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Pediatric cardiac NGOs: collaboration and coordination

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Abstract: The steep decline in global childhood mortality has revealed an increasing contribution of congenital heart disease to infant mortality and increases the need to make it a health care priority in low- and middle-income countries (LMICs) access to appropriate, quality pediatric cardiac care. Pediatric cardiac non-governmental organizations (NGOs) have been working to address barriers to pediatric cardiac care for over 50 years. This review describes different NGO programmatic models, the challenges of the NGO landscape, and offers opportunities for collaboration. Collaborative NGO advocacy based on an agenda rooted in equity and human rights and supported by improved outcomes data, can establish the legitimacy of pediatric cardiac NGOs with policymakers and donors, bring new opportunities for many and save many lives. Whether that is technical assistance and advising on international best practices, strengthening local clinical capacity, or building advocacy skills with patient and family organizations, NGOs can leverage their unique strengths to increase sustainable and equitable access to pediatric cardiac care across the world. Justice and equity focus and linking health to human rights are important synergies for NGOs to assure better health for children in need of heart care.

Keywords: Congenital heart disease; advocacy; global health; pediatric cardiac nongovernmental organizations

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Introduction

Heart diseases in children are more common than most in the world understand or believe them to be. Congenital heart defects (CHD) are the most common major birth defect in the world, one in every 100 children is born with CHD. In 2019 (1,2), there were over 13.3 million people living with CHD in the world and 217,000 people died from CHD and most of the deaths were in low- and middle-income countries (LMICs) and almost 70% of the deaths were in infants. CHD was the 4th cause of infant mortality globally and it is number two cause of infant mortality in upper middle-income countries according to the 2019 Global Burden of Disease data. The prevalence of rheumatic heart disease (RHD) has been increasing over the years and in 2019 reached 40.5 million. While RHD mortality decreased until 2012, it started increasing again since 2017, reaching 306,000 in 2019. Despite these compelling numbers, some estimate that over 90% of children in need of cardiac care live where medical care is inadequate or unavailable (1,2). This number coupled with the steep decline in global childhood mortality from other causes reveals the increasing contribution of CHD to infant mortality, and increases the need to make it a health care priority in LMICs where access to appropriate, quality pediatric cardiac care most lacking.

Between 2015 and 2017 Children's HeartLink published the Invisible Child series policy papers (3) which described the tremendous global inequity in access to pediatric cardiac care and outlined the barriers to access the pediatric cardiac care. Those fall largely in four categories—financial,

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infrastructure, workforce and data or necessary evidence for policy makers. Pediatric cardiac non-governmental organizations (NGOs) have come into existence to address these barriers and this review will try to give an overview of the global pediatric cardiac NGO landscape and the opportunities for collaboration among them.

The history of pediatric cardiac NGOs is long and this review will not get into the details of it. Over the course of the last 40 years pediatric cardiac medicine has grown and developed greatly. CHD is largely not preventable so children with CHD continue to be born and new techniques and strategies continue to be developed. Yet, the benefits of this growth have mostly been felt in high income countries, despite the fact that the burden is the greatest in countries with higher birth rates and lower development indices where RHD is also still endemic. A number of pediatric cardiac NGOs were started mostly out of the interest and desire of an individual clinicians to help and to provide care and to share their expertise outside of their country. Most NGOs were founded with a humanitarian mission, and many continue to be humanitarian in nature today. That means that they exist to save lives and to relieve suffering, often to do it in extreme circumstances. Often their activities are referred to as "medical missions", a term that originated with religious organizations but today it has taken on a more secular meaning (4).

Cardiac NGOs characteristics

The current NGO landscape is diverse with the majority of the organizations originating in North America and Western Europe but also many new ones coming up in LMICs. A 2015 study (5) did a landscape analysis of NGOs working in the cardiac space. The authors surveyed 80 NGOs working in 92 LMICs with 42% providing outreach in South and Central America, 18% in Africa, 17% each in Europe and Asia, and 6% in Asia-Western Pacific. This is the only such effort to describe what cardiac NGOs are doing globally. The one limitation of the study is that the authors focused on language relevant to medical missions and did not explore more in depth the training, capacity building or advocacy work some organizations do.

