

The pediatric cardiac surgery as a philanthropic activity in the country and humanitarian mission abroad

Miguel Angel MALUF¹, Marcos FRANZONI², Eneida MELGAR³, Alfredo HERNANDEZ⁴, Raul PEREZ⁵

According to the World Health Organization (WHO), out of a thousand surviving neonates at least eight present congenital heart diseases. The statistics would not be a problem if all of these children received the proper treatment. Out of the six million children that are born each year in Brazil, about 45 thousand present some type of heart malformation, but around 25 thousand of these are not submitted to surgical intervention. The most crucial thing is that 80% of the cases require operation within the six months of life.

In the statistic data published annually by the National Health Organization (ANS) state that between 6,000 to 7,000 patients undergone surgical intervention in order to correct their cardiac defects each year. These data does not include the fortunate patients who do hold health insurance, operated in hospitals associated to Health Insurance Companies, but, however, they represent a very insignificant number.

This reality shows that due to the fast process of technological development in medicine, the particularity of each patient has become secondary and his disease has become merely a scientific subject. The medical procedures have become, therefore, inhuman.

In the same process, there have been some changes in the medical formation and in the working conditions, increasingly more and more specialized, restricting the availability of physicians for either a contact with the patient or for the search of a more specialized formation.

The actual conditions in Medicine practice have not contributed for the improvement of the relationship between

physicians and patients, as well as for the high quality humanized assistance.

Nowadays, several actions aiming the implementation of humanitarian programs in health institutions have been proposed, especially in the Pediatric Hospital Assistance, where several projects and actions develop activities connected to plastic arts, music, theater, leisure and hobbies.

The current trend of humanitarian actions being carried out in the Institutional and Inter-actional area deserves to be taken into account; as the relationship established between institution-Physicians-Patients.

There are institutions that claim to be already humanized, but in some cases, this so called Humanization applies only to the improvement in the physical structure of the buildings and medical assistance aiming merely tax deduction.

Undoubtedly, they are relevant measures for an institution; nevertheless, they can be merely precise factors unless they are inserted in a complex process of Humanization of Institutional relations.

The considerations about the Assistance Service lead us also to Ethics. As far as Ethics are concerned, they reflect the preoccupation with the consequences of one's conduct upon another.

In order to have ethics prevail it is definitely necessary to have a conscious perception of other individuals. Therefore, if it becomes necessary to perceive others in order to have a Humanizing Assistance, it is safe to say that Humanizing Assistance and Ethics walk hand in hand.

1. Full professor; Associate Professor.
 2. Cardiovascular surgeon. Member of Brazilian Society of Cardiovascular Surgery.
 3. Professor of Pediatric Cardiac Surgery Service of Instituto para la Salud Del Nino, Lima, Peru.

4. Surgeon-in-chief of Pediatric Cardiac Surgery Service of Instituto para la Salud Del Nino, Lima, Peru.
 5. Pediatric cardiologist. Chief of Pediatric Intensive Care Unit of Instituto para la Salud del Nino, Lima, Peru.

The work of a professional, whatever his activity might be, depends either on technical quality or interaction quality. In Medicine, the preoccupation with quality causes each specialty to develop its technical capacities that are part of the Know-how and Relative Abilities in the technical area. For the Interaction Capacitating of the physician, of any specialty, it becomes necessary the instrumentation in order to recognize and deal with the Emotional Aspects of the assistance service, that is, developing attitude.

Humanization is a vast, long and complex process, to which some resistance is still offered because it involves changes in behavior which always arise insecurity. The already established standards seem to be safer, besides the fact that the new ones are not fully developed or currently effective; not having general characteristics; for each professional, group or institution has its own humanizing process. In this process several instances must be involved: professionals of all areas, Directory Board of the institution, politicians, counselors and philanthropic entities.

There are only a few public or private hospitals that offer conditions for a total medical assistance for children, that is, a Pediatric Hospital constituted of equipment and professionals of all specialties. The pediatric assistance loses its characteristics due to long lines in E.R.s, unavailability in ERs, nurseries, ICU, and so on. On the other hand, children in need of transfer to more complex hospitals end up losing their opportunity due to unavailability in hospitals, which in turn contributes for a natural selection of these patients.

These examples allow us to perceive the complexity in the management of the assistance in the pediatric area.

In 1994, our group of pediatric cardiac surgery, based in the Hospital Israelita Albert Einstein (HIAE), was invited by the Board of Pediatric Assistance, to develop a Philanthropic Program for the surgical intervention in children holding heart defects, assisted and followed up by the Institution. Between 1994 and 1999, our group operated 133 patients.

