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*RESEARCH ARTICLE*

# CHANGING THE MAP OF CONGENITAL HEART DISEASE PATIENTS SERVICE IN EGYPT AND BEYOND: 25 YEARS OF INTERNAL CHARITABLE OUTREACH

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## *Abstract*

**Background:** Congenital heart disease is a global health problem that disproportionately affects patients from low-income areas. In some developing countries, the ratio of cardiac surgeons to the population is a staggering 1:38 million. The role of internal charitable outreach services is necessary to bridge this gap in patients' care. We assessed 25 years of charitable initiative of internal missions and surgeries conducted by the Egyptian Society for Congenital Disease, from 1996 to 2019 in Egypt, and other areas throughout Africa and the Middle East. The method adopted, involved training local doctors and nurses alongside direct medical service to patients, so that once missions ceased, a functional, reliable, and trusted health care service was left in place.

**Result:** A total of 3910 cases were examined in the time period from July 1996 to Aprip 2019. A total of 1040 patients underwent surgical interventions which started in May 2002. With collaborative efforts of other NGOs, the longevity of the missions was maintained, and reach expanded to several Egyptian governorates and beyond. Through these internal missions, we were able to survey the pervasiveness of congenital heart disease in areas that otherwise were once inaccessible to health care, and through years of advocacy for these patients we have successfully transformed the natural history of congenital heart disease in these areas. These areas are nowadays hubs for the treatment and care of congenital heart disease in Egypt.



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**Conclusions:** Congenital heart disease is a growing health concern in developing areas; the treatment of which is often impeded by disparity and inadequacy of health services. Our style of internal outreach missions in such areas, are necessary to bridge the gap in care in underserved areas. Efforts are needed to ensure the longevity of the influence of these projects; coordination between teams rather than single center attempts may be more effective at achieving necessary goals. Harmonization between local administration and doctors to facilitate learning is essential to increase the impact and trust in the care provided once an NGO leaves.

## Introduction:-

## Background:-

Congenital heart disease (CHD) is an umbrella term that refers to heart defects discovered at birth that may occur as a singularity or in combination; they are the most common birth defects and the leading cause of defects related deaths[1]. Ultimately, surgery is the mainstay treatment of CHD and may be curative, reparative, or palliative, and may include heart transplant[2]. The estimated global prevalence of CHD as of 2017 is 1.8/100 live births (a 4.2% increase since 1990) [3]. In Egypt, CHD is a significant problem. One study examining patients from Cairo University Children's Hospital, the country's largest tertiary and referral center, revealed that of 9379 children referred to their echocardiography unit, CHD was found in 41.9% of them[4].

Gender disparity among Egyptians with CHD is an additional issue[5]. Another study also suggests a significant correlation with CHD and other congenital anomalies in Egyptian patients[6]. According to the Global Burden of Diseases, Injuries, & Risk Factors Study 2017, mortality of CHD in Egyptian children under one year of age from 1990 to 2017 was 68.5-<113.6/ 100 00, and proportion of total infant deaths was 6.7-<9.0%[3]. In order to overcome the burden of CHD, proper allocation of resources to the aim of cost effective strategies of clinical care, and screening are needed, along with tackling socio-economic factors[7]. However, these efforts may be hindered by the extreme maldistribution of cardiac surgeons to the population, where in Africa alone there is 1 cardiac surgeon for every 38 million people[7]. Moreover, according to the World Society for Pediatric and Cardiac Surgery to the Manpower Survey, 75% of the world population has no access to cardiac surgery.

Pediatric cardiac surgical outreach are necessary in the efforts to treat CHD, especially in developing countries, which act as a vehicle to extend the reach of health care to underserved areas[8]. Here, we report on the efforts and results of 25 years of pediatric cardiac internal missions for the treatment of CHD in Egyptian patients and beyond, as well as the experiences we undertook to maintain the longevity of such a project, to the result of improving the natural history of congenital heart disease in these areas.

