

Parents' knowledge of infective endocarditis in children with congenital heart disease

Conhecimento dos pais sobre profilaxia de endocardite infecciosa em crianças portadoras de cardiopatias congênitas

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Abstract

Introduction: The guidelines to prophylaxis of infectious endocarditis changed, but many congenital heart diseases continue to be considered as high risk for the development of the disease.

Objective: To evaluate the knowledge of parents or guardians of children and adolescents with congenital heart disease seen at a referral center in Rio Grande do Sul, Brazil on infective endocarditis and its prevention.

Methods: Cross-sectional study with 90 patients with congenital heart defects in regular outpatient treatment. The parents' knowledge was assessed using a specific questionnaire and other data were obtained through medical records.

Results: The median age of patients was 5.6 years (3 months -14 years), being 57,7% males. The median follow-up time in service was 3.49 years (1.20-7.38). The years of formal schooling of the parents had a mean of 7.67 ± 3.25 years. According to the score previously established, the knowledge of the interviewed parents was considered satisfactory in 37,7%, regular in 33,3% and unsatisfying in 28,8%. There was significant correlation between the index of parents' knowledge and monitoring of children at service ($r=0.584$; $P=0.796$). There was no correlation between parents' education and knowledge of them ($r=0.028$; $P=0.796$).

Conclusion: The parents' knowledge about endocarditis and its prevention was inadequate, requiring greater attention to the orientations passed in consultations.

Descriptors: Primary Prevention. Endocarditis. Knowledge.

Resumo

Introdução: As diretrizes para profilaxia de endocardite infecciosa mudaram, mas muitas cardiopatias congênitas seguem sendo consideradas de alto risco para o desenvolvimento da doença.

Objetivo: Avaliar o conhecimento dos pais ou responsáveis pelas crianças e adolescentes portadores de cardiopatias atendidos em um serviço de referência no estado do Rio Grande do Sul, Brasil, sobre endocardite infecciosa e sua profilaxia.

Métodos: Estudo transversal com 90 pacientes portadores de cardiopatias congênitas em acompanhamento ambulatorial regular. O conhecimento dos pais foi avaliado com o uso de questionário específico e os demais dados foram obtidos por meio da revisão de prontuários.

Resultados: A mediana da idade dos pacientes foi de 5,6 anos (3 meses - 14 anos e 7 meses), sendo 57,7% do sexo masculino. A mediana de tempo de acompanhamento no

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serviço foi de 3,49 anos (1,20-7,38 anos). Os anos de estudo formal dos pais apresentaram média de $7,67 \pm 3,25$ anos. De acordo com o escore previamente estabelecido, o conhecimento dos pais entrevistados foi considerado satisfatório em 37,7% dos casos, regular, em 33,3% e insatisfatório, em 28,8%. Houve correlação significativa entre o índice de conhecimento dos pais e tempo de acompanhamento das crianças no serviço ($r=0,584$; $P<0,001$).

Não houve correlação entre a escolaridade dos pais e o conhecimento dos mesmos ($r=0,028$; $P=0,796$).

Conclusão: O conhecimento dos pais sobre endocardite e sua profilaxia mostrou-se inadequado, requerendo maior atenção nas orientações transmitidas nas consultas.

Descritores: Prevenção Primária. Endocardite. Conhecimento.

INTRODUCTION

The guidelines for prevention of infective endocarditis (IE) have changed in recent years with significant differences between the recommendations adopted by accredited committees of several countries [1-3]. The use of more antibiotics has been recommended and the justification to review the previous recommendations and to reduce situations of prophylaxis indicate that IE results, more commonly, from bacteremia associated with daily activities, such as regular teeth brushing and warn of the adverse effects of the use of antibiotics, which could outweigh the benefits.

The effectiveness of prophylaxis has never been proven by randomized studies. This issue has aroused much discussion and still remains controversial [3-7]. Currently, the American Heart Association (AHA) recommends antibiotic prophylaxis only for patients who are found to be at high risk for IE. Patients with uncorrected cyanotic congenital heart disease or palliative corrections, and patients who underwent surgical correction of heart disease are included in this group, but persist with residual lesions adjacent to prosthetic material. These criteria include many pediatric patients with cardiopathies. Prophylactic measures include education of high-risk patients and their caregivers about the need for oral and meticulous skin hygiene, frequent visits to the dentist, as well as avoid unnecessary invasive procedures.

Maintaining a perfect state of oral health would be a much more important strategy than the use of prophylactic antibiotics before certain procedures [8]. Among the current indications for IE prophylaxis (procedures in the oral mucosa, respiratory tract infection, skeletal muscle tissue and infected skin), the manipulations of the oral cavity are the most frequent in everyday life and invariably affect all patients from a determined age group.

