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ORIGINAL ARTICLE

Family Functioning of Adolescents with Congenital Cardiopathy in a Sample from Public Schools in Porto Alegre - RS

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Abstract

Background: The impact of chronic diseases on the patient and the family ranges from minimal to severe distress. Family functioning has been often investigated as a psychosocial measure having an essential role for social adjustment in chronic diseases.

Objectives:: To compare family functioning among families of adolescents with congenital heart disease (CHD) and healthy controls (H) in relation to cohesion, adaptability, and family risk.

Method: Cross-sectional exposed-control study with 2 groups of adolescents (12 -18 years). The exposed group included adolescents with congenital heart disease (CHD), from a specialized public health system hospital (SUS), and adolescents from 7 public schools, considered healthy, composed the control group. In the hospital, the data collection was individual, before the medical consultation. In schools, the collection took place in groups. Adolescents and parents responded to the FACES III scale. The following statistical tests were used: Pearson's chi-square, Fisher's test, T-test for independent samples, Poisson multivariate regression analysis with 95% reliability, significance established at 5% and a statistical power at 99% (ß = 0.01).

Results: A total of 161 (41.6%) adolescents with CHD and 226 (58.4%) healthy adolescents participated. There was greater family cohesion among adolescents with CHD, with a higher frequency of connected families, while among healthy adolescents, there are more families of the disengaged type. Regarding adaptability, a higher proportion of families of the chaotic type were found among healthy adolescents compared to adolescents with CHD. A higher frequency of high-risk families was identified among healthy adolescents (16.8%).

Conclusion: The families of the adolescents with CHD have a more balanced functioning and low risk when compared to the families of healthy adolescents; with greater cohesion between the members and greater adaptability. Congenital heart disease was not an independent factor for high-risk family.

Keywords: Heart Defects, Congenital; Adolescent; School Health Services; Social Cohesion; Compliance; Academic Performance.

Introduction

In situations of affected health, parents and children may have difficulties to overcome adversities for a good psychological and social adjustment[1,2] and family functioning is important to predict psychosocial results. Chronic diseases shed light on changes in family functioning,[1] as well as family interaction influences health care.[3] It is not clear whether families of children with congenital heart disease have more difficulties in family functioning than families of healthy children.

Congenital heart diseases accounts for 15% of infant deaths. [4] Adolescents can be affected in their

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development, health perception, cognitive and relational skills, daily activities, adherence to treatment, and transition to adulthood,[5] have a greater risk for a healthy emotional[6] and behavioral development, as well as greater difficulties in adaptation.

Olson et al., [7-10] consider 2 factors to diagnose family functioning: cohesion (bond and autonomy between members) and adaptability (how the family reacts to situations). The combination of factors defines family risk. This study compared family functioning between adolescents with congenital heart disease and healthy adolescents to support the treatment of these children and adolescents and their families.

Methods

Cross-sectional, exposed-control study with adolescents (12 to 18 years of age), approved by the Research Ethics Committee of the Fundação Universitária de Cardiologia - Porto Alegre, state of Rio Grande do Sul, Brazil. The exposed group, with congenital heart disease (CHD), attended a specialized hospital, while the control group, with healthy adolescents (H), included students from public schools. Once the exposed group came from the public health system, it was defined the public education system as one of the criteria for the control group, minimizing possible biases related to the socioeconomic condition of the adolescents' families.

Adolescents with cognitive difficulties or other chronic illnesses were excluded.

Adolescents with CHD, authorized by their parents by the informed consent form (ICF), answered a sociobiodemographic questionnaire and the FACES-III scale (Family Adaptability and Cohesion Evaluation Scale) at the hospital's outpatient clinic. The parents also answered the FACES III scale. Of the 7 participating schools, 2 were suggested by the Municipal Education Secretariat (only elementary school) and the other state schools, were selected by convenience in different areas of the city of Porto Alegre. Data collection was made according to the school calendar. All students attending the grades with adolescents within the stipulated age group were invited and each one took home an envelope containing the ICF for parents and the FACES-III scale, so that a parent or guardian could respond. Participants included students who agreed to participate, brought the signed authorization, responded to the FACES III scale, and met the inclusion criteria. The school provided a list of students considered special, with cognitive difficulties, to control the sample. The collection was made in groups of students, in a specific room for this purpose. Parents answered the FACES-III scale at home.

