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Current structure and needs of congenital heart surgery in Europe - a narrative review

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Abstract

Background/Objectives: Congenital heart surgery is a relatively small discipline dealing with a circumscript patient population. The statement contrasts with the discipline's significant clinical impact for individual patients, and with the public health effect on the healthcare system. The aim of this narrative review is to survey the current landscape of congenital heart surgery in Europe, and especially to revisit the specific points of the recommendation document on the optimal center structure twenty years on.

Methods: European demographic patterns and prevalence/incidence of congenital heart disease were studied in national/international information resources. English-language literature of current congenital cardiac surgery practices, outcomes were reviewed. Recommendations on the optimal structure of a pediatric cardiac surgical department were specifically revisited.

Results: Europe is an ageing continent with stagnating birthrate. Promoters of congenital heart disease, e.g., consanguinity, segregated generative populations and lack of termination of pregnancy for fetal anomaly are absent. Congenital heart surgery has a long and successful history with world-renown centers of excellence. European professional organizations - joining forces with international counterparts - pioneer cooperation for establishing standards of quality-of-care, risk stratification and international databases. A review of the original recommendations for the optimal center and regional care structure show that statements on volume, quality are still valid; countries with higher socioeconomical index may have an abundance of centers that, in the pursuit of excellence to achieve the best possible outcomes, regionalization is advised. Owing to a much-improved survival, an increased adult population with operated congenital heart disease transits towards the adult services and requests specialized multidisciplinary teams to care for them.

Conclusions: Europe enjoys an advanced and accessible healthcare system for congenital heart disease. In fostering development, and focusing on quality-of-life rather than just a mere survival, a concentrated collaborative effort seems essential from the multidisciplinary team, researchers, and policymakers.

Keywords: Congenital heart disease, congenital heart surgery, pediatric, outcomes, quality care, health-care organization.

Introduction

Congenital heart surgery (CHS) is a relatively small discipline dealing with a limited patient population that contrasts with its significant clinical impact for individual patients, as well as, a public health effect^{1,2} on families and the healthcare system³⁻⁵. CHS has emancipated from cardiothoracic surgery and became a specialty on its own right⁶. It even expanded the name from 'pediatric' to 'congenital' heart surgery. Compared to adult cardiac surgery, where investments may be capitalized in the short term⁷ - a patient who paid contributions is being operated on, recovers, and may return to the workforce in a short period of time -, congenital heart surgery may only expect its benefits to surface after many years^{5,8}. CHS relies on multidisciplinary effort rather than surgical ego⁹. On a programmatic level, there is high threshold to meet as patient outcomes under public scrutiny^{10,11}. There is a strong quantity/quality correlation where teams with high volume experience may avert complications to save improved outcomes¹². As CHS remains a high-risk modality¹³, comprehensive recommendation frameworks had been proposed for center setup, case-load and casemix, staffing¹⁴ and key performance criteria¹⁵. The aim of this narrative review is to survey the current landscape of CHS in Europe and especially to revisit the specific points of the recommendation document¹⁴ on the optimal structure twenty years on.

Materials and methods

Demographic patterns and prevalence/incidence of congenital heart disease in Europe was studied in national/international information sources. We also searched PubMed, Cochrane and Embase databases using key search words 'pediatric' and/or 'congenital cardiac surgery' and 'Europe'. Peer-reviewed articles including original articles, meta-analyses and systematic reviews that were in the English language were analyzed. Compilation of these articles yielded a volume of literature relevant to the understanding the current landscape of congenital cardiac surgery in Europe; that, as well as, the personal experience of the Authors constituted the material of this narrative review. Recommendations on the optimal structure for a congenital cardiac sur-

gery department in Europe¹⁴, published in 2003 were revisited.

Results

Socio-demographic trends in Europe

Europe is an ageing continent¹⁶ affected by variable but altogether decreasing birthrate¹⁷. The current birth rate for Europe in 2024 is 9.805 births per 1000 people, a 0% increase from 2023. It is expected that European birthrate will stabilize at around 9.5 birth per 1000 people producing 0-0.1% population growth until the end of the 21st century¹⁷. Higher sociodemographic index, urbanization and education are the key factors that inversely affect infant mortality and fertility rate¹⁸. Europe traditionally excels in all these aspects and shares the experience of other countries, e.g., China¹⁹ and Japan²⁰ where rapid development of the infrastructure, family planning policies and opening avenues in education for women resulted in a sharp decrease of birthrate and an ageing society.

