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PAEDIATRIC CARDIAC SURGERY AND EUROPE: TODAY´S SITUATION AND FUTURE ASPECTS

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Abstract

Depending on the definition as geographical entity, economical or political union or as ethical, philosophical or cultural community referring to the historical Occident, the term "Europe" shows a wide spectrum of varieties. This is even true for regional medical systems and quality and structural availability of medical care and so even true for paediatric cardiac surgery.

In western Europe, after decades of steadily improving performance on the base of an all-inclusive social coverage, nowadays for nearly all CHD optimal treatment is guaranteed with low mortality rates and exceptionally good long term results. In (south)eastern Europe still major differences are present: there are regions with good conditions and – on the other side of reality – areas with no or no local care option. While in western Europe today there are too many surgical centres and surgeons with decreasing numbers of patients of native origin, in some regions in south-eastern Europe there is limitation in centres and trained surgeons for comparably more complex and not everywhere completely recorded children (and adults) with CHD.

This presentation is to deal with options in supporting forced development of paediatric cardiac surgical care, especially in south-eastern Europe. Based on own experiences, the considerations will focus on various activities to improve the situation in Bosnia and Herzegovina and neighbouring countries. This analysis will deal with the evaluation of the reasonability of humanitarian projects, the option of cross-border cooperation and the prerequisites for long lasting care systems including the need for clear strategic political decisions within the health and insurance system.

Keywords: paediatric cardiac surgery – humanitarian programme – development

Introduction

"The evolution of congenital heart surgery has reached a point in time when we should extend care to patients in underserviced emerging countries" (Bill Williams,

1). And indeed, there is an immense demand for logistical and medical support: referring to the ratio between population and number of cardiac centres, a global survey in 1999 outlined a significant regional misdistribution of access to paediatric cardiac care: about 75% of human population has very limited or no access to specified cardiac care including surgery (2, 3). There is no good reason to presume an overwhelming progress over the last years. But in addition to manifold efforts in regions concerned, there are numerous organizations and even more small multidisciplinary groups addressing the problems. Although these activities often may be like a drop of water on a hot stone, step by step regional improvements are achieved. This essay is to deal with topics referring to medical management and logistics of a humanitarian project as well as some of our own experiences.

In paediatric cardiac surgery, the last six decades since implementation of the heart-lung machine have witnessed a steadily ongoing improvement in perioperative management, surgical techniques, mortality rates and functional long-term results. In the privileged part of the world – especially Europe, North America, and Australia – nowadays for nearly all congenital heart diseases optimal treatment is guaranteed, most often on the base of an all-inclusive social coverage.

As in other regions with well-developed cardiac care, after long lasting struggle for progress and finally reaching the best possible quality of sophisticated treatment options, even Europe has to face a decrease in need of paediatric cardiac surgery: beside widespread prenatal diagnosis and consecutive liberal abortion, improved perinatal care, progresses in interventional cardiology, and the policy of single-stage early and complete repair have caused a decrease in children needing cardiac surgery and numbers of procedures per child with congenital heart disease (4, 5, 6). As a consequence, in several countries numbers of surgical institutions have been reduced by fusion (6). But still many paediatric cardiac surgery programmes suffer lack in patients and raise their case load by including significant numbers of patients from abroad. Without a doubt, this approach offers a unique chance for children from less privileged countries, thus treated with highest standards. Although this may be of some short-time benefit for specialized centres in question, on long turn this policy just means delaying unavoidable adaptations in medical infrastructures – and no advantage for the patients' underdeveloped home countries.

In this context, definition of "underdeveloped countries" identifies to regions less privileged in paediatric cardiac surgery. The inability to obtain satisfactory cardiac care for children with congenital heart disease is not limited to 3rd World Countries but is a reality even in Europe, namely in some eastern and south-eastern areas (7).