Family functioning was identified using 2 dimensions (cohesion and adaptability) of the FACES III scale. [9] The values were obtained by adding the odd items for cohesion and the even items for adaptability. In cohesion, families can be agglutinated (high cohesion), connected (medium / high cohesion), separated (medium / low cohesion), and disconnected (low cohesion). The sample's mean values define the center point. Up to a standard deviation (SD) on the left (-1 SD) are the separated families, on the right (+1 SD) are the connected families and, from standard deviation (SD), the disconnected and joined families, respectively. A similar classification was used for adaptability in which families are chaotic (high adaptability), flexible (medium / high adaptability), structured (medium / low adaptability), or rigid (low adaptability). For adaptability, the values up to 1 SD, to the left of the midpoint (-1SD) are the flexible families and to the right (+1 SD), the structured families. In addition to a standard deviation, families are chaotic or rigid. One considers a functional family if it is not included in the extremes of these levels. The combinations between the 2 dimensions define the family risk: low, medium, and high. Low risk is the combination of families with connected or separate cohesion and separate or flexible type adaptability. High risk is defined for families with disconnected or bonded cohesion and with rigid or chaotic adaptability. Other combinations between dimensions are medium-risk families. FACES III [11]was identified through the average responses given by the adolescent and their guardian.

Symptoms related to physical limitation had 4 classifications and were analyzed based on 4 questions: 1. If the adolescent had medical restrictions to the practice of physical activities; 2. What physical activities they practiced besides school; 3. What is the weekly frequency of sports practice, and 4. If the patient had "shortness of breath or felt very tired" even when at rest. Therefore, adolescents who practiced mainly aerobic sports, and with frequency above 2 weekly hours, obtained a rating of 1. And those who only performed activities such as reading, table games, computer or walking had a rating of 2. Those who mentioned medical restrictions had a rating of 3 or 4 according to reports of fatigue at rest.

Statistical analysis: SPSS for Windows, version 24, was used. The Shapiro-Wilks test was used to assess the normality of the continuous variables. As they all

presented normal distribution, their description was made based on the average and standard deviation. Categorical variables were described using frequency and standard deviation. The following tests were used: Pearson's chi-square, Fisher's exact test, t test for independent samples, and multivariate Poisson regression analysis with 95% reliability. The sample was calculated to detect a difference of 0.5 in the standard deviation of the average and standard deviation of the family functioning scores; significance was set at 5%, and statistical power at 99% (ß = 0.01). It was estimated that at least 97 adolescents per group would be evaluated. [11]

Results

Participants included 387 adolescents, 161 (41.6%) with CHD and 226 (58.4%) healthy adolescents (H). Table 1 reveals the characteristics of the study population and Table 2 shows the prevalence of family types according to cohesion, adaptability, and degree of family risk. There were significant differences in the averages of cohesion and adaptability, in the frequency of the types of family functioning in each dimension, and in relation to the degree of risk between the groups. There was greater cohesion in the families of adolescents with CHD, with a higher frequency of connected families than among controls (H), which had more disconnected families. As for adaptability, there was a higher proportion of families with chaotic functioning among controls (H) than among adolescents with CHD. There were more low-risk families among CHD adolescents, and more high-risk families among H adolescents.

Among adolescents with CHD, there is greater cohesion in 2-parent families and with mothers with elementary education. Adaptability showed, among the exposed (CHD), a borderline difference for maternal age (p = 0.051).

