

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

Helm P.C. (1,2), Diller G.-P. (3), Kaemmerer H. (4,5), Bauer U.M.M. (1,2), Asfour B. (6), Tutarel O. (4,5)

(1) National Register for Congenital Heart Defects, Augustenburger Platz 1, 13353 Berlin, Germany

(2) DZHK (German Centre for Cardiovascular Research)

(3) Muenster University Hospital, Center for Adults with Congenital Heart Defects (EMAH-Center), Albert-Schweitzer-Str. 33, 48149 Muenster, Germany

(4) German Heart Centre Munich, Department of Paediatric Cardiology and Congenital Heart Defects, Technical University of Munich, Germany

(5) DZHK (German Centre for Cardiovascular Research), Partner Site Munich, Germany

(6) Asklepios Klinik Sankt Augustin GmbH, German pediatric heart center, Sankt Augustin, Germany

Background: Infective endocarditis (IE) is associated with significant morbidity and mortality. Whether and to what extent the guideline changes in the last decade have been implemented into clinical practice is unknown. Especially the knowledge level of patients has not been studied.

Purpose: To study the current knowledge level of ACHD patients regarding IE and antibiotic prophylaxis of IE.

Methods: Patients recruited via the German National Register for Congenital Heart Defects to an online survey about IE. 1,458 individuals participated and 1,211 patients with detailed clinical data available (mean age 30.5 ± 11.8 years, female = 44.1 %) were included into the study.

Results: Group A (IE prophylaxis recommended): 343 patients (mean age 31.8 ± 11.2 years, female = 53.1 %); Group B (IE prophylaxis is not required): 714 patients (mean age 29.1 ± 10.8 years, female = 53.9 %); Group C (a conclusive statement regarding IE prophylaxis not possible): 154 patients (mean age 33.9 ± 15.7 years, female = 57.1 %). A regular treatment in a tertiary medical environment took place in 76.1 % (group A), 66.1 % (group B) and 40.9 % (group C). Within the last five years, 67.3 % (group A), 52.8 % (group B) and 26.6 % (group C) were informed by a physician about IE. In 47.8 % (group A), 28 % (group B) and 16.9 % (group C) the discussion was initiated by a physician.

Knowledge regarding IE was present in 82.5 % (group A), 73.2 % (group B), and 62.3 % (group C), while in 70.6 % (group A), 37.7 % (group B) and 16.9 % (group C) an increased risk of IE was present according to their own opinion. Knowledge of antibiotic prophylaxis was present in 82.2 % (group A), 63.7 % (group B), and 42.2 % (group C).

Conclusions: This study reveals important knowledge gaps regarding IE/antibiotic prophylaxis in ACHD. Even 20-30 % of ACHD with a strict recommendation for using antibiotic prophylaxis, did not possess knowledge about IE and misjudged their risk for IE. A discussion about IE and antibiotic prophylaxis should take place with every ACHD patient during regular clinical contacts to close this knowledge gap.