

Delivery of care for adult patients with congenital heart disease in Europe: results from the Euro Heart Survey

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KEYWORDS

Congenital heart disease;
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Provision of care;
Adult

Aims The increasing number of adults with congenital heart disease (CHD) has prompted the development of recommendations for the management of these patients and for the organization of their healthcare. The aim of this report is to describe the delivery of care in Europe for adults with congenital cardiac anomalies.

Methods and results As part of the Euro Heart Survey on Adult Congenital Heart Disease, we obtained data from 71 voluntarily participating centres that detailed their care practices for these patients. Forty-eight of these centres were specialist centres and 23 were non-specialist centres. We found that only 19% of the specialist centres complied with defined standards for optimal care structure. The criteria that appeared to be most difficult for all centres to achieve were performing 50 congenital heart operations or more per year and involving nurse specialists in the care of these patients.

Conclusion This survey indicated that the provision of care in Europe for adults with congenital heart defects is suboptimal. To fully realize the benefits of cardiac surgery performed in infants and children, continuous effort must be applied by healthcare professionals in order to implement the recommendations on the organization of care for these patients.

Introduction

Because of advances in paediatric cardiology, intensive care medicine, and cardiac surgery, the number of children with congenital heart disease (CHD) surviving into adulthood continues to increase. Hence, adults with CHD constitute an ever-growing population. As a complete and systematic register of patients with CHD is lacking, no reliable data exist on the prevalence of congenital cardiac anomalies. Several attempts to estimate the prevalence of CHD have been undertaken over the past decade.^{1–5} Applying the calculations of Hoffman and colleagues to the European population of 728 million civilians (esa.un.org/unpp), we arrive at an estimate between 1.9 and 3.9 million patients with CHD, 1.2–2.7 million of which are 15 years of age or older.⁴

This growing patient population requires specialist care and attention. Therefore, several North American and

European task forces and expert panels have been formed to develop recommendations for the management of these individuals and for the development of the best healthcare practices.^{2,6–17} In some countries, standards of care have been established by governmental quality review boards in response to the tragic failures of paediatric heart surgery.¹⁸ It is unknown, however, to what extent clinicians and healthcare administrators follow these standards. Therefore, the Euro Heart Survey on Adult Congenital Heart Disease (ACHD) was initiated. The overall aim of this Euro Heart Survey were: (1) to assess existing clinical practices in relation to established recommendations for diagnosis and management of adult patients and (2) to describe the organization of care for adult patients with CHD. Here, we address the latter aim and describe the caseload of healthcare givers, the type of healthcare professionals involved in caring for these patients, and the extent to which these patients receive optimal care in Europe. An extensive description of the design of the Euro Heart Survey on ACHD can be found elsewhere.^{19,20}

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Methods

Definitions

Although no randomized controlled trial studies have been done on the organization and delivery of care for adults with CHD, several descriptive and qualitative studies have proposed appropriate and feasible key elements in care practices for these patients.¹²

The Task Force on the Management of Grown Up Congenital Heart Disease of the European Society of Cardiology states that patients requiring ACHD care can be categorized into three types: (1) patients who require care provided exclusively by specialist centres; (2) patients who can receive care from appropriate general adult cardiac facilities in strong collaboration with a specialist centre; (3) patients who can be managed by non-specialist centres that have access to specialized care, if needed.¹¹ Specialist centres specifically manage patients with moderate and complex CHD and deal with adult patients with acute or chronic long-term complications.^{10,14} This type of speciality treatment is mainly provided by tertiary centres.⁹ Patients with a less complex form of the disease can receive either shared care in which the attending regional medical team maintains collaboration and communication with a specialist centre, or receive follow-up care in a non-specialist centre.^{10,11} For this Euro Heart Survey, the expert committee defined specialist centres as those complying with the following criteria: (1) must offer paediatric cardiology or congenital cardiac surgery; (2) must have on-staff at least one cardiologist dedicated to ACHD; (3) must have more than 200 ACHD patients under regular follow-up care.

Recommendations for the minimal or optimal structure of ACHD care have been previously published (*Table 1*). Optimal ACHD care requires that all eight of the listed recommendations be fulfilled. For specialist centres, recommendations 1, 2, and 3 need to be fulfilled. In addition, complying with recommendations 5–8 is critical to achieve an optimal ACHD care programme. For non-specialist centres, recommendation 4 is applicable.

