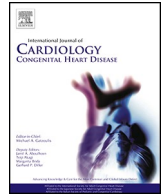




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Surgical management of adults with congenital heart disease in Serbia: A pilot model

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ABSTRACT

Background: In 2014 a professional collaboration was established between IRCCS Policlinico San Donato, Milan, Italy (PSD) and the Institute for Cardiovascular Disease Dedinje, Belgrade, Serbia (ICDD) to support and improve the care of adult patients with congenital heart disease (ACHD) in the country. Since 2018, this collaboration has become more structured, with a specific focus on surgery for adults with complex congenital heart disease (CHD). Aim of the study was to evaluate the outcomes of this collaboration.

Methods: We conducted a retrospective study on all consecutive adult patients (aged over 18 years) with CHD who underwent surgery at the Institute for Cardiovascular Disease Dedinje (ICDD) over a ten-year period, from January 2014 to December 2024. Collected data included number of cases, mean age at surgery, types of surgical procedures performed, number of previous operations, distribution of cases based on complexity, patient outcomes, and follow-up.

Results: Between 2014 and 2024, a total of 244 ACHD patients underwent surgery at ICDD. Eighty-eight of these patients (88/244 = 36%) required complex procedures and were referred to the visiting PSD cardiac surgeon. Mean age at surgery was 34.8 years (± 14 years). The most common diagnosis was right ventricular outflow tract (RVOT) pathology, accounting for 89% of cases. Seventy patients (80%) underwent reoperations following previous procedures. In-hospital mortality was 4.5% (4 patients). No additional deaths or reoperations occurred during a mean follow-up of 58 months (2–122 months).

Conclusions: This ten-year international partnership demonstrates that high-quality ACHD surgical care can be delivered sustainably in countries with limited case volumes and expertise. By combining local access with external specialist support, the model has achieved outcomes comparable to high-volume Western European centres. Increased access to ACHD surgery in their home country and reduced financial burden suggests that this model of care may potentially serve in other countries facing similar healthcare challenges.

1. Introduction

The adult population with congenital heart disease (CHD) continues to grow, with recent data estimating an adult congenital heart disease (ACHD) cohort of 2.3 million patients in Europe, exceeding the

paediatric CHD population of 1.9 million [1–4]. This growing patient demographic has resulted in the establishment of recognized centres in Western and Northern European countries to address the needs of these patients [5–7]. The Working Group on Grown-up Congenital Heart Disease (WG-ACHD) of the European Society of Cardiology (ESC)

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published recommendations on the organization of these centres [5], and subsequently, various institutions have been evaluated regarding structure, activities, dedicated staff, and services offered. However, a recent study by Brida et al. [8] highlighted significant disparities in the Central and South-Eastern European (CESEE) region, where access to ACHD care remains limited due to inadequate infrastructure and considerable disparities between countries. Data on surgical procedures and outcomes in the CESEE region remain scarce [8]. In response to these challenges, a professional collaboration was initiated in 2014 between IRCCS Policlinico San Donato (PSD) in Milan, Italy, and the Institute for Cardiovascular Disease Dedinje (ICDD) in Belgrade, Serbia, focused on ACHD surgery with the goal to support and optimize ACHD outcomes in the region. In Serbia there are two services performing paediatric cardiac surgery, while the ACHD care is provided only at ICDD, where all the adult patients are referred to the ACHD Unit. The collaboration between IRCCS-PSD (Italy) and ICDD (Serbia) involves regular visits of an experienced cardiac surgeon from PSD, to perform the most complex elective ACHD surgeries. This study reports the 10 years outcomes of this collaborative effort.

2. Methods

Retrospective data from the cohort of consecutive ACHD patients operated on at the ICDD between January 2014 and December 2024 were collected, including number of cases, mean age at surgery, type of surgical procedure performed, number of previous operations, perioperative mortality risk using the PEACH score [9], a validated risk score specifically developed for adult congenital heart disease surgery, length of ICU and in-hospital stay, early outcomes and follow-up data. Every 6 months an international multidisciplinary meeting is held at ICDD, where ACHD patients are discussed by both the local and the international cardiology and surgical team.

Procedural complexity was defined pragmatically based on surgical criteria, including redo sternotomy, prior cardiac operations, anatomical complexity (e.g., RVOT reconstruction, TOF re-repair), and requirement for combined or staged procedures. Once the surgical indication was given, the patients were then scheduled for surgery at the local hospital with proctoring by the PSD surgeon.

The study was approved by the local Ethical Committee (n. 5969 of November 18, 2024) and the need for consent was waived due to its retrospective nature and anonymized data.