In the comparison between groups according to family risk, it was found that in high-risk families, mothers have a lower level of education, there are more adolescents with tiredness or dyspnea, and fewer adolescents playing sports among the CHD. It is understood that the focus of clinical interventions should be on high-risk families. In this sense, after a bivariate analysis between low and medium risk families (grouped) with high-risk families, considering the general population and their family characteristics, we identified that high-risk families had a higher proportion of healthy adolescents, between 15 and 18 years old; females, from 2-parent families, and 25% had no siblings. Other variables were not significant for high-risk families. Multivariate regression analysis (Table 3) shows that being healthy represents a 148% increase in chances for high risk compared to CHD adolescents; being female increases the chance by 120% compared to males; being an only child increases by 101%, and living with both parents increases the chances of having a high-risk family functioning by 114%.

Discussion

The values of cohesion and adaptability were close to Olson's,[12] normative values of family functioning, of a non-clinical population, and the values of the exposed group (CHD) were higher than the controls (H), with a significant difference in the investigated dimensions and degree of risk.

Studies with children and adolescents with CHD are scarce and it is essential to conduct them because the epidemiological profile is specific and with different severity than heart disease in adults. [13] The identification of behavioral factors that can be targeted in the intervention for families at risk for cardiovascular disease (CVD) has become a priority,[14] and this concern extends to families where heart disease has been present from birth. The family environment is the cradle of the development of behaviors and psychosocial aspects that aim at the adaptation of the individual and affect his or her Quality Of Life (QOL). The psychological resources of parents, the child, and family functioning contribute to the child's adaptation to the disease.

Most families of adolescents with CHD presented connected functioning, suggesting that members care about each other and have a certain emotional dependence between them. Among H adolescents, more families of the disconnected type were observed, in which there is less affective connection and more emotional independence. It may be that care for the member with a chronic illness favors a more cohesive family environment and, if so, CHD may represent an integrating function among members. On the other hand, studies on QOL in children with CHD have identified that the autonomy domain is one of the most compromised due to the overprotection of parents, developed during treatment, and can contribute to a relationship of dependency among children. [15]

In the adaptability dimension, H adolescents revealed more chaotic families. This result denotes that when faced with the unforeseen, there may be a certain