## Methods:-

This retrospective review was conducted on patients with congenital heart disease who underwent surgical/catheter intervention from the start of this charity service which spanned the time from 1996, and is still ongoing. The start of this initiative was led by a group of doctors and health team workers with a starting goal of surveying areas in Egypt that were virtually untouched by professional cardiac care, to assess the pervasiveness of congenital heart disease in these areas. How the missions worked: We gathered the donating team which included 2 or 3 doctors and echocardiographers, a cardiac surgeon, and one or two social workers. We got in touch with an interested local physician ready to collaborate aiming to serve his patients and learn from the team. The local doctor arranges the most suitable date then a NGO funds the transportation and the accommodation.

In the visited area, we worked in the central hospital, as well as trained all interested doctors and nurses. We suppled medical treatment according to needs. We also supported the patients and their families financially to travel to the site where the operation or catheterization will be done There are 2 methods that could have been adopted 1) CHD patients would need to be transferred along with their families from these underserved and underprivileged areas to metropolitan publically funded or private hospitals – this approach is extremely costly and exhaustive for the patient and family, and 2) the second option was to establish a health care team of volunteers and through these humanitarian outreach missions, and the establishment of a working local service, the needs of these areas could be addressed. We adopted the second approach for the majority of these cases; patients were treated in their local area upon establishment of a reliable service, and or transferred to public/private hospitals when needed. The method of relying on cardiac missions served two purposes 1) it decreased the burden on tertiary metropolitan care areas, on which locals of underserved areas were reliant due to social attitudes or misconceptions about the quality of local care, and 2) provided a framework of trust and care at a more local level to those in need in their available resources.

Our goals were to treat children with CHD by either cardiac surgery or/and cardiac catheter interventions, as well as to share and transfer our knowledge to the local medical staff. This was necessary to build trust the trust of the local peoples in their local service. This was obtained by working hand in hand with the local staff, transferring our skills to them, as well as inviting them back to our centers for further training. Our efforts were aided by collaborative efforts from other national, local, and even international NGOs which allowed for more missions and the general longevity of the project which spanned for a total of 25 years. The aim was to reduce morbidity and mortality of Egyptian children with CHD in underserved areas with limited access to the essential pre – intra – and post-operative care of CHD. Local doctors were invited back to our center for additional training after the development of their hospitals. During these missions we supplied the needed drugs and equipment, as well as, supported financially the transfer of the patients to the hospitals where they will be served.

It was necessary for the mission teams to actively interact with local government and administration to advocate for the health of their patients in order to increase awareness and funding for the treatment of congenital heart disease. A call for community action was needed, which incorporated 1) local health personnel 2) local or national administration/governments, 3) outreach to other NGOs with similar public health interests. Our outreach attempts were able to connect local communities, national government, and even international alliances for the sole cause of addressing CHD in Egyptian patients. Through this integral part of our missions, our reach extended well beyond Egypt to other neighboring countries to include Ethiopia, Syria, Tunisia, Yemen, Sudan, and Palestine.

## Results:-

A total of 4714 patients were examined in the time span from 1996 to 2019 (supplementary tables); 1000 were considered for surgery. 691 underwent cardiac catheter interventions and 309 underwent open surgery privately and 731 surgeries were done in the governmental hospitals (the project of privately sponsored surgeries was started on May 18$^{th}$ 2002. (see table 1).The collaborative efforts of other NGOs allowed for more interventions to be performed during each mission, and the general longevity of the project. The reach of our missions extended to several of Egyptian governorates and beyond including; Luxor, Aswan, Suez, Al-Fayoum, Damietta, El-Sharkia and even the oases (see figure 1). Furthermore, with the national and international recognition of our service, our reach extended even further to include countries such as Yemen, Sudan, Ethiopia, Tunisia, Syria, and Palestine, with either our team alone or in conjunction with other NGOs (see figure 2).

Initially at the start of our practice, we reached out to the parents of CHD children, and tried to convince them to travel to the metropolis, where they can be treated by experts given the lack of resources in their areas. However, this option was limited by the immense financial burden on these families. Moreover, gender-based discrimination within families influenced their decision, as underprivileged families were more likely to use their minimal savings on sons that had CHD, rather than daughters. Comorbidities affecting patients with CHD are also known to disproportionately affect females in Egypt, perhaps for the same reason. The next approach was to extend the reach of doctors, nurses and other health care personnel to these underserved governorates as a part of volunteer cardiac missions for some weeks, on preselected patients. The preferred approach involved collaborative teaching efforts between the visiting team and the local doctors and nurses, so that upon the end of the mission, a functional and improved health service remained in place. This is the model we adopted over the course of the missions and still use.

Community outreach and patient advocacy was able to bring to the attention of underprivileged governorates the points of defects in the service. Attempts were made on their part to overcome these challenges by purchasing well needed equipment to maintain the service, though it may be limited by substantial investment that underprivileged governorates may not be able to support or maintain. Further costs were ameliorated by local buy in of tools and equipment instead of expensive imports. Our once small humanitarian initiative grew to attract the support and cooperation from other organizations such as the Chain of Hope foundation, started by Sir Magdi Yacoub, with whom we have worked for several years and later inspired to permanently establish themselves in the area of Aswan Egypt. The collaborative efforts with other NGOs allowed for larger teams and improved the longevity and impact of these missions.

Additionally, local doctors were invited back to our center to be trained for some months, to be able to serve their patients in their areas after developing their local hospital. Interactions with local government administration were necessary to communicate the impact of our efforts on local families, and the importance of adequate care for CDH children, as well as defects in the service that needed additional support. These outreach attempts motivated their funding and investment of local hospitals to improve their standard of care, as well as the purchasing of new

equipment. The phenomenon of sex related disp. Our success suggests a new method of conducting internal cardiac missions, one where longevity is maintained, trust is established in the local resources, and the natural history of congenital heart disease may be improved. Today stands in the middle of the Egyptian oasis several cardiac catheterization centers and hospitals, in places that were once unreachable.

## Discussion:-

CHD is a public health concern, especially in Africa with up to 500,000 born each year with CHD (figure 3). This burden of CHD is better appreciated by examining this number per million in population, which takes into account the fertility rate of women in each country. Therefore, countries with higher fertility rates will also have more children born with CHD (see figure 4). This burden is further exemplified when considering the age distribution of each population, where in Africa, care of those with CHD falls almost exclusively on those of wage-earning age. Additionally, fertility rate is directly associated with countries with lower per capita income. These factors, along with poor socioeconomic status, greatly impact the provision of suitable care for those with CHD (see Figure 2). It is important to note however, that reports of disease prevalence especially in the case of CHD maybe be subject to survivor bias [9], as those with the more severe condition are likely to die before being diagnosed which can complicate estimations[10].

In Egypt, fertility rates impact the burden of care for CHD patients where governorates with high fertility rates have more children with CHD per wage earner. Worldwide, the burden of supporting CHD patients falls most on countries with higher fertility rates. Additionally, high fertility rates are associated with lower income per capita which increases the disparity[7]. A fertility rate of 8 per woman suggests that the population has to support 4 times as many patients with CHD, as compared to a town with a fertility rate of two[7]. According to data obtained from the World Bank, the fertility rate of Egypt, as of 2017, is 3.37 per woman and rising, while for the rest of North Africa it is 2.89, and Sub-Saharan Africa is 4.693. The proper care of CHD is challenged by many factors including the expensive costs which are further exemplified by additional treatment and hospitalizations, even after the point of surgical treatment. Children with CHD are at risk for infective endocarditis which produces considerable morbidity, and involves costly treatment and hospital delays.