Birth control strategies and termination of unintended pregnancies are widely available within Europe. Both unintended pregnancy and abortion rate fell in Europe by 54% and 64%, respectively, between periods of 1990-1994 and 2015-2019 (30y)²¹. Owing to multiple factors, e.g., improving social climate and infrastructural environment, better family planning and contraceptives, Eastern Europe witnessed the most dramatic drop of unintended pregnancies by 64% (v 5% in Western Europe) and abortions by 70% (v 1% in Western Europe). Nevertheless, overall termination rate remains high at 65.9% (Eastern Europe) and 38.1% (Western Europe)²¹.

Prevalence and incidence of congenital heart disease (CHD)

Constant live-birth incidence of CHD is around 0.55-1.22%^{22,23}. Factors²⁴ promoting a higher CHD prevalence, e.g., consanguinity²⁵, segregated or generally smaller generative subpopulations, and the lack of termination of pregnancy for fetal abnormality (TOPFA) are uncommon in Europe²⁶. Population demographic studies found close correlation between consanguinity and prevalence of congenital heart disease²⁷⁻²⁹.

Segregated and progressively inbreeding generative subpopulations show an increased CHD prevalence that was demonstrated among subsequent generations of immigrants³⁰. The European Union (EU) allows freedom of movement within its borders. Internal migration among member states (1.5 million; 0.3% in 2021), immigration (1.5 million; 1.1% in 2021), and the 27.3 million (6.1%; 2023) non-EU citizens living in the EU produces multi-ethnicity and it possibly contributes to the mixing of the genetic pools and a larger generative population size³¹.

Antenatal screening has become the standard in countries with higher socio-demographic index, especially in Europe³². Comparison of studies from Denmark²³ and Singapore³³ shows around 70% sensitivity and over 90% specificity for all CHDs, and 93% and 99% for the critical CHD, respectively. TOPFA for major CHD ranges from 57.8% (Denmark) to 92% (Singapore); the divergence could be attributed to socio-cultural values in South-East Asia, where family circumstances, financial burden of treatment, and expected competitiveness in society is a major factor towards TOPFA³³. Antenatal screening appears to result in a 39% decrease in live-birth incidence of major CHD, and it definitely contributes to the transformation of CHD presentation pattern²³.

Outcomes of congenital heart surgery in Europe

First data (2002) from the European Congenital Heart Defects Surgery Database presented

30-days mortality rates of neonates: 17.94%, patients between 1-12 months: 6.41%, and beyond 12 months: 5.58%³⁴. Recent (2024) outcomes of neonatal cardiac surgery show a significant improvement to 5.9% in 30-days mortality³⁵. Nevertheless, neonatal cardiac surgery continues to pose a substantial challenge, particularly for neonates with functionally univentricular physiology and systemic obstruction; database 30-days mortality of modified Norwood-1 procedure is still at 16%³⁵. A higher complexity in the average European CHS case-mix appears to correlate with multidisciplinary expertise, open access to professional services and on a broader scale with infrastructure, and advanced healthcare policies³⁶.

Structure of congenital heart surgery (CHS) in Europe

Based on the authors' personal experience in the professional community, current European CHS activity patterns accumulate into two patient clusters that represent the majority of the case-load. (1) neonates and young infants with high complexity and acuity are candidates for primary complete repair, and (2) on the other end, there is a growing population of adult-CHD (ACHD; grown-up congenital heart: GUCH) patients³ and reoperations². In between these focal groups, complete repairs and staged operations continue. **Figure 1.**

ACHD is a growing, often complex patient population that needs to be centralized, as they require cooperation of pediatric and adult mul-

