Addressing Global Disparities in Pediatric and Congenital Cardiac Care: introduction to the special series

Over one million children are born with congenital heart disease (CHD) each year around the world (1). Approximately one in two children with CHD will require surgical or interventional care at least once in their lifetime (2), whereas one in five will need an intervention to survive to their first birthday (3). In addition, rheumatic heart disease (RHD) represents the most common acquired cardiovascular disease among children and adolescents (4). RHD is a disease of poverty largely eradicated in high-income countries, yet it continues to affect dozens of millions of people across low- and middle-income countries (LMICs) (4,5). Despite this considerable burden of cardiac surgical disease, over 90% of children in LMICs no access to cardiovascular care (6,7) resulting in more than 90% of deaths and disability-adjusted life-years (DALYs) in children to be "excess" (8).

The current special series on "*Addressing Global Disparities in Pediatric and Congenital Cardiac Care*" provides a detailed overview of cardiovascular care for children living with cardiovascular diseases worldwide, with a particular emphasis on variable-resource contexts, where the disparities are greatest. Articles are briefly introduced in this editorial and include:

(I) Addressing Global Disparities in Pediatric and Congenital Cardiac Care: introduction to the special series.
(II) Narrative review in pediatric and congenital heart surgery in sub-Saharan Africa: challenges and opportunities in a new era.
(III) "Regale una Vida" a successful social program for underprivileged children with congenital heart disease in a middle-income country.
(IV) Pediatric cardiac NGOs: collaboration and coordination.
(V) Fostering a sustainable pediatric cardiac workforce in the developing world during the current coronavirus disease 2019 (COVID-19) pandemic.
(VI) Pediatric Cardiac Development Assistance in Conflict Zones.
(VII) The road to regionalization in congenital heart surgery: a narrative review.
(VIII) Generating political support for cardiac surgical care in resource-limited contexts: experience from Nepal.
(IX) Ethics of resource allocation to congenital heart surgery in variable-resource contexts.

This special series may expand upon and accelerate the contemporary global health discourse, which largely lacks the integration of pediatric and congenital cardiovascular care. Without an urgent recognition of the importance of pediatric and congenital cardiovascular care, the 2030 United Nations Sustainable Development Goal Agenda cannot and will not be attained (9).

Global disparities

Recent data confirm great disparities in the number of pediatric cardiac surgeons per million population. In high-income countries, there are approximately 9.51 pediatric cardiac surgeons per million under-15 population compared to only 0.07 per million in low-income countries (10). However, the number of pediatric cardiac surgeons managing neonates and infants with CHD is assumed to be far lower, although not exactly quantified (11). As such, Murala *et al.* (12). discuss opportunities to scale pediatric and congenital cardiac care capacity through the lens of the ongoing COVID-19 pandemic, which exacerbated disparities in access to cardiac care (13,14). These opportunities include but are not limited to (I) frugal innovation, which has enabled programs to do more with less as a result of resource constraints and lacking supply chains (15,16); (II) online learning, which reduced barriers to educational participation by bringing workshops and classrooms into one's own home, regardless of one's location (17,18); and (III) simulation training, which facilitates technical skills training in a low-, medium-, or even high-fidelity manner when real-world opportunities are not available or the risks of real-world exposure are too high (19-21).

Disparities further vary by and within regions (22). For example, Manuel *et al.* (23) illustrate how, in sub-Saharan Africa, late diagnosis after the first year of life is common and associated with considerably higher mortality, reduced access to

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surgical care to less than 3% of children with CHD, high rates of catastrophic expenditure, and few local training programs. Indeed, data suggest that there are only 135 surgeons for 1.2 billion people across sub-Saharan Africa, of which only a fraction are able to perform congenital heart surgery (22). Similarly, Novick *et al.* (13) highlight additional nuances surrounding pediatric and congenital heart surgery in conflict zones. Various conflict settings have seen their cardiac surgical programs pause or even disappear, whereas others have seen much-needed progress towards the first local program regress; in Yemen, for example, the necessary resources cannot enter the country, resulting in an inability to maintain services (22). The Novick Cardiac Alliance has committed to continue to support conflict zones in the delivery of and capacity-building for pediatric and congenital heart surgery, saving the lives of thousands of children over the years.

Beyond infrastructure: socioeconomic disparities

Access to care must be approached through geographical accessibility, infrastructural capacity, healthcare quality, financial affordability, and social acceptability (24). From a surgical perspective, especially for high-cost interventions such as congenital heart surgery, financial affordability constitutes the most pressing barrier to access to care (25,26). Socioeconomic disparities exist in access to pediatric and congenital heart surgery in high-income countries and LMICs alike (27), and may not be forgotten in the development of global surgical interventions.