Measurements

To assess the extent these recommendations were implemented at the centres, we devised a questionnaire (*Table 2*) to evaluate the

Table 1 Recommendations for optimal ACHD care

1. An ACHD referral centre must employ at least one, preferably two, cardiologist(s) specifically trained and educated in the care of adults with CHD.^{6,9–11,13,14,17}
2. Specialized ACHD centres should provide care in connection with paediatric cardiology and/or congenital cardiac surgery.^{6,10,11,13,14,17}
3. Specialist centres must treat a sufficient number of patients and perform a sufficient number of procedures to be effective and to develop and maintain high levels of performance.¹¹
4. General adult cardiac facilities and non-specialist centres should have an established referral relationship with a specialist centre.^{6,11,14}
5. A minimum of two cardiac surgeons trained in and practising adult and paediatric cardiac surgery are required.^{10,11,14,17}
6. The optimal activity for a paediatric and congenital cardiac surgeon is 125 operations per year.¹⁷ Specifically for ACHD, a minimum of 50 operations per year is recommended.¹⁰
7. A fully equipped electrophysiology laboratory staffed by properly trained electrophysiologists with experience in detecting arrhythmias inherent to CHD and with experience in pacemaker technology, ablation technology, and defibrillator implantation must be available.^{6,10,11,13,14,17,18}
8. An ACHD referral centre must employ at least one nurse specialist that is trained and educated in the care of ACHD patients.^{6,9,11,14,18}

structure of ACHD programmes in Europe. To test the content and face validity as well as the feasibility of the questionnaire, the expert committee of the Euro Heart Survey reviewed and commented on previous versions of the questionnaire. Adaptations were made accordingly. The final questionnaire contained 20 items, five of which could be answered by the participant in a binary way (yes/no) and 15 of which could be assigned an exact number.