A second overview (6) tried to quantify the impact of NGOs delivering surgical care and using a global medical missions database, identified 86 NGOs actively providing cardiac surgery services in LMICs or treating patients from LMICs. In this study, NGOs originated from 23 different countries, with 61.6% from the US, followed by the United Kingdom and Italy. In this study the NGOs were operational in 111 countries, 96 of them being LMICs. Almost half worked in only one country, and 40 NGOs operated in multiple countries, ranging from two to the surprising number of 80 countries.

What both of these studies didn't explore was the size of the NGOs such as annual budgets, staffing levels and number of active partnerships, or go in more depth on the type of work they did. A review of several organizations' websites and financial statements showed that except for one, most NGOs in the field of pediatric cardiac care have budgets not exceeding 6 million USD. The one exception is an organization that engages in noncardiac work as well and has a much larger budget. This demonstrates that the field of pediatric cardiac care NGOs is comprised of many but rather small organizations. Still, for a specialized field, it is impressive how many organizations exist globally to address this issue. It is indicative of the persistence of this global health problem and the inadequate level of access to services around the world.

NGO operational models

To address the global burden of heart disease in children, NGOs have employed several models. All approaches have emerged from genuine desire to help children in need of cardiac care, and all come with advantages and shortcomings. It is important to understand what those are, before exploring different opportunities for collaboration among the NGOs.

Providing financial and medical assistance to patients and families

Most NGOs were started with providing patient support by either bringing patients to high income countries for surgery, a model popular in the early years, or providing financial support to the families. For example, Children's Heartlink was started in 1969 to bring patients to the United States for surgery, and today there are several NGOs that continue to bring patients to high-income countries for surgery. In the United States, with the increase in health care prices this model became less and less popular. NGOs such as Chain of Hope (UK), La Chaîne de l'Espoir (France) and Save a Child's Heart (Israel), continue to bring patients for surgery from mostly African countries, since the pricing of health care services in their countries makes it more

feasible for foreign patients to be treated there. It should be noted that the abovementioned organizations apply also the capacity building model described below. A new trend in recent years has been local NGOs fundraising in African countries to send children for surgery abroad, mostly to India because of the low cost of the surgical services there. Many pediatric cardiac centers in India sign agreements with African NGOs from African countries, or even in some cases their governments, to provide heart care for children. Given the low costs in India, this has been a viable option for countries without any pediatric cardiac surgical services. The drawbacks of this model are that only few and a certain type of patients can benefit from it. Most children with critical CHD who need surgery in the first year of life, and often emergency services, will face risks with transportation, will require more resources and quick access to health services that will not be available to them. In addition, sending patients abroad prevents local programs from treating the patients locally and delaying the development of local capacity even further.

Medical missions

Another very popular model is the medical mission model. This model originates in the early 1800s when Western missionaries and physicians traveled to colonized parts of Africa, Asia and South America to provide medical care to the indigenous population (7). Today, it is employed by many different medical specialties when surgical services need to be performed. Examples include birth defects such as cleft lip and palate, emergency obstetric surgery, orthopedic surgery, etc. The goal of a medical mission is with the help of medical volunteers to provide treatment to as many patients as possible. Similar to sending patients abroad, the medical mission model serves best only certain type of patients whose care is not very complex and who do not require much follow-up care. Medical missions have received criticism over the years for not building local capacity and not planning for follow-up care for the patients who have undergone surgery, however they can be useful in environments where there are no local teams to receive training and in humanitarian and disaster settings.

Medical missions to train

The third model used by an increasing number of NGOs is medical missions with both patient care provision and training focus. Today almost all NGOs intend to provide training during their medical missions, but a criticism of this model has been that it is hard to provide effective training when missions happen only once a year due to the limited volunteer time availability. To address this problem, there are organizations such as the Novick Cardiac Alliance that in the course of a year organize several training medical missions to the same sites.

Capacity building

The capacity building assistance model focuses not only on clinical training but also on building interdisciplinary expertise and improving best practices to build clinical and organizational capacity and develop full pediatric cardiac teams. NGOs employing this model organize training exchanges in both directions between the hospital and the volunteers where the focus is exclusively on training, improving quality and developing local sustainability through engagement with the hospital administration and less on provision of patient care.

Capacity building is a compilation of different activities that may involve clinical skills development and improvement through on and off-site training visits, change management, partnership building, and program planning and implementation. Team Heart, Heart to Heart International and Children's HeartLink have successfully employed this model of assistance, building on their previous experiences with medical missions. A criticism of this approach is that it takes long to develop a self-sustaining center, therefore it's expensive and in the meantime many patients may lose their lives if surgeries take second seat to training. This model is most effective in middle-income countries and hospitals with some existing local investment in workforce and infrastructure. In these settings the NGO partnership builds on the existing infrastructure and the skills of a local team and can gradually grow the local capacity towards more complex care. This model and the model of frequent medical missions have the strongest chance of developing sustainability in the long run for the highly specialized tertiary care of pediatric cardiac services.

Patient and family NGOs

A variety of NGOs and groups have been organized locally to provide a range of services to local patients and families. The support ranges from peer-to-peer, psychological, financial through community fundraising, capacity building to advocacy for policy changes. These organizations are

often founded and led by family members or patients and harness the passion and lived experience of people affected by CHD and RHD. Because they are local, they can be especially effective advocates for policy changes in their countries. NGOs who fundraise for financial support to send patients abroad are especially active and successful in regions without sufficient or any surgical capacity.

Different NGOs are implementing all of the above-mentioned models and have published about their successes and challenges. As noted with each model, the applicability varies by the level of local availably and capacity of the local pediatric cardiac professionals, and by the investments made by local government or private sources. Some NGOs use multiple models such as Chain of Hope, La Chaîne de l'Espoir and Save a Child's Heart. What appear to be fundamental success factors across all models are having long-term partnerships with committed centers, committed volunteers and individuals who are champions for the needs of children with heart disease. All NGOs involved in providing, supporting or training medical professionals use medical volunteers, which brings incredible value but can also be a major constraint given the limited time volunteers can provide. Another constraint to the growth of all models is the relative lack of funding for the training and capacity building models because those take long time and require both the donated time of volunteers and funding of the costs of managing the partnerships. The funding space for pediatric cardiac care is still fairly limited today which limits the growth of the impact and expansion of the services.

NGO collaboration challenges

NGOs in the pediatric cardiac field do not collaborate very often and there are several reasons for that. As mentioned earlier, most pediatric cardiac NGOs are small. A unique characteristic of most NGOs globally is the reliance on volunteers. However, in the pediatric cardiac field the medical services the volunteers provide or improve are complex and require highly specialized workforce, without which NGOs would not be able to exist. Similarly, most NGOs have dedicated clinicians as founders which makes it hard for them to drive strategic growth, fundraise and do clinical work. The organizations that have hired professional NGO staff tend to be the ones able to focus on strategy and to raise more funds.

Generally, nonprofit organizations (NPOs) operate in much more precarious financial situation compared to for-profit corporations. Small NPOs especially, tend to operate with smaller cash reserves, about 2–3 months while expenses are used to serve the mission, the revenue comes from constituents not benefitting from that mission, rather coming from an outside community's generosity and desire to help. It is hard for NPOs to grow sustainably when many donors prefer giving directly to programmatic expenses and less for so-called overhead and general operating expenses. As a result, most NGOs spend a lot of efforts fundraising through special events to raise support for staff salaries and office expenses.

