



Newsletter from the Association for European Paediatric Cardiology

Paediatric cardiology: a future model or a shrinking subspecialty

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A FEW CENTURIES AGO, ALMOST THE FULL RANGE of disease was treated by doctors, albeit that surgeons were not then considered to be medical. That was the time before Harvey had recognized the circulation, Koch had identified the causative agent of the tuberculosis, and many more things were unknown. In the second half of the twentieth century, it was major improvements in almost all medical fields that resulted in the presently available technologies. As the quantity and depth of our knowledge increased, so the medical field became divided into smaller and smaller regions. This, of course, carried the risk of practitioners “not distinguishing the forest from the trees”.

The newly formed smaller specialities, however, tended to find each other, and gradually to form new alliances. Thus, the clinical challenges faced daily enforce new collaborations between the medical teams. A few decades ago, neonatal cardiac surgery, or neonatal catheter interventions, were not feasible. Because of this, the contribution of neonatologists and intensivists to the cardiac field was not that large. Nowadays, one-third of our patients are neonates, or small infants, or even those born prior to term. At least two-thirds of our patients undergoing surgery with cardio-pulmonary bypass have their operations below the age of one year. In the earlier times, paediatric cardiologists were content to restrict their activities to children, and did not focus too much on the long-term fortunes of their patients who had already reached adulthood. Indeed, twenty years ago it remained a fact that quite a proportion of those children did not live to become adults. Now, we have realized that adults with congenital cardiac disease require specialized medical care and, paediatric cardiologists need to be involved in their problems. Twenty-five years ago, interventional procedures undertaken in children involved only balloon atrial

septostomy and, apart from pharmacologic therapy, it was the surgeon who exclusively treated our patients. Presently, paediatric interventionists and surgeons have to work “hand-in-hand”, and cooperate in establishing the appropriate therapeutic strategies.

The new team comprising the paediatric cardiologist, surgeon, intensivist, and anaesthetist is already formed, but the involvement of neonatologists and more frequently adult cardiologists, is still required. In addition, newer imaging techniques, and interventional electrophysiology, have been introduced into our practice. These specialities take an ever-growing proportion of our daily activities.

Although the role of the paediatric cardiologists is well determined, it is now obvious that a compact alliance will appear of the different specialties. From the aspect of the Association for European Paediatric Cardiology, it should be realized that greater involvement and representation of our “allied companions” can be nothing but beneficial. Such coherent activity does not necessarily mean fusion of the different associations, but it is often palpable that paediatric cardiac surgeons, and/or paediatric intensivists and anaesthetists may well feel themselves an inferior minority within their respective “mother societies”. It is also obvious that the impact of an alliance of specialties on the decision-makers can result in markedly improved “lobby” activity.

New techniques are constantly introduced into our daily clinical practice. The majority of our techniques were initially used by adult cardiologists, and later adopted to the practice of paediatric cardiology. In spite of the similarities of technique, nonetheless, substantial differences are recognized when the techniques are used in children. The “philosophy” underscoring the procedures are substantially different when used in those of younger age. A good example is the implantation of stents in congenitally malformed

hearts. The size, bodyweight, and age of the patient can significantly change the indications for the procedures. The same is true for the use of different pacemakers in children. "Adult" cardiology, therefore, serves as a large source of these newer modalities. According to that, it is important to maintain continuous contact with our adult colleagues, so that we have access to their newest data and results without unnecessary delay.

It is crucially important that use of the new medical approaches and therapeutic modalities is based on new guidelines representing the consensus of the users. These recommendations and guidelines should be formulated by those who are involved in the specific procedures. It would be a mistake simply to transfer protocols from adult cardiology without modification into paediatric applications. It would also result in a skewed practice. On the other hand, the politicians and economists responsible for making decisions in the medical fields are usually biased towards their financial impacts, often without possessing professional knowledge. Detailed knowledge is essential if the proper decisions are to be made. One of the most important tasks of our Association, therefore, is to formulate and update these recommendations and guidelines, and be ready at any time to put them on the table of the decision-makers.

The question arises, therefore, "how important is the voice of our Association?". We should not overestimate the impact of our small medical field. We need to realize that there are large medical fields with much stronger lobby activities. Hence, we need to emphasize our advantages.

We are growing continuously. Neonatal interventions, and new surgical modalities, have increased the numbers and chances of those surviving. Better results are constantly increasing the number of individuals who are growing up to require proper medical care as adults. This means that our relative proportion and size among other medical fields is also improving, and will continue to improve in the future. If we can structure ourselves in a proper way, and can find allies such as surgeons, intensivists, and anaesthetists, our opinion will be much less likely to be neglected, and our Association will less frequently be bypassed.