Several studies indicate that parents' knowledge about their children's heart problems is inadequate, as well as the necessary precautions to prevent EI [9-13]. The Brazilian Society of Cardiology has no guidelines for IE prophylaxis

and the various departments of pediatric cardiology embraced the AHA recommendations by 2007. When the pediatric cardiologists are questioning themselves about all the controversial recommendations to be followed, it would be interesting to evaluate the patients/parents adherence to the recently adopted guidelines in order to plan new strategies and adopt effective behaviors.

There are no studies in the Brazilian population to assess the knowledge of caregivers of children with heart disease on the prevention of IE. The aim of the present study was to evaluate the knowledge of parents or guardians of children and adolescents assisted at a pediatric outpatient service on IE and its prophylaxis.

METHODS

A cross-sectional study was conducted in the period from November 5 to December 15, 2007, with parents of patients in a regular follow-up at the pediatric cardiology outpatient clinic, at a reference cardiology hospital. Four hundred and sixty-four patients were assisted in return visit during that period, belonging to a universe of about 7,000 registered patients. All patients included had a formal indication for IE prophylaxis (IEP) according to the 1997 AHA Guidelines [14], which were adopted by the service. Data collection was made at the first visit after the publication of 2007 guidelines [1], therefore, the patients had not received the new guidelines.

Patients over 15 years, patients not accompanied by parents or guardians, and patients who were being consulted for the first time and those whose parents did not agreed to participate, were excluded from the study. Some days were chosen by the researchers during the data collection period. On these days, patients were sequentially excluded, and not intentionally ruled out. A specific questionnaire was prepared with related to the patient's heart, IE and IEP (Table 1). A pilot questionnaire was administered to 20 parents, which allowed some adjustments to the data collection instrument. The questionnaire was always administered by the same researcher after routine check-ups.

Chart 1. Parents' Questionnaire

1. What is the name of your child's heart disease?
2. What medications does your child routinely take?
3. Do you know what endocarditis is?
4. Do you know what the risk procedures are for developing infective endocarditis?
5. Have you been informed about the importance of the care that your child should have with oral hygiene?
6. Are you aware of the medicines that your child must take before some procedures performed by the dentist?

By reviewing medical records, the following data were obtained: patient age, follow-up period, diagnosis of heart diseases, procedures performed and medications prescribed at the last visit.

Parents were considered aware of the name of the disease when they provided the correct cardiopathy diagnosis or when demonstrated knowledge of the problem and physiology of the disease, using expressions like "the open little heart channel," "little hole that connects both sides of the heart." Parents were considered to know the medications regularly used when they answered the questions correctly or showed the prescription. The knowledge of IE was considered adequate only they mentioned "infection of the heart" or "infection of the valve." They were only considered to be aware of the risk procedures when at least the dental procedures were mentioned. The knowledge was classified as satisfactory (4-6 right answers), regular (2-3 right answers) and unsatisfactory (0-1 right answer). The education level was measured in years of formal study.

The project was approved by the Institutional Research Ethics Committee and all participants signed the informed consent.

The SPSS software version 17.0 was used for statistical analysis. Qualitative variables were described by absolute and relative frequency, whereas quantitative variables were described by mean and standard deviation or median and interquartile range. The dependent variable in this study was the level of parental knowledge on IE. The Spearman correlation coefficient was used in order to correlate the degree of parents' knowledge with their years of formal study and the follow-up period of patients at the institution.

The student's t test was used to compare the average level of parental knowledge in relation to the presence or absence of intervention and type of heart disease (cyanotic and acyanotic). The *P*-value <0.05 was considered significant.

RESULTS

Out of the 90 patients, 52 (57.7%) were male. The children's ages ranged from 3 months to 14 years and 7 months, median of 5.6 years (2.2 to 11.0 years). The median

follow-up period was 3.49 years (1.20 to 7.38). The most common diagnoses were tetralogy of Fallot (TOF) in 23 (25.56%) patients, interventricular communication (IC) in 18 (20.0%), complex cyanotic congenital heart disease (CCCHD) in 9 (10.0%), atrioventricular septal defect (AVSD) in eight (8.9%), patent ductus arteriosus (PDA) in 4 (4.4%) and aortic stenosis in three (3.3%) (Table 1). Sixty-one (67.7%) patients had undergone at least one therapeutic procedure (surgical or catheterization). Regarding the type of heart disease classification, 35 (38.90%) patients had cyanotic heart disease. The education level of parents interviewed showed a mean of 7.67 ± 3.25 years of formal study. Thirty-five (38.9%) parents knew the name of heart disease or adequately explain the diagnosis. The remaining 55 (61.1%) parents only knew that their children suffered from a heart problem, but failed to specify the problem.