Another reason for the lack of collaboration is the nature of the nonprofit financing model. A major challenge for all pediatric cardiac NGOs is the limited fundraising space given the complexity of pediatric cardiac care. Most cardiac NGOs tend to fundraise from the same corporate donors which are biomedical and pharmaceutical companies with pediatric cardiac products, as well as from the communities they come from. Despite the large burden, CHD and RHD are still considered lower priority conditions and very few other funding options exist globally. Globally, most of the large donor funding goes directly to LMIC governments and development assistance for health has been decreasing (8). In 2018 only 18% of the total donor health funds went to international NGOs (9) and that amount was mostly contributed for specific health areas such as infectious diseases.

Not only is the fiscal space for pediatric cardiac NGOs small and competitive but the global COVID-19 pandemic has made that even more challenging with many donors redirecting their funding to fighting the pandemic.

NGO collaboration opportunities

Despite the outlined challenges there are also collaboration opportunities for NGOs to consider that haven't been explored before in this field. Collaboration should be a serious strategic issue for the leadership of every NGO when it offers an opportunity to grow the impact of their work. The Bridgespan Group, a US-based nonprofit consultancy, developed a tool to use when identifying potential partnerships and alliances and outlined several best practices for NPOs/NGOs (10) (*Figure 1*). Important steps in this process need to be determining needs and the consideration of potential challenges of a collaboration such as organizational culture and structure, strengths, weaknesses, leadership, and governance.

Assessing collaborative opportunities for pediatric cardiac NGOs should start with an assessment of the barriers to

Figure 1 Methodology for successful NGO partnership. NGO, non-governmental organization.

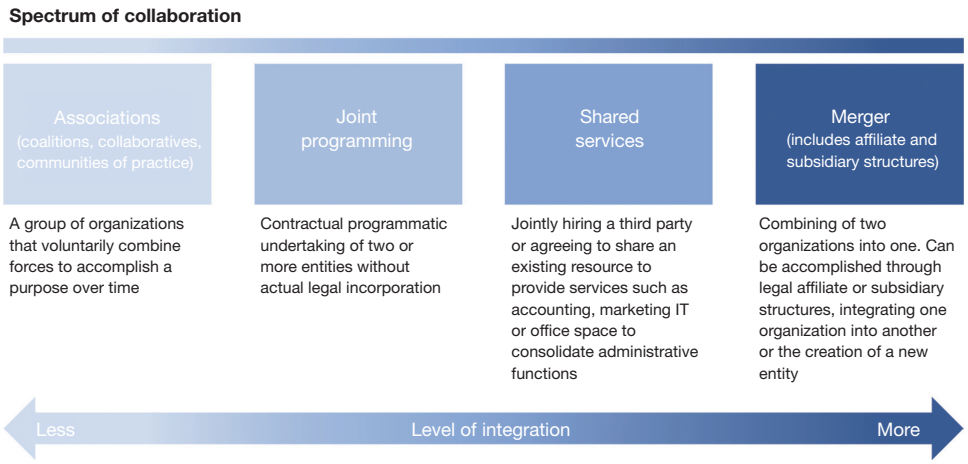

Figure 2 Spectrum of collaboration framework. The Bridgespan Group, bridgespan.org.

sustainable and quality pediatric cardiac care in underserved regions of the world outlined earlier—insufficient financing for pediatric cardiac services, insufficient infrastructure, insufficient specialist pediatric cardiac workforce, and lack of data or necessary evidence for policymaking. Those can help focus the opportunities for development of strategic alliances for NGOs.

Bridgespan also offered a framework for levels of collaboration (*Figure 2*) that can be used as a blueprint by NGO leadership when making decisions on the depth of collaboration activities.

Some examples of NGO strategic collaboration are developing new approaches and models, building awareness, and advocating for policy changes. This review discusses building awareness and advocating for policy changes, as the development of new models would require deeper collaboration.

Advocacy

Probably the most notable example of pediatric cardiac NGO collaboration is the development of the International Quality Improvement Collaborative (IQIC) for Congenital Heart Disease in LMICs (11) which was founded at the 2007 Global Forum on Humanitarian Medicine in Cardiology and Cardiac Surgery in Geneva, a regular conference for NGOs and clinical leaders providing cardiac care to children from around the world. The IQIC is hosted by leaders at Boston Children's Hospital and provides quality improvement strategies and a clinical outcomes database to participating sites, as well as benchmarking reports for CHD in LMICs, with the overall goal of guiding quality improvement efforts and reducing mortality for congenital heart disease. The IQIC database was piloted from September 2008 to December 2009, and included sites from Guatemala, Pakistan, India, Belarus, and China all introduced by several NGOs interested in developing the data tracking and benchmarking, as well as quality improving capacity at hospitals in LMICs. Today, the IQIC enrollment has grown to 78 sites in 32 countries and over 130,000 cases entered in the surgical and cath databases. Over the years, many NGOs have supported their partner hospitals' participation with both IQIC data entry and publications, but also financial support to attend IQIC learning sessions, meetings for collaborative learning. The IQIC is an example of NGO collaboration that has moved the field forward and has demonstrated that good outcomes can be achieved by hospitals in LMICs.

A recent publication (12) performed a stakeholder analysis within the field of pediatric global cardiac surgery and proposed a collaborative framework that can align advocacy initiatives to increase the efficiency of the different actors' efforts in the global community to advocate at the national and at the global levels holding national and international policy makers accountable for existing gaps and disparities in CHD care. The framework helps to plan for structured advocacy activities through analysis of the needs, stakeholder and target audience analysis, goals development through multi-stakeholder discussions ensuring the integration of all voices, especially those of the patients and families, and finally monitoring and evaluation of the outcomes and impact.

National/sub-national advocacy

On national, and also sub-national level (for countries with decentralized systems), NGOs can engage with local stakeholders to influence health policy and programs relevant to improving access to quality pediatric cardiac care. This would mean engaging in awareness building, education, collaboration and policy formulation and support local partners in implementation efforts, as any national advocacy efforts need to be locally driven. Some organizations act as technical experts to advise the design of health policies. This is a rather new role for NGOs and only few have done it successfully in pediatric cardiac services. This is due mostly to lack of capacity, lack of previous examples to go by and the still lacking interest among countries to address pediatric cardiac care needs.

One notable example of national policy advising success comes from Australia. HeartKids Australia, a local patient and family NGO, led and participated in a patient, family and clinician experts collaboration to develop the Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) (13). The project is now in its final stages after gathering national feedback and will influence the health policies for years to come in Australia. While the standards themselves are specific to Australia, the process of engaging patients and families is worth noting and learning from for others to replicate.

The Lancet Commission on Global Surgery developed a framework for national planning for the development of surgical systems, the National Surgical Obstetric and Anesthesia Plan (NSOAP) (14). The NSOAP framework addresses the five major domains of surgical systems development presented by the commission: infrastructure, workforce, service delivery, information management, and financing. This framework can successfully be used to advocate for pediatric cardiac services as well and NGOs can convene and be active participants in national consultative meetings with experts to propose government commitment to implementing guidelines and policies.

The biggest gap in pediatric cardiac care is in financing, specifically for clinical services, specialist workforce development and development of infrastructure, and that offers a great opportunity for national level advocacy. Ideally, a partnership for better financing should be done locally with patient and family NGOs who bring the important perspective of lived-experience and with health economics academic partners who can help advise on the details of financing a complex chronic disease. Like any advocacy for policy changes, it will require a long-term commitment to work with political leaders who may change frequently. Some international NGOs have been trying to support local partners to drive such changes, but no recorded examples exist in the literature.

On national level NGOs can collaborate on building awareness and changing perceptions about children with heart disease through community educational gatherings and campaigns and development of educational for the general public. Organizational and individual members of the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH), a global alliance of patient and family organizations and individuals affected by CHD and RHD, regularly engage in national awareness building campaigns through social and the conventional media, fundraising and support for new patients' families, and recently some have started directly engaging with their governments to improve financing of pediatric cardiac care.