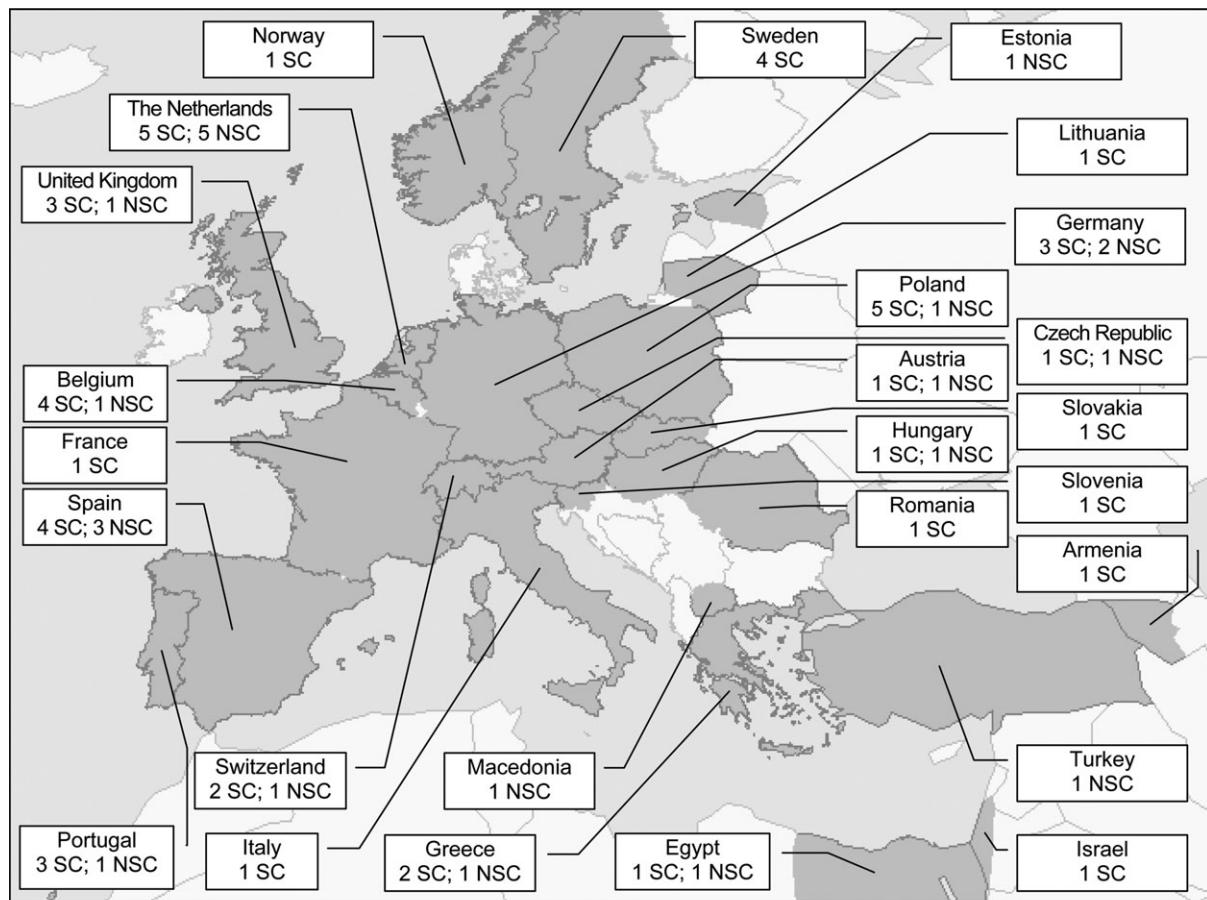
Participating centres

As previously described,¹⁹ centres were identified from the lists of European hospitals with facilities for care of adults with CHD, provided by the national coordinators of the EHS programme, and through the Working Group on Grown-Up Congenital Heart Disease of the European Society of Cardiology. We invited potential centres to participate in the Euro Heart Survey on ACHD by mailings, advertisements on the EHS website, in the European Society of Cardiology's web news, and by announcements at conferences.

Overall, 79 centres from 26 European countries voluntarily participated in this survey (*Figure 1*). From these centres, 72 centres completed the web-based questionnaire on the organization of ACHD care. One centre was excluded because their questionnaire answers did not refer solely to ACHD activities. Using the definitions outlined earlier, we considered 48 centres (67.6%) to be specialist centres. The remaining 23 centres (32.4%) were regarded as general adult cardiac facilities or non-specialist centres. Although we do not have full data on the distribution of mild, moderate,

Table 2 Questionnaire about the structure of ACHD programmes

1. Is there at least one cardiologist dedicated to ACHD?
2. Is paediatric cardiology and/or cardiac surgery available?
3. Is there at least 200 ACHD patients under follow-up care in your centre?
4. If not, does your centre formally collaborate or is it affiliated with an ACHD centre?
5. How many ACHD patients visit your centre's outpatient clinic?
6. How many ACHD patients visit your centre for hospital admission?
7. How many ACHD patients visit your centre for cardiosurgical procedures related to their CHD?
8. Does your centre formally collaborate with or is it affiliated with a paediatric cardiology programme?
9. How many paediatric cardiologists are employed at your centre?
10. How many total hours per week do your paediatric cardiologists spend in ACHD care?
11. How many ACHD cardiologists with a paediatric background are employed at your centre?
12. How many total hours per week do your ACHD cardiologists with a paediatric background spend in ACHD care?
13. How many ACHD cardiologists with an adult-care medical background are employed at your centre?
14. How many total hours per week do your ACHD cardiologists with an adult-care medical background spend in ACHD care?
15. How many congenital heart surgeons are employed at your centre?
16. How many total hours per week do your congenital heart surgeons spend in ACHD care?
17. How many electrophysiologists are employed at your centre?
18. How many total hours per week do your electrophysiologists spend in ACHD care?
19. How many nurse specialists, consultants, or practitioners specialized in ACHD are employed at your centre?
20. How many total hours per week do your nurse specialists, consultants, or practitioners specialized in ACHD spend in ACHD care?



SC, specialist centre; NSC, non-specialist centre

Figure 1 Geographic distribution of 48 specialist centres and 23 non-specialist centres participating in this survey.

and complex heart defects in each centre, we can assure that the participating centres do not only care for patients with mild heart lesions. In a related article,¹⁹ we presented data on 4110 patients having one of the following heart defects or syndromes: atrial septal defect type II, ventricular septal defect, tetralogy of Fallot, coarctation of the aorta, transposition of the great arteries, Marfan syndrome, Fontan circulation, and cyanotic defects. The median age of the included patients was 27 (Q1 = 23; Q3 = 37) years. This suggests that the patients followed-up in the participating centres are the typical patients for whom follow-up care is provided and that an over-representation of mild defects is unlikely.