Adult congenital cardiac surgical procedures were defined as those performed for a cardiac defect present from birth. Bicuspid Aortic Valve (BAV) disease was included up to a maximum age of 35 years, in accordance with the National Congenital Heart Disease Audit in the United Kingdom [10]. Patients with patent foramen ovale (PFO) were excluded.

2.1. Statistical analysis

Statistical analysis was performed using SAS version 9.4 (SAS Institute, Cary, NC, USA). Categorical data are reported as number (%), continuous variables are expressed as mean (standard deviation) or median (interquartile range) in case of normal or non-normal distribution, respectively. Pearson's chi-square test was performed to analyse categorical variables, Student's t-test for comparison between continuous, normally distributed variables, and non-parametric tests for assessment of continuous, non-normally distributed variables. A p value < 0.05 was considered significant.

3. Results

Between 2014 and 2024 a total of 244 ACHD patients underwent surgery at ICDD. Eighty-eight of these patients (88/244 = 36%) required complex procedures and were referred to the visiting PSD cardiac surgeon, while the others were operated on by the local team. The 88

complex patients are the subject of this study.

Mean age at surgery was 34.8 years (± 14 years). Baseline characteristics and surgical data are summarized in Table 1. Pathology of the right ventricular outflow tract (RVOT) was the most common (89%), including n = 70 surgical pulmonary valve implantations (PVI) and n = 8 Tetralogy of Fallot repairs. Thirty-one patients (35%) required additional associated surgical procedures (Table 1). 70 patients (80%) had undergone previous cardiac surgeries, with the median number of previous cardiac surgeries being 1 (mean 1.33) (Fig. 1).

Patients were stratified according to the PEACH score to assess perioperative mortality risk [9,11]. Most patients had low or intermediate risk (85/88 = 97%) and only 3 patients (3%) were included in the high-risk category (Fig. 2). Due to the COVID-19 pandemic the project was interrupted in 2020 and 2021 and then resumed in 2022. In-hospital mortality was 4.5 % (n = 4 patients): one patient with Ebstein's anomaly died from cardiac arrhythmia after tricuspid valve replacement on postoperative day seven; one patient with previous TOF repair died from bleeding due to aortic arch rupture at the cannulation site; two patients passed away for low cardiac output syndrome after TOF repair. All deaths occurred during the early period with no adverse outcomes recorded after 2018.

The mean ICU stay was 2.5 days (range 1-22 days). One patient remained 22 days in ICU due to a COVID-19 infection in 2022. The mean in-hospital stay was 8 days (range 5-30 days).

Mean follow-up of 58 months (range 2-122 months) was 99% complete, with yearly clinic appointment and echocardiogram. No late deaths or major adverse cardiovascular events were recorded in this cohort of patients during follow-up.

In the same period 2014-2024, 156 ACHD patients with low PEACH score were operated on by the local team (15 pt/year). Main diagnosis included atrial septal defect closure and mitral valve repair or replacement in patients previously operated for atrioventricular septal defects.

Over the study period, we observed a progressive reduction in the number of ACHD patients referred to Italy for surgical treatment. While complete annual data were not consistently available, this trend was evident from clinical practice and became particularly apparent after 2018. From 2022 onwards, only two patients required surgical treatment in Italy with the support of the National Health Commission: 1 conversion from atrio-pulmonary to extracardiac

Table 1
Baseline characteristics.

Number Of Patients	88
Mean Age	34.8 Years
Female, n (%)	48 (55%)
Surgical Procedures	
Surgical Pulmonary Valve	70 (80%)
Tetralogy Of Fallot Repair	8 (9%)
Aortic Valve Surgery	4 (5%)
Cor Triatriatum Repair	2 (2%)
Mixed TAPVD	1 (1%)
TV Replacement In CCTGA	1 (1%)
Ebstein's Anomaly Repair	1 (1%)
Double Aortic Arch Repair	1 (1%)
Associated Surgical Procedures	
TV Repair	18 (20%)
Residual VSD Closure	6 (7%)
Arrhythmia Surgery	4 (5%)
Aortic Valve Surgery	3 (3%)
MV Repair	2 (2%)
LV Aneurism Removal	1 (1%)
Left PA Patch Enlargement	1 (1%)

Table 1. Baseline clinical and surgical characteristics of the cohort of complex ACHD patients. Abbreviations: TAPVD = total anomalous pulmonary venous drainage; TV = tricuspid valve; CCTGA = congenitally corrected transposition of the great arteries; VSD = ventricular septal defect; MV = mitral valve; LV = left ventricle; PA = pulmonary artery.

