

TRANSITION IS THE CHANGE FROM PEDIATRIC MEDICINE TO ADULT MEDICINE BY THE EXAMPLE OF CONGENITAL HEART DISEASE. EPIDEMIOLOGY AND HEALTH CARE

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Owing to significant medical progress in the last decades, at present there are more adults with congenital heart disease (CHD) than children and adolescents. The three cardiac scientific societies — Deutsche Gesellschaft für Kardiologie — DGK (German Society of Cardiology), Deutsche Gesellschaft für Pädiatrische Kardiologie — DGPK (German Society of Pediatric Cardiology) and Deutsche Gesellschaft für Thorax-, Herz- und Gefäßchirurgie — DGTHG (German Society for Thoracic and Cardiovascular Surgery) — have taken this fact into consideration and developed the statement of an integrated medical care of adult patients with CHD, the curriculum of post-doctoral education of pediatric and adult cardiologists and medical guidelines for diagnosis and therapy of CHD patients. The certification of adult CHD physicians and interregional centers of CHD in adults have been started. The approach enables to smooth the transition of CHD patients from children group to adult age group.

Key words: congenital heart disease, adults with CHD, epidemiology, health care, transition.

In March 2011 German Chamber of Doctors held the symposium “Transition” where special requirements for medical care in patients’ transition from children group into adult one were discussed. An example are pediatric cardiology, and a new form of doctors’ advanced training, the doctors being certified in specialty “Cardiology in CHD in adults”, the subject matter of the latter is congenital heart disease (CHD) in adults. The progress in the field of pediatric cardiology and pediatric cardiosurgery, as well as anesthesiology and intensive care has led to the improvement of survival prognosis of children with CHD. Before pediatric cardiology had started developing CHD mortality was about 80% [1], and over the last ten years the epidemiologic situation is the following: total mortality is only 2.2%, early mortality of operated patients — only 6%. C. Wren and J.J. O’Sullivan [2] determined in the North of Great Britain the survival rate among those born between 1985 and 1994, under the age of 16, was 78%, while according to the 32nd Bethesda conference report, survival rate is up to 85% [3]. Thus, there has arisen an entirely new group of patients with corrected CHD, partially corrected or cured by palliative therapy. And these patient having new, unexpected problems are seeking medical advice. And the problems of pediatric cardiology have intertwined with problems of cardiotherapy, general care and other branches, so that the result is to be achieved by interdisciplinary interaction only.

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Epidemiology. The study on CHD prevalence in newborns carried out by A. Lindinger et al. [4] within the framework of “CHD Research Association” has revealed 7245 newborns with CHD in 260 medical institutions of Germany from July 2006 to June 2007. At the time in Germany the number of live-born children was 673282 [5], the prevalence rate of children with CHD amounting to 1.08%, 7245 newborns; and 60% of them had mild form of cardiac defect, 27% — medium form, and 12% — severe heart failure (Table 1). However, mild forms can need operation or palliative treatment (atrial septal defect, patent ductus arteriosus).

There is no data on the number of surgeries in pediatric cardiology in German, but the number of patients operated on for CHD is known. According to Bruckenberg, in 2009 in 37 cardiological centers there were performed 4458 cardiac surgeries on children, and 858 operations — on adults with CHD. Over the last ten years, the number was being varied from 4000 up to 5000 operations a year. And 30-days mortality in newborns was 11.8%, in infants — 5.06%, in other children — 1.93% (the database on congenital heart defects of European Cardiothoracic Surgery Association). Thus, in rough estimating, taking into account the information over the last ten years, the number of survivals with CHD after invasive operation or cardiac surgeries ranges 6500–7000 annually.

Table 1
Epidemiology of congenital heart disease

Germany 31.12.2008.	Prevalence of CHD in newborns (from July 2006 to June 2007)
Population: 81802257	7245 newborns with CHD
665126 newborns in 2009	Prevalence rate of CHD in newborns — 1.08%
Population aged under 15 years 11022600	Mild forms of CHD — 60%
Population aged under 18 years (approximately) 13700000	CHD of medium severity — 27%
	Severe CHD — 12%
	Approximate number of children with CHD over a year, who survived the first year of life — 6500–7000

