SOCIODEMOGRAPHIC AND CLINICAL PROFILE OF CHILDREN WITH CONGENITAL HEART DISEASE ASSISTED AT A HOSPITAL INSTITUTION

Perfil sociodemográfico familiar e clínico de crianças com cardiopatia congênita atendidas em uma instituição hospitalar

Perfil sociodemográfico familiar y clínico de niños con cardiopatía congénita asistidos en una institución hospitalaria

Original Article

ABSTRACT

Objective: To characterize the sociodemographic and clinical profile of children with congenital heart disease assisted at a hospital institution. Methods: A descriptive, crosssectional study conducted in the pediatric cardiology outpatient clinic of a hospital in Fortaleza, CE, Brazil, in the period from March to August 2012. It comprised a non-random convenience sample of 80 parents of children with heart disease aged 5 to 12 years. Information was obtained from primary data of medical records and through questionnaires covering the parent's sociodemographic characteristics, family data and the children's clinical aspects. Results: Regarding socioeconomic data, 77 (96.2%) caregivers were female, 50 (62.5%) were married or in a stable relationship, 39 (48.7%) had 10-12 years of formal education, and 69 (82.6%) reported a household income between 1 and 2 minimum wages. In the sample of children studied, 43 (53.8%) were female. The median age of the children was 8.4 years, ranging from 5-13 years. As to the age at the heart disease diagnosis, 44 (55%) occurred under the age of 6 months, regardless of the type of cardiopathy. It was detected that 19 (23.75%) were related to the disease. **Conclusion**: Children's caregivers were predominantly their mothers, with low income and satisfactory schooling. Early diagnosis was predominant, mainly among the children with cyanotic cardiopathy.

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Descriptors: Heart Defects, Congenital; Child; Health Profile.

RESUMO

Objetivo: Conhecer o perfil sociodemográfico familiar e clínico de crianças com cardiopatia congênita atendidas em uma instituição hospitalar. Métodos: Estudo descritivo, transversal, desenvolvido no ambulatório de cardiologia pediátrica de um hospital em Fortaleza-CE, durante o período de março a agosto de 2012. Contemplou uma amostra não aleatória por conveniência de 80 pais de crianças cardiopatas entre 5 e 12 anos. Obtiveram-se informações a partir de dados primários de prontuário e por questionários, abordando as características sociodemográficas dos pais, dados familiares e condições clínicas das crianças. Resultados: Quanto aos dados sociodemográficos dos pais, 77 (96,2%) dos acompanhantes eram do sexo feminino, 50 (62,5%) estavam casados ou em união estável, 39 (48,7%) tinham entre 10 e 12 anos de estudo, e 69 (82,6%) relataram renda familiar entre 1 e 2 salários mínimos. Na amostra de crianças estudada, 43 (53,8%) eram do sexo feminino. A mediana das idades das crianças foi de 8,4 anos, variando entre 5 e 13 anos. Quanto à idade do diagnóstico, 44 (55,0%) ocorreram em idade inferior a 6 meses, independentemente do tipo da cardiopatia. Detectou-se que 19 (23,75%) tinham parentesco com a cardiopatia. Conclusão: Os pais acompanhantes de crianças com cardiopatia eram predominantemente mães, de baixo nível econômico e com escolaridade satisfatória. Houve predominância do diagnóstico precoce, principalmente nas crianças com cardiopatia do tipo cianótica.

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RESUMEN

Objetivo: Conocer el perfil socio demográfico familiar y clínico de niños con cardiopatía congénita asistidos en una institución hospitalaria. Métodos: Estudio descriptivo, transversal, desarrollado en el ambulatorio de cardiología pediátrica de un hospital de Fortaleza-CE, en el período entre marzo y agosto de 2012. Se incluyó una muestra no aleatoria por conveniencia de 80 padres de niños cardiópatas con edad entre los 5 y 12 años. Se obtuvo informaciones a partir de datos primarios del historial clínico y a través de cuestionarios incluyendo las características socio demográficas de los padres, datos familiares y condiciones clínicas de los niños. Resultados: Respecto a los datos sócio demográficos de los padres, 77 (96,2%) de ellos eran del sexo femenino, 50 (62,5%) eran casados o vivían en unión estable, 39 (48,7%) habían estudiado durante 10 y 12 años y 69 (82,6%) relataron una renta familiar entre 1 y 2 ingresos mínimos. En La muestra de niños estudiada, 43 (53,8%) eran del sexo femenino. La mediana de las edades de los niños fue de 8,4 anos, variando entre los 5 y 13 años. Respecto a la edad del diagnóstico, 44 (55,0%) se dieron en edad inferior a 6 meses, independiente Del tipo de cardiopatía. Se detecto que 19 (23,75%) tenían algún familiar con cardiopatía. Conclusión: Los padres que estaban con los niños cardiópatas eran en su mayoría madres con bajo nivel económico y escolaridad satisfactoria. Hubo predominio Del diagnostico precoz principalmente en los niños con cardiopatia del tipo cianótica.