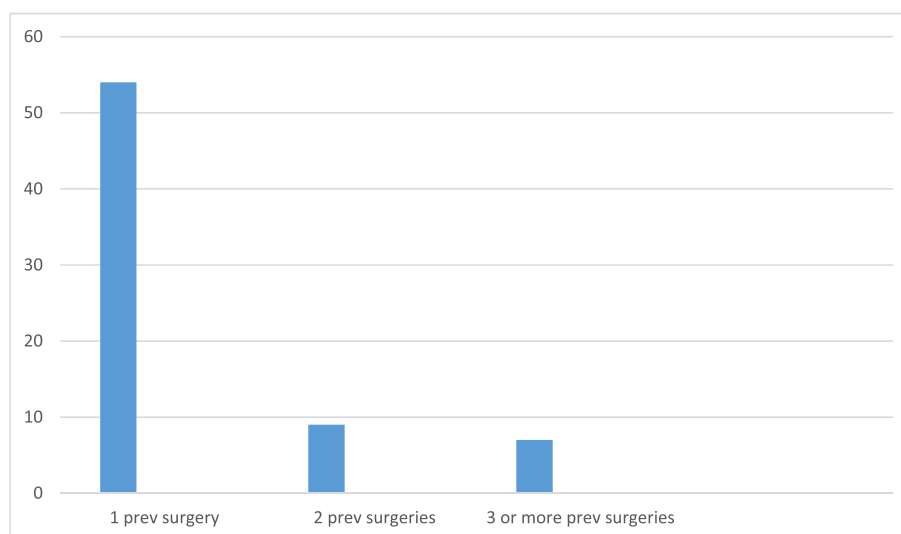


Fig. 1. Number of previous operations (70/88 = 80%).

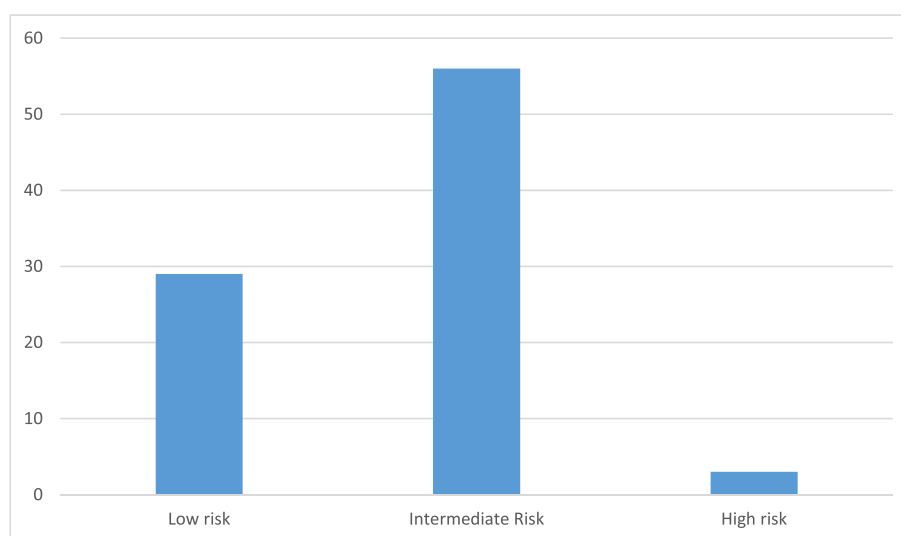


Fig. 2. Risk score for ACHD patients according to PEACH Score.

Fontan, and 1 Bentall operation plus pulmonary artery conduit replacement in multiple previously operated patient with truncus arteriosus. Importantly, patients who currently wish to undergo surgery abroad can do so but with their own financial support

4. Discussion

This retrospective study focuses on the clinical outcomes and surgical results of the partnership between two centres in Europe.

The limited number of surgical procedures performed per year, in line with the few data available in the literature [8], is the result of the demographic characteristics of Serbia, which has 6.6 - 6.7 million inhabitants and a birth rate of 8.9 per thousand and influences the development and autonomy of the centre. The limited number of annual ACHD surgical procedures, especially complex ones, reduces the volume of appropriate cases available to each surgeon and consequently challenges their ability to develop and maintain expertise. The Canadian Cardiovascular Society guidelines for the management of ACHD [11] and the American College of Cardiology/American Heart Association Guidelines for the management of ACHD [12], in fact, indicate that

surgery for congenital patients should be performed by surgeons with considerable training and expertise in congenital heart disease. Data from multiple registries demonstrate that surgery for ACHD performed by expert congenital cardiac surgeons yields better results in terms of mortality, morbidity, in-hospital length of stay, and consequently lower hospital charges [13–15]. The reported 4.5% overall mortality was observed only during the first 4 years of collaboration and is in line with the outcomes published by other specialized ACHD surgical programmes in Western and Northern European countries, which ranges between 1 and 4 % [16–18]. Notably, no deaths were observed after 2018. This improvement over time likely reflects a combination of factors, including increased surgical team experience, improved patient selection, better perioperative and intensive care management, and enhanced coordination between the local and visiting teams.

