

Centralization of Pediatric Heart Surgery in Sweden

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Abstract. In Sweden, which has a population of 8.9 million people, pediatric heart surgery was previously performed in four cities. After a long, difficult process, centralization of pediatric heart surgery to two centers was achieved in 1993. The overall 30-day mortality for open-heart surgery on infants and children of 9.5% before the centralization (1988–1991) was reduced to 1.9% in 1995–1997. A causal relationship between the mortality rates before and after the centralization is impossible to prove. Heart surgery was concentrated to the two centers with the lowest surgical mortality, and the reduction in surgical mortality was observed over a short period of time which makes it likely that the centralization of the surgical activity promoted the improved results. During the later time period the amount of more complex surgery was clearly increased compared to that performed previously.

Key words: Congenital heart surgery — Centralization

The relation between operative mortality after surgery for congenital heart malformations and the number of operations performed has been discussed for many years. Although small units may obtain excellent results, there is evidence that a concentration to larger units is advantageous [1, 3, 5, 7]. In Sweden centralization of pediatric heart surgery (PHS) has been discussed for the past 20 years. A centralization was finally achieved in 1993, and we report the effects of this major change in pediatric cardiac care in Sweden, especially in relation to mortality after surgery. The difficult process of achieving the concentration is also summarized.

Background

Sweden is a relatively large country with an area of 449,690 km², but it is sparsely inhabited with a popula-

tion of 8.9 million people. The majority live in the middle and southern part of the country. In Sweden the 24 different counties have responsibility for medical care, whereas the state has only a supervisory role mediated through the National Board of Health. Specialized medical care is given by university hospitals and pediatric heart surgery was previously performed in four cities; Göteborg, Lund, Stockholm, and Uppsala (Fig. 1). In Göteborg and Stockholm, closed- and open-heart surgery for congenital heart defects was performed in different hospitals, whereas in both Lund and Uppsala all pediatric heart surgery was performed in one hospital.

The Process of Achieving Centralization

Discussions among pediatric heart surgeons and pediatric cardiologists since the early 1980s indicated that a majority thought that a concentration of pediatric heart surgery would improve the surgical results. Initially, a proposal of a “functional” concentration, with the different units specializing in some operations, was put forward but never accepted.

Within the profession, a concentration of pediatric heart surgery to fewer units was accepted, but it was impossible to agree on how to achieve this goal. Therefore, in 1988, the National Board of Health performed a survey of pediatric heart surgery. The survey included surgical results, resources available, arrangement of pediatric cardiology in the various regions, and research at the different centers. It was concluded that a concentration of pediatric heart surgery would be beneficial, and although a one-center model was discussed, a centralization to two centers was proposed, mainly to promote competition. Another argument for a two-center model was to minimize the risks of production disturbances in case of unforeseen events such as nosocomial infections or even the sudden and unexpected incapability of key persons to perform the most demanding surgical proce-

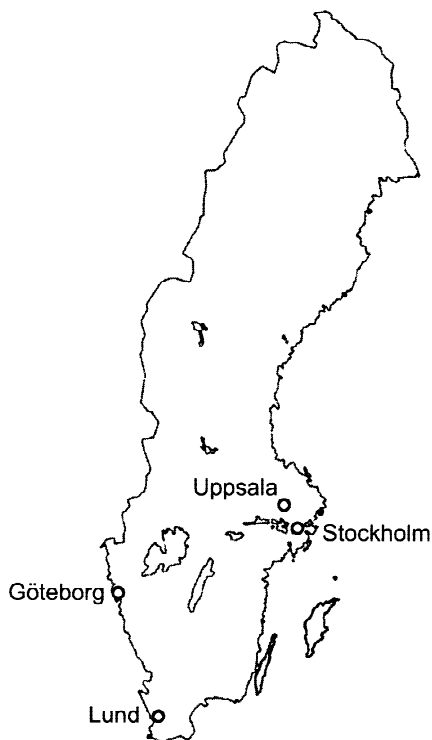


Fig. 1. Map of Sweden with the locations of the original four centers for pediatric heart surgery.

dures. The recommendation created much discussion but failed to change the referring pattern from the local pediatric hospitals. However, in Göteborg and Stockholm, a concentration of all open and closed PHS to one hospital in each city was achieved.