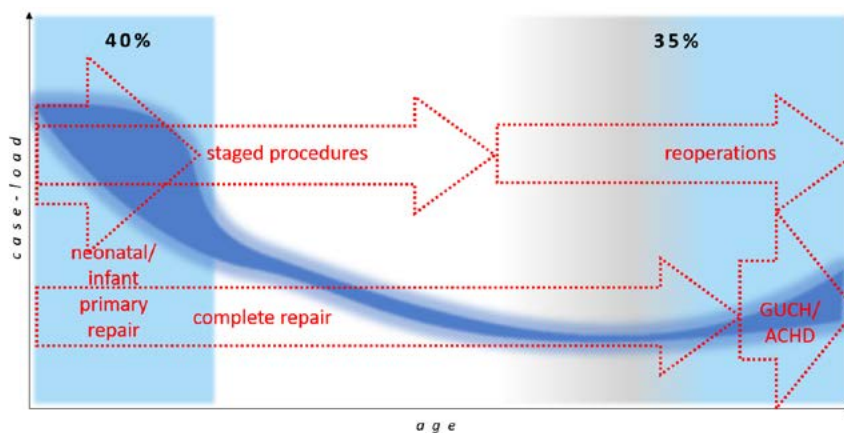


Figure 1. Contemporary CHS service patterns. Abbreviations: ACHD: adult congenital heart disease, GUCH: grown-up congenital heart (disease).

tidisciplinary teams (MDT), and sometimes an input from non-medical professionals, too^{3,8,37}. Most European centers have already set up comprehensive ACHD services³⁷.

Daenen et al. published recommendations for the optimal structure of a congenital heart surgery department in Europe in 2003¹⁴. This seminal document advised about a minimal overall center activity (250 patients operated per year), case-mix and complexity (at least 100 neonates and infants operated per year; availability of ACHD, and concentration of transplantation into

specialized centers). Surgical manpower was stipulated as at least two fully trained surgeons individually performing 125 procedures per annum. A personalized, i.e., patient-centered approach (surgery vs. interventional procedure) for every complex anomaly was proposed in the form of MDT discussion and agreement. The document also formulated estimations about the need for CHS in European countries based on population demographic data. Twenty years onwards, we have updated the demographic statistics and estimations applying the original methodology. **Table 1.** presents the updated and

Table 1. European population and birth rate, estimated CHS need and estimated CHS center activity

Country	Population (million) ^a	Birthrate (1/104pop) ^b	Births (2023) ^b	CHS need (0.4% of births) ^c	Center (No) ^d	New patient/Center/year	130% (staged-reops)
Albania	2.791	1.23	34329	137	1	137	178
Austria	9.12	0.93	84816	339	4	85	111
Belgium	11.738	1.08	126770	507	6	85	111
Bosnia	3.164	0.82	25945	104	1	104	135
Bulgaria	6.757	0.79	53380	214	1	214	278
Croatia	3.875	0.85	32938	132	1	132	172
Czech Republic	10.735	0.98	105203	421	1	421	547
Denmark	5.977	1.13	67540	270	1	270	351
Finland	5.617	1.02	57293	229	1	229	298
France	66.548	1.09	725373	2901	15	193	251
Germany	84.552	0.89	752513	3010	31	97	126
Greece	10.047	0.74	74348	297	2	149	194
Hungary	9.676	0.91	88052	352	1	352	458
Ireland	5.255	1.11	58331	233	1	233	303
Italy	59.342	0.71	421328	1685	22	77	100
Latvia	1.871	0.83	15529	62	1	62	81
Lithuania	2.859	0.89	25445	102	1	102	133
Moldova	3.034	0.84	25486	102	1	102	133
Netherlands	18.228	1.06	193217	773	4	193	251
Norway	5.576	1.04	57990	232	2	116	151
Poland	38.539	0.84	323728	1295	28	46	60
Portugal	10.425	0.8	83400	334	3	111	144
Romania	19.015	0.85	161628	647	4	162	211
Russia	140.82	0.84	1182888	4732	10	473	615
Serbia Montenegro	7.355	1.09	79570	318	2	159	207
Slovakia	5.505	1	55050	220	1	220	286
Slovenia	2.118	0.8	16944	68	1	68	88
Spain	47.91	0.71	340161	1361	15	91	118
Sweden	10.606	1.07	113484	454	2	227	295
Switzerland	8.921	1.01	90102	360	5	72	94
Ukraine	35.661	0.6	213966	856	3	285	371
United Kingdom	69.138	1.08	746690	2987	12	249	324

Adapted and updated from *Daenen et al.*¹⁴. **Methodology notes:** not all reporting centers are full CHS programs; not all CHS centers report to ECHSA Database; no data are available on individual centers' case-mix, caseload, characteristics, and regional roles. **Information sources:** ^a Population demographic data in Europe 2024³⁹. ^b Population demographic data in Europe 2024⁴⁰. ^c UK Cardiothoracic Surgery. SAC and SCTS Workforce report 2019⁶. ^d Centers registered at the European Congenital Heart Surgeons Association Database³⁸.

presumed surgical output of centers registered at the European Congenital Heart Surgeons' Association (ECHSA) Database in 2024³⁸.

