
Exercise and sports participation after surgery for congenital heart disease: the European perspective

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The success of surgery for congenital heart disease which has been performed since many years has created a population of patients who require careful follow-up in order to determine their clinical progress and to establish the type and intensity of physical activity which they can safely perform.

The authors illustrate the opinion of the European Community regarding children, sport and organizational aspects and also problems concerning the management of pediatric cardiac patients in Europe and Italy. Cardiological and surgical aspects are considered together with the practice of physical activity, with emphasis upon the differences between the various countries. Particular attention is paid to the Italian legislation regarding the certification to participate in competitive or non-competitive sport in such a population of patients. Great importance is given to pediatric cardiac rehabilitation programs which aim at improving the aerobic fitness of patients operated upon for complex congenital heart disease and at illustrating their own cardiovascular limitations so that they can perform physical exercise with the utmost safety.

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The success of surgery for congenital heart disease, which has been performed since many years, has created a population of patients who require careful follow-up in order to determine their clinical progress and to establish the type and intensity of physical activity which they can safely perform. The aim of this study was to illustrate the various modalities by means of which children with heart disease are approached in Europe, with regard to physical activity with particular emphasis upon the differences between the various countries.

Politically, Europe can be viewed as a union of 15 countries allied into a "European Community". However, from a pediatric cardiology and sports point of view, Europe consists of 28 countries, including many from Eastern (i.e. Rumania, Bulgaria, Ukraine), and Northern Europe (i.e. Norway, Iceland). These countries represent very diverse cultures with often different views on the practice of sports during childhood. In the formal group of the European Community, there is a population of 350 million persons while European continent has a population of 550 million persons. In short, Europe is a community of rapidly changing political, social and cultural elements. Much is changing quickly including the efforts of the governments to

create laws that are similar for all countries. In this context, the global perception of sport is the result of often divergent public and personal views. In Northern Europe, the governments are less involved in sports safety and in giving formal permissions for such activities compared to the countries of Southern Europe. The organization of sport in Europe follows a pyramidal model. Sport usually starts from local clubs that organize sports activities for a small geographic area. Traditionally, at this level there are no commercial purposes. On the other hand, profit is one of the purposes of clubs at higher competition levels as, for example, in soccer. Local clubs offer all children in the locality the opportunity to devote time to sports activities thus implementing the idea of sport for everybody and favoring the growth of generations of sportsmen. Above this local level are the regional, national and international sport federations, such as UEFA for soccer¹.

It is generally accepted that physical fitness through exercise is important for the optimal physical and psychosocial development of children and adolescents. Fitness programs for all youths should be recommended and encouraged^{2,3}. Though this recommendation is the norm for all youths, special procedures must be established for

those youngsters with a history of cardiac surgery in whom physical activity may have serious sequelae.

The International Federation of Sports Medicine (FIMS) recommendations establish that, prior to participation in sports programs, detailed medical examinations are required for all participants. However, the conduct of the sport and its instruction are the responsibility of the coach. Therefore, good communication is needed between the coach and the physician so that the exact level of the child's physical activity is understood by both. Moreover, if children are exposed to a wide variety of sports, the rules and duration of physical activities should be appropriate to the age of the participant. For example, excessively long-distance (competitive) running events are not recommended for children prior to maturation⁴.

In 1992, the European Society of Pediatric Cardiology sent a questionnaire to 151 pediatric cardiology centers in Europe. The questionnaire dealt not only with the quantitative aspects of diagnostic procedures and therapeutic measures but also with those regarding the infrastructure and staff, in order to obtain detailed information about the activities and facilities available in European pediatric cardiology practice. The survey resulted in responses from 85% of the centers. Thus, the results can be applied to the whole of Europe. At the time of the survey there were 553 million inhabitants in the whole of Europe. The following numbers of patients with congenital heart disease had been treated: 70 366 in hospital, 378 799 outpatients, 25 939 had been submitted to cardiac surgery, 334 775 had been submitted to echocardiography, 28 145 had been submitted to 24-hour Holter monitoring, and 13 878 had been submitted to exercise testing⁵. The incidence of congenital heart disease in Europe/year varied from 9.1‰⁶ to 7.2‰⁷. More recent data regarding the European population are not available. However, the above data, though partial, indicate that in Europe there are even larger numbers of patients operated upon for congenital heart disease and who are exposed to the risk of delayed exercise-related problems. In recognition of this problem, the European Society of Cardiology plays an important role and organizes working groups for various problematic areas such as the grown-up with congenital heart disease and exercise and psychosocial issues and also sponsors various symposia on congenital heart diseases and sport⁸.