Data analysis

Data were analysed with SPSS statistical software version 10.0 (SPSS Inc., Chicago, IL, USA). Nominal level data were expressed in percentages. Medians and quartiles (Q1–Q3) were calculated for continuous, non-normally distributed variables. Data that apparently comprised non-ACHD related activities were excluded from the analysis.

Results

Caseload

Specialist centres had a median of 500 ACHD outpatient visits (Q1 = 225; Q3 = 950; range 100–2600); 50 ACHD hospital admissions (Q1 = 40; Q3 = 157; range 5–450), and 42 ACHD cardiosurgical procedures (Q1 = 22; Q3 = 67;

range 5–250) per year. Non-specialist centres had a median of 75 ACHD outpatient visits (Q1 = 35; Q3 = 150; range 20–700), 10 ACHD hospital admissions (Q1 = 5; Q3 = 25; range 2–50), and 4 ACHD cardiosurgical procedures (Q1 = 0; Q3 = 27; range 0–60) per year.

Healthcare professionals involved in ACHD care

In 90% of the specialist centres, care for ACHD patients was provided by specialized cardiologists that had an adult cardiology background (Table 3). Forty percent of the specialist centres had on-staff one or more ACHD cardiologists trained in paediatric cardiology. Eighty percent of the specialist centres had on-staff a paediatric cardiologist, a congenital heart surgeon, and an electrophysiologist. Forty-two percent of the centres had on-staff one or more nurses specializing in ACHD care. The median number of ACHD cardiologists (paediatric or adult cardiology background) employed by the specialized centres was 2. ACHD cardiologists with paediatric background spent a median of 7.5 h per week attending to ACHD patients, whereas ACHD cardiologists with adult care background spent 14 h per week attending to these patients. The median number of nurse specialists at the specialized centres was 2; each nurse spent 20 h per week attending to ACHD patients (Table 3).

Table 3 Healthcare professionals involved in caring for ACHD patients in Europe

	Number of centres that employ this professional n (%)	Number of professionals in the centre ^a median (Q1–Q3)	Hours per week spent in ACHD ^{a,b} median (Q1–Q3)
Specialist centres			
ACHD cardiologist with paediatric background	19 (40%)	2 (1–2)	7.5 (3–15)
ACHD cardiologist with adult cardiology background	33 (90%)	2 (1–3)	14 (5.8–28.25)
Paediatric cardiologist	38 (79%)	4 (2.75–7)	3.9 (0.8–11.25)
Congenital heart surgeon	31 (85%)	2 (2–3)	5 (2–9.5)
Electrophysiologist	42 (87%)	2 (1–3)	1 (1–4.75)
Nurse specialist	20 (42%)	2 (1–2)	20 (6.7–35)
Non-specialist centres			
ACHD cardiologist with paediatric background	7 (26%)	2 (1–4.25)	3 (1–5)
ACHD cardiologist with adult cardiology background	18 (78%)	1 (1–4)	4 (1.25–9.25)
Paediatric cardiologist	14 (70%)	2 (1–3)	6 (2.25–24.5)
Congenital heart surgeon	7 (30%)	2 (2–2)	5 (1.75–23.75)
Electrophysiologist	10 (43%)	2 (1–3.25)	3.75 (3–8.5)
Nurse specialist	5 (22%)	1 (1–4.5)	16 (3–17.5)

^aOnly centres employing this professional are included in the calculation of the median.

^bThis median represents the median time per person (total number of hours per week divided by the number of professionals in the centre).

In 78% of the non-specialist centres, care for ACHD patients was provided by specialized cardiologists having an adult cardiology background. Twenty-six percent of these centres had on-staff one cardiologist trained in paediatric cardiology. Twenty-two percent of the centres had on-staff one or more nurses specializing in ACHD care. Except for paediatric cardiologists and electrophysiologists, health care professionals in non-specialist centres spent lower amounts of time caring for ACHD patients when compared with their counterparts in the specialist centres.

Optimal care

Figure 2 contains a flow chart indicating to what extent the respective recommendations were fulfilled by the European specialist centres. Nine of 48 specialist centres (18.8%) fulfilled all applicable recommendations (Figure 2). According to the guidelines, only these nine centres had the optimal structure necessary to provide ACHD care. This small number of compliant centres reflect the fact that the majority of centres could not fulfil two criteria: performing the minimum number of cardiosurgical procedures and involving specialist nurses.