The lack of effect of the previous investigation and recommendation stimulated the National Board of Health to perform a new and more detailed study concentrating on the surgical activities during a 4-year period, 1988–1991. In this study it was agreed to compare 30-day mortality rates of closed- and open-heart surgical procedures, the latter being graded into three levels according to severity (see appendix). Other aspects that were examined were age at surgery, types of procedures, the surgical activity in relation to the size of the population in each region, research activities, and the physical resources of the different hospitals including transportation facilities.

The results of this comprehensive study were published by the National Board of Health in June 1992 [8]. Significant differences in 30-day mortality between the hospitals were demonstrated (Fig. 2). It was recommended that centralization of PHS occur to the two centers with the lowest 30-day mortality (Göteborg and Lund). An agreement was also made between the National Board of Health and the recommended hospitals

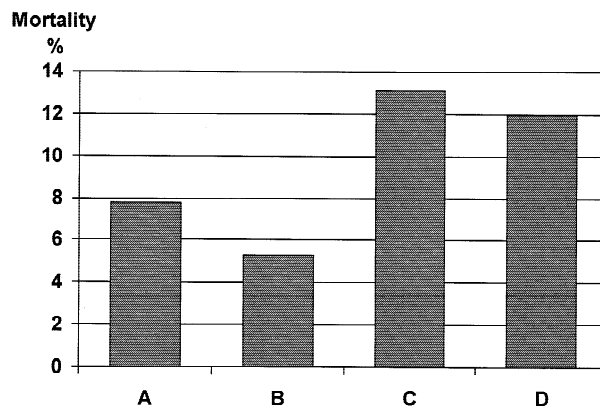


Fig. 2. Thirty-day mortality in pediatric open-heart surgery at the original four centers (A–D) in 1988–1991. The mean number of pediatric open-heart operations/year during this time period was as follows: center A, 93; center B, 80; center C, 92; and center D, 71.

that adequate resources for the increased activity should be provided. Based on the previous failure, it was obvious that the implementation of the recommendation was a crucial issue. Meetings were therefore arranged with the doctors responsible for pediatric cardiac care in the county hospitals; the results of the investigation were presented and special emphasis was placed on the differences in operative mortality between the centers. The pediatricians were reminded of their responsibility for the patients' best interests and that they would decide where to refer them. With some exceptions the pediatric departments started to change their referral patterns to the two recommended hospitals for PHS.

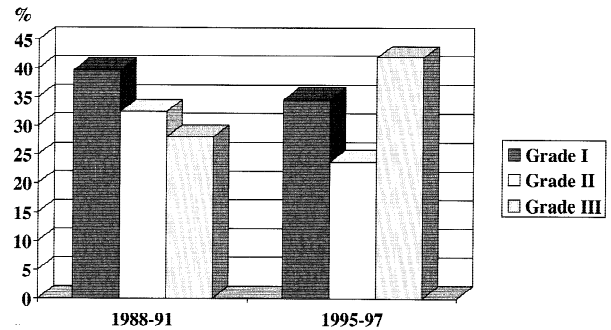
The investigation was criticized because there was no statistically significant difference in mortality if the difference in case mix was taken into account. The National Board of Health therefore decided to perform an additional, more detailed study of the surgical results of the complex lesions (grade II and III procedures; see appendix). These data comprised all grade II and III surgery performed during 1992 and were analyzed by two foreign surgeons who performed a detailed study and also regrouped some of the reported data from the different hospitals. The statistical analysis was also performed by a foreign expert. This additional study on more recent data concluded that there was a statistically significant higher surgical mortality in one of the hospitals. Another hospital had a low operative mortality but the data included few high-risk patients (grade III surgery). The previous recommendation of a concentration of PHS to Göteborg and Lund was reemphasized. As a result of this additional investigation, the hospital with the highest mortality stopped their PHS activity. Since 1993, almost all county hospitals have referred their patients to the two recommended hospitals.

Table 1. Mortality within 30 days after surgery in all pediatric (< 18 years of age) closed- and open-heart operations in Sweden in 1988–1991 and in 1995–1997

Type of surgery	1988–1991	1995–1997
	N(%)	N(%)
Closed	24/885 (2.7)	8/397 (2.0)
Open		
Grade I	13/531 (2.0)	0/476 (0)
Grade II	48/435 (11.0)	1/376 (0.3)
Grade III	67/375 (17.9)	27/615 (4.4)
All open	128/1341 (9.5)	28/1467 (1.9)

