



Are adults with congenital heart disease informed about their risk for infective endocarditis and treated in accordance to current guidelines?



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ABSTRACT

Background: Adults with congenital heart disease (ACHD) have an increased risk for infective endocarditis (IE). In the last decade, the recommendations for IE prophylaxis have changed substantially. The knowledge level of patients about IE and IE prophylaxis has not been studied.

Methods: Patients recruited via the German National Register for Congenital Heart Defects were invited to an online survey about IE. Patients were divided into two groups based on ESC guidelines: high IE risk (antibiotic prophylaxis recommended) and low IE risk (prophylaxis not recommended).

Results: Overall, 1458 patients participated and out of these 1211 (age 30.5 ± 11.8 years, female = 54.2%) with detailed clinical information were further analyzed. 343 patients had a high IE risk, whereas 868 had a low risk. Overall, 74.5% ($n = 902$) stated to know what IE is (low IE risk: 71.3%, high IE risk: 82.5%). Out of these who stated to know what IE is ($n = 902$), 76.5% ($n = 690$) chose the correct answer in a multiple choice question (low IE risk: 76.4%; high IE risk: 76.7%). Antibiotic prophylaxis was known to 66.2% (low IE risk: 59.9%; high IE risk: 82.2%). Out of these who stated to know what antibiotic prophylaxis is ($n = 802$), 83.8% ($n = 672$) chose the correct answer in a multiple choice question (low IE risk: 82.9%; high IE risk: 85.5%).

Conclusions: This study reveals important knowledge gaps regarding IE and antibiotic prophylaxis in ACHD patients. A discussion about IE and antibiotic prophylaxis should take place with every ACHD patient during regular clinical contacts to close this knowledge gap.

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1. Introduction

Adults with congenital heart disease (ACHD) have an increased risk of infective endocarditis (IE) compared to the general population [1]; it accounts for up to 4% of admissions to a tertiary ACHD centre, with an associated mortality of approximately 4% [2]. In the past many ACHD patients received antibiotic prophylaxis for IE when undergoing invasive investigations or procedures. However, the lack of prospective evidence in support of antibiotic prophylaxis on efficacy and the potential hazards of antibiotic use, particularly anaphylaxis and the development of antibiotic resistance, led to a major shift in practice between 2007 and

2009 [3], when IE prophylaxis recommendations were abolished for most or all patients, depending on national and international guidelines [4–7]. Whether and to what extent these changes have been implemented into clinical practice remains a matter of question. A few studies have investigated the knowledge of healthcare professionals, especially dentists [8,9]. These studies showed significant gaps of knowledge and the need for a better IE education for healthcare professionals. Current data regarding patients' knowledge of the definition, and preventive measures of IE is lacking [10]. Therefore, the aim of the current study was to evaluate the current knowledge level of ACHD patients regarding IE and antibiotic prophylaxis of IE.

2. Methods

An online survey was conducted by the German National Register for Congenital Heart Defects (NRCHD) to assess patients' knowledge of IE and IE prophylaxis. The NRCHD is the largest patient database for CHD in Europe. Patients and their families

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have the opportunity to take part in studies, to provide blood and tissue samples to the register's biobank and to receive information on the current state of research in the field of CHD. The NRCHD currently comprises data from approx. 51,134 members (as of October 2016) including children, adolescents, and adults with CHD. Details on the National Register and its representativeness have been reported previously [11].

For identifying potential study participants, the database of the NRCHD was systematically scanned for patients aged 18 years or older and of whom a current e-mail address was available. The identified individuals (N = 3874) were invited via e-mail to participate in the online-survey. Each patient received an individual access code which was used to identify the patient. The survey was open for 1 month (November 06 to December 06, 2015). For the online survey the survey tool EFS-Survey (Questback, Cologne/Germany) was used.

Patients were divided into two groups based on current European Society of Cardiology guideline recommendations [4] for antibiotic prophylaxis of IE: (A) IE prophylaxis necessary/high IE risk, (B) IE prophylaxis is not required/low IE risk.

Complexity of cardiac lesions was classified according to the Bethesda classification [12]. Furthermore, patients were assigned to five diagnostic groups: left heart lesions (e.g. coarctation of the aorta), right heart lesions (e.g. tetralogy of Fallot, Ebstein's anomaly, obstructions of the right ventricular outflow tract), septal defects/vascular malformations (e.g. anomalous pulmonary venous return), complex lesions (e.g. Fontan, single ventricle physiology, transposition of the great arteries), and others (Marfan, anomalous origin of left coronary artery from pulmonary artery, etc.).

Educational status was divided into three groups: low (less than secondary school), medium (secondary school), and high educational level (high school diploma qualifying for university admission and higher).

2.1. Statistical analysis

Values are presented as mean \pm standard deviation (SD). Comparisons between groups were made using non-parametric methods. All tests were performed two-sided and for all analyses, a p-value <0.05 was considered statistically significant. Statistical analyses were performed using SPSS 22 (IBM Corp., Armonk/USA).

Approval by the local Ethics Committee was obtained.

3. Results

Overall, 1458 patients participated in the survey (response rate 37.6%). Out of these, in 1211 patients (mean age 30.5 ± 11.8 years; 54.2% women) detailed medical information was available that allowed a risk allocation regarding IE. These were included into the study. Detailed information of the patient cohort is presented in Table 1.