Sandoval *et al.* (28) share their experience in Colombia with scaling access to cardiac surgery for children from families from lower socioeconomic status. Through the social responsibility program "Regale una vida," the authors established efforts outside the private healthcare sector and on top of governmental healthcare delivery to complement rather than replace existing cardiac surgical care delivery within the country. This has resulted in over 50,000 children being screened, more than 1,000 echocardiograms performed each year, and nearly 100 fully-subsidized congenital heart surgery procedures per year. Similarly, Koirala (29) shares their experience with developing a microinsurance program for cardiac surgery for the poor, the young, the elderly in Nepal, which results in more than 100 free cardiac surgical procedures every year. Models such as those developed in Colombia and Nepal are examples to be adopted and adapted in other countries to ensure that patients and families may more freely seek the life-saving and life-changing cardiovascular care they need.

Optimizing cardiovascular healthcare delivery

Moving forward, cardiovascular care must not merely be scaled but rather scaled in the most efficient, effective, and ethical manner. Ghandour *et al.* (30) eloquently discuss the potential benefits and harms of regionalization for pediatric and congenital heart surgery, drawing from experiences across the globe. In Europe and Canada, a gradual movement towards regionalization in the past few decades resulted in the consolidation of pediatric cardiac programs to increase institutional volumes, improve outcomes, and reduce costs (31). In contrast, in the United States, there remains considerable decentralization: modelling suggest that only one-third of the 153 existing pediatric cardiac surgery programs may be necessary to provide the necessary care for patients with CHD across the country, as 101 (66%) of programs are located within 25 miles of each other and no geographical access barriers would arise with consolidation/regionalization thereof (32). In LMICs, where cardiac surgical programs are few and far between, a process of "natural" regionalization of services may be observed: as a result of limited resources, programs may inherently seek to centralize and pool resources to most efficiently allocate these to the populations they serve (33). However, the large population across LMICs, the vast geographical barriers, and the financial costs associated with transportation and time away from work for patients and families introduce considerable barriers that must be considered. Thus, although centralized hubs with higher volumes, fewer complications, and lower costs appear ideal, their effects on geographical access and hidden costs require further study.

Fenton (34) eloquently describes the ethical considerations of congenital heart surgery in LMICs through the lenses of principlist ethics (respect for autonomy, nonmaleficence, beneficence, and justice), public health ethics (moral justification to promote public and population health), and consequentialist ethics (right-or-wrong based on the consequences of interventions). Regardless of the lens applied, resource allocations must be efficient and balance the competing needs on the ground. For example, many LMICs have fragmented primary care structures affecting entire populations' daily lives, which cannot be forgotten (35).

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Lastly, Zheleva highlights the important role of NGOs in helping expand global cardiovascular care (36). Previous data suggested that 86 NGOs are active in global cardiac surgery delivery, of which most (94.2%, N=81) are involved with pediatric and congenital heart surgery (37). Although fly-in-fly-out missions were traditionally a major focus of NGOs, the lack of local continuity of care (e.g., patient follow-up) and capacity-building (e.g., empowering local teams) resulted in more sustainable efforts, including bilateral and longitudinal partnerships between programs and capacity-building initiatives. Nevertheless, many NGOs continue to practice in the same countries and hospitals, resulting in overlap, inefficiencies, and fragmented communication channels that may harm rather than benefit local programs; efforts to improve the efficiency of and collaboration between NGOs are critical in order to best support partner programs (27).

Looking ahead

Cardiovascular (surgical) care remains neglected within current national and international policy prioritization (38-41). This neglect exists despite the proven cost-effectiveness of pediatric cardiac surgery in LMICs (42), which is even more favorably cost-effective when compared to many current global and public health priorities, such as oral rehydration therapy for diarrhea and antiretroviral therapy for human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) (43). This phenomenon illustrates the importance of cardiac surgeons' engagement in health policy and advocacy (44). Societies have started to become increasingly involved at the national and international level (45). Opportunities through the World Society for Pediatric and Congenital Heart Surgery, the African Society for Pediatric and Congenital Heart Surgery, and other societies highlight the growing global cardiac surgery momentum that must be applauded and expanded into the future. Ultimately, multidisciplinary, multisectoral, and international collaboration will be the key to ensuring that no child is left behind.

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