Seventy-nine (87.8%) parents knew the names and daily doses of the drugs in use or had a prescription to control their children's medication, and 11 (12.2%) failed to report these information (Figure 1).

Table 1. Clinical and demographic characteristics of patients (n = 90).

Variables	
Age (years)	6.5 ± 4.5
Parental education (years of schooling)	7.67 ± 3.25
Male	52 (57.7%)
Types of Heart Diseases:	
TOF	23 (25.5%)
IC	18 (20.0%)
CCCHD	9 (10.0%)
AVSD	8 (8.9%)
PDA	4 (4.4%)
Aortic stenosis	3 (3.3%)
Others	25 (22.24%)

Variables expressed as mean ± standard deviation or n (%). TOF (tetralogy of Fallot), Intraventricular Communication (IC), CCCHD (complex cyanotic congenital heart disease), AVSD (atrioventricular septal defect), PDA (patent ductus arteriosus)

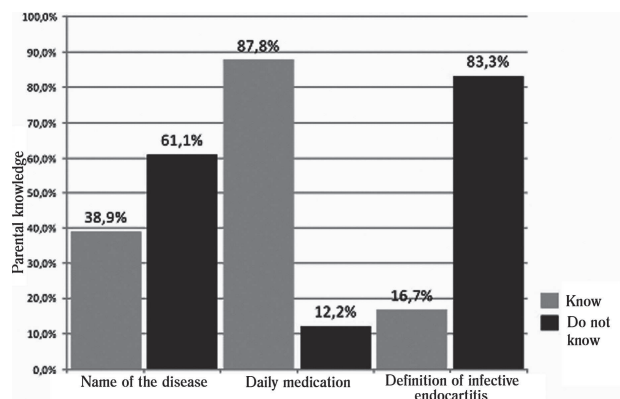


Fig. 1 – Questions related to knowledge of the disease

Fifteen (16.7%) parents interviewed adequately answered the question “what is endocarditis?” and 75 (83.3%) failed to provide the correct answer (Figure 1). In relation to risk procedures for the development of IE, 39 (43.3%) parents reported at least on the risk dental procedures and 51 (56.7%) did not know to inform anything (Figure 2).

Regarding the oral hygiene care, 50 (55.60%) parents said they received information and 40 (44.4%) reported not having received any kind of information related to the care for their teeth. In relation to the medications given before some types of dental procedures, 37 (41.1%) parents knew to inform the name of the medication and 53 of them (58.9%) did not have this information (Figure 2).

The results of the survey questions are presented in Table 2. According to the score previously established, the knowledge of respondents was considered satisfactory in 34 (37.7%), fair in 30 (33.3%) and unsatisfactory in 26 parents (28.8%).

There was a direct and moderate significant correlation between the level of parental knowledge and the follow-up period of children ($r = 0.548, P < 0.001$). There was no significant correlation between the level of parental knowledge and their years of formal study ($r = 0.028, P = 0.796$). Parents of children with cyanotic heart disease had a average rate of knowledge of 3.23 ± 1.73 , while the parents of acyanotic children was 2.60 ± 1.62 . This difference was not statistically significant ($P = 0.084$).

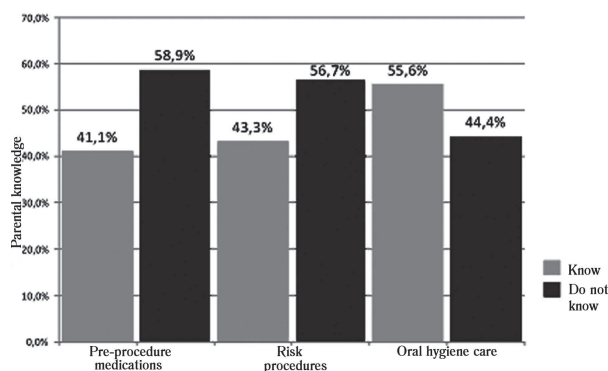


Fig. 2 – Questions related to the prophylaxis of IE

Table 2. Correct answers to the questionnaire (n = 90).

Questions	Right answers (%)
Name of the child's heart disease	35 (38.9%)
Daily Medications used	79 (87.8%)
Definition of endocarditis	15 (16.7%)
Risk procedures for IE	39 (43.3%)
Oral hygiene care	50 (55.6%)
Medications for IEP	37 (41.1%)

IE: infective endocarditis; IEP: infective endocarditis prophylaxes

There was no difference in the mean score of parental knowledge regarding the presence or absence of intervention ($P = 0.555$).