Table 1 - Sample Characterization

Characteristics	Adolescents			p
	Total 387 (100.0) n (%)	Bank account 161 (100.0) n(%)	H 226 (100.0) n(%)	
Sex				0.006
Male	187 (48.3)	91 (56.5)	96 (42.5)	
Female	200 (51.7)	70 (43.5)-	130 (57.5)	
Age – M (sd)	15.3 (1.6)	14.8 (1.7)	15.7 (1.5)	< 0.001
12 to 14 years old	147 (38)	91 (56.5)	56 (24.8)-	< 0.001
15 to 18 years old	240 (62)	70 (43.5)	170 (75.2)+	
Schooling (n = 386)				< 0.001
Primary education	256 (66.3)	127 (79.4)+	129 (57.1)	
High School	130 (33.7)	33 (20.6)-	97 (42.9)	
Family configuration				0.001
Biparental family	195 (50.4)	97 (60.2)+	98 (43.4)-	
Monoparental family	55 (14.2)	22 (13.7)	33 (14.6)	
Reconstituted family	123 (31.8)	34 (21.1)-	89 (39.4)+	
Living with other relatives	14 (3.6)	8 (5.0)	6 (2.7)	
Only child	54 (14.0)	25 (15.5)	29 (12.8)	0.451
Father's age (n = 338)				0.653
Up to 40 years old	102 (30.2)	45 (30.8)	57 (29.7)	
41 to 50	141 (41.7)	57 (39.0)	84 (43.8)	
Over 50	95 (28.1)	44 (30.1)	51 (26.6)	
Mother's age (n = 371)				0.771
Up to 40	175 (47.2)	77 (49.4)	98 (45.6)	
41 to 50	131 (35.3)	53 (34.0)	78 (36.3)	
Over 50	65 (17.5)	26 (16.7)	39 (18.1)	
Father's schooling (n = 342)				< 0.001
Up to complete primary education	193 (56.4)	104 (69.3)+	89 (46.4)-	
Complete secondary education	102 (29.8)	39 (26.0)	63 (32.8)	
Complete higher education	47 (13.7)	7 (4.7)-	40 (20.8)+	
Mother's schooling (n = 375)				< 0.001
Up to complete primary education	198 (52.8)	114 (72.6)+	84 (38.5)-	
Complete secondary education	120 (32.0)	39 (24.8)-	81 (37.2)+	
Complete higher education	57 (15.2)	4 (2.5)-	53 (24.3)+	
BMI – M (sd)	55.9 (32.1)	55.3 (32.7)	56.4 (31.8)	0.733
Regular	284 (73.4)	120 (74.5)	164 (72.6)	0.666
Overweight	103 (26.6)	41 (25.5)	62 (27.4)	
Health				
Cardiac surgery	88 (54.7)	88 (54.7)	-	
Congenital heart disease				
Cyanotic	43 (11.1)	43 (26.7)	-	
Acyanotic with repercussion	77 (19.9)	77 (47.8)	-	
Acyanotic without repercussion	41 (10.6)	41 (25.5)	-	
Symptoms for physical limitation				< 0.001
1 - Asymptomatic	329 (85.0)	118 (73.3)-	211 (93.4)+	
2 – Symptoms in everyday activities	50 (12.9)	35 (21.7)+	15 (6.6)-	
3 – Symptoms in effortless activities	7 (1.8)	7 (4.3)+	0(0)-	
4 – Symptoms at rest	1 (0.3)	1 (0.6)	0 (0)	

Note: CC: Congenital heart disease; H: Healthy;
Symbols + and - mean respectively significantly higher and lower than expected percentage of cases for the category (+: adjusted standardized residuals > +1.96; - : adjusted standardized residuals < -1.96;
M (sd) = Average (standard deviation)
Pearson's chi-squared, Student's t

Table 2 - Cohesion, adaptability, and family risk in different groups of adolescents

Dimensions	Adolescents			
	Total 387 (100.0%) n (%)	Bank account 161 (100.0%) n (%)	H 226 (100.0%) n(%)	p
Cohesion – M (sd)	36.7 (4.9)	37.5 (3.9)	36.1 (5.5)	0.004
Types of cohesion				0.002
Disengaged*	56 (14.5)	12 (7.5)-	44 (19.5)+	
Separate	122 (31.5)	50 (31.1)	72 (31.9)	
Connected	152 (39.3)	77 (47.8)+	75 (33.2)-	
Enmeshed*	57 (14.7)	22 (13.7)	35 (15.6)	
Adaptability – M (sd)	26.2 (5.0)	26.9 (4.4)	25.7 (5.8)	0.026
Adaptability – Types				0.002
Chaotic*	61 (15.8)	12 (7.5)-	49 (21.7)+	
Flexible	133 (34.4)	61 (37.9)	72 (31.9)	
Structured	134 (34.6)	62 (38.5)	72 (31.9)	
Rigid*	59 (15.2)	26 (16.1)	33 (14.6)	
Family risk				0.001
Low risk	202 (52.2)	99 (61.5)+	103 (45.6)-	
Average risk	137 (35.4)	52 (32.3)	85 (37.6)	
High risk	48 (12.4)	10 (6.2)-	38 (16.8)+	

Note: CC: Congenital heart disease; H: Healthy. Symbols + and - mean respectively significantly higher and lower than expected percentage of cases for the category (+: adjusted standardized residuals > +1.96; - : adjusted standardized residuals < -1.96;
** Dysfunctional types of cohesion or adaptability*
Pearson's chi-squared, Student's t; m: mean; sd: standard deviation

disorganization of these families, with possible absence of leadership or rules for facing changes, with an excessive change in the roles of members and discipline tends to be irregular,[16] since families of adolescents with CHD revealed more capacity to adapt to the unforeseen, characterizing the 'functional flexibility'. Research has shown that having a child with a chronic disease results in improvement in certain areas of family functioning such as solving health-related challenges, since living with the disease makes them more proficient in these issues. [1,17]