Descriptores: Cardiopatías Congénitas; Niño; Perfil de Salud.

INTRODUCTION

All the abnormalities that affect the heart structure at birth are defined as congenital heart disease. They can occur in the heart wall, valves or in blood vessels. Congenital heart defects present broad clinical spectrum and comprise defects that evolve in asymptomatic and symptomatic forms, causing high mortality rate. The majority of the cardiac anomalies have unknown etiology, however, several aspects are associated with increased incidence, such as prenatal events, mother over the age of 40 years and genetic factors ^(1,2).

Congenital heart disease (CHD) involve the heart and/or major blood vessels of the child still during the intrauterine development, affecting the anatomy and physiology. They are divided into acyanotic and cyanotic. Among the acyanotic, there are the communications (atrial, ventricular

and patent ductus arteriosus - PDA) and the valves stenosis (aortic and pulmonary). Among the cyanotic, there are the tetralogy of Fallot (TF), transposition of the great arteries (TGA), the anomalous pulmonary venous return (APVR), among others. They also have great chances to be surgically corrected, making possible the normal life expectancy⁽³⁾.

Worldwide, 2% to 3% of live births have congenital anomalies. In the United States of America (USA), 44.5% of them died within the first year of life and had some type of congenital heart disease (CHD). In Latin America, congenital heart defects are the second leading cause of death in children under one year, thus becoming a significant public health problem⁽⁴⁾.

The technological breakthrough has increased the survival rate of children with congenital heart disease; however, meeting the needs (food, physical activity, oral health care etc.) is a topic that deserves attention. Congenital heart defects have varied presentation and can progress without associated symptoms, up to the related symptoms and high mortality, reflecting the variety and degrees of morphologically observed cardiovascular structural impairment^(5,6).

Congenital cardiac malformations are a heterogeneous group of diseases with variable hemodynamic consequences and different needs of monitoring and intervention. The cardiopathic patients' perspective and interests may differ from the health professionals' opinion with regard to physical activity, regular doctor visits, medication use, among others^(7,8).

Health promotion (HP) emphasizes, among its actions, to identify health priorities and establish public policies for their implementation, develop research that improves knowledge on the priority areas, and implementation of action plans focused on quality of life (QOL) ⁽⁹⁾. In congenital heart diseases, health promotion comprises the valuation of different aspects such as nutrition, social support, health responsibility, valuation of life, exercise, stress management, and overall health promotion behaviour, personal and oral hygiene.

The congenital heart diseases identification, diagnosis, and treatment are the result of the collective work of a multidisciplinary team, and the degree of involvement and participation of each expert is directly related to the quality of the obtained result. Knowledge about the profile of the population with which those professionals work can thus support them in developing care plans and interventions for prevention and early detection of cardiac abnormalities.

In view of this context, this study had was aimed at knowing the family, clinical, and sociodemographic profile of children with congenital heart disease assisted at a hospital institution.

METHODS

A study with quantitative, descriptive and cross-sectional design was conducted in the pediatric cardiology outpatient clinic of a large referral hospital for pediatric cardiovascular diseases in Fortaleza, CE, Brazil.

From the population universe, a non-random convenience sample was obtained, composed of 80 parents of children with heart disease, aged 5 to 12 years, during the period from March to August 2012.

For the sample definition, the study used the selection criteria establishing that the children had medical diagnosis of CHD, regardless of gender and disease stage.