DISCUSSION

Many studies conducted in several centers have shown that parental knowledge of the care needed to prevent IE in children with heart disease is lower than expected [9-11,13,15,16]. In the present study, only 34% of parents/caregivers have demonstrated satisfactory knowledge, and only 15 respondents seemed to know what IE was. Cheuk et al. [11] observed that great parental knowledge was related to their better educational level and professional qualifications, but it did not occur in the present study, because there was no correlation between duration of formal study of parents and the score obtained in the questionnaire. This finding may be explained by the low education of the group. Among the parents of our patients, only two had completed 16 years of formal study, characterizing an academic degree.

A research conducted in England compared the attitude, knowledge and oral health practices of children's parents with heart disease with parents of healthy children, and found that, the group with heart disease received less oral health care than the group without cardiopathy [12]. The authors suggest that parents have neglected dental care due to the increased over the heart and other diseases such as respiratory infections, but these findings also show that the strategy of the team failed in information, recommendations and setting priorities.

It was observed in the comparison between cyanotic and acyanotic patients that there was a tendency to greater knowledge among parents of children with cyanotic heart disease. Cyanotic heart diseases are generally more severe than the acyanotic ones, and the symptoms can be more easily identified and recognized by the parents. From these facts, we can infer that parents have more involvement with their children's disease and, consequently, better knowledge.

The frequency of various heart diseases is noteworthy in the analyzed group, but if all the patients were assisted, the expected results would not be the same. This is due to the fact that in routine outpatient follow-up, patients with repercussive diagnosis, had the visits scheduled more frequently. For instance, the number of patients with tetralogy of Fallot who attended the consultation in the period studied was greater than in patients with isolated ventricular septal defect.

Only 16.7% of the parents interviewed indicated knowing what endocarditis was, but a larger number (43.3%) knew about the risk procedures for developing the disease. This finding, apparently inconsistent, may indicate that the

respondents had already been informed about the problem and the risk conditions, but they did not feel confident to give a "definition" of the disease.

The number of patients with congenital heart disease reaching adulthood is increasing with advances in pediatric cardiology in recent decades, changing this population profile. [17-20]. The targeted outcomes in the treatment of these patients are no longer survival, but they seek to provide an almost normal life in terms of longevity and quality [21]. These adolescents and young adults' motivation for the proper care for their general health, preventing and retarding complications, should be initiated since their childhood [15,16,22]. The correlation between parental knowledge and the follow-up period of these children suggests that more the link between the health team and the patient's family is reinforced, the adherence to treatment increases, according to previous reports [23].

It has been widely discussed in the literature that poor adherence to treatment with antibiotics for IEP is due in part to the ambiguity of successive guidelines published since 1955 [4]. The new AHA guidelines provoked controversy and are far from a consensus among cardiologists, taking into account that specialists with extensive experience in specific and rare diseases advocate the maintenance of previous indications for PEI [24,25]. The 2007 guidelines [1] greatly reduced the risk situations, but the professionals still remain doubtful on some aspects which were not discussed, especially with regard to patients who underwent surgical treatment and have residues from initial heart disease or secondary surgery sequelae. Particular situations strengthen the argument that the IEP regime should be individualized.

Some authors argue that the decision on whether or not to adopt the new guidelines should be shared between doctor and patient or between doctor the person responsible for the patient, characterizing an informed decision making [24]. This alternative can not be generalized, considering that the parental and patients' knowledge on the subject has been disappointing in many services where it was evaluated.

Studies in recent decades indicate the need for continued education of parents and patients with active participation of physicians, nurses, dentists, social workers, psychologists and other professionals involved in health promotion. In addition to educational programs that have patients as the target, other education programs addressed to health professionals are also necessary. The access to the dentist of child population is deficient in our community, and also some professionals refuse to assist children with heart disease by not knowing how to proceed [26].

There are gaps between what is provided to the patients and what they really learn about it [27,28]. Many difficulties involved in the parental knowledge about the risks their

sick children are running are associated with the doubts they have no opportunities to remove and the difficulties in assimilating explanations through technical words. There are also other common conditions that need to be recognized and overcome by the health team [29]. Whatever the system adopted for IEP, every effort should be made in order to resolve the parents doubts that should be instructed to educate their children following strict oral health care. The best prevention of IE is the oral health maintenance.

In this study, parental knowledge about endocarditis and its prevention has shown to be inadequate, requiring greater attention to the orientations given during consultation. However, every professional must be careful when generalizing the results obtained.

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