Results of studies[18,19] on family functioning and the upbringing of children with chronic diseases are controversial. Some found deficits in family cohesion, family adaptability, parent-child interactions, family conflict and problem-solving skills while others[20] did not identify significant differences in family functioning when compared to healthy families. Such differences in results can be attributed to the diversity of measures, the specificities of the diseases, or to the fact that they are studies focused on the perception of parents and not on the carrier of the disease, whether a child or adolescent. In this case, maladjustments may be more related to the way the family perceives the disease than to the child's own behavior, related to the disease. [21] It is unusual to verify the perception of the disease from the patient's perspective, which results in discrepancies in response and clinical evolution.[22,23] One of the prerogatives of this study was to seek the evaluation of family functioning using the joint responses of 2 members - the teenager and one of the parents - for a broader perception of the family.

In the combinations between cohesion and adaptability in the groups studied, it was identified

Table 3 - Prevalence of high-risk functioning families and factors independently associated with high family risk

Variables	Prevalence of high-risk functioning families	Factors independently associated with high family risk		
	N(%)	p	PR	CI 95%
Congenital heart disease				
Yes	10 (6.2)		1	
No	38 (16.8)	0.015	2.48	1.193 – 5.142
Gender: female				
Male	13 (7.0)		1	
Female	35 (17.5)	0.013	2.20	1.184 – 4.083
Age				
12 to 14 years old	12 (8.2)		1	
15 to 18 years old	36 (15.0)	0.280	1.44	0.745 – 2.774
Only child				
No	36 (10.8)		1	
Yes	12 (22.2)	0.012	2.01	1.165 – 3.475
Family configuration				
Biparental	32 (16.4)	0.008	2.14	1.222 – 3.763
Other	16 (8.3)		1	

Note: Dependent variable: High Family Risk - Extreme Cohesion and Adaptability
PR: prevalence ratio,
CI: 95% confidence interval

a higher frequency of high-risk family among H adolescents compared to those with CHD, and that being healthy is independently and positively associated with high family risk . When it comes to a study on family functioning associated with chronic diseases, there are many variables to be considered. [1,14] Due to this complexity, studies related to family functioning need to unravel parts that integrate the whole. In a review study, the domains of communication, interpersonal involvement, discipline management, and role definition were significantly lower in families with chronic diseases compared to families with healthy children. [1] This study, however, makes reservations about issues such as instruments, severity and lifespan with the disease, whether they are hereditary or genetic, having other family members with the disease, whether data were collected from all members, and it does include congenital heart diseases.

On the other hand, there are studies that analyzed QOL in children with chronic diseases and found satisfactory values, despite the aspects inherent to the pathology. [22,24] There are QOL factors that are related to family dynamics, indicating their proper functioning.[25] The fact that families of adolescents with CHD proved to be more functional than families of control adolescents (H) may be associated with these factors and assume a satisfactory QOL, suggesting further investigation of this relationship.

Many aspects may have contributed to the result of this study: CHD is present since birth and, therefore, the lifetime with the disease makes the demands of the disease and treatment part of everyday reality, implying the strengthening of family bonds and favoring interactions. Compared to the reality of healthy adolescents, adolescents with CHD have already overcome adversities and risks of the disease from an early age, including the imminence of death. Nevertheless, treatments (surgery or other procedures) were successful and it is possible that they have developed capacities to deal more resiliently with situations of uncertainty or risk.