It is readily admitted that our extrapolations suffer from possible methodological flaws as not all reporting centers may be full CHS programs; not all CHS centers report to ECHSA Database, and no information is available on individual centers' case-mix, caseload, characteristics, and regional roles; assumptions presented herein only serve as an illustration about CHS landscape in Europe. Furthermore, 'CHS need' column only estimates the annual volume of new CHD patients requiring CHS so, in wanting to estimate a more realistic workload of the program, an additional column was added to tabulate 30% additional surgical volume² of staged operations, reoperation ('130%' column). A review of the original recommendations for the optimal center and regional care structure show that European countries provide adequate coverage for CHD/CHS. Countries with higher socioeconomical index - and/or located closer to the ECHSA Database - seem to have an abundance of centers.

Discussion

Europe is an ever-changing continent of too many, too small countries with wide a variety of traditions and languages¹⁶. The European Union

that now conjoins 60% of Europe's population started as an economic project, based on the freedom of movement of goods, services, people, capital, and data, the artery of the modern economy. However, healthcare remains in the hands of individual member countries⁴¹. Likewise, the congenital cardiac domain is ever changing, and a 'project' once started as a transatlantic cooperation⁴² has become worldwide profession⁴³. However, our profession is rather small in comparison to adult cardiothoracic surgery, let alone adult cardiology, and it is somewhat fragmented by its essentially multidisciplinary nature^{8,9}. Given the high acuity and often high complexity of our work, there are cognitive blind spots¹². Therefore, teamwork, open communication is a must, despite *'marrying teamwork to your own ego is quite difficult at times - and now, we're still learning that'* (WJ Brawn)⁹.

Europe has always been a driver for development in congenital cardiac care and surgery⁴. The following observations and recommendations may contribute to ensure high-quality care and serve to preserve the esteemed status:

Equitable access to specialized care. There are regional disparities in access to congenital cardiac surgery across Europe, with some countries/regions having a high-density of specialized centers. **Figure 2.** is a graphic representation