Global advocacy

The greatest collaborative advocacy opportunity for international NGOs is at the global level. Within international multilateral organizations such as the World Health Organization (WHO), UNICEF and the World bank, NGOs can collaborate to engage in the policy influencing and agenda setting processes to increase attention to the disparities in access to pediatric cardiac care and linking the asks to the United Nations Sustainable Development Goals. This can be achieved by joining committees and working groups, driving research and

publications and bringing evidence to those meetings, and participation in multilateral forums where the commitments to the SDGs are discussed.

In the same vein and with the same goal of connecting SDG commitments to the needs of children with heart disease, NGOs can also use the resources of larger advocacy organizations, such as the Partnership for Maternal, Neonatal and Child Health at the WHO, The NCD Alliance, NCD Child, and others, to influence global policymakers. Being part of a larger group brings strength, but also adds the risk of the message to be diluted by many other competing global health priorities.

NGOs may also develop a coalition to start a global movement and bring strength with collective advocacy. One such coalition, the Global Consortium for Children's Hearts (GCCH), was started in early 2021, by 15 pediatric cardiac NGOs and several individuals working globally in pediatric cardiac care. The goal of the GCCH is to enable organizations and individuals to advocate on a national level for improved investments in services for childhood-onset heart disease through strategies, information and tools sharing and the objective is to collectively advocate for the development of sustainable pediatric cardiac surgery centers in underserved areas of the world and lifelong care for people with childhood-onset heart disease. The GCCH has not been very active but for now has a framework to develop different initiatives in support of its goal and objective.

Finally, a new and growing global advocacy effort is that of Global ARCH. Patient and family advocacy groups have a unique outlook and can successfully advocate for policy changes that promote pediatric cardiac care access improvement and to hold governments accountable for the international and domestic commitments they have made. With 52 member organizations from 30 countries and a mission to empower CHD and RHD patients and family groups around the world to make an impact in their communities and globally, Global ARCH has been gradually increasing its advocacy and awareness-building activities. It also serves as a learning platform for its members with regular ideas sharing, online advocacy training events, and development of advocacy resources in several languages. The organization aims to build global awareness of CHD and RHD and partners with professional and NGOs to represent the CHD and RHD community.

In 2020 Global ARCH published the Declaration of Rights for Individuals with Childhood-onset Heart Disease (15). The Declaration describes the basic health rights for every person affected by CHD and RHD and lists actions that governments should take to assure them. It is based on foundational human rights documents such as the 1948 WHO founding constitution, the UN Convention of the Rights of the Child, and the UN Convention on the Rights of Persons with Disabilities. The declaration has been well received by the global cardiac community, has been translated in 6 languages and is currently endorsed by 80 organizations and over 1,000 individuals. It aims to generate change both on global and national level by educating patients, families, health professionals, policy makers, and the general public about the needs of people with CHD and RHD.

Conclusions

The goal of this review paper is to describe the global pediatric cardiac NGO landscape and describe opportunities for collaboration. The five models under which NGOs operate are not exhaustive and some organizations may employ several at a time. Not much collaboration among NGOs has happened in the past but there is an increasing number of opportunities for NGOs to partner, notably in advocating for policy changes and awareness building, like the objectives of Global ARCH.

Pediatric cardiac NGO collaboration is not easy. Most global NGOs struggle with securing financial resources and in the field of pediatric cardiac care this is a problem of even higher magnitude. But we must turn the collaboration model around and consider collaborative opportunities from the point of view of abundance, rather than scarcity. Collaborative NGO advocacy based on an agenda rooted in equity and human rights and supported by improved outcomes data, can establish the legitimacy of pediatric cardiac NGOs with policymakers and donors, bring new opportunities for many and save many lives. Whether that is technical assistance and advising on international best practices, strengthening local clinical capacity, or building advocacy skills with patient and family organizations, NGOs can leverage their unique strengths to increase sustainable and equitable access to pediatric cardiac care across the world. Justice and equity focus and linking health to human rights are the most important synergies for NGOs to assure better health for children in need of heart care.

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Footnote

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