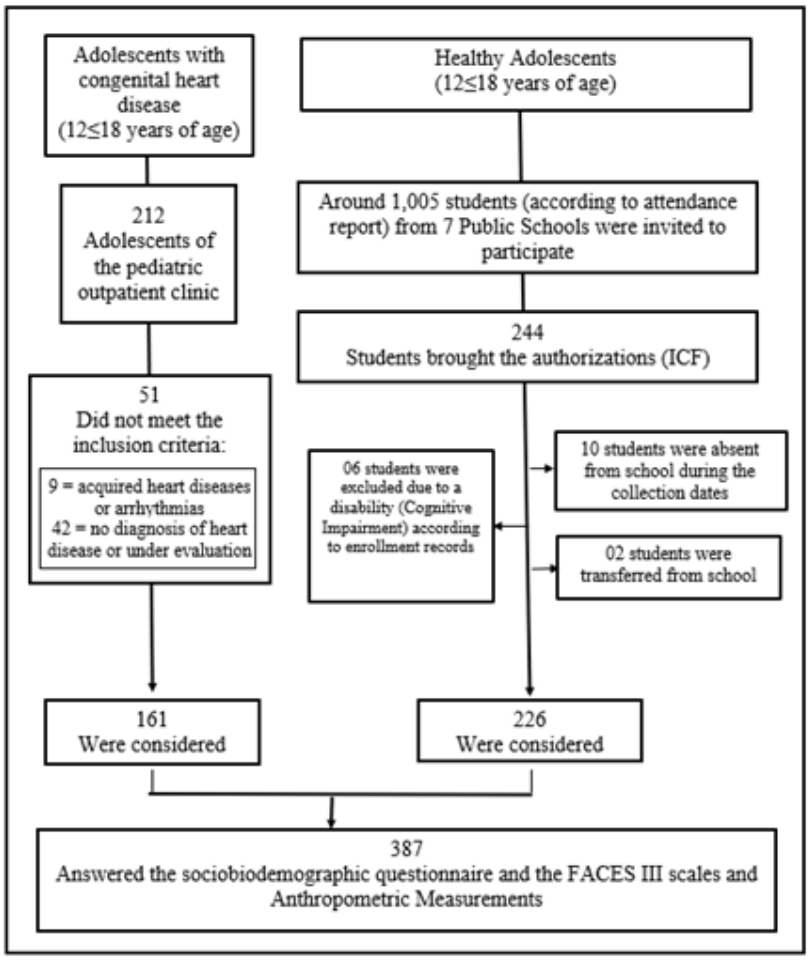

Figure 1 – Data collection flowchart.

Another relevant point is that, although there are authors who recognize that hospitalization, catheterization, anesthesia, surgical procedures, and the various experiences inherent to the course of heart disease, affect children and their families,[24] there are studies that highlight that there were few deviations in the normal behavior of children in the postoperative period, whether immediate or late. [24] The fact that adolescents with CHD and their families remain under medical and health care since birth, in systematic and regular care with a multidisciplinary team, promotes feelings of care and protection, in addition to the bond established with some of these professionals throughout their lives. Such feelings can contribute to the dynamics of a more balanced family functioning.

This study showed a small number of adolescents with severe physical limitations (only 4.9% of the congenital). A study with children with CHD, pre and post-surgical, identified cases in which deficits in child psychomotor development were determined by the variables sex, age and socioeconomic status and were not related to the treatment of heart disease, information, understanding of the disease, and the way parents treat their children. [26] A study, however, points out that the way the disease is perceived by individuals influences the way they act on it[27] and the perception of physical and health limitations on the part of the patient and/or parents affects the family functioning. [24] Adolescents with CHD recognize their physical and emotional limitations as part of their condition and rely on the support of their family and social network as a protective factor, remembering that physical exercise limitations are for different reasons, sometimes with very small dimensions, not bringing early repercussions, with normal development and absence of symptoms,[28] not restricting activities that give

them pleasure. Caregivers only perceive the disease when it manifests; children without symptoms and who are able to perform daily activities are not considered sick.