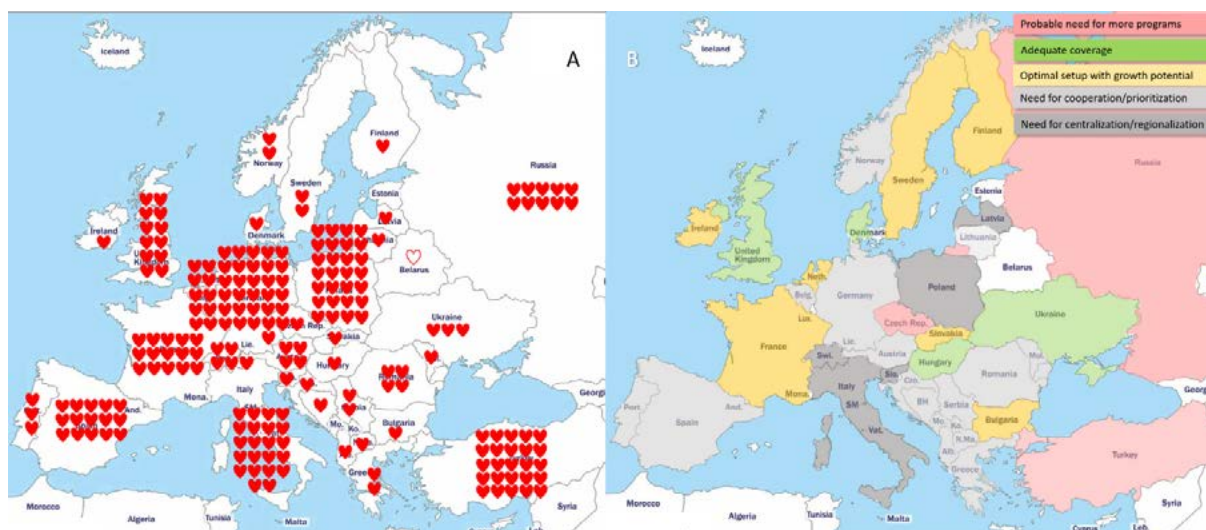


Figure 2. A: Graphic representation of European congenital cardiac centers reporting to the ECHSA Database⁴⁰. **B:** Presumed country performance based on a minimal center requirement of 250 operations per annum. Methodical limitation: not all reporting centers are full CHS programs; not all CHS centers report to ECHSA Database; no data are available on individual centers' case-mix, caseload, characteristics, and regional roles.

of centers in the ECHSA Database on Europe’s map.

Distribution of services may seem unequal in Europe, but overall, it is adequate. Countries with higher socioeconomic index appear with an abundance that results from local traditions, existing infrastructure and knowledge, politics and culture. Combined realization of accessible care, the best possible outcomes and a (financially) sustainable system is demanded by the public, regulator, and the financier.

Higher volumes - where experience ameliorates earlier detection and rescue complications¹² - theoretically offer the best possible outcomes. In pursuing excellence, regionalization is advised for centers with less than 75 operations/year; prioritization between 75-150 operations/year. Centers with an annual output between 150-250 could grow with regional cooperation. Traditionally, smaller programs are divisions of a cardiothoracic surgery department; middle-sized services are situated in children hospital and large supercenters (with a surgical output more than 500 operations per annum) constitute stand-alone congenital cardiac institutes. Supercenters typically embrace strong research and education faculties and they assume roles in professional policy-making on an international level.

Establishing efficient referral systems and centralization of services into larger centers has been repeatedly attempted⁴⁴⁻⁴⁷. Regionalization instead of a mere centralization should be based on professional agreement, e.g., experience sharing and funneling patients towards regional/comprehensive centers in the pursuit for

excellence. Thus, networks should be created that maximize expertise, diminish duplication, minimize impact on access and variation and cut costs. **Table 2.** proposes a cooperation scheme between comprehensive, regional and essential centers in CHS based on the original principles¹⁴.

It is preferred that organic development of comprehensive centers is initiated by local (professional, patient/family, public) forces based on existing infrastructure/knowledge, traditions, culture. Experts on healthcare inequities, and healthcare leadership contribute with financial structure considerations, and arbitration. By applying a balanced, practical approach, reduced access to care should be avoided. CHS regionalization is not for benefitting few/large centers, but for promoting excellence and providing the best possible outcomes⁴⁸.

Training the next generations of congenital cardiac surgeons. Medicine in general, and congenital cardiac surgery in particular, nowadays, may not attract the best candidates for the long training period, increased responsibilities, non-proportional remuneration packages, and work-life imbalance^{49,50}. Limited career opportunities coupled with elevated public expectations on performance and outcomes, and the steep learning curve complicate CHS training in this narrower super-specialty¹⁰. CHS, thus, remains a vocational career path⁴³. Individual and team mentoring, education of trainees at high-volume, high-quality centers, and provisions of continuing coaching appears to be a successful avenue that is increasingly applied⁵¹. A number of European CHS centers are recognized as world-leading

Table 2. Characteristics of proposed congenital cardiac comprehensive, regional centers and essential centers

Care delivery	General principles 2003(14)	Comprehensive center	Essential center
Volume	Over 250 patients operated/year	250+	150+
Case-mix, complexity	Neonatal and infant surgery: over 100/year Specialist MDT for complex ACHD Heart and/or heart-lung transplantation at dedicated centers	Full spectrum of complexities and modalities	Ceiling for complexity Neonatal, transplant activity only in collaboration with comprehensive center
Accessibility	24/7	24/7	24/7
Manpower (surgical)	at least two fully trained surgeons; minimum 125 operations/operator/year	3+	2+: minimum 75 operations/operator/year
Setup	Individualized approach (surgery vs. interventional procedure): every complex anomaly discussed at MDT meeting	Individualized approach (surgery vs. interventional procedure): every complex anomaly discussed at MDT meeting	

education programs offering fellowship opportunities, and attracting trainees from all over the world.