The data collection was divided into two phases. The first one related to family sociodemographic characteristics. For this phase, a questionnaire was applied on the consultation day, standardized and designed by the researchers, and not validated in previous research. The studied variables related to the accompanying parents' gender, age (divided into periods of five years), marital status, religion, formal education (in years), family income (in minimum wages), number of children, number of residents at home, and origin.

The second phase addressed the child's clinical characteristics. To collect this information, the primary data from medical records were used by recording in a standardized form designed by the researchers and not validated in previous research. The variables studied were age, gender, time and age at diagnosis, CHD type, family history and kinship with the cardiopathy.

The data analysis consisted of performing distributions of univariate frequencies and descriptive measures (median, minimum and maximum), followed by bivariate analysis, stratified by the type of cardiopathy according to the children's clinical characteristics. For the nominal qualitative variables (children's clinical data), the Pearson's chi-square test and Fisher's exact test were applied (frequencies < 5). For ordinal qualitative variables, the linear trend chi-square tests were employed, in order to verify trends of increase or decrease between the proportions and the observed characteristics (age at diagnosis). For this, the study used the statistical program STATA version 8, adopting significance level of 5%.

The research, in its conduction, respected the ethical principles for research involving human beings, according to Resolution 466/12 of the National Health Council. All parents signed the free informed consent form. It

was approved by the Ethics Committee (Coética) of the University of Fortaleza - Unifor (Opinion No 430/2011) and by the Ethics Committee of the Hospital where the research was carried out (Opinion No 868/2012).

RESULTS

In the sample of 80 parents accompanying the studied children, regarding the sociodemographic characteristics, 77 (96.2%) were mothers. The companion's age ranged from 20 to 61 years, with a median of 33.7 years. The predominant age group was between 30 and 34 years, with 25 (31.2%) participants. As for the marital status, 50 (62.5%) were married or were in a consensual union (Table I).

The Catholic religion was prevalent in 51 (71.2%) subjects. For the years of study, 39 (48.7%) had 10-12 years companions of study. When taking into account the minimum wage, the income of 69 (86.2%) companions ranged from R\$ 622.00 and R\$ 1,200.00, that is, 1-2 times the minimum wage.

Of the families studied, 58 (72.5%) had 2 to 4 children. Of the total, 46 (57.5%) lived in households with 4 to 5 people. On the family origin, 38 (47.5%) lived in Fortaleza.

Of the total sample, 43 (53.8%) children were females and 37 (46.2%), males. The median age was 8.4 years and ranged from 5 to 13 years.

Groups were proportionally similar in age distribution. As for the age at the diagnosis of heart disease, the age group under 6 months prevailed in both cyanotic (n=26/65%) and among acyanotic (n=18/45%) patients. There was an inverse relationship between the age of diagnosis and the diagnosis identification (p=0.04).

When related to gender and the classification of the CHD, there was a higher frequency of females with acyanotic heart disease (n=23/57.5%), whereas in males, 20 (50%) had this type. Significant proportional differences were not found between the cardiopathy type and the child's gender (p=0.501).

Among the acyanotic type of cardiopathies, there was a higher incidence of ventricular septal defect (VSD) in 11 (13.7%) children. Among the cyanotic heart defects, tetralogy of Fallot was found in 10 (13.7%) children. Relating disease type and at the age at diagnosis, there was a higher occurrence of these in children under the age of 6 months (Table III).

Table I - Socio-demographic characteristics of companions of children with cardiopathies (n=80). Fortaleza-CE, 2012.

Characteristics	n (%)
Companion's kinship	
Father	3 (3.7)
Mother	77 (96.2)
Companion's age range (in years)	
20 to 24	7 (8.7)
25 to 29	19 (23.7)
30 to 34	25 (31.2)
35 to 39	14 (17.5)
40 to 44	7 (8.7)
45 years and more	8 (10)
Parent's marital status	
United	50 (62.5)
Separated	30 (37.5)
Religion	
Catholic	57 (71.2)
Evangelical	21 (26.2)
Protestant	1 (1.2)
No religion	1 (1.2)
Formal education (in years of school)	
Up to 4	1 (1.2)
5 to 9	2 (2.5)
10 to 12	39 (48.7)
14 or more	38 (47.5)
Family income ^a (in minimum wage)	
<1	5 (6.2)
1 to 2	69 (86.2)
Above 2	6 (7.5)
Number of children	
1 child	19 (23.7)
2 to 4 children	58 (72.5)
5 children or more	3 (3.7)
Number of persons sharing the household	
Up to 3 persons	26 (32.5)
4 to 5 persons	46 (57.5)
6 persons or more	8 (10)
Family origin	
Fortaleza	38 (47.5)
Ceara countryside	29 (36.2)
Other States	5 (6.2)
Coastal and metropolitan region	8 (10)

Note: *Minimum wage (MW) adopted in the research: R\$ 622.00.