This study showed that there are no differences in the levels of cohesion in the families of adolescents with CHD when considering the age of the patient. This result was reversed in a study of children (6 to 16 years old) with juvenile rheumatoid arthritis (JRA)[1] in which this difference was found in families with only younger children when compared to families without JRA. Our results suggests that, health care demands are prioritized, depending on the disease, according to the child's developmental stage and over other related demands and they define the level of interaction between people over the period. In the families of H adolescents, the search for greater autonomy can be an alert factor for parents to the needs of their children, increasing cohesion. The greater adaptability in this age group is justified by the need for greater coping capacity related to phase changes.

The education of mothers in the control group (H) was higher compared to mothers of adolescents with CHD among high-risk families. The assumption that the higher the level of education, the lower the chances of risk is not valid when it is understood that education or knowledge is not always associated with behaviors and attitudes. Studies reveal that the level of education or information about diseases is not associated with the importance attributed or even with learning itself. [29] In this sense, being aware of family functioning associated with the family's ability to understand the disease is important for the efficacy and effectiveness of treatment.

It was found that being healthy, female, living with both parents, and being an only child proved to be positively associated factors, independently, for high family risk, characterizing the dysfunctional family dynamics. In families of the agglutinated type, among adolescents with CHD, 77.3% were girls. We can consider the multiple roles that contemporary women have played in society; girls with CHD may need more support and support from their families for these achievements. Such data deserves further study.

Living with both parents was positively associated with an increased family risk, which is surprising considering the belief that the joint participation of parents in the education of their children requires more balanced families. There are few studies on this aspect; however, a review on marital adjustment identified results without significant differences in divorce rates between groups with and without children with chronic diseases; 4 out of 7 studies showed that marital distress was increased in parents of children with chronic illnesses, stating that additional studies are needed to understand marital adjustment to chronic childhood illnesses. [30] Such studies demonstrate the effects of chronic disease on parental conjugality, however, they do not focus on the reverse relationship, on how relationships or marital conflicts affect the patient with chronic disease, or more specifically, with CHD. Being an only child was also associated with a high family risk, which suggests that the presence of other healthy children can be an element of balance in living with the disease.

In terms of the limitations of this study, as it is transversal, the groups, collected in different environments (hospital and school), showed significant differences, limiting the comparative results. Another limitation was the finding that studies on family functioning have a variety of measurement instruments with specific factors, which made it difficult to compare results among studies. Still, most studies involving younger children focus on the parents' perception of their children's adjustment and do not include the child's perception. Another difficulty in the comparisons is that many studies on family functioning are conducted with several chronic diseases, and few exclusively on CHD.

Conclusion

The results obtained in the present sample suggest that congenital heart disease does not represent a factor associated with high-risk family functioning and that the families of these adolescents with CHD are generally considered to have a balanced functioning and lower risk when compared to the family of healthy adolescents. The results are not in line with the paradigms that define chronic disease as a family dysfunction factor.

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Author Contributions

Conception and design of the research: Piccoli AB, Neiva-Silva L, Pellanda LC. Acquisition of data: Piccoli

AB. Analysis and interpretation of the data: Piccoli AB, Neiva-Silva L, Pellanda LC. Statistical analysis: Piccoli AB, Neiva-Silva L. Writing of the manuscript: Piccoli AB. Critical revision of the manuscript for intellectual content: Piccoli AB, Neiva-Silva L, Pellanda LC. Ângela Piccoli, Lucas Neiva-Silva, Lucia Campos Pellanda

Potential Conflict of Interest

No potential conflict of interest relevant to this article was reported.

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Study Association

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Ethics Approval and Consent to Participate

This study was approved by the Ethics Committee of the *Instituto de Cardiologia/FUC* under the protocol number 5041/14. All the procedures in this study were in accordance with the 1975 Helsinki Declaration, updated in 2013. Informed consent was obtained from all participants included in the study.

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