Collaboration among the subspecialties already happens more and more, restructuring continuously the entirety of medicine. Everyday demands have forced a very effective and well-functioning alliance between paediatric cardiologists, surgeons, intensivists and anaesthetists, which can serve as a model for other domains, showing the way to improve efficacy. We can now present our Association as a "newly organized body", having strong links to other specialties involved in the treatment and care of patients with congenital cardiac problems. To cement these goals,

we need to convert our association into an "open-type" one, which is willing to admit all those interested in the congenitally malformed heart. Such an acceptance did not come easily. This activity still needs to be dominated by paediatric cardiology, since this is the specialty that links all the others together. On the other hand, we have to formulate again training recommendations as to who should be recognized as a paediatric cardiologist. Universal rules, and internationally applicable requirements, are now necessary for the recognition of the title "European Paediatric Cardiologist". Although "specialty examinations", such as a European diploma, are not yet officially recognized, our Association needs to think about establishing them so as to be prepared for the future demands, to "get ready for the future questions", and to facilitate the restructuring of our field by determining accurately the professional and scientific content of our profession.

Specification of our "rules" requires more and more data, which must be valid and evidence-based. Because of the relatively small numbers of patients and experience in any particular centre or country, when compared with those encountered by adult cardiologists, multicentric studies are likely to be needed to provide the evidence. It still remains questionable whether even such multicentric data can provide sufficiently robust evidence, but this seems to be the only way to reach consensus with regard to almost all the therapeutic measures used in children with cardiac disease. Such evidence is increasingly required from the side of the pharmaceutical companies. There is already the tendency, at least in the United States of America, that all drugs newly introduced for use in children must have supporting data. It may be too idealistic to imagine the universal application of one preferred and particular drug for treatment of a well-defined paediatric cardiological situation. Many drugs already well introduced and used in adult cardiological practice, however, have minimal or no paediatric cardiological reference. In my opinion, it is definitely the duty of our Association, as a professional body, to take the initiative in collecting as much precise scientific data as possible concerning the applicability and efficacy of these new drugs. Once the data are collected, we should then elaborate recommendations for their use in paediatric cardiological practice. It is clear that there is the willingness of the pharmaceutical companies to provide reserved finances to support such studies. So, why not to use them? The same philosophy is true for the devices used in the paediatric cardiac interventions. To my knowledge, although there is undoubtedly competition among different manufacturers on the market, they all support multicentric trials to provide reliable data concerning the use and long-term follow-up of their devices.

Amongst the hardest issues currently encountered in our daily work are the conditions of finances and reimbursement. There are tremendous differences among the various European countries, but in general all complaints are heard in all about the insufficient resources involved. It is not my duty to discuss international, political, financial and geographical differences in the European continent but, at least geographically, the eastern border of Europe is the Ural mountains in Russia. There is a striking difference between the level of health care in the western and eastern parts of the continent thus defined. The difference is much bigger between the parts than that of the differences among the countries making up western Europe. It is not the job of our Association to solve, or even interfere, with the problem of the particular budgets, systems and health care philosophies, but at least this striking difference must be consciously recognized and understood. It is often impossible, and not even applicable, to use the same scale and standards. On the contrary, there are completely opposite examples. Those less privileged countries can sometimes offer solutions and examples that prove also to be useful for the others. Besides, they also exhibit much larger populations of patients. If they can be involved in multicentric studies, the problems of small numbers and lack of evidence may rapidly be solved.

In simple terms, the difference among these parts of Europe can be expressed as the difference in the life expectancies of our patients, living in different countries. Very often, even simple procedures are not feasible in rather large parts of Europe, due to the lack

of facilities and money, and often the lack of specialized knowledge. The latter is a feature that our Association can, and should, influence. Transfer of knowledge and experience is demanded in different ways. It is not only the annual meeting of our Association that should be a forum to share new results and experience, but custom-made and well-tailored projects and training courses should markedly improve the situation. Although it may seem a small field to develop, the large slogan of European collaboration consists precisely of such small fields. If not applied in this fashion, the slogan will remain only words without content.

Once all contributors join forces to treat a sick cardiac patient, and settle in the same camp, the weight of their words and opinions will increase significantly, and therefore their impact in the decision-making processes will be bigger. In turn, that will influence the companies and sponsors to maintain their contribution in our Association.

Taking together all the aspects that I have discussed, it is my preference that our association represents a future model for the evolution of medicine rather than that of a shrinking subspeciality. Only when we are able to achieve the goals I have listed earlier, and spread more widely the recipe of "know-how", can we say that we have taken the largest step since the foundation of our Association.

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