Table 2
The number of patients with CHD in Germany

CHD	Years of birth	The number of newborns, Mio	Patients with CHD	Survival rate of patients over 18 years, %	Survivals over 18 years
Complex (prevalence rate is 1.5/1000)	1950–1959	10.00	15000	10	1500
	1960–1979	21.18	31770	35	11120
	1980–1989	8.86	13290	50	6645
	1990–1999	8.04	12062	70	8443
Simple (prevalence rate is 4.5/1000)	1950–1959	10.00	45000	90	40500
	1960–1979	21.18	95310	90	85779
	1980–1989	8.86	39870	90	35883
	1990–1999	8.04	36180	95	34371
					Total: 181427
Determination of the number of patients with CHD in Germany: the transfer of empirically obtained data on CHD prevalence in adults in Quebec to Germany (4.09×1000 patients) shows 278500 adults with CHD in Germany in 2009, with total population over 18 years being 68102000 [5, 6].					

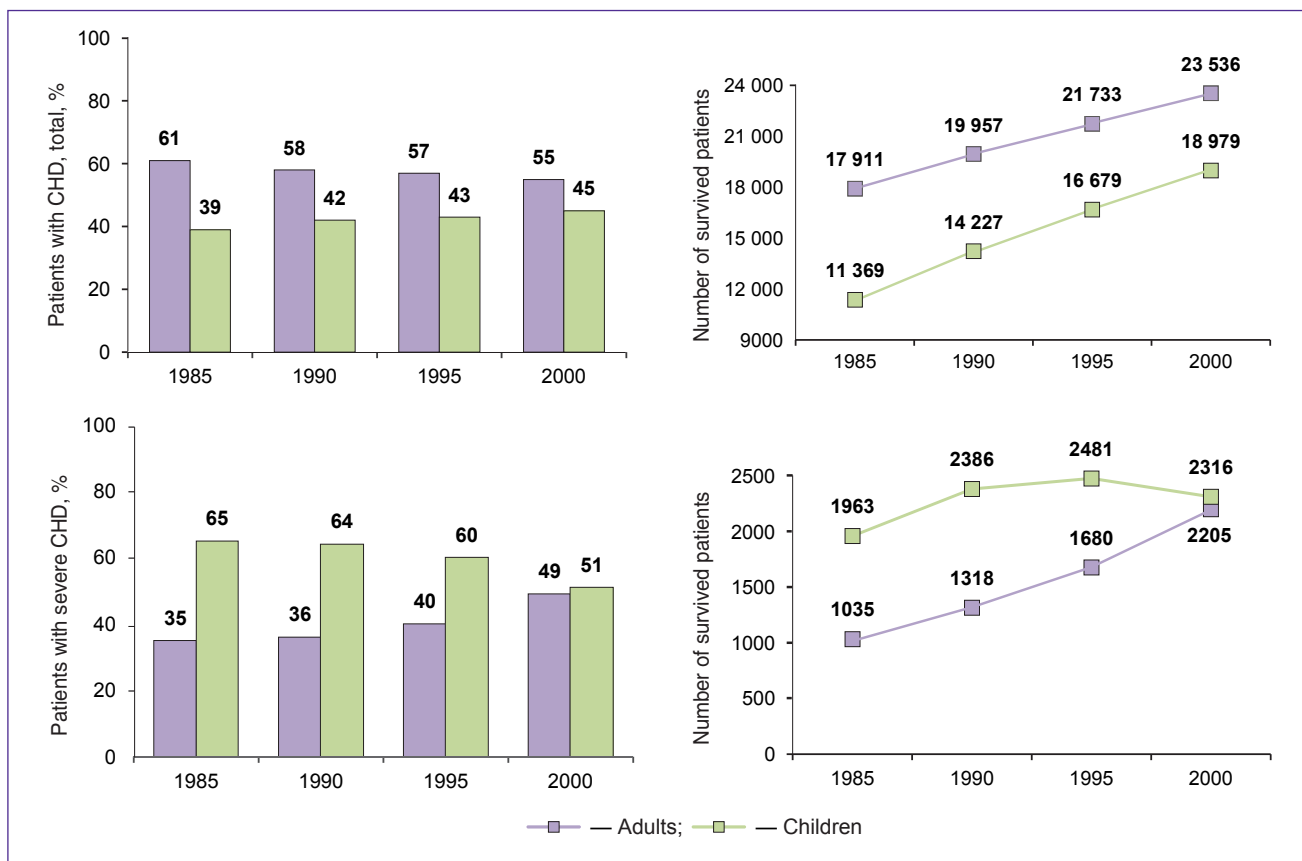


Fig. 1. The number and percentage of adults and children with CHD in Quebec

It is difficult to estimate the number of this group of patients during the previous years in Germany. If we take as basis the 32nd Bethesda conference report and the British Cardiologic Society data on adults with CHD to reveal CHD incidence (mild and severe forms), then the total number of adult patients with CHD in Germany is 181500 (Table 2). If use the data on CHD prevalence in adults recently empirically obtained in Quebec based on complete information from insurance companies and transfer it to Germany, the number of adult patients with CHD will be 278500 [5, 6]. Meanwhile, the number of adults with severe CHD is reaching the number of CHD children. There are even more adults with various forms of CHD than children (Fig. 1). So, the number of patients with CHD is a challenge for health care system, and the latter has to take the challenge. To determine the number of these patients in Germany, in 2003 National Congenital Heart Defects Register was established [7] including all the patients — children and adults with CHD — with their principal data and diagnoses. All attending doctors and conscientious patients should be registered in their region.

Medical support. Who has been treated these patients before? According to the survey of German Society of Pediatric Cardiologists, in 2010 in Germany there were 344 pediatric cardiologists, and 223 of them were doctors of clinics, and 121 doctors having the license for private practice were employed in various organizational structures. For comparison, there are 4003 cardiologists specializing in cardiac diseases in adults, 2722 of them having private practice. So, annually doctors perform 865000 left heart catheterizations. Cardiosurgical treatment is provided in 37 centers, 84.5% of all the operations being performed on infants in 15 centers [8].

The problem is that survived patients with CHD, due to their age, are increasingly not to be followed up by pediatric cardiologists. And the cardiologists concerned with adults' treatment have no CHD expert report.

After Canada in 1998, and USA and Great Britain in 2001 have started elaborating the concept of structural support of adult patients with CHD, in Germany in 2004 three research cardiologic societies — German Cardiologic Society, German Pediatric Cardiologic Society, and German Society of Thoracic and Cardiovascular Surgery — took the challenge. Jointly with the Society of Chief Cardiologists employed in hospital, the Society of Pediatric Cardiologists having private practice, Cardiologists Association with private practice, as well as Public Association of Patients, there was established a special group that elaborated recommendations for quality improvement of interdisciplinary support using qualified cardiologists treating adults and children with CHD, specialized institutions, regional and interregional centers [9], and the recommendations for further education and advanced training of physicians. The working group finally elaborated medical guidelines on diagnosis and treatment of adult patients with CHD [10], the guidelines being based on the principles used by Canadian, American and European scientific societies [11–16].

The recommendations for quality improvement of interdisciplinary support relies mainly on the Canadian model suggesting three-stage base support by general practitioners and regional and interregional centers for adults with CHD (Fig. 2).

The model is based on providing all CHD patients with family doctors due to general practitioners, therapists, pediatricians, who are to guarantee basic support as agreed by regional/interregional centers specialized in treating adults with CHD. Simple cases of heart defects with uneventful clinical course (patent ductus arteriosus, atrial septal defect and a slight ventricular septal defect) can be certainly treated by cardiologists without special qualification in CHD in adults. Complex heart defects (Fallot's tetrad, transposition of great vessels, etc) should be treated by cardiologists with qualification in CHD in adults whether in specialized institutions or in clinic. More serious patients should always be examined in institutions which are in close contact with interregional centers for

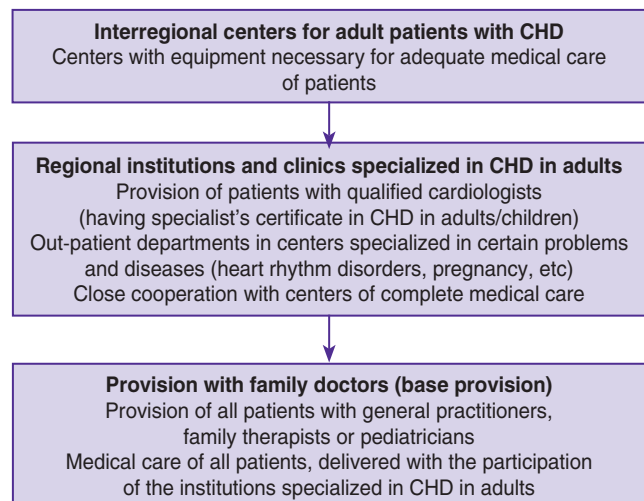


Fig. 2. The structure of medical care of adults with congenital heart disease

Table 3

Requirements for interregional center for adults with CHD: staff composition

Personnel	Number of persons
Cardiologist for CHD in adults	≥1
Pediatric cardiologist	≥1
Electrophysiology expert (complex operations with the assistance of the Centre of Electrophysiological Therapy)	≥1
Cardiologist (in CHD)	≥1
Anesthesiologist	≥1
Imaging specialist (diagnostic imaging expert)	≥1
Nurses/male nurses trained to work in cardiosurgery	if necessary
Psychologist	≥1
Social worker	≥1
Public relations officer	≥1

Table 4

Equipment of interregional centre for adults with CHD [9]

Medical diagnostic equipment
ECG, load ECG, long-term monitoring (daily monitoring ECG, daily measurement of blood pressure, long-term ECG), ergometry, spiroergometry, echocardiogram, conventional radiology, magnetic resonance tomography, computer tomography, scintigraphy
Cardiac catheterization laboratory
Biplanar angiograph for diagnosis and aggressive treatment
The laboratory of electrophysiological therapy and the operating theatre for implantation of pacemakers and defibrillators
Biplanar X-ray and display systems for location diagnosis, ablation
Out-patient department for follow-up of patients with pacemaker and defibrillator
Associated equipment
Cardiosurgical operating theatre (for CHD)

adults with CHD. The center has special requirements for the staff (Table 3) and equipment (Table 4).

Thus, there should always be at least one certified cardiologist to treat adults with CHD and a pediatric cardiologist who can if possible manage the institution together in regard to medical problems. In complex heart defects, heart rhythm disorders emerge to prominence, therefore there should be an electrophysiology expert with appropriate qualification. There should also be present a cardiologist with specialty in CHD surgery, an anesthesiologist, and image specialist (a diagnostic imaging expert). Concerning the equipment, the laboratory for heart catheterization should be equipped by biplanar angiograph enabling to reduce radiation exposure on a patient in complex examination. There should necessarily be cardiac magnetic resonance tomography and the pacemaker laboratory. The certification for obtaining the status of interregional center for CHD in adults through head organizations has just begun. The details of the applications for certification can be found in internet, home pages of German Cardiology Society and German Pediatric Cardiology Society.

As German Chamber of Doctors declined the proposal for introducing subspecialty “Cardiology of CHD in adults”, both scientific societies — of cardiology and pediatric cardiology — within the framework of doctors’ advanced training, developed the training course on CHD in adults. The course can be taken by both: adult cardiologists and pediatric cardiologists. The course provides two-year additional training for pediatric and adult cardiologists in the sphere of CHD cardiology in adults. And a year can be spent for subspecialty training and over a half-year period they are to receive instruction in “parallel cardiology”, i.e., for adult cardiologist — in pediatric cardiology, and for pediatric cardiologists — in adult cardiology. More detailed information is given in the study [17]. On completing the advanced training, a collegial interview is held after which a certificate is given. The certificate of CHD in adults is a unique qualification characteristic. At present (April, 2011) in Germany there are 224 doctors of CHD in adults who have the certificate, and 168 of them are pediatric cardiologists and 56 — children cardiologists. In years past 60 candidates did not fulfill the preliminary requirements and were not admitted to an examination, about 20 doctors did not pass an interview. The information proves that there are no certificates as “gifts” or bought certificates.

A special working group developed Regulation S2 on rational diagnosis and treatment of adult patients with CHD in a clinic and a specialized institution. In the Regulation individual heart defects, in particular, complications of the late postoperative period and the possibilities of their treatment are considered in accordance with the peculiarities of CHD cardiology in adults. The Regulation published both in its abridged version [18], and a full version, as a special publication [10] is a good basis for medical care of patients.

Perspectives. As it was stated, medical assistance to adult patients with CHD is to be delivered by pediatric and adult cardiologists together. In the instructions of Joint Federal Committee in medical insurance agreements according to §116 adults with CHD have not been taken into consideration. Therefore, the doctors with private practice are advised to cooperate with social specialized institutions or medical centers. The rigid boundaries between the fields are declared as unauthorized by the last decision of Federal constitutional court for private medical insurance. Besides, the work of pediatric cardiologists with adult patients is paid at the expense of medical insurance to provide adult patients with qualified medical care near their homes.

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