Of the 23 non-specialist centres, 14 (61%) formally collaborated with a specialist ACHD centre (recommendation 4), whereas nine centres (39%) did not.

Discussion

Although the number of formal recommendations for delivering care to adult patients with CHD has increased steadily, the extent to which healthcare workers and administrators follow these recommendations remains unknown. One of the aims of the Euro Heart Survey on ACHD was to describe the current provision of care that these patients in Europe receive. Seventy-nine centres participated in the survey, 48 of which were labelled as specialist centres.

The survey revealed a broad range in the number of outpatient visits, hospital admissions, and cardiosurgical operations in both specialist and non-specialist centres. This

confirms the heterogeneity of caseloads in these centres. In this respect, it is remarkable that some of the specialist centres had fewer outpatient visits, hospitalizations, and operations than did some of the non-specialist centres. This observation raises the question of whether the criteria we used to define specialist centres were too strict, or whether some non-specialist centres failed to refer patients to specialized facilities, as should be done with patients with moderate to severe heart defects.

Most specialist centres employed ACHD cardiologists with an adult cardiology background. Many of these centres also employed paediatric cardiologists and ACHD cardiologists that have a paediatric cardiology background. Even non-specialist centres had on-staff a considerable number of ACHD specialists. Remarkably, 15% of the specialist centres did not have on-staff a congenital cardiac surgeon. Another surprising observation was that 22% of the non-specialist centres had on-staff nurses specializing in ACHD care.

If the recommendations cited in this article represent the gold standard of best clinical practice, the European provisions for caring for ACHD patients can be considered to be less than optimal. Indeed, at present most healthcare programmes for ACHD are not structured in a way to meet all the care needs of adults with CHD. Thus, to fully realize the benefits of treating CHD during childhood,¹¹ an ongoing effort is required to implement the recommendations on the management and organization of ACHD care. This survey indicates that there is much room for improvement in the care of ACHD patients.

The criteria (Table 1) that appeared to be the most difficult for centres to fulfil were performing the minimum number of congenital heart operations and involving nurse specialists. The median number of operations in specialist centres was 42, indicating that more than half of these failed to fulfil the criterion of performing 50 operations or more per year. It is unknown whether the number of cardiac operations in ACHD patients will decrease or increase in future decades. One can assume that some cardiac operations will be replaced by interventional procedures,

