Euro Heart Survey on adult congenital heart disease: concern for the complexity of care

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This editorial refers to ‘Delivery of care for adult patients with congenital heart disease in Europe: results from the Euro Heart Survey’ by P. Moons et al., on page 1324

Management of adults with congenital heart defects

Progress in paediatric cardiac surgery over the last decades resulted in a growing number of adult patients with (surgical corrected) congenital heart defects. Most of these patients require lifelong care, as the long-term outcome of the complex surgical procedures is often complicated by heart failure, atrial or ventricular arrhythmias, pulmonary hypertension, or endocarditis. In addition, surgical re-interventions are frequently necessary in case of, for example, obstruction of conduits or residual defects. Taking into account the complexity of the late post-operative sequelae, adequate monitoring and care for the adult patient with a congenital heart defect are of paramount importance.

Therefore, guidelines for medical, surgical, and psychosocial management of adults with congenital heart disease were developed. However, little is known about the actual implementation in routine clinical practice. So far, only one survey has evaluated the delivery of care for adults with congenital heart disease at the six tertiary centres in North America and Europe. Moons et al. report the outcome of a study, which is a first attempt to evaluate the implementation of structured care for adults with congenital heart defects at the multiple centres in Europe as recommended by the Euro Heart Survey on Adult Congenital Heart Disease.

Importance of the complexity of congenital heart defects

In this study, it has been analysed to which extent recommendations of the Euro Heart Survey were implemented in the so-called ‘specialist’ and ‘non-specialist’ centres. These centres provided care to patients with a variety of congenital heart defects, including atrial or ventricular septal defects, tetralogy of Fallot, co-arctation of the aorta, transposition of the great arteries, marfan syndrome, or single ventricle physiology. Unfortunately, the study provides no data on the distribution of these different congenital heart defects for each of the individual centres. In order to study the delivery of care, it would be of interest to know the level of care for the various congenital heart defects separately; e.g. is care mainly insufficient for those patients with more complex congenital cardiac anomalies?

However, a striking finding of this study is that only 19% of the specialist centres provided an optimal care structure according to the recommendations of the Euro Heart Survey. Importantly, the major cause of non-compliance to the Euro Heart Survey advisories was that most centres were not able to perform the minimal annual number of cardiosurgical procedures required. Therefore, it would have been useful to provide information about the case-mix of each of the individual centres. For example, not reaching the minimum number of procedures is probably less important in case of less complex cases. However, in case of complex surgical procedures, it is of importance to reach a certain minimum case-load.

It is most likely that more complex congenital defects were concentrated at specialist centres and simpler defects such as atrial septal defects at non-specialist centres. This may also account for the reported higher number of out-patients visits, hospital admissions, and cardiosurgical procedures in some specialist centres, as the incidence of late post-operative complications will be associated with the complexity of the congenital heart defect.

Hence, further studies about the relation between the complexity of the congenital heart defects and the delivery of care will be of great value to gain more insight into healthcare delivery in this intriguing patient population.

Care of adults with congenital heart disease: future research

As already stated by the authors, a limitation of this study is that the results merely indicate the level of care in the participating centres. This may not be representative for entire Europe, as the number of centres with facilities for care for adults with congenital heart defects and their level of healthcare are not known. From the data presented by Moon et al., it can nevertheless be concluded that delivery of care for adults with congenital heart disease in a large number of centres in Europe is far from optimal. However,
in order to evaluate the level of healthcare more accurately, future studies providing a quantitative analysis of the characteristics of the centres, cardiologists, and nurses involved are mandatory. In addition, the relation between the level of healthcare and the long-term outcome in terms of morbidity and mortality will be of significance.

As the continuously growing population of adults with congenital heart defects requires specific management, data on the level of healthcare and also on the outcome of diagnosis and management strategies are of major interest.

Technological progress has resulted in the availability of new diagnostic tools and therapeutic options. A typical example is the management of the frequently occurring drug refractory atrial tachyarrhythmias in patients with complex congenital heart disease. The introduction of three-dimensional mapping techniques for the guidance of endocardial catheter ablation procedures offered a new potentially curative treatment modality for late post-operative atrial tachyarrhythmias in patients with complex arrhythmogenic substrates.7

Technological progress will undoubtedly continue to alter the management of adults with congenital heart disease, and in the long-term, also the established recommendations. Implementation of these recommendations in clinical practice will in turn need to be re-evaluated, thereby eternalizing the interplay between guidelines modifications and evaluation of realization in clinical practice. The study presented by Moon et al. is therefore a promising initial assessment of healthcare for adults with congenital heart defects in Europe and subsequent reports will be looked forward to.

Conflict of interest: none declared.

References