The reason for poor cardiac care is usually multi-factorial, including economical limitations and widespread poverty, limited access to an insufficient health care, poor and aimless governance, corruption, and other obstacles like lack of resources, scarce specifically trained personnel, combined with inadequate equipment and monitoring (8). In the case of the Balkan conflict, the war 1991-1995 did not only change

the geographical, political, and economical landscape: with gained sovereignty of the post-Yugoslavian constituent republics, for patients from some areas the referral pathways were disrupted, the former allocation centres were found located abroad and charging diagnostics and treatments. With political independence, one of these regions is Bosnia and Herzegovina, self-governing but under the supervision of the international community since 1995.

Concepts for delivering paediatric cardiac care in underserviced emerging countries

There are numerous programmes bringing hundreds of children to countries eager to provide cardiac surgery for free (3, 6). This approach is more frequent after catastrophes or wars, but usually of limited duration: similar problems arise elsewhere and thus the focus of interest is put on other regions. Although this reflects a real humanitarian attitude, it is the least favourable option and creates high costs. This approach is of marginal value for the developing country.

Other medical groups travel around offering their expertise to treat children with cardiac disease at regional sites. Even this is of great value for a small number of children in need but usually without lasting effect for the underserviced country as this approach does not include (systematic) teaching and training. This approach is also very common after some disaster. In principle, we agree with the opinion that surgical tourism is not acceptable unless those visiting are truly interested in building capacities of the local medical and surgical teams (9, 10).

In some places, new centres have been established out of nearly nothing pre-existing. This is usually only possible and successful with a powerful acting institution behind and financial resources guaranteed for long-term service.

In recent years, more and more the policy of humanitarian medicine has shifted away from transferring children to some host countries towards taking care of them in their local environment (11). The majority of donor programmes focus on developing an ongoing relationship with a host programme with the primary goal to improve care and increase the number of children receiving adequate care within the region. This relationship involves teaching, training, collaborative research, and donation of equipment. Basically, this "twinning process" results in transfer of knowledge, ideas, and skills to other people (3, 6). Main part of specialized training may occur either at the site or in the specialized centre (6).

In order to avoid wasting of time, energy and financial resources, in planning a programme it is of decisive benefit to identify places where basic requirements already do exist and hopefully receptive individuals in various sub-specialities are available. Important requirements asked for are a paediatrician (cardiologist), some pre-existing institution (clinical unit including operation room) and postoperative care, access to an echocardiography machine and laboratory as well as blood bank. In

establishing a humanitarian institutional development project, the choice of a partner is critical to the success of the programme. Usually the structures of universities meet requirements best possible (6).

The Viennese project "Kinderherzchirurgie Sarajevo – Hilfe zur Selbsthilfe" (Paediatric cardiac surgery Sarajevo – help to self-help)

After a fact-finding mission in 1999, in March 2000 the Viennese team started the humanitarian activities at the University Clinics of post-war Sarajevo. The aim of our developmental project was to train local partners in all professions with professionalism as well as humility, thus striving for the professional standards but accepting all reasonable differences and limitations of the local environment. The final goal was to establish a regional paediatric cardiac surgical centre. The members of the Viennese team are all active in working process at the General Hospital and Medical University of Vienna. Three to four times per year, missions are performed, usually with a schedule for one week. Many members of the team spend their regular weeks of holidays working in Sarajevo (or other sites like Damascus). Even here it proves true that all humanitarian activity depends on the ideals and spirit of individual medical professionals with the skills, experience and confidence to perform teaching and professional activities safely and efficiently, even in an unknown surrounding with limited resources!

However, a humanitarian mission is not for free. At the beginning of our work, every child treated required financial resources in the range of about € 1.500, to cover all expenses for treatment and the visiting team, including disposables for the heart-lung-machine. This funding was possible due to many private spenders and contributions from medical industry. In exceptions, special materials or drugs were much more expensive and had to be covered in addition. Successively costs were taken over by the University Clinics of Sarajevo, thus reducing the average total costs to about € 300 per patient treated these days.

In addition to the direct commitment in Sarajevo, selected key partners from all professions were invited to spend weeks at the University Clinics in Vienna as visitors thus having the opportunity to take part in everyday life of our home-institution and to observe established procedures. Usually these visits were scheduled immediately before our team went to Sarajevo for the next mission.