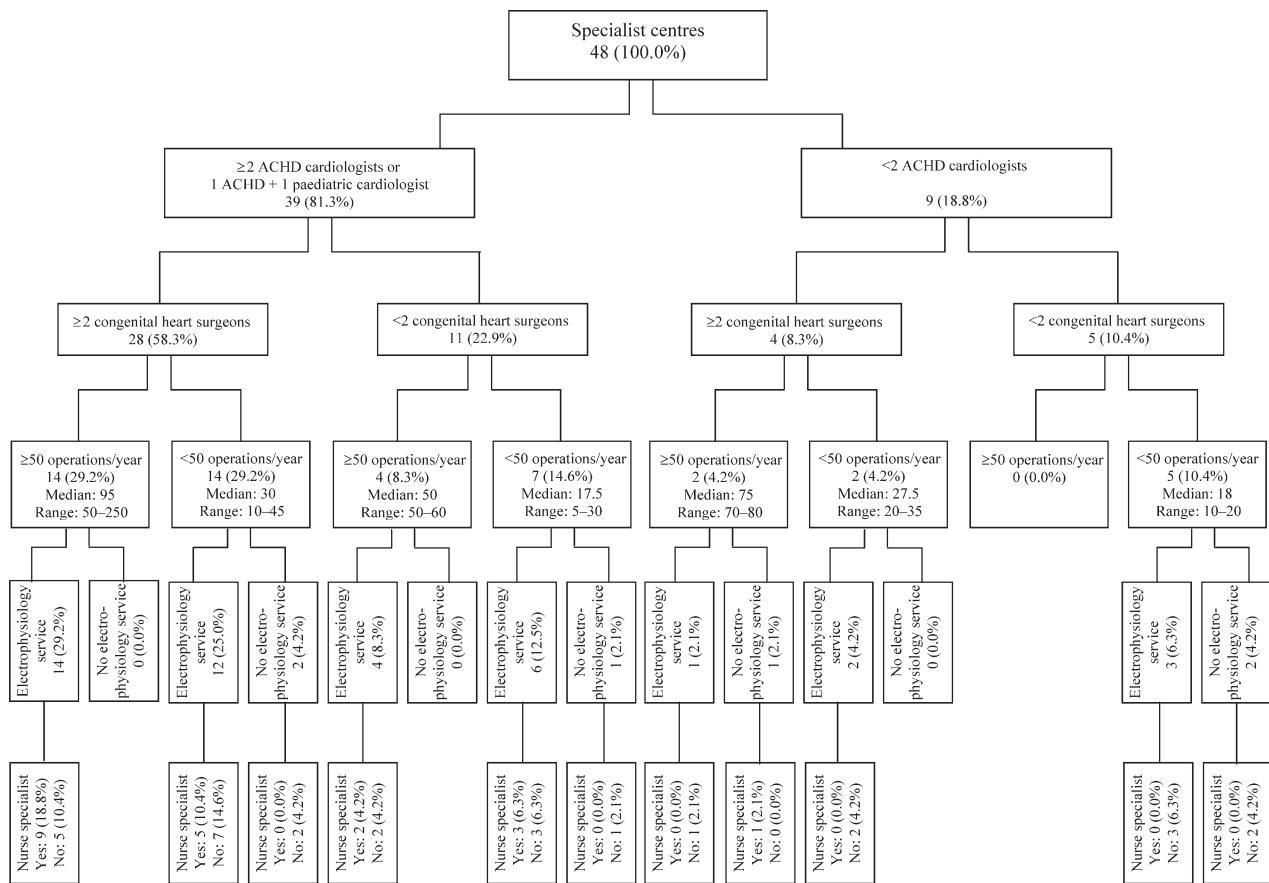


Figure 2 Flow chart showing the organization of specialist ACHD centres in Europe.

such as percutaneous closure of ventricular septal defects, balloon dilatation, and stent implantation in patients with aortic coarctation, or deployment of covered stents to treat aortic aneurysms that occur after prior coarctectomy. The development of more interventional treatment options will reduce the number of surgical procedures. On the other hand, because of the growing population of adults with CHD and the increasing probability of residua and need for reoperation during long-term follow-up of this population, it is likely that the number of ACHD operations will increase. This is exactly what Srinathan *et al.*²¹ have found. They stated that the total number of congenital cardiac operations remained unchanged, but the complexity of the cases increased substantially.²¹

The involvement of nurse specialists in ACHD care is equally problematic. Although nurses' role in the care for these patients is expanding,²² less than half of the specialist centres have on-staff nurses specializing in ACHD care. Because the level of involvement, education, and activities of nurse specialists in CHD in Europe was not yet known, the Undertaking Nursing Interventions Throughout Europe (UNITE) Research Group²³ devised a specific questionnaire, which was distributed among all centres in Europe with nurse specialists in ACHD. That specific survey showed that physical examination was the most prevalent activity undertaken by nurse specialists in ACHD, followed by telephone consultation (free access for patients to call), patient education, co-ordination of care, and follow-up after

hospitalization or outpatient visits.²⁴ Prevention and prophylaxis of endocarditis is systematically discussed by all nurse specialists. Other topics that are frequently covered in patient education are: cardiovascular risk factors, sport activities allowed, the type and characteristics of the heart defect, the definition and aetiology of endocarditis, cardiac risk in case of pregnancy, and heredity.²⁴

Data from the present survey can be used by ACHD centres as a benchmark to organize their ACHD care programmes and to identify possibilities for structural improvement. The ultimate goal for these centres is to try to mould their programme towards the optimal structure, that is to comply with the recommendations described in Table 1.

Governments and healthcare professionals are obliged to deliver optimal care not only for patients with acquired heart disease but also for those with CHD. When developing healthcare programmes, one must consider that one specialist centre should cover a population of 5–10 million people to maintain the high caseload volume needed to maintain a high level of expertise.^{6,10,11} Although this Euro Heart Survey included only a subset of European centres, our findings suggest that the number of adequately equipped centres is too limited to support the more than 1.2 million adults with CHD currently living in Europe. The issue of an inadequate number of qualified centres, as well as a critical shortage of trained and experienced professionals to care for adults with CHD, has been reported previously.^{5,11,25}

Comparison with the literature

To date, only one survey exists that has described the organizational setup, workload, and patient characteristics of major ACHD centres in North America and Europe.²⁶ These six centres typically have 100–660 ACHD admissions and 50–170 congenital cardiac operations per year. The number of healthcare professionals involved in ACHD care in these centres is, to a large extent, proportionate to that in our survey. However, the results of the survey conducted by Niwa *et al.*²⁶ cannot be directly compared with ours, as we included a wide range of specialist and non-specialist centres, whereas they only surveyed the six largest ACHD centres.

