (31-63).<sup>12</sup>

The study was divided into three stages (Figure 1):

**Figure 1** - Flowchart of the study division and the research stages corresponding to the educational intervention performed in the cardiopediatrics service.



Source: Author

The data were stored in the program Microsoft Excel 2010, for further analysis in statistical software Epi-info7 and SPSS 20.0, version (SPSSInc, Chicago, United States). Quantitative variables are presented as means ± standard deviation and medians. Categorical variables are presented in their absolute and relative frequencies (percentage). For all analyzes, the level of statistical significance considered was 5%. Normality analysis of the distribution of anxiety scores was performed using the Kolmogorov-Smirnov test. The comparison of the means of anxiety obtained in the evaluations before and after the intervention was performed with paired t-test.

The research followed the norms disciplined by Resolution No. 466, of December 12, 2012, of the National Health Council, of the Ministry of Health, was approved by the Ethics and Research Committee of the Oswaldo Cruz University Hospital / Pernambuco Emergency Medicine, which is linked to the University of Pernambuco, with the CAEE: 30622214.8.0000.5192 and all the participants involved signed the Term of Free and Informed Consent.

## RESULTS AND DISCUSSION

Among the caregivers who participated in the research, 3 were male and 29 were female, being 26 mothers, 2 fathers, 2 grandparents, a grandfather and an aunt. Regarding the time between the hospitalization of the children with heart disease and the beginning of the participation in the study, the mean time in days was of  $2.81 \pm 2.81$ . The mean age was  $33.19 \pm 11.24$  years. It is verified a predominance of female caregivers (90.6%), Afrodescendant (53.1%) and family income of 1.84 minimum wages (Table 1).

The majority of inpatient caregivers for the surgical correction of congenital heart disease came from other Brazilian states (37.5%) or from other municipalities in the state of Pernambuco (37.5%). Regarding the educational level of the participants, there was a predominance of elementary/middle (46.9%) and high school (40.6%). Thus, a clearer and simpler language was used in health education actions to facilitate communication about the subject matter discussed. Regarding professional occupation, 46.9% of the caregivers performed household activities, followed by 15.6% public servant, 12.5% self-employed and 12.5% unemployed (Table 1).

Variables related to caregivers and children with congenital heart disease were investigated. The family situation showed to be a reality of great absence of companions in the home (46.9%) and with number of children near the Brazilian average ( $2.63 \pm 1.68$ ). Of the spouses, 41.18% participated in the care in the hospital and 58.85% were collaborative with the situation of the caregiver in the home activities (Table 1).

**Table 1** - Socio-demographic characterization and health background of caregivers. Recife - PE, 2014. (n=32)

VARIABLES	md	±dp
Length of stay (days)	2,81	2,81
Age (years)	33,19	11,24
Family Income (* number of wages)	1,84	0,57
Number of children	2,63	1,68
	<b>n</b>	<b>%</b>
<b>Sex</b>		
Male	3	9,4
Female	29	90,6
<b>Education</b>		
Higher education	4	12,5
High school	15	46,9
Elementary/Middle School	13	40,6
<b>Occupation</b>		
Public Employee	5	15,6
Private Employee	3	9,4
Self Employed	4	12,5
From home	15	56,9
Retired	1	3,1
Unemployed	4	12,5
<b>Provenance</b>		
Recife	8	25,0
Other cities from PE	12	37,5
Other states	12	37,5

<b>Ethnicity</b>		
White/Caucasian	14	43,8
Afrodescendent	17	53,1
Indigenous	1	3,1
<b>Marital status</b>		
Partner	17	53,1
No partner	15	46,9
<b>Situation of the spouse in relation to the care</b>		
Collaborative in the hospital	7	21,9
Collaborative in the home	10	31,2
Absent	15	46,9

\*For the calculation, the value of the minimum wage in reais was considered: R\$ 724.00

mean ± sd = mean ± standard deviation

Source: Authors

As to the diagnosis of congenital heart diseases, 12 types were identified, the most frequent being Tetralogy of Fallot (25%), ventricular septal defect (21.9%) and atrial septal defect (12.5%). Caregivers sought care for their children to have heart murmur identified by another professional (40.6%), fatigue (28.1%) and cyanosis (15.6%). During the prenatal period, only 9.4% of the children had received a diagnosis, the majority of which were discovered in the first year of life (75%) (Table 2).