In 1999, our group sent a questionnaire to 70 members of the European Society of Pediatric Cardiology, to 20 members of the European Group of Pediatric Work Physiology and to 29 addresses of members of FIMS. We chose colleagues or institutions who we knew were interested in the evaluation of physical activity in children previously operated upon for congenital heart disease. The data obtained from the questionnaire are original and the authors stress the fact that the first author is a member of the European Group of Pediatric Work Physiology, of the North American

Society of Pediatric Exercise Medicine, of the Italian Society of Sports Cardiology and of the Italian Society of Pediatric Cardiology. Seventy-two percent of the questionnaires were answered. The first question in the questionnaire was related to the incidence of congenital heart disease. It averaged 8‰ for the respondents (range 6.7‰ in Norway to 10.5‰ in Rumania). The second question was about the incidence of sudden death during physical activity in children operated upon for congenital heart disease. The group response was that there were none despite the most recent data in the literature regarding sudden death in this type of patients. Wren⁸ has emphasized that the incidence of sudden death in patients operated for transposition of the great arteries was 5-7‰, for tetralogy of Fallot was 1.5‰ and about 0.1‰ for other cardiac abnormalities. He stated that the risk of sudden death seems to be higher after atrial repair for transposition of the great arteries, probably due to arrhythmias, with atrial flutter being a special problem. The risk of sudden death after repair of tetralogy of Fallot is lower and is declining as more attention is being given to the hemodynamic results of surgery and as any significant residual defects are being dealt with by means of prompt re-operation.

The third question asked the respondents to distinguish physical activity from competitive sport. Eighty-two percent answered yes and 18% said no. We then asked the group to define physical activity for these patients. The group felt that it was active movement at home, during recreation or at school. When asked who was responsible for the child during physical activity, the answers varied. Forty-six percent stated that physician was responsible (France, UK, Germany), 31% said the parents (Scandinavia), and 23% stated that there were no established laws (Belgium). When asked if a physician had to produce a specific certificate of approval, an affirmative answer was given by 63% of respondents. When asked about the credentials of the certifying physician, 38% answered that it could be the family physician, 42% stated that it had to be a specialist, and 20% said that it had to be both. As for the nature of the specialist, 71% replied that it had to be a pediatric cardiologist while 29% said that the certifying physician had to be specialized in sports medicine. In Belgium and in France, for example, a certificate issued by either type of physician was acceptable.

When asked which diagnostic work-up was employed for the ascertainment of fitness before physical activity, 54% included a physical examination, an electrocardiogram at rest, exercise testing and blood pressure measurement. Twenty-six percent added 24-hour Holter monitoring, 14% an echocardiogram, and 6% a chest X-ray. A cycle ergometer or a treadmill was used for exercise testing. It is interesting to note that in Eastern Europe (especially in Rumania), functional dynamic tests (exercise testing and Holter monitoring) were very rarely required.

The final question asked was whether there were any rehabilitation protocols for children after cardiac surgery. The answer was generally no but in some countries (The Netherlands, Macedonia, Romania, Poland, and Norway), supervised physical activity protocols were required.

We shall now focus on one country in order to learn more about the complexity of the problem of sports for children with heart disease. Italy is a country with 57 million people and an area of about 300 000 km², similar to Florida but with a higher population density. Colonna et al.⁹ have found that the incidence of congenital heart disease/year in children is similar to the European average for newborns (8%). In 1995, out of 526 064 newborns in Italy, 4670 presented with congenital heart disease. As in other countries, surgical corrections are usually done when the patients are as young as possible. The global survival rate for patients with cardiac malformations is about 80%. Colonna et al.⁹ further showed that 40% were submitted to cardiac surgery or other interventional procedures during the first year of life whereas 40% were operated upon later. In 20% of cases, re-operation or else cardiac surgery performed in sequential stages was necessary. About 5000 patients/year are thus submitted to either cardiac surgery or other invasive procedures. In Italy, there are primary, secondary and tertiary pediatric cardiac centers. The tertiary centers are equipped with laboratories for all advanced non-invasive procedures, both prenatal and post-natal, for all hemodynamic procedures necessary for pre- and post-surgical diagnosis and with operating theatres in which major cardiac surgery may be performed. There are formal departments of pediatric cardiac surgery and critical care⁹. In Italy, there are 16 tertiary centers, 9 in Northern Italy, 3 in the central area and 4 in the south. There is a higher concentration of centers in the north where the need is lower in relation to the territorial area. In 1995, in only 9 of the 16 centers had more than 100 diagnostic catheterizations and more than 30 therapeutic interventional procedures been performed. In only 5 centers had more than 200 operative procedures, which is considered to be the minimum for the pediatric cardiac surgeon to remain proficient, been performed¹⁰.