Poverty is considered the greatest barrier for the successful treatment of CHD, as its causes are complex and difficult to remove[7]. Corrupt governance of developing nations allows for the maldistribution of resources. It is important to note that even though many African countries have national hospitals that cover the cost of care, oftentimes additional studies and diagnostics not available in funded hospitals, and may necessitate more costs that prevents the poor patient from seeking care[11]. Additionally, while well experienced surgeons and physicians may work in the public health care system, most doctors are underpaid, and the incentive to leave main cities and work on a volunteer basis in rural areas is low. Care in underserved areas may also be limited by geographic, cultural, and language barriers[11]. When we started our internal missions, there was an alarming deficit of cardiac surgeons in developing areas, especially in Africa (1 cardiac surgeon:38 million)[7], and Egypt was only slightly better but over the past 25 years this ratio has become much narrowed down to 2 cardiac surgeons/ 10 million population. Furthermore, the treatment of CHD either by surgery or catheterization is expensive, though health care costs in developing countries may be much cheaper in terms of care and hospitalizations which may offset this.

There are 3 models proposed by Helwitz and Zilia with cardiac-specific goals in the treatment of CHD in developing countries[7]. The preferred model involves the development of teams that travel to underserved areas that train local doctors, nurses and other healthcare professionals, where upon completion of a mission, a functional medical service is left in place. This strategy however is limited by substantial investments that a host country may be unable to provide and maintain. Additionally, it is unclear whether it is more appropriate and effective to allocate critical resources for the preferential treatment of CHD alone, when other conditions that complicate CHD are often much cheaper and easier to manage (such as antibiotics for infective endocarditis). Congenital anomalies overall account for only 5% of global mortality of children under 5 years of age, while on the other hand diarrheal diseases (17%) and pneumonia (29%) are a more prevalent cause of mortality, and are much easier and cheaper to manage than CHD[7]. These factors may prevent funding bodies and governments from prioritizing CHD treatment on their already limited budgets. We adopted a mission's based approach in dealing with health disparities in our under-served areas.

Medical outreach programs provide a necessary bridge for essential care for those who would otherwise not receive it, in underserved areas. However, they are not without critique, as they require significant funding. Local opinions about missions are also variable. One African study bluntly states that missions tackle the "tip of the iceberg" when addressing medical needs of underserved areas, where the more deeply rooted issue of poverty (the most influential

factor in health disparity) is kept in place by corruption, lack of resources, and lack of education[11]. "Poverty is the root of the problem, and surgery does not address poverty"[11]. Additionally, support for charitable outreach programs requires approval and communication, all the way from staff to the highest levels of local administration and beyond. Four rules have been suggested to enhance the outcomes of medical missions; 1) local buy-in 2) effective mentorship 3) institutional partnerships with local medical schools and university surgical programs, and 4) program continuity[12] . In the current study, we resorted to local buy-in of equipment to ameliorate costs as well as direct communication with local government to help increase the funding for equipment and supplies needed to continue our missions. We provided the necessary learning experiences for local health care personnel, as well as opportunities for additional training in more advanced centers. Support from other NGOs, and local support from governorate administration over the years ensured the continuity and longevity of our missions.

Maintenance of such missions are critical for their impact, long term goals the essential as short-term missions are criticized by their limitations. With regards to Africa, short term medical outreach cannot address the health needs of those in rural areas [13]. One study suggests that it is the lack of health care resources, and not trained physicians, that defines the disparities observed in rural areas. Nevertheless, there is still recognition for the impact of even short-term volunteer medical work, as missions in general provide the accessibility of care to low-income populations. Another interesting critique of healthcare outreach involves patient dependence on the free care[11]. Patients may wait for the next mission to arrive, rather than seek out care themselves. This may prove counterproductive if the NGOs leave and patients are unaware of where to go to find care[14], or if trust in local resources is diminished in the presence of mission services. That is why adopting a model that facilitates the transfer of knowledge to local hospitals and their workers is essential in ensuring the longevity of impact and trust.

Lastly, there is a call to ensure that medical outreach meets an ethical standard[15], and that the volunteering is done to serve the needs of local people and not that of the volunteer team[14]. Recently, there is a growing body of literature on the ethical concerns of medical volunteering, and the need for necessary guidelines. Volunteer medical care should be performed with the following in mind; spirit of solidarity, social justice, equality, and collegial collaboration[14]. Without the inclusion of local doctors and nurses plus the government representatives, the sudden appearance of "unsolicited help", might actually decrease the confidence of the patients in the local system that is attempting to grow and improve itself [1416].