During the stay in Sarajevo, intramural training was offered to the local team. Therefore, in recruitment of volunteer medical personnel for the teaching and local team, emphasis was laid on highest possible level of qualification and experience. Over the years the structure of our mission team changed according to requirements: only in the beginning a scrub nurse and a pump technician were part of the team until the local peers soon were able to take over full responsibility. At same short phase an interventional cardiologist was included. But technical equipment proved to be insufficient and monitoring in the catheter lab to be dangerous. Therefore interventional

cardiology was stopped for years until the unit moved into a new and well equipped part of the hospital and a revival of interventional cardiology took place in 2011.

Intervals between humanitarian trips were the reason for prolonged learning curve. This demonstrates that an efficient training requires a continuum, but for the Viennese team this was out of reach. As the local team became more and more proficient, it started to perform less complex operations without us being in Bosnia. Even during our stay nowadays about 80% of all procedures are covered by the local team leaving the Viennese team in the position of a supervisor, not active but all the time available to sort out problems arising. Over time, the local medical professionals, in essence, gradually replace their teaching partners.

In cooperation with our counterparts in Sarajevo, we are now in the process of accumulating and evaluating all data for a reviewing study, analysis and following publication.

As we know, teaching surgery is one of the most important responsibilities of an academic surgeon. So in addition to practical clinical training, one of the aims of the programme was to promote academic education: this goal was not only due to the fact, that the paediatric cardio-surgical program was located within the complex of the University Clinics of Sarajevo. In addition, there is no doubt that this emerging field and persons working in cardiac surgery will only have a prosperous future if there is some integration into academic structures. For this, training included clinical practice, administration, and education, but was even encouraging leadership skills and a high sense of ethics and integrity (12). As a highlight, this focus on academic activities has contributed to the fact of one (paediatric) cardiac surgeon being able to defend his thesis with success...

At the beginning, there were some structural and logistic restrictions (such as missing option to wash hands on the PICU), lack in relevant drugs or implants. But these shortcomings were soon solved by adaptations and at each arrival our team imported everything necessary, including disposables for the operating room and intensive care unit as well as pharmacological products and even hardware. Medical equipment at the site was mostly as good as new and donated by humanitarian groups, mostly international. Over the years we were faced with the fact that these products were without maintenance contracts and after eight years in action, nearly all ventilators and even the heart-lung-machine were outdated and suffered life-threatening malfunction at the same time. Since then, major investments have taken place.

If social and economic problems are not solved, it is difficult to ensure that certain groups are not excluded from society and, as one consequence, from access to cardiac surgery. With regard to the realities in Bosnia, still suffering from the war wounds and being a politically divided multiethnic and multi-religious country, as a maxime we offered our help to children from all regions including the people of Roma population.

Without doubt, if any possible there should be only one level of care, whether it is at home or in another country. The well known attitude of hopefully rare surgeons overestimating their abilities "see one – do one – teach one abroad" is dangerous and exceeding the borders of medical ethics by far; same is true working without being familiar and experienced in the specific field of medicine. But with humanitarian missions, the justified claim to equal approach regardless of situation and geographical location is to be evaluated carefully. But sometimes local circumstances promote the decision for palliation instead of primary repair, as well as performing an operation under suboptimal conditions (for example regarding infectious status) instead of waiting a week or two as would be the case in the home-centre. Other dilemmas relate to failure to comply with standards in care, concerns about coercion and consent as well as reusing disposables or exceeding the date of expiration. These decisions are to be made after conscientious medical and ethical consideration taking into account the waiting time until next mission, uneasiness about how the child in question will develop over the next weeks or months until next chance for treatment, the shortness in intensive care capacity, and the substantial mortality in patients left behind still intubated when the team leaves at the end of the stay. The responsibility for patient´s welfare thus may influence decision-making.