Effects of the Concentration of Pediatric Heart Surgery

A change of referral pattern concerning PHS was observed in 1993 and became more marked in 1994. The official statistics of PHS in Sweden during 1995–1997 reveal that 93% of all surgery was performed at the two recommended centers. However, a small number of operations were performed at a third hospital, including mainly less complex cases (closed-heart surgery and group I and group II open-heart surgery). In the years 1988–1991, approximately 550 pediatric heart operations were performed each year in Sweden, with 60% being open-heart procedures. After the centralization (1995–1997), approximately 620 pediatric heart operations were performed each year, with 79% being open-heart procedures. The 30-day mortality after PHS before (1988–1991) and after (1995–1997) the centralization is given in Table 1. The overall mortality rate for open-heart surgery of 9.5% in 1988–1991 was reduced to 1.9% in 1995–1997 ($p < 0.001$). A significant reduction of mortality rates in both group II surgery (11% vs 0.3%, $p < 0.001$) and group III surgery (17.9% vs 4.4%) was found (Table 1). During the process of centralization of PHS a change in the case mix occurred in that more complex surgery was performed (group III surgery) during the latter time period (Fig. 3). The most evident change between the two time periods is that the Norwood surgery for hypoplastic left heart syndrome has been included in the programs of both the recommended centers, whereas this type of surgery was not performed in 1988–1991. The Fontan type of surgery, usually in the form of a total cavopulmonary anastomosis, was performed much more often in 1995–1997. At the beginning of the centralization process, many older children with complex heart disease who had undergone only palliative surgery were reoperated and, in several cases, had corrective surgery. During the time of the centralization the development of interventional catheterization procedures also affected the number of patients referred for surgical treatment.

**Fig. 3.** The proportion (%) of grade I, II, and III pediatric open-heart operations in Sweden in 1988–1991 and in 1995–1997. A mean of 336 open-heart operations/year were performed in Sweden 1988–1991 and 507 open-heart operations/year in 1995–1997.

During the period 1995–1997, 469 catheter interventional procedures were performed, whereas from 1988 to 1991 the only catheter interventions performed in pediatric cardiology were atrial balloon septostomy, balloon dilatation of pulmonary valvular stenosis, and recoarctation.

Discussion

The main focus of this report is on mortality rates during and after the time period when the centralization of PHS occurred. A causal relationship between the significantly reduced mortality rates before and after the centralization is impossible to prove. The concentration was made to the two centers with the lowest surgical mortality and the reduction in surgical mortality was observed over a short period of time, which makes it likely that the concentration of the surgical activity promoted the improved results. A detailed comparison of surgical mortality rates would demand equal selection criteria for surgery. However, it is obvious that more complex surgery, such as surgery for the hypoplastic left heart syndrome and Fontan surgery, is included during the period 1995–1997.

We have not been able to find any published nationwide reports on mortality in PHS. However, two large registers have published surgical mortality data over a long time period: The Society of Cardiothoracic Surgeons of Great Britain and Ireland cardiac surgical register [6] and the German Society for Thoracic and Cardiovascular Surgery cardiac surgery registry in the Federal Republic of Germany [4]. In comparison with data from these two registers (Fig. 4) it can be seen that the mortality in pediatric open-heart surgery in Sweden was reduced significantly. This change occurred during the first year of the centralization of PHS (1993) and has continued during the past years (1995–1997).

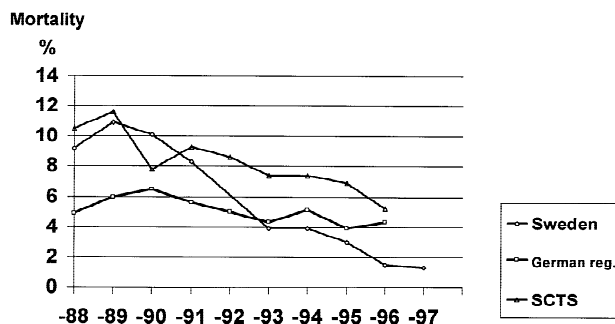


Fig. 4. Thirty-day mortality in pediatric open-heart surgery in Sweden since 1988 compared to data from the cardiac surgical register of the Society of Cardiothoracic Surgeons of Great Britain and Ireland (*SCTS*) and the Federal Republic of Germany register of the German Society for Thoracic and Cardiovascular Surgery (*German reg.*). In the Swedish register data from the year 1992 are missing since the registration in that year comprised only the more complex heart surgery as referred to in the text.