During the years 1992 and 1993, 15 pediatric cardiology centers registered 1445 new patients with congenital heart disease from a population of 341 647 newborns. Thus, the incidence of these congenital cardiac diseases is similar to that of other countries. In particular, it may be observed that the most frequent lesion is the ventricular septal defect while the complex cardiac diseases are less frequent¹¹.

In Italy, the legislation regarding sports and health is very strict. The law defines two kinds of activity, competitive and non-competitive sports. With regard to competitive sport, there is activity performed within a tournament and recognized by a league. This level of sport involves training during the week and games dur-

ing the weekend and necessitates a higher physical and psychological effort by the participant.

Two committees, one of the Italian Society of Sports Cardiology and one of the Italian Society of Pediatric Cardiology, have produced, in the last few years, guidelines for the correct management of these patients in relation to the practice of physical activity, both competitive and non-competitive. In these guidelines, specific recommendations regarding each pathological lesion, the anatomic-functional requirements and the limits on or the indications for the level of physical activity are reported. From a legal point of view, the Italian physicians are responsible, both according to the civil and penal codes, for their clinical assessments and the resulting certificates which have a validity of 1 year. While a certificate for a non-competitive sport can be made by a "family" doctor, for competitive sports evaluation by a certified sports medicine physician is mandatory¹²⁻¹⁵. The reason for this difference is that patients operated upon for so-called "simple" congenital heart disease (atrial septal defect, ostium secundum, ventricular septal defect, aortic coarctation without hypertension or hemodynamic obstruction), often wish to participate in competitive sports and the family physician is fully not trained for adequate assessment of these patients and besides he is not equipped with the instruments which would be necessary for such an evaluation.

According to Italian law, children with congenital heart disease have to be submitted to functional evaluation once yearly. In our experience, for each lesion, at least some specific testing is needed in each case. For example, in patients operated upon for aortic coarctation, we have used exercise testing, echocardiography and in particular 24-hour ambulatory blood pressure monitoring. Each patient is further selected for more detailed evaluation performed using the best diagnostic techniques available for his or her condition, in order to determine the results of cardiac surgery and the possibility of participation in safe physical activity¹⁶⁻¹⁸. The rapid progress in cardiac surgery, the younger age at which it is performed and new techniques such as mini-surgery and interventional catheterization constantly change the natural history of the various cardiac defects. Given this changing arena, it is important to periodically verify that the protocols of functional evaluation are appropriate and to select new and specific approaches for individual lesions with the goal of safe participation in competitive sports.

In children with complex congenital heart disease (tetralogy of Fallot, transposition of the great arteries, etc.), even the most expert heart surgeon cannot completely restore the anatomy of the heart. We have to understand that these patients have been treated but that they have not been cured. It is with this philosophy in mind that the Italian legislation does not permit the practice of competitive sport in these patients¹⁹. In this context, great importance has been given to pediatric

cardiac rehabilitation programs for patients operated upon for congenital heart disease with the aim of improving their aerobic fitness and in order to illustrate their own cardiovascular limitations so that they can achieve the greatest safety during physical activity. However, numerous problems limit these programs, in particular the distance from home to the hospital, the traffic delays and, most important, the family's desire to make the effort that is needed if their child participates in such a rehabilitation program²⁰.

In the United States the laws that regulate the certification for the attitude to competitive sports are completely different when compared to the Italian laws; in fact in Italy the laws are more severe and a greater responsibility is attributed to the physicians: the Italian physicians are responsible both from a civil and penal point of view whereas in the United States the responsibility is only civil and the persons really responsible are the parents. Thus, the physician has only a "counseling" role. This results in a wider view of the concept of permission to practice competitive sports, because we have to consider that the judge's interpretation is not only legal but ever more clinical. We also have to underline the different approach of the United States when compared to the Scandinavian countries and Italy; the legislation of the former is very similar to that of the United States, maybe owing to social and cultural differences with respect to Italy. We must not forget that our duty is to ensure that this population of special patients should have a better future, as it is related to their physical performances, in a manner as safe and fulfilling as possible for each patient.

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