Table II - Clinical characteristics of children according to type of cardiopathy (n=80). Fortaleza-CE, 2012.

Child's characteristics	Card		
	Cyanotic (n=40) n (%)	Cyanotic (n=40) n (%)	p
Gender	n (70)	11 (70)	
Male Female	20 (50.0) 20 (50.0)	17 (42.5) 23 (57.5)	0,501ª
Age group (in years)			
5	8 (20,0)	6 (15.0)	
6 to 9	15 (37.5)	21 (52.5)	0.402a
10 or more	17 (42.5)	13 (32.5)	0,403ª
Age at the diagnosis of heart disease			
Menor que 6 mese	26 (65.0)	18 (45.0)	
from 6 months to 1 year	6 (15.0)	4 (10.0)	0.04^{b}
between 1 and 3 year	4 (10.0)	9 (22.5)	0,04
above que 3 year	4 (10.0)	9 (22.5)	
Family history of heart disease	` ,	, ,	
Yes	12 (30.0)	7 (17.5)	0,189a
No	28 (70.0)	33 (82.5)	
Relationship to heart disease $(n = 19)$	` ,	, ,	
Uncles, grandparents or great-grandparents	7 (58.3)	4 (57.1)	
Son / Brother	4 (33.3)	1 (14.3)	$0,666^{c}$
Brother-in-law/ nephew	1 (8.3)	2 (28.6)	, -

Nota: aTeste Qui-Quadrado de Pearson; bTeste Qui-Quadrado de tendência linear; cTeste Qui-Quadrado Exato de Fisher.

Table III - Percentage distribution of children according to diagnosis of heart diseases by age at diagnosis. Fortaleza-CE, 2012.

Heart Disease Diagnosis	Age at Heart Disease Diagnosis				
	Under 6 months n (%)	From 6 months to 1 year n (%)	From 1 to 3 years n (%)	Above 3 years n (%)	
Ebstein's Anomaly (EA)	2 (4.5)	-	-	-	
Pulmonary Atresia (PA)	2 (4.5)	_	1 (7.7)	-	
Single Atrium (SA)	-	_	1 (7.7)	-	
Aortic coarctation (AC)	2 (4.5)	_	1 (7.7)	2 (15.4)	
Interatrial Communication (IAC)	5 (11.4)	1 (10.0)	4 (30.8)	2 (15.4)	
IAC, IVC	2 (4.5)	-	-	-	
IAC, Anomalous drainage (AD)	1 (2.3)	_	_	-	
Interventricular Communication (IVC)	6 (13.7)	2 (20.0)	3 (23.0)	-	
IVC, PA	2 (4.5)	1 (10)	-	_	
IVC, AC	-	-	_	1 (7.7)	
AD	1 (2.3)	_	_	-	
Aortic stenosis (AS)	1 (2.3)	-	-	-	
Pulmonary stenosis (PS)	1 (2.3)	-	_	-	
Rheumatic fever (RF)	-	-	-	1 (7.7)	
Mitral Regurgitation (MR)	1 (2.3)	-	-	1 (7.7)	
Tricuspid regurgitation (TR)	-	1 (10.0)	-	-	
Ductus Arteriosus Ligation (DAL)	-	-	-	1 (7.7)	
Patent Ductus Arteriosus (PDA)	-	-	-	2 (15.4)	
Heart Murmur (HM)	7 (16.0)	2 (20.0)	2 (15.4)	1 (7.7)	
HM, IAC	-	-	-	1 (7.7)	
HM, PE	1 (2.3)	-	-	-	
HM, TGA	1 (2.3)	-	_	-	
Tetralogy of Fallot (TF)	6 (13.7)	2 (20.0)	1 (7.7)	1 (7.7)	
Transposition of the Great Arteries (TGA)	3 (6.9)	1 (10.0)	-	-	

DISCUSSION

The identification of women as a care provider in the family context of sociocultural construction involves giving up many things such as work, study etc., in support of this role, particularly when the child has special healthcare needs. However, comprehensive care is completed by entering the father in this context, providing greater safety, especially after the child's discharge from hospital, which increases the love and family sharing^(11,12).