Another experience, although with a less significant number of patients, was performed through the project Atendimiento Multi Asistencial (AMA), of the Hospital Samaritano (HS). Between 2000 e 2003, our group operated 20 patients.

Consequently, with the success of this experience and sensitive with the technical difficulties of our colleagues in the Instituto para la Salud del Niño (ISN) in Lima and the social and economical difficulties of Peru, our group decided to take on this new challenge, beginning Humanitarian Missions at the ISN, where operations for the surgical correction of complex heart diseases would be performed jointly with the help of professionals of our Institution. In these missions there were performed theory and practical

courses aiming the multi-discipline training of professionals. Between 2004 and 2008 there were operated 51 patients.

In the recent gathering of pediatric cardiac surgeons at the *World Summit on Pediatric and Congenital Heart Surgery*, held in Montreal (Canada) in June 2008 [1], it was possible to mobilize Cardiac Surgery Groups and multi-discipline groups of wealthy countries planning to perform humanitarian missions in Third World Countries.

Nowadays, health institutions are increasingly becoming an integrated system, consisting of a number of organizations seeking to harmonize mutual actions: Community / Physician / Hospital, more adequate to the current reality and with no boundaries.

Aiming to participate in Philanthropic Activities and willing to solve drawbacks such as children waiting in long lines for surgical intervention, we decided to assemble a multi-discipline group seeking to give complete assistance to patients and their relatives. Between July 1994 and December 2008, 204 patients holding congenital heart diseases were submitted to surgical correction.

Among the latter, 153 (75%) of these patients were operated under the philanthropic category at the Hospital Israelita Albert Einstein (HIAE) and at the Hospital Samaritano (HS). The remaining 51 (25%) patients were treated at the original Institution: through Humanitarian Missions at the Instituto para la Salud del Niño (ISN), in Lima – Peru.

The patients who underwent surgery ranged from 1 day-old to 18 years-old; in 163 (80%) cases the surgical procedure was being performed for the first time and in 41 (20%) cases consisted of reoperation. In 176 (86.%) patients it was performed surgical correction and in 28 (23.8%) patients, palliative operation.

All patients had clinical evaluation performed by a pediatric cardiologist, who required additional examinations and prepared the post-operative and follow-up of the patients. In all three institutions which participated in the study, the intensive care was performed in the Pediatric ICU and the physicians were also pediatricians.

Patients holding complex heart diseases and referred to surgical intervention, as well as methods and post-operative care were discussed at a meeting of the Specialty aiming the improvement of results.

The cardiac malformations operated belonged to the groups: acyanogenics and cyanogenics, from the simplest such as Persistence of the Arterial Channel (PAC) to the most complex such as Left Heart Hipoplastic Syndrome (LHHS).

The patients results were classified according to the seriousness of their cardiac defects and surgical risk, according to the international rules: Risk Adjustment Congenital Heart Surgery (RACHS) [2]

In the total analysis of results, there were 28 (13.7%)

deaths in the immediate post-operative. As for the results of each institution separately, the numbers are as follows: HIAE: 20 (15%) deaths; HS: one (5.0%) death and ISN: seven (13.7%) deaths.

The statistical analysis (Q2 Pearson), showed that there was no significant statistical difference between the groups ($P=0.137$).

As a consequence of this experience as well as in other Groups [3], we are still engaged in humanitarian programs, now associated to the Instituto para o Desenvolvimento da Saúde do Paciente (IDESP) -- in search of financial resources as well as professionals in order to train all those who are interested in participating in charitable causes.

Patients with congenital heart disease are already a public health problem in underdeveloped countries. Factors such as rate of population growth, inefficient welfare policies, higher hospital costs for high complexity diagnostic and therapeutic procedures, improper specialist medical training for the current demands, increasing need for reoperations due to the improvement of surgical outcomes, which would allow higher survival of patients, currently with cardiologic follow-up of their natural evolution.

Only the multiplication of these philanthropic and humanitarian actions might bring effective mid- and long-term results and hope to minimize this serious social problem.

Although our group, in order to perform our work, had available two different types of institutions: one well structured for the assistance of pediatric patients with

technical, diagnosis and therapy resources, as well as highly qualified professionals (HIAE and HS) and another lacking structural, technical and professional resources (ISN); the final results were quite similar.

Perhaps the good will, dedication, heart and abnegation of the professionals involved, guided by collective motivation that forwarded them to participate in these programs, acted as a kind of synergy in order to achieve results that were no different from one another.

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