As the main goal of our humanitarian mission was helping to establish a paediatric cardio-surgical unit, most of operative capacity was bound to the fact that operations are selected according to suitability within the stepwise progress of the teaching program. As a consequence, during the short stay of the teaching team only few other operations could be included into the workload. In addition, especially at the beginning of our programme, there was an allocation of the scarce resources to patients who were expected most likely to benefit from cardio-surgical procedures. In the first years, patients with low expectation for satisfactory outcome or less expectation for long-term survival were not listed for operation within the humanitarian mission. The need for some triage - meaning to deny treatment for certain patients - is traumatic for both the families and the whole staff.

In literature, performing operations on the last day of the mission is discussed controversially (9, 10). In our opinion and experience this would mean wasting most valuable time as there are too many children awaiting operations. However, it remains an ethical question evaluating the risk for patients still needing substantial care when the visiting team is leaving, knowing about a very high mortality in complex patients left behind. For this reason, our policy has always been to schedule operations on the last day expected to be easy-going with lowest calculated risk, often non-pump-cases.

But there is one problem, underestimated at the beginning of our programme in Sarajevo. There are patients not treatable in the given surrounding (depending on the situation yet improving significantly over the years of cooperation) due to complexity of the underlying disease, missing special implants necessary, or expected to consume too much postoperative capacity for too long, thus blocking the option to

treat other children. And there are children born or diagnosed in the periods between our mission weeks, urgently in need for cardiac surgery or interventional cardiology. Over many years we were covering the need in Sarajevo alone but not able to offer the optimal solution of monthly visits as a reliably organized structure.

In order to solve the medical, ethical, and structural challenge of required evacuation of children from Bosnia to centres abroad, in 2008 an agreement was found between the insurance company responsible for children from the Bosnian federation and our team: if necessary, an evacuation is feasible within three days aiming for one of the four Austrian centres offering paediatric cardiac care. On the base of this agreement, more than 130 children have been treated, mostly in Vienna. All together, about 500 children have been treated this way, either in Sarajevo or in Austria.

Discussion

Compared to specialized centres, there is a series of differences in less privileged regions. There are some fundamental conditions and prerequisites as well as experiences to be taken into consideration before beginning a project

- countries less privileged in the field of cardiac surgery suffer limited infrastructure, human, and material resources.
- rural areas may be medically underserved, poor infrastructure, long and time consuming distances to clinical centres, poverty of families from secluded areas may make coverage of travelling and housing difficult
- patients often present very late with advanced consequences and effects of complex congenital heart defects. This state may be complicated by malnutrition, inappropriate sanitary conditions, and infections as well as – rarely – parasites.
- patients are more often in poor condition, which contributes to increased perioperative risk (13, 14)
- infectious complications contribute significantly to morbidity and mortality
- in underserviced countries, for children who receive cardiac surgery, perioperative mortality and morbidity remain high (8)
- even in relatively well-established centres, basic systems (such as cardiopulmonary resuscitation, reliable blood services, and constant gas supply) are often absent and adequate supplies are rather the exception than the norm (8, 14)
- there is often a fatalistic approach to problems (8, 14)
- financial limitations do not necessarily imply an insufficient medicine
- well-trained and skilful surgeons, while being able to generate excellent results in children, have difficulties reproducing the same kind of outcomes with neonates and infants (3)
- healthcare professionals trained in adult cardiac care may not be able to provide optimal care for neonates and critically ill small infants – they may be afraid of unused dimensions (16).

