Congenital Heart Disease

Tech Science Press

DOI: 10.32604/chd.2024.049814

EDITORIAL

Health Systems Strengthening to Tackle the Global Burden of Pediatric and Congenital Heart Disease: A Diagonal Approach

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Received: 19 January 2024 Accepted: 01 April 2024 Published: 16 May 2024

KEYWORDS

Congenital heart disease; pediatric heart disease; global health; health systems; health policy

1 Background

Congenital heart disease (CHD) is the most common major congenital anomaly, affecting approximately one in every 100 live births [1]. Among congenital anomalies, 66% of preventable deaths are due to CHD, and 58% of the avertable morbidity and mortality due to congenital anomalies would result from scaling congenital heart surgery services [2]. Every year, nearly 300,000 children and adults die from CHD, the majority of whom live in low-and middle-income countries (LMICs) [3]. Approximately 49% of all individuals with CHD will require surgical or interventional care at some point in their lifetime [4]; as a result of advances in access to and the delivery of such services, over 95% of children born with CHD in high-income countries now live into adulthood [3]. Here, adults have surpassed children in the number of CHD cases at a ratio of 2:1 [5]. In contrast, in LMICs, over 90% of children born with CHD do not receive the care they need, often not surviving past their childhood [6]. Indeed, even programs able to perform congenital heart surgery report limited resources, which are correlated with procedural volumes and complexity, and, thus, indirectly with long-term outcomes [7]. The 8th World Congress of Pediatric Cardiology and Cardiac Surgery, which took place in Washington DC, United States in August 2023, was themed in large part around global gaps in CHD care. Here, a call to action on '*Addressing the Global Burden of Pediatric and Congenital Heart Diseases*' was issued, which aligned with the 2030 Global Agenda for Sustainable Development and proposed 2030 goals for CHD-oriented capacity-building, data generation, and financing worldwide [8].

This article gives an overview of the need for a health systems-oriented and lifespan perspective on CHD care. We discuss the advantages and disadvantages of vertical and horizontal approaches to CHD care and

argue for a more pragmatic diagonal approach to address the historical neglect of CHD care on the global health agenda whilst ensuring sustainable and cross-cutting health systems strengthening efforts.

2 Continuum of Care for Congenital Heart Disease

CHD is a lifelong condition, requiring close follow-up over a lifetime. Even when operated, there is a risk of requiring reinterventions, recurrence or progression of cardiovascular symptoms, and a risk of associated comorbidities. As a result, adult CHD has been coined a "growing epidemic" in high-income countries, reflecting both the improvements in pediatric cardiac care and the continued, multidisciplinary care needs across the lifespan [5]. However, there are common misconceptions among both patients and their families as well as healthcare professionals about the lifelong needs of patients with CHD. As a result, patients often get lost-to-follow-up when transitioning into adulthood as their care shifts from pediatric to adult cardiologists [9]. Overcoming these gaps in transition will require a coordinated effort between care teams, patients, and families to develop multifaceted and collaborative approaches to transition in care [10].

Individuals with CHD do not just suffer from physical symptoms or increased risks of health events but also more frequently report poorer mental health. Children with CHD, regardless of its severity, report higher rates of anxiety, depression, and attention deficit hyperactivity disorder compared to children without CHD [11]. Similar trends are observed in adults with ACHD, where mental health and (fear of) stigma commonly pose the biggest health issues [12]. Furthermore, childhood adversity and other social determinants of health, which are closely linked to mental health into adulthood, are associated with higher risks of cardiovascular disease and symptomatology [13]. As such, mental health services are essential as part of comprehensive CHD care across a lifetime for individuals living with CHD [14]. This is particularly important in the context of concomitant neurodevelopmental disorders or other associated conditions regardless of pediatric and congenital heart disease (PCHD) complexity [13,15].

3 Approaches to Healthcare Upscaling

3.1 Vertical Approaches

Historically, global health efforts have been focused on individual conditions, such as efforts to address malaria or HIV/AIDS. These programs generally fall outside the scope of national health policy plans and often rely on delivery mechanisms beyond local health infrastructure [16]. Efforts with singular disease foci, while often cost-effective, represent vertical approaches that have limited spill-over effects on other parts of the health system; these approaches are generally more affordable and have shorter timelines (e.g., small pox eradication, distribution of mosquito nets, one-off screening programs, nutrition programs). Vertical interventions often focus on primary care and, while helpful to many patients, are not inherently supportive of overall health systems strengthening because they often create silos and are difficult to sustain. In global health, these have tended to be developed and sustained by foreign aid funding that is earmarked to that specific vertical silo. In addition, vertical programs have historically been associated with limited capacity-building and academic equity, resulting in local collaborators being excluded from program deliverables or being "stuck in the middle" of academic authorship [17,18].

For PCHD, vertical approaches predominantly include mission trips. The majority of non-governmental organizations (NGOs) involved in global cardiac surgical care delivery are focused on congenital heart surgery [19]. While several of these organizations are involved in the capacity-building of non-surgical members of heart teams and their ongoing work has resulted in thousands of lives saved worldwide, only few NGOs are involved in supporting health policy development and health systems strengthening efforts that go beyond providing PCHD care. In addition, through vertical approaches, individuals with PCHD are often poorly followed up over time. After initial management, individuals may be sent back to their community with inadequate attention for referral or follow-up mechanisms, the importance of which was outlined above.

3.2 Horizontal Approaches

To sustainably address public health programs and clinical care delivery, health systems strengthening efforts are needed. Horizontal approaches are characterized by their cross-cutting health systems focus (i.e., horizontal throughout the system) compared to vertical approaches that silo in parallel. Moreover, horizontal efforts generally embed themselves within local (public) health infrastructure, from community and primary health care to tertiary care [16].

Examples of horizontal approaches for cardiovascular disease are limited but promising. For example, PEN-Plus integrates care for chronic conditions and has been spearheaded by the Lancet NCDI Poverty Commission [20]. The program expands the traditional World Health Organization PEN package, which is focused on primary health, by connecting primary health care with outpatient and inpatient care at the district (first-level) and referral hospital level.

While more impactful in the long-term, investments into horizontal programs are considerable and the timelines are generally longer than vertical approaches. As a result, stakeholder interest, including from funders and policymakers, is comparatively lower than for vertical approaches, which is reflected in current global health financing streams [21]. Moreover, there may be concern regarding the efficiency of purely horizontal approaches. Lastly, while authorship inequity may be less frequent compared to vertical approaches due to greater political and health system engagement, horizontal approaches do not inherently preclude inequities from happening.

3.3 Diagonal Approaches

Vertical and horizontal approaches have different characteristics that make them advantageous and disadvantageous to implement. A pragmatic approach to scaling CHD care may involve a diagonal approach, whereby a population-based health systems lens is applied to a given disease area [22]. Accordingly, pitfalls of vertical approaches, such as siloing and limited collaboration, are avoided. Similarly, difficulties of horizontal approaches, which include limited focus and often poorly specified interventions, are minimized. Diagonal approaches also inherently cut through health systems, recognizing the intricate role of social determinants of health in influencing health outