

**ESTABLISHMENT OF A NATIONAL PEDIATRIC
AND CONGENITAL CARDIAC SURGERY
CENTER AT THE MEETING POINT OF ORIENT
AND OCCIDENT: EVALUATION OF
PROFESSIONAL AND SOCIOCULTURAL
FACTORS**

Ph.D. thesis

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Introduction

While establishing a new comprehensive tertiary-care program for congenital heart disease (CHD) from neonatal to adolescent age in the multicultural environment of the United Arab Emirates (UAE), many challenges are faced. The chief test is living up to the high patient-expectations to meet contemporary excellent surgical results achieved worldwide. Dealing with patients and families with CHD is a commitment for life as clinical encounters may span from neonatal to adolescent age.

Nouveau richness, abundance on exhibition is a stereotype that is often mentioned in relation with the United Arab Emirates. The country's wealth is based on its rich oil reserves. The exploitation requested mass immigration that increased resident population by a hundredfold over the last fifty years. Birth rate stays on the double of the European (e.g. Hungarian) average, whereas perinatal mortality has decreased to the level of the developed countries. Indigenous Emiratis (15% of the total population) and resident immigrants form segregated population groups where little mixing exists in between. Small and sealed reproductive populations with consanguinity as prevailing tradition would give rise to an increased prevalence of birth anomalies and especially enhance complexity. Religious creeds preclude termination of pregnancy that annuls the point of prenatal screening. Traditionally, Emirati patients were sent abroad for treatment; however, no congenital cardiac modality existed for non-nationals. These aspects necessitated the foundation of a specialized treatment center for CHD.

Immigrants brought their own traditions and cultural traits that amalgamated with local customs on the common basis of Islam. This has resulted in a continuing and fundamentally peaceful multicultural social experiment. Although Islam in the Western media is often associated with news of religious intolerance, fundamentalism and terrorism, it is a way of life for more than 1.5 billion rather peaceful fellow humans. The heart bears core significance in Islamic thinking.

God communicates with the believer through the heart. Beginning and end of life is marked by the commencement and cessation of the heart's activity, respectively.

Modern science regards the heart as an *organ* that solely exists in the physical reality. Our *symbolic* heart, however, - since eternity - is a repository of feelings and emotion, good or bad intentions. Islam does not split the double meaning, so our heart but the brain remains the seat of the soul and conscience. In Islam, our heart acts as an internal sensory organ that observes and links metaphysical spheres with the physical realm.

According to Islam, God created all diseases and He also provided remedies for each of them. Cure is entirely dependant on God's will and grace. This alters the role of physicians and healthcare providers rendering them to mere assistants of treatment. It also bears repercussions on doctor-to-patient relationship and the social status of medical personnel.

In our study - by using management models - we describe an effective organizational setup, team-structure and function. We will characterize the special features of a newly-founded treatment center for congenital cardiac disease with an emphasis on the sociocultural background at the meeting point of Orient and Occident. Institutional setting to house our program is Sheikh Khalifa Medical City (SKMC), a 550-bed government hospital, a principal organization in UAE's healthcare.

Study objective

1. To establish a new, comprehensive, tertiary-, quaternary-care Service for the treatment of congenital heart disease (CHD). Professional, organizational, facility-staff-equipment aspects of the program are systematically evaluated, along with general questions, such as:

- what are the differences between the author’s detailed professional project proposal and the realized project (i.e. implemented Service)?
 - how does the Service fit in the institutional organizational structure and – from a broader perspective – into the healthcare network at national level?
 - to what extent has the Service integrated into the social fabric of local society: social awareness of treatment possibility, acceptance of treatment locally (i.e. rather than abroad)?
2. To identify key performance factors in the Pediatric Cardiac Service’s maintenance and development:
 - do the outcome measures (complexity adjusted mortality/morbidity, key performance indicators (KPIs), length of stay (LOS) measures, etc.) meet expectations and international standards?
 - is the Service sustainable and prone for development?
 - is the Service a financial benefit or hindrance for the institution (SKMC)?
 - are there implicit future potentials in quality assurance and development model we employed for our Service?
 3. Do the sociocultural aspects in the UAE have any effect on the treatment program for CHD? If so, what are these effects?

Methods

Documents and data of the project are utilized as primary sources. Texts of the Qur’an and Hadith are also quoted as primary sources. Scientific literature as well as guidelines is employed as secondary sources. First, a detailed project proposal was submitted followed by the author’s viability study and realization roadmap. The latter proposed estimates for the patient population, outline of the service: patient pathways and continuity of care plan. Next, relevant elements of the organizational structure: facilities (operating room, intensive care unit, cathlab, etc.), equipment and personnel were founded. An international multidisciplinary team led by the author then put into existence the preparatory steps. Quality assurance and development

system was instituted along with KPIs, outcome indicators and benchmarks to monitor care. Having established the necessary facilities, technical interfaces and their respective teams, a full range of pediatric cardiac services was offered from complex neonatal open-heart surgery to grown-up congenital heart care, and all complexities. Special modalities e.g. extracorporeal membrane oxygenation (ECMO), hybrid approach, grown-up congenital heart (GUCH) service, etc. were also launched and pioneered. On-call rota on 24/7 was set up. Continuous quality control and development allowed a feed-back to both daily clinical practice and strategic decisions. Outcomes were compared to data at the International Congenital Database. Our Service was surveyed by external audit in every second year (three times).

Results

The need for a new, comprehensive, tertiary-, quaternary-care Service for the treatment of CHD in the UAE was prompted by the country's rapidly growing population, higher prevalence of CHD and the lack of specialized treatment center. We established full Service to meet these requirements. Continuous audit and outcome review as quality assurance allowed adjustments in organizational and professional care to maintain excellent results.

Since the start of the program in April 2007 to December 2014, 2268 pediatric cardiac operations were performed. Dictated by the special social fabric of the UAE, neonates with higher complexity, requiring urgent interventions have been overrepresented since the start. The neonatal-complex-urgent group enjoyed the same excellent outcome as with other age- and complexity groups. Overall morbidity-mortality outcomes and KPIs met international standards in all aspects. In comparison to the International Congenital Database, we conclude that our Team encountered a casemix of higher complexity and achieved equal or even better survival results. Quality metrics - introduced for local use by the author - have later been justified by international databases and recommendations.

Our Service successfully integrated into the organizational structure of the institution, despite the fact that leadership meanwhile changed its mission policy. SKMC, formerly a flagship hospital of UAE healthcare with numerous tertiary-care modalities was turned into a general hospital model. We consider a sign of flexibility and viability of the pediatric cardiac program that it successfully survived and accommodated to the change of organizational structure and management model. Our Service has gained recognition from local population; Emiratis who otherwise enjoyed a choice of having treatment abroad, would prefer to undergo cardiac operation at our center. Increasing numbers of patient-referrals from all over the country and the region signifies that our Service is regarded as dedicated provider for the treatment of CHD. Transparent insurance schemes, government-sponsored healthcare for most patients resulted in sound finances that is profitable for the institution and local community.

Our Service's special modalities developed with a different pace. ECMO progressed remarkably well and won the status of Extracorporeal Life Support Organization's (ELSO) regional training center. Our GUCH-program necessitated the establishment of a multidisciplinary "heart-team". Critical analysis of outcomes of univentricular patients with initial palliation by using a hybrid approach resulted in a fundamental change of their treatment algorithm.

Application of complexity-adjusted morbidity-mortality, as well as quality metrics allowed continuous feed-back to clinical practice (e.g. for hybrid approach). External audits and comparisons with data from the international database highlighted strengths and weaknesses.

Strategic analysis reveals that our cohesive multidisciplinary team, established clinical pathways are internal, our market-leading position is an external strength. Our Service's weaknesses arise from skeletonized staffing, rapidly changing institutional leadership structure, etc. Our program has the potential to develop into a major

regional center of excellence in our specialty. Inappropriate prioritization, overbureaucracy are regarded as threats to our Service.

We previously suggested that UAE was an ongoing multicultural experiment. We now propose that the country's oil fortune only serves as a basis or starting point for development, and adequate answers for modern economic and cultural challenges are needed in achieving success. Effects of the 2008 world financial crisis in Dubai have highlighted the vulnerability of success. Within a fortnight Dubai drove to the verge of collapse. With substantial federal monetary infusions, economy recovered, however it took five years. We apply the same example to demonstrate the vulnerability of a highly specialized program for pediatric cardiac care.

Rapidly growing population and special characteristics in the social and demographic fabric of the UAE dictated the foundation of a national pediatric cardiac service. Continuous review and audit permits a developing model of care. Initial experience demonstrates that our program as a center of excellence is capable of becoming a national/regional pediatric heart center.

Conclusions

1. We successfully established a brand new, comprehensive treatment center for pediatric and congenital cardiac surgery in the United Arab Emirates (UAE). This Service now offers all therapeutic modalities – excepting for cardiac transplantation - for the entire spectrum of age, from neonates to grown-up congenital heart patients, and for all complexities.
2. We arranged respective elements of the program according to the author's detailed project proposal:
 - We established respective facilities, arranged equipment and recruited staff for major sections of the Service, e.g. OR, ICU, etc.
 - We adopted international standards of quality control and continuous quality improvement.

- Team-work, multidisciplinary approach and a sense of ownership are identified as key factors in creating a learning institution in a multicultural working environment.
3. We achieved clinical results that compare favorably with international database both in terms of outcome and complexity:
 - all KPIs were met at a low rate of complications,
 - we successfully pioneered novel and unique therapeutic modalities, e.g. neonatal primary repairs, hybrid approach for a spectrum of congenital cardiac anomalies, grown-up congenital heart service, extracorporeal life support, etc.,
 4. We successfully integrated the Service into the structure of the institution at hospital level, and the same of the local and national healthcare indicated by:
 - an overrepresentation of Emirati patients in our patient population as a sign of their preference for our services,
 - Health Authority's selection of our Service as one of their center of excellence,
 - a growing numbers of referrals from all over the country as a sign of recognition that our Service is the national provider for congenital heart disease.
 - Due to its transparent financial framework, our Service is a financial asset for the institution, provided that it can perform at its full capacity.
 5. We identify as key aspects and future possibilities for development:
 - a market-leading position has been achieved by offering unparalleled, comprehensive care for congenital heart disease;
 - our program can develop into a treatment center for neighboring pediatric cardiac populations in Oman, Yemen, and the south of Iran, etc., and also a mother institution of affiliated regional centers that provides professional guidance, training of personnel, etc.
 6. Our comprehensive pediatric cardiac program is fundamentally influenced by local socio-demographic factors:

- higher birth rate conjoined with small and segregated population groups, consanguinity and lack of prenatal screening programs translate into a higher prevalence of congenital heart disease, and especially, into higher complexity of anomalies;
 - our cardiac surgical case-mix - already biased towards neonates of high complexity and acuity - is further modified by the effect of outbound patient referrals and inbound surgical tourism;
 - our program enjoys high customer comfort index;
 - a developing service remains vulnerable to the effects of rapidly changing healthcare organizational structures. This effect is more pronounced in the UAE, a country at a meeting point of Occident and Orient, than in countries with firmly established healthcare infrastructure.
7. By assessing geographical, cultural and social aspects of the UAE, we conclude that:
- concepts of Islam about the beginning and end of life and that our body belongs to Allah preclude termination of pregnancy, suicide, and euthanasia. In the UAE, prevailing definition of death as irreversible cessation of the heart's (rather than the brain's) activity prohibits heart transplantation;
 - in Islam, it is Allah who created diseases, and from Him cure emanates for each of them. This perspective regards medical personnel as secular professionals. Decisions pertinent to clinical course are rendered to the family of the patient. Local hospitals follow North-American rather than European patterns in patient-to-healthcare provider relationship.

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