As a consequence of the centralization of PHS in Sweden, major organizational changes both in pediatric cardiac surgery and in pediatric cardiology were promoted. In the two centers with PHS there has been a formation of surgical teams, including anesthesiology and intensive care, that are devoted almost exclusively to pediatric cardiac surgery. This has been beneficial for surgical results but has also resulted in better care of the infants and children and their parents. In addition, the working conditions of pediatric cardiologists and the organization of pediatric cardiology have also changed dramatically. The pediatric cardiology units at the surgical centers have expanded and deal with all aspects of pediatric cardiology. They are also mainly responsible for the national educational program. The pediatric cardiology has also changed markedly at the units that no longer perform PHS. Heart catheterizations are still performed at these units and the preoperative investigations are discussed directly with the surgical team at the center with which they are collaborating. Late postoperative care and follow-up of the patients are also maintained at the units that no longer perform PHS.

The intense discussion about PHS has also increased the interest in pediatric cardiology at the county hospitals. At the centers with PHS, educational positions for pediatricians responsible for the pediatric cardiac care in local hospitals have been created. Not only are new treatment strategies in complex situations more easily adopted but also information about such changes is more easily directed to the local hospitals. The formation of both surgical and cardiology teams in the two centers has promoted an intensified interest in the field and encouraged research activities and facilitated fund-raising for such activities.

Sweden is a large country and the centralization of pediatric cardiac surgery has increased the need for

longer travel distances for the patients and their families. Air transport is necessary more often than it was previously. In a study during a 2-year period no increased risks of air transport could be found compared to ambulance transport [2]. In order to reduce the necessity of transporting the patients for follow-up studies at the two surgical centers, regular outpatient clinics are performed at local hospitals by pediatric cardiologists from the centers that perform PHS. In addition, such clinics promote information and education of young doctors working in the local hospitals.

Throughout the process, the patient and parent organization played a very active role in promoting the centralization of PHS. The efforts of the organization increased as more complex surgery was introduced (i.e., mainly the Fontan surgery). It was clearly stated by the families that surgical results were most important, whereas travel distances and inconveniences were considered less important.

After a long and frustrating period, the centralization of PHS in Sweden has been achieved (since May 1998 all PHS has been performed in the two recommended centers). Efforts to achieve further cardiological and surgical improvements must continue. Studies on long-term results after surgery for PHS are of utmost importance. The improved control of the larger number of patients caused by the organizational changes has facilitated such studies.

Appendix

Grading of pediatric open-heart surgical procedures according to severity:

Grade I surgery: ASD secundum (all types), ASD primum, VSD, pulmonary valve stenosis, aortic valve stenosis (>1 year of age), subvalvular aortic stenosis (>1 year of age), supravalvular aortic stenosis

Grade II surgery: tetralogy of Fallot, VSD and aortic valve stenosis, VSD and pulmonary valve stenosis, VSD and coarctation of the aorta, ASD and partial anomalous pulmonary venous return, single atrium, aortic valve stenosis (<1 year of age), coronary artery fistula, atrioventricular septal defect (complete), tetralogy of Fallot with conduit insertion, double-outlet right ventricle, VSD closure in double discordance, mitral stenosis and/or mitral regurgitation (>1 year of age), tricuspid valvuloplasty, anatomical correction for simple transposition of the great arteries, Mustard or Senning operation

Grade III surgery: (a) bidirectional Glenn, conduit insertion in pulmonary atresia with VSD, conduit correction in double discordance, pulmonary atresia with intact ventricular septum, unifocalization procedures, atrial septectomy, mitral stenosis and/or regurgitation (<1 year of age), total anomalous pulmonary venous return, aortopulmonary window, anomalous coronary

artery from the pulmonary artery, cor triatriatum; (b) Fontan and TCPC operations, complex arterial switch procedures, Rastelli operations, aortic root reconstructions, truncus arteriosus correction, interrupted aortic arch reconstructions, Damus Kay Stansel procedure, atrioventricular septal defect with tetralogy of Fallot; (c) open-heart surgery in premature babies, total anomalous pulmonary venous return in univentricular hearts, unbalanced atrioventricular septal defects, aortic stenosis with hypoplastic left ventricle, hypoplastic left heart syndrome

Acknowledgments. The task of achieving a centralization of pediatric heart surgery and improving the surgical results is the result of efforts of many individuals, particularly pediatric heart surgeons, pediatric cardiologists, and pediatric anesthesiologists. This report has been compiled by the heads of the departments of pediatric heart surgery and pediatric cardiology in Göteborg and Lund together with N.-R. Lundström who initiated this study.

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