Regarding the same theme, a study performed in Lisbon⁽¹¹⁾ evidenced that parents are concerned about the family financial support, not abdicating their functions of provider, while the mother becomes the caregiver of the child with CHD.

In the present study, most parents were married or were in a consensual union. Study⁽¹³⁾ developed in Cartagena, Colombia, in order to establish the relationship between the features and the quality of life of family caregivers of children with congenital heart disease, showed different results as regards to marital status, with sample corresponding to 67% of separated parents.

The Catholic religion prevailed in the current research. Parents and relatives of children with chronic diseases have used spirituality and religion in different ways as a coping mechanism. Respect and favouring of religious practices represent a form of support and emotional balance, and can be significant tools for the family recovery⁽¹⁴⁾. In this sense, religion is a relevant factor in the behavior and outcome in cases of children with heart disease, particularly because the emotional aspect is intrinsically related to their QOL.

Regarding the parents' years of formal education found in the present study, 10-12 years, it is considered satisfactory for good performance in the care of the cardiopathic child, since the knowledge of the pathology can be better understood. The cultural aspect conditions decisive action on the relationship between health and disease, revealing ways of caring determined from each individual's values and life context⁽¹⁵⁾. In a study on parents' knowledge about the disease of their children with CHD, it was shown that there are important gaps. The data from this study suggests that the way of approaching is insufficient in the aim of promoting a better understanding by parents about the child's heart disease, and enable them to transmit this knowledge accurately to their children⁽¹⁶⁾.

Family income is related to the opportunities of a good child development. According to a study in Fortaleza⁽¹⁵⁾, which addressed the impact of economic factors on child care, in CHD, the picture is more relevant, since the investment for the care of cardiopathic child makes

precarious the family budget, as it imposes the need of income to ensure transportation to the hospital, routine tests etc. The importance of intensifying the monitoring of low-income children is thus verified, because they are exposed to several factors which, combined, increase the chances of an unfavourable outcome to the development of the disease⁽¹⁷⁾.

As for the age at diagnosis of the heart disease, the most prevalent age group in the current study was under 6 months, being in line with the literature⁽³⁾, which reports that the disease can be identified early during pregnancy, at birth, or even in the first months of life. The ultrasound obstetric examination, however, can detect only the most serious injuries, without detection of smaller defects⁽¹⁸⁾.

A significant part of the children investigated in this study had multiple cardiopathies, especially atrial septal defect and pulmonary atresia, with 4.5% in neonates. A study⁽⁶⁾ identified a total of 357 congenital heart defects, and the cardiopathies were multiple in 133 patients, differently from the present investigation.

The precocity of surgical interventions in the neonatal period is justified by the seriousness and complexity of the diagnosed malformations and the hemodynamic repercussions, with risk of exposing the newborn infant to complications and death. In complex and simple heart defects, the surgical procedure becomes necessary in order to control symptoms and improve QOL of patients, besides preventing future disorders.

In health in general, more specifically in the cardiopathic child's health, there are many obstacles to be faced. Tracing these children's sociodemographic and clinical profile becomes fundamental so that actions are implemented with a view to a new paradigm, which does not prioritize the disease and establishes health promotion facilitating concepts. Therefore, it becomes relevant to work together with the five health promotion strategies. The articulation between these fields of action represents a greater strength, driving changes in the reality of the child's health and family^(19,20).

Therefore, as care policies in long-term deposit in the family an expectation, solutions should be sought to provide greater support, especially social and financial, for the family is the key to the excellence of health programs.

The care activity tends to erode the lives of some family members. Measures to protect the patient's and family's health should thus be carried out to allow, for example, planning and carrying through interests other than the care itself.

As study limitation is the small number of children with congenital heart disease who participated in the study. It is believed that further studies are needed, with larger

populations in which age groups and type of cardiopathies are compared.

CONCLUSION

Accompanying parents of children with heart disease were predominantly mothers, with low economic level and a satisfactory schooling. There was a predominance of early diagnosis, especially in children with the cyanotic type of heart disease.

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