**Table 2** - Main pathologies presented by children, main complaints and confirmation of diagnosis. Recife - PE, 2014. (n=32)

Variables	n	%
<b>Diagnosis</b>		
Ebstein's anomaly	1	3,1
Coarctation of the Aorta - CoAo	2	6,3
Defect of the Atrioventricular Septum	2	6,3
Atresia Tricuspid	2	6,3
Congenital Atrioventricular Block	1	3,1
Interventricular Communication - VSD	7	21,9
Tetralogy of Fallot - T4F	8	25
Truncus arteriosus	1	3,1
Interatrial Communication - IAC	4	12,5
Aortic Valve Stenosis	1	3,1
Transposition of Great Arteries - TGA	2	6,3
Persistence of the Arterial Canal	1	3,1
<b>Main complaints leading to hospitalization</b>		
Tiredness	9	28,1
Heart Blow	13	40,6
Bradycardia	1	3,1
Deformity of the thoracic structure	1	3,1



Difficulty gaining weight	1	3,1
Tachycardia	1	3,1
Cyanosis	5	15,6
Inapetence	1	3,1

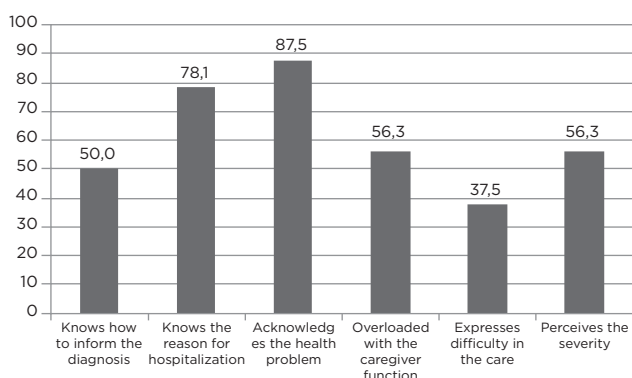
**Diagnostic Confirmation**

During prenatal care	3	9,4
In the first year of life	24	75,0
After one year of age	5	15,6

Source: Authors

Regarding knowledge about child care and illness, it was identified that half of the participants knew the name of the diagnosis of the child with heart disease and 78% correctly informed the reason for the hospitalization. Regarding feelings, 87.5% of the caregivers were aware of the health problem and of the responsibility for child care, 56.3% felt alone and overwhelmed with care responsibilities, 56.3% had a perception of the commitment of the child's growth and development, and only 37.5% had difficulty caring for the child (Graph 1).

**Graph 1** - Perception of diagnosis, degree of commitment and responsibility of caregivers of children with congenital heart disease. Recife-PE, 2014.



Source: Authors

Anxiety before and after the intervention had a normal distribution in the statistical test. The sample was maintained at both evaluations in the mild anxiety range, but a comparison between the values before ( $17.12 \pm 10.46$ ) and after the intervention ( $12.47 \pm 8.98$ ) showed that it was effective in the reduction of scores ( $p = 0.001$ ) (Table 3).

**Table 3** - Comparison between the means of the anxiety degree assessed between the caregivers before and after the educational intervention. Recife-PE, 2014. (n=32)

mean ± sd	Mín	Máx	p*	p**
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Previous anxiety	17,12±10,46	0	34	0,897	
Anxiety after educational intervention	12,47±8,98	0	38	0,863	0,001

\* P-value for the Kolmogorov-Smirnov test

\*\* Paired t test

Source: Authors

In the current literature, there are few studies on caregiver of children with congenital heart disease. However, a growing number of surveys have been reported that portray the caregiver of chronic disease in general.<sup>13</sup>

A psycho-educational intervention research offered to the cancer patient encouraged the use of approach strategies, such as problem solving, which are useful for promoting health and reducing anxiety. Such evidence can be observed in the correlation between anxiety and the use of strategies focused on the emotions, indicating that there may be a relation between a decrease in the use of this strategy and an improvement in the anxiety score.<sup>14</sup>

In a systematic review on nursing care for children hospitalized for congenital heart disease, it was observed in professional practice that caregivers are extremely anxious about the birth of a child with congenital heart disease, often unable to assimilate the team's guidelines, are worried about the possibility of surgery and the risk of death of the child.<sup>15</sup>

In the present study, caregivers who received nursing guidelines showed a decrease in anxiety level ( $17.12 \pm 10.46$  to  $12.47 \pm 8.98$ ), suggesting that health education actions in the preoperative period of cardiac surgery offered by the nurse contribute to the reduction of anxiety.