**Based on our 25 years' worth of experience, we suggest the following model for the promotion the longevity and overall success of future congenital heart disease services in underserved areas in Africa and beyond:-**

1) An initial survey of the underserved area to grasp some idea of the disease prevalence, in order to prioritize limited resources to the areas most in need of care.
2) Building trust of the locals in their local care through collegial cooperation – this is paramount to overcome misconceptions of the local people in their neighboring hospitals. It is a common belief that tertiary centers in the capital will provide better care, and many patients' families will skip over other resources that may already be in their area to reach these centers. This is costly and tiresome for the family and patient. Instead, efforts should be made to build trust in the local resources, and this begins with a spirit of cooperation with the visiting team and the local team. A transfer of knowledge and skills is needed to strengthen the service they are able to provide.
3) Maintaining the mentorship : inviting the local teams back to larger centers to maintain the transfer of knowledge and refinement of their skills.
4) Local buy-in:of equipment and tools
5) Outreach to other NGOs: the cooperation of even one more mission team can ensure the longevity of a mission. Efforts should be made to collaborate with other humanitarian medical missions, to maintain longevity.
6) Community outreach: Making sure that the government representatives know the points of weakness in the service provided, and hearing the requirements needed in each governorate visited by our missions increased the distribution of diagnostic equipment like echocardiography machines and Cath Labs provided to the poorest governorates with high burden of CHD. This also allows for the recruitment of young trained doctors to these places. Community outreach and patient advocacy is absolutely necessary and a key factor for the success of our missions. This promotes the longevity of the project through funding and support from the local government, as well as national support.

Overall, critiques of the volunteer medical care may serve as learning point for how to improve and advance the current standard, and should consider improved planning, monitoring and evaluation [17]. CHD patients in underserved areas are still dependent on such services[181920], which can greatly relieve morbidity and mortality due to the inaccessibility of care. CHD missions are a staple in care of these patients where lack of reach and finances due

to poverty are a great risk to the outcome to these patients. The strategy of cardiac missions in Africa should aim for long term educational support[2122], where even the cooperation of one additional party can ensure longevity [823] .
After 25 years of missions the mortality and morbidity from CHD had changed dramatically. More than 10 centers are currently distributed all over Egypt and are well equipped and run by well-trained doctors, who upon their training returned to their towns to serve their patients, who no longer need to travel to the Capital. Ultimately, our internal missions to underserved areas helped to alleviate the burden on urban tertiary care centres. By improving the reliance on health care other areas, only the most complicated and challenging cases were referred back to the metropolis hospitals. Furthermore, patient families burden decreased as they no longer needed to travel from their remote areas to the metropolis. Our success in missions for CHD covering all under privileged places in Egypt can be considered a role model for other African countries.

## Conclusions:-

Medical missions are an important component of healthcare that provide an extended reach of care to those living in underserved and underdeveloped communities. We adopted a similar approach to external missions while conducting our own internal charitable outreach; this model was highly successful. Medical outreach missions provide an established method for bridging the deficit in care and leaving behind a functional medical service for those in need. Buy in of local equipment and tools, instead of relying on expensive imported equipment was essential. Moreover, collaborative efforts[24] from other NGOs in the form of financial support, man power, recruitment and organization of charitable outreach, is essential to ensure the longevity and impact of cardiac missions. Facilitating learning experiences with local workers is needed, as well as providing them with continued learning experiences when needed. It is essential to work with local administration and government; communicating the impact of volunteer medical work on local families may motivate them to increase their support and funding of local doctors and hospitals. Patient advocacy was an essential part of bringing well needed attention to the social, economic, and healthcare platforms of the region.

| List of Abbreviations | |
|---|---|
| CHD | Congenital Heart disease |
| NGO | Non-Governmental Organization |

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