Standardized protocols, continuity-of-care principles can help standardize care through a comprehensive clinical quality assurance program that monitor outcomes. Working groups from the European Society for Cardiothoracic Surgery (EACTS) and ECHSA as well as the Society of Thoracic Surgeons (STS) created a conjoint terminology system, established a risk stratification system, key performance indicators and their respective Congenital Heart Surgery Databases⁵². Convergence of the existing national and European registries for congenital heart disease would help track outcomes and could launch long-term care strategies. Subscription and adherence to the guidelines of one of the international registries is now a criterion of CHS center recognition¹⁴. CHS, dealing with a well-defined patient population, employing transparent and measurable methods naturally offers itself for systematic standardization.

Research and innovation have always been a core signifier of CHS in Europe. The segmental approach in cardiac morphology - championed by *Professor RH Anderson* and the *Leiden school* - is one of the celebrated achievements of European academic research contributed to the world. Increased funding for research initiatives focused on congenital heart defects can lead to innovative surgical techniques and better perioperative care strategies^{10,37}. Professional organizations e.g., ECHSA and EACTS establishing networks, pioneer multicentric projects across countries or even continents can facilitate large-scale studies and the sharing of the best practices³⁶.

Sadly, CHS's market share is low, thus research and innovation does not attract the financial incentives for the healthcare industry. Despite significant efforts and advances, availability of a living and growing bioprosthesis remains unresolved⁵³. This Holy Grail of CHS holds a promise of significant public health impact/benefit as it could profoundly change the outlook of many patients by avoiding repeated reoperations². As new modalities transpire from adult cardiotho-

racic surgery, CHS is now armored with hybrid⁵⁴, endoscopic⁵⁵, robotic⁵⁶ techniques, although they did not fully distribute into the specialty⁵⁷.

As mentioned, CHS is a multidisciplinary effort, however, it extends beyond the clinical team. It involves patient/family support groups, social services and online information resources, educational websites, etc. Providing clear information and resources to families about their child's condition and treatment options can alleviate stress and improve understanding as well as adherence. This is especially crucial with **transition programs** when pediatric patients change over to adult care, as many of them will require ongoing management into adulthood^{3-5,8,37}. Multidisciplinary care teams consisting of cardiologists, surgeons, nurses, nutritionists, and psychologists can provide holistic care for patients and their families⁵. They also form personal connections, build trust. Since Europeans are less prevalent to frequently change residence than e.g., Americans, one may find shining examples for long-term follow-up: *'caring for congenital heart disease is a lifelong commitment'*.

Funding and Resources. Most European countries provide tax-based and/or health insurance through payroll taxes national health services in which access to CHS coverage is a statutory right^{39,41}. In the light of spiraling healthcare costs, advocacy for increased funding from governments and private organizations can enhance resources available for pediatric cardiac care. Investing in the latest surgical technologies, imaging techniques, and postoperative care equipment is necessary for improving surgical outcomes⁵⁷.

Limitations of the study

This review is a snapshot in time and is limited to selected aspects of CHS in Europe. Authors did not have direct access to ECHSA Database.

Conclusion

Europe enjoys an advanced and accessible healthcare system for congenital heart disease. In focusing on quality-of-life rather than just a mere survival, a concentrated collaborative effort seems essential from the multidisciplinary team,

researchers, and policymakers. The profession (CHS) as a modality and practice is heterogeneous, its organization evolving. Its progress happens in front of the colorful socio-economic-demographic landscape of Europe. This landscape thrives on deep cultural roots, intellectual achievements, current economic and political turmoil. Despite the traditional fragmentation, Europe has always had the potential to unite and rejuvenate as the Welsh poet, *Sheenagh Pugh* put it⁵⁸:

*Sometimes things don't go after all,
From bad to worse. Some years, muscadel
Faces down the frost. Green thrives. The crops
don't fail,
Sometimes a man aims high, and all goes well.*
(from Sometimes)

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Institutional Review Board Statement: Ethical review and approval were waived for this study for it reviews describes well established and accustomed surgical techniques and policies, published in relevant literature, and for the fact that the current study does not involve humans or animals.

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