ACHD patients are becoming increasingly complex, with multiple previous operations and multiple comorbidities. On the other hand, expectations from patients and families are high.

Large volumes of congenital patients appear to be the fundamental factor for a successful surgical program dedicated to ACHD [19]. However, the limited number of ACHD patients requiring surgery hinders the professional growth of cardiac surgeons and reduces the

possibility that they will want to dedicate themselves full time to a complex sector with a limited number of cases. A recently published American study described the burden of training to become a congenital heart surgeon, which is very long, costly and unpredictable [20]. In fact, at least 10 ± 2 years of post-graduate training are required to complete a congenital heart surgery fellowship in a high-volume dedicated training centre [20]. In this context it can be difficult, in a small country, to have a dedicated competent surgeon for ACHD and our experience might represent a potential solution.

Brida et al. [8] provided a comprehensive analysis of the current status, gaps, and needs of ACHD services in the Central and South-Eastern European region (CESEE), highlighting significant disparities in access to care, due to the lack of infrastructures and the profound differences among individual countries. According to this study, in fact, it was found that the limited number and complexity of the procedures performed was in part due to restrictive government reimbursement policies imposing financial caps at hospital level. The paper concluded with the need for greater investments and more well-trained individuals, including dedicated interventional and surgical colleagues.

Undoubtedly, insufficient economic support represents a limiting factor for the development of surgery for ACHD in the CESEE. However, we believe that an additional major limitation is represented by the limited number of patients, their complexity and the need for highly experienced surgeons to achieve results comparable with those reported in the literature.

This study presents a model of collaboration that achieves good surgical outcomes. Patients with a low degree of complexity, in fact, can be operated on by local cardiac surgeons, while the most complex ones, limited in number, should optimally be operated conjointly with an experienced congenital cardiac surgeon in a joint venture. ACHD patients who need surgery can thus be managed in their own countries, reducing the discomfort for the patients and their families. We submit, herewith, that the figure of the visiting surgical consultant, inserted in an already functional and established ACHD unit, can represent a response to a need of care, reducing costs for national systems.

Quoting a previously published motto, even in adult congenital cardiac surgery there is a “need for more Europe for better care” [21].

4.1. Limitations

This study has several limitations. First, it is retrospective in nature and therefore subject to the limitations of observational data collection, including potential selection bias and incomplete data availability.

Second, the analysis was focused on the subgroup of patients undergoing complex procedures within the collaborative program. A direct comparison with patients undergoing less complex procedures was not feasible due to the lack of systematically collected and comparable data in this group, as these patients were managed independently by the local team.

Third, detailed information on postoperative complications, comorbidities, and functional status (e.g., NYHA class) was not consistently available for all patients and could therefore not be included in the analysis.

Finally, this study reflects the experience of a single collaborative model between two centres and may not be fully generalizable to other healthcare systems with different organizational structures or resources.

5. Conclusions

In countries with a limited annual volume of ACHD surgical procedures, especially complex ones, surgeons often have insufficient case exposure to fully develop and maintain advanced ACHD surgical expertise. To address this, a professional collaboration was initiated in 2014 between IRCCS Policlinico San Donato (PSD) in Milan, Italy, and the Institute for Cardiovascular Disease Dedinje (ICDD) in Belgrade,

Serbia, focused on ACHD surgery. This ten-year partnership has shown outcomes comparable with high volume Western European ACHD centres, highlighting an alternative approach to ACHD care that may be sustainable in countries with limited resources and expertise. The reduced financial burden and increased convenience for patients receiving treatment in their home country suggest that this model could be successfully replicated in other countries with similar healthcare needs.

CRedit authorship contribution statement

Alessandro Giamberti: Writing – review & editing, Writing – original draft, Validation, Supervision, Conceptualization. **Federica Caldaroni:** Writing – review & editing, Writing – original draft. **Giulia Guglielmi:** Supervision. **Stefan Veljkovic:** Writing – review & editing, Writing – original draft. **Ana Perunicic:** Writing – review & editing, Writing – original draft. **Margarita Brida:** Writing – review & editing, Validation, Supervision, Conceptualization. **Massimo Chessa:** Writing – review & editing, Validation, Supervision, Conceptualization. **Aleksandra Nikolic:** Writing – review & editing, Validation, Supervision, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Prof. Brida and Prof. Chessa serve on the Editorial Board of the journal, but had no involvement with the handling of the paper. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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