- WHO and other international organisations decree that facilities and treatments provided by donors to less privileges countries should correspond to the economic realities of those regions (15)
- parallel to development there is a growing need for trained personnel in all subspecialities. This tendency is increased if there is migration from the local cadre to centres abroad. As meagre salaries are one of the underlying reasons, offering better incentives may help
- a team-oriented focus allows all members of the project to have emotional and intellectual ownership in the developing program, thus exploiting the full advantage of each individual team member and it´s professional discipline (16).
- the teaching team has to be composed of specialized and experienced experts in their individual discipline. The teaching and training has to strive for creating a cadre of specially trained professionals.
- as the successful management of children after cardiac surgery is depending on unique requirements, the development of a robust paediatric cardiac intensive care (PCICU) unit is critical to the success of paediatric cardiac programs including heart surgery (16). A well-defined autonomous PCICU with a dedicated multidisciplinary team is to be favoured as with progress of developing there is an increasing demand for experienced personnel. But to keep realistic, often and at least in the starting or upgrading of an institution, a limited resources environment will not allow a specialized facility but an intensive care being part of adult cardiac surgery or even general surgery.
- for intensive care use, a manual as used in most specialized centres worldwide is of highest value in order to streamline the repetitive procedures, although the content should be translated into the local language and adapted to realistic local circumstances.
- out of ignorance of the abilities of the counterparts, the respect they deserve is too often underestimated (13): a humanitarian project will only be successful if the supporting team and the local team view themselves as equal partners.
- a humanitarian project will only be successful if the local partner is active and willing to take over responsibility for the selection of personnel needed and to be trained.
- in medicine, including humanitarian missions, we do not treat numbers but are aiming for best possible results for every individual patient. So for ethical reasons, body count mentality is to be dismissed.
- as to be expected, in a limited resources environment the obviousness of unrestricted equipment and devices as used in the own home institution is not available or possible. This is a fact and has to be changed to the better over time. Most activities are possible with less financial coverage and fewer and less sophisticated tools. Nevertheless, the issue of effective resource utilization and cost containment assumes an overwhelming importance (16). Part of this concept and a question to be answered is the re-use of disposables after appropriate sterilization as experienced in our centres decades ago. Under the light of limited resources, even the choice

of expensive drugs, blood products, or gases such as nitric oxide is to be evaluated according to strict individual indication.

- it seems ideal for a senior member of each of the local sub-specialities to visit a well-established centre and observe the day-to-day functioning of a specialized unit (16). Additional training possibilities offered abroad contribute to improved motivation for engagement and active participation in a program.
- maintaining of accurate records is the fundament for quality control and may help analysing continuously ongoing improvement
- for training reasons, all staff available should be invited to join the daily ward-rounds and should be encouraged to actively contribute to discussions.
- the PICU should be located close to the operating rooms and – if any possible – to the cardiac catheter laboratory. For emergency situations, life support equipment and the access to the operating room (including elevators etc.) have to be guaranteed at any time.
- intra-operatively, accurate closure of the chest with focus on bleeding is mandatory to minimize the necessity for reoperation consuming time, personnel, and even resources due to prolonged postoperative care
- the optimized strategy according to the well known KISS approach (Keep It Simple and Safe) is in principle most favourable: although we did strive for early primary surgical repair even during early infancy or within the newborn period, young age at operation proved an incremental risk factor.
- postoperatively – and suited to the patients profile – the policy of early extubation and fast tracking helps reducing costs, reduces the need for intensive care treatment, offers more capacities for following patients and may decrease the risk of prolonged intubation and catheter-induced infections. As expected, the patients requiring prolonged ventilation after surgery were younger, smaller, and more critically ill than those who met the criterions for early extubation (3)
- with the cooperation between our team and the local one, language barrier was rarely relevant. However, this was a major issue in contact with patients. Many were of very poor and low social origin and, with exceptions, direct communication between our team and parents was on a very low level and we had to rely on translating. Sometimes we got the impression that parents or patients had not fully understood the perioperative risks. Usually this mostly neglected topic was without consequences due to parents frighten but fatalistic attitude.
- a major impairment for developing projects is losing members of the local team after years of training. Although the striving for better financial and social living conditions abroad may be understandable, the waste in resources is aggravated when these persons never return to their home country.
- in limited resources environment some triage is mandatory in order to offer as many children as possible the options of cardiac surgery and at the same time to concentrate on teaching and training
- one should never perform operations abroad that one would not do on one´s own private patients at home (13)

– with the visiting team once in action, there is no time limit of working hours ensured
– opportunities to learn are bilateral

Patients with congenital heart disease are a public health problem in underdeveloped or less privileged countries. Factors such as rate of population growth, inefficient welfare policies, higher hospital costs for high complexity diagnostic and therapeutic procedures, specialist medical training improper for the current and local demands, increasing need for reoperations due to the improvement of surgical outcomes and prolonged survival are limiting the resources even more (17). According to this situation with increasing requirements and last but not least financial demands, several instances have to be involved in a developing process: beside the professionals of the local team and the team from abroad, persons heading the institutions (board of the clinic, head of the hospital), politicians responsible, insurance companies and others not only have to support the project full-heartedly in theories, but must even offer back-up over time and in difficult periods. There has to be a clear consent about the goal to strive for. In our experience, the continuous support of a cardiac programme by public media is most valuable to overcome dissent and problems with officials.