These findings corroborate a national survey showing that anxiety can be caused by fear and lack of knowledge about the surgical process, and that preoperative information, when effective, reduces stress and anxiety.<sup>16</sup>

Several researches on children with chronic diseases pointed to inferences relating to the age factor of caregivers. The data points to relatively young caregivers with low schooling and direct kinship. It was verified that the mother was considered as the main companion of the child with congenital heart disease. As for the marital situation, married or consensual union predominated.<sup>13,17-18</sup> These findings are similar to those found in this study.

Other studies have demonstrated similar findings to this study in the socioeconomic level, considering that caregivers with high socioeconomic status control their well-being better when compared to caregivers with lower socioeconomic status. In addition, caring for a child with a disability increases the demand for resources, including time and money, which can increase the burden on caregivers when they are economically active members.<sup>19</sup> More than all treatment and additional expenses, financial loss also occurs because at least one parent leaves the job to fully devote himself/herself to the child.<sup>20</sup>

In the studies conducted to evaluate the quality of life and growth rates among children with congenital heart

diseases, a higher frequency of ventricular septal defect was observed, followed by atrial septal defect, persistent ductus arteriosus, total atrioventricular septal defect, coarctation of the aorta, tetralogy of Fallot, pulmonary stenosis, and total anomalous drainage of the pulmonary veins.<sup>18,21-23</sup> Due to the research performed in a hospital north-northeast reference, a prevalence of more serious heart diseases such as tetralogy of Fallot was observed, followed by ventricular communication, septal defect and atrial septal defect, in disagreement with the findings in the literature.

The main reason for referrals for admission to the cardiology service was the presence of cardiac murmur in the medical and nursing consultation in childcare, followed by fatigue and cyanosis. A similar finding was found in the study on congenital heart disease in the newborn, in which the main reasons for hospitalization for surgical treatment were the presence of breath auscultation, which was quickly detected in the physical examination of the newborn. Although infrequently, the presence of cyanosis and heart failure indicated a high probability of diagnosing congenital heart disease.<sup>22</sup>

Generally, heart disease is diagnosed when the child is newborn, which leads the family to seek health services for the follow-up of the children. Other publications pointed to the time of diagnosis, which averaged 11.2 months, with a median of six months, the shortest being one month and the largest 48 months.<sup>17-8,23</sup>

At least half of the participants knew the diagnostic name of the child with congenital heart disease, just as they knew how to correctly report the reason for the hospitalization. A systematic review study on the need for information to parents and caregivers of children with congenital heart disease identified that the knowledge of the caregivers on the diagnoses of congenital heart disease was unsatisfactory, where some knew only the name of the heart disease, and these were related to a greater knowledge of children with cyanotic heart diseases, regardless of their severity. It should be noted that knowledge ranges from information on diagnosis to the most important clinical consequences.<sup>5</sup>

In relation to work / occupation, it was found that, at the time of illness / need for hospitalization, most caregivers practiced activities outside the home when the child became ill and about two-thirds had other children. Predominantly, families have between 2 and 4 children, live in households between 4 and 5 people and have a family income of 1 to 2 minimum wages.<sup>17-8</sup> Similar findings were scored in this research.

Other research indicates that the majority of the children resided in the city where they receive treatment and follow-up. However, a significant portion comes from other localities.<sup>18,23</sup> In particular, in the reality investigated, several children and caregivers moved from other Brazilian states of origin or from other municipalities of the state of Pernambuco for evaluation, follow-up and health treatment in Recife. The unit in which the research was performed is a regional reference in pediatric cardiac surgery. Some

of them arrive at the service with a previous diagnosis of cardiopathy, requiring conduct and better follow-up, and others only with suspicions raised by pediatricians or other professionals of the city of origin.

One-third of the mothers of children with chronic diseases had to stop working to care for their children who are being treated. This change in the routine affects several areas of the caregiver's life, since he/she had to give up on work, income, study, hours of sleep, social life, leisure, pleasure, family life and personal care.<sup>19-20</sup>

## CONCLUSION

Based on an analysis of the data obtained through the present research, it can be verified that, in fact, the strategies of educational intervention have demonstrated a very significant contribution with regard to the production of positive effects for the improvement of the degree of anxiety of the caregivers of children with congenital heart disease. In this sense, it is necessary to emphasize that the strategy of educational intervention used brought greater effectiveness to the control of negative strategies focused on the emotions of the caregivers involved.

Finally, it is expected that the results of the present study will not be singled out, as they are restricted only to the professional scope analyzed, but that they multiply and be pulverized in other health services, thus giving priority to provide the best and highest quality possible of subsidies for the control of anxiety experienced by caregivers of children with congenital heart disease.

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