The distribution of patients according to the prespecified diagnostic groups was as follows: left heart lesions (n = 247, 20.4%), right heart lesions (n = 295, 24.4%), septal defects/vascular malformations (n = 368, 30.4%), complex lesions (n = 181, 14.9%), and others (n = 120, 9.9%). According to current guidelines 868 patients were deemed low risk for IE (71.7%, mean age 29.9 ± 11.9 years), and 343 as high risk for IE (28.3%, 31.8 ± 11.2 years).

Overall, 65.7% (n = 796) of those surveyed were treated mainly at specific ACHD clinics at a heart center, 17.6% (n = 213) by a practice-based cardiologist, 9.4% (n = 114) were treated by a practice-based pediatric cardiologist, and 7.2% (n = 88) were treated by a non-specialist.

Table 1
Demographics and baseline characteristics.

	All patients (n = 1211)	Low IE risk (n = 868)	High IE risk (n = 343)
Age (years)	30.5 ± 11.8	29.9 ± 11.9	31.8 ± 11.2
Female (n)	656 (54.2%)	473 (54.5%)	183 (53.4%)
Complexity of CHD			
Simple	368 (30.4%)	300 (34.6%)	68 (19.8%)
Moderate	465 (38.4%)	384 (44.2%)	81 (23.6%)
Complex	340 (28.1%)	150 (17.3%)	190 (55.4%)
Others	38 (3.1%)	34 (3.9%)	4 (1.2%)
Diagnostic group			
Left heart lesion	247 (20.4%)	180 (20.7%)	67 (19.5%)
Right heart lesion	295 (24.4%)	149 (17.2%)	146 (42.6%)
Septal defects	368 (30.4%)	325 (37.4%)	43 (12.5%)
Complex lesion	181 (14.9%)	116 (13.4%)	65 (19.0%)
Others	120 (9.9%)	99 (11.3%)	22 (6.4%)

IE = infective endocarditis.

3.1. Patient communication

Patients with a low IE risk reported in 48.2% (n = 418) that a conversation with a physician about IE took place in the last five years, while 67.3% (n = 231) of patients with a high risk recalled such a conversation.

Out of the patients who were treated by practice-based pediatric cardiologists, 63.2% (n = 72) reported a communication with a physician in the last five years about IE, while 46% (n = 96) of patients treated by cardiologists, and 55.7% (n = 443) of patients treated in ACHD clinics reported such a communication.

3.2. Self-assessment

The study participants were asked to answer five questions on a six tiered Likert scale (1 = very good, 6 = very bad). Significant group differences were found between patients with increased IE risk and patients with no increased IE on these items: current health status (p < 0.001), to be informed about IE in general (p < 0.001), to be informed about risk of IE regarding your CHD (p < 0.001), and to be informed by treating physician about IE (p < 0.001). Regarding the item to be informed about their CHD, the difference was not significant (p = 0.421) (Fig. 1).

3.3. Knowledge of IE risk

Regarding their general IE risk, 44.3% (n = 537) of patients stated to have an increased IE risk, 13.5% (n = 163) stated to have no increased IE risk, and 42.2% (n = 511) reported that they don't know whether they have an increased IE risk or not. Out of those patients who stated to have an increased IE risk, only 45.1% (n = 242) had indeed an increased IE risk, while 10.4% (n = 17) of patients, who thought to be low risk, had an increased risk and therefore, an indication for antibiotic prophylaxis. Out of the patients, that did not possess knowledge regarding their IE risk, 16.4% (n = 84) had an increased risk.

3.4. Knowledge of IE

Out of all patients, 74.5% (n = 902) stated to know what IE is (patients with low IE risk: 71.3%; patients with high IE risk: 82.5%). Out of the respondents who stated to know what IE is (n = 902), 76.5% (n = 690) chose the correct answer in a multiple choice question (patients with low IE risk: 76.4%; patients with high IE risk: 76.7%).

Regarding, antibiotic prophylaxis, 66.2% (n = 802) stated to know what it is (patients with low IE risk: 59.9%; patients with high IE risk: 82.2%). Out of these respondents who stated to know what antibiotic prophylaxis is (n = 802), 83.8% (n = 672) chose the correct answer in a multiple choice question (patients with low IE risk: 82.9%; high IE risk: 85.5%).

3.5. Possible confounding factors

Gender had no significant influence on the self-perceived knowledge of IE (male 73.2% vs. female 75.6%, p = 0.355). Male patient provided significantly more often the correct answer to the multiple choice question than female patients (83.2% vs. 70.9%, p < 0.001). Further, gender had no significant influence on the self-perceived knowledge of antibiotic prophylaxis (male 64.9% vs. female 67.3%, p = 0.394), and also not on the knowledge assessed by the multiple choice question (correct answer: male 81.1% vs. female 84.7%, p = 0.188).

The level of education had a significant influence on the self-perceived knowledge of IE and antibiotic prophylaxis, with those with a higher achieved degree rating their knowledge better (p = 0.020 for IE, and p = 0.019 for prophylaxis). Considering the multiple choice question, patients with a higher degree achieved a better correct answer rate for IE (p = 0.028), but not for prophylaxis (p = 0.299).

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