Limitations of our survey

Although the present survey provides for the first time comprehensive information on the delivery of care for ACHD patients in Europe, there are some limitations that have to be considered. One limitation is that the centres participating in this survey are not necessarily representative of all ACHD centres in Europe. As participation in the survey was voluntary, it is likely that only the most motivated and active centres completed our questionnaires. In this respect, our results may mask the real situation. In addition, we did not have in-depth information on the characteristics of the centres or on the physicians working in the ACHD programmes. Future research needs to address these issues.

A second limitation is that the list of recommendations we described earlier and used to define the optimal structure is not exhaustive. Indeed, the role of other healthcare professionals, such as specialized obstetricians and anaesthesiologists, in caring for ACHD patients is also indicated. If the presence of these professionals at a centre were also used as a criterion, the proportion of centres fulfilling the standards for optimal structure would be even lower. Hence, the question arises whether the criteria we used in the present study support optimal structure or, more likely, support minimal structure. On the other hand, the available recommendations relevant to healthcare provisions for ACHD patients are based on either expert committee reports or opinions, or clinical experience of respected authorities. No evidence from experimental studies exist. Hence, from a scientific point of view, the strength of these recommendations should be questioned. Empirical evaluation of these recommendations is needed to appraise their appropriateness and validity.

A third limitation is that our analysis was limited to specialist vs. non-specialist centres, leaving the distinction between cardiac facilities for shared care and non-specialist centres unaddressed. However, we acknowledge the relevance of these three types of facilities (as defined by the Task Force of the European Society of Cardiology) in some countries. This stratification of care is particularly important in large countries, where patients may live far from the specialist centres.¹¹

A fourth limitation is that this survey focuses on the structure of ACHD healthcare programmes. Thus, our findings do not permit us to draw conclusions in terms of processes or outcomes, as our data is not necessarily related to mortality and morbidity data. This needs to be scrutinized in future studies.

Conclusion

We surveyed various healthcare centres in Europe to determine what type of care adults with CHD receive and what type of healthcare professions deliver this care. Our findings indicate that the provision of care for ACHD patients in Europe is suboptimal, as the majority of ACHD healthcare programmes do not comply with the standards for optimal care structure. To bring to fruition the enormous success achieved in the treatment of children with CHD, sustained effort is needed to implement the recommendations on the organization of care for ACHD patients. Our survey indicates that there is much room for improvement in the care of adult patients with CHD. Governments, ministries of health, and healthcare providers are obligated to provide adequate human and financial resources to meet the increasing needs of the growing population of adults with CHD and to achieve optimum care for this population.

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Clinical vignette

Trans-septal route may be hazardous

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Trans-septal approach has to be performed by trained cardiologists, and even after the obligatory learning curve it entails some risky complications. Sometimes the dilator and the introducer sheath passes through a narrow foramen ovale and glides into the left atrium without needle puncture. This seems to be a convenient and harmless way to push the introducer into the left atrium, avoiding the risk of puncturing structures outside the atrium.

By doing so, we experienced two times a passage of the trans-septal introducer set between the leaflets of the ostium primum and secundum into the septal and anterior wall of the left atrium causing partial dissection and haematoma just behind the aortic wall. Fluoroscopy showed a clear left-oriented course of the introducer. However, the disappearance of the pressure curve and the impression of a stucked introducer precluded to push it further (Panels A and B).

A transoesophageal echocardiogram showed a localized haematoma in the anterior atrial wall, just behind the aortic posterior wall (Panels C-F). The evolution was uneventful except for short-lasting thoracic pain.

These cases illustrate the need for careful monitoring of pressure during the trans-septal procedure and the importance of performing always a classical trans-septal puncture and not to try to create a passage through a supposed open foramen ovale by forcing a catheter or an introducer into it.

Panels A and B. Dye injection in the atrial septum through the introducer.

Panels C-F. Left atrial-aortic junction before and after dissection: TEE 141-121° and TEE 58-46°.

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