Success in establishing a paediatric cardiac care in a less privileged country by a humanitarian mission is depending on a dedicated team of experienced experts in all sub-disciplines required including teaching ability, good and realistic planning of the project, sustained efforts and perseverance, the competence to accept working in more limited and difficult circumstances without time limit as well as to deal with problems of all kinds. But all of this will not be enough to reach the goal without a collective motivation of local counterparts in all professions and accepting a huge workload even if remuneration is not adequate. In our experience the most important step is taken as soon as members of the local team – who were unenthusiastic at the beginning of the programme – recognize that every single person is important and absolutely necessary for the project and that the program brings advantages not only for the patients but even for themselves: knowledge, sense, and purpose. The cooperation creates a synergy with positive motivation to proceed towards increasing autonomy with good quality in performance and improving therapeutic results.

Unfortunately, there are no humanitarian solutions for humanitarian problems and – due to the complexity that exists in providing paediatric surgical services – a humanitarian solution will only provide palliation at best (3). The development of institutions such as a paediatric cardiac care unit in a region less privileged will only be successful if this process is supported by the national health care systems, local politicians, and governments as well as hospitals and if there is a genuine interest – for whatever reason. It is well known that, unfortunately, not all sites aiming for a paediatric cardiac surgical programme realize the complexity of this wish and the commitment necessary for succeeding (9). Humanitarian missions may demonstrate and underline the demand for cardiac surgery as well as confirming principle

feasibility. In addition, these "pro bono" campaigns can contribute to a developing process and assist and stimulate further progress.

But there is no doubt that in humanitarian medicine there is much room for co-operation rather than competition (3). For that reason we were happy to see the German Heart Centre Berlin organizing an adult cardiac surgery in "our" place in the University Clinics of Sarajevo. And as expected, the more intense surgical program with daily operations has proved to be substantially beneficial for the general skills of the local team. A similar development took place in the field of paediatric cardiac surgery with additional activities of a Swedish team on regular basis. With all this support and substantial contribution, we may expect the local paediatric cardiac care programme to become more and more autonomous with the initiating programmes from abroad assuming a consultant role.

But this is not enough: other areas in the Balkans are without proper solution for the surgical care of children with congenital heart disease. The numerous European centres with humanitarian projects and programmes are asked to contribute in solving this humanitarian demand. And a solution will be even easier with better cooperation and coordination of the humanitarian missions existing. In addition, the areas in question (mostly smaller countries with low population numbers) are well advised to avoid suboptimal and expensive nationalistic solutions but to strengthen cooperation and by this solving similar and comparable problems by establishing supra-regional centres of competence – backed with strong and concerted effort from more privileged European countries.

Individuals and groups supporting counterparts in less privileged regions are not just philanthropists or simply the "good ones". The important work of assisting development is an ethical duty as well. Analysis of European realities over the last decades made it very clear that the now flourishing cardiac surgery in Western Europe was substantially supported by American unselfish help after the World War II. Before this, medical fundamentals were severely damaged. Within a short period of time, help from abroad made possible a rise from ruins till highest standards. Until today many European countries, mainly in the former communist eastern part of our continent suffer poor economic conditions, some even severe socioeconomic consequences after the war in the Balkans, as Bosnia and Herzegovina. Even here the medical fundaments still are very good and help is needed to overcome economic problems and focussed educational and developmental deficits. Similar to the history of nowadays privileged Western Europe, these neighbouring countries today need help to help themselves in recovering ground, lost to fateful circumstances. All of us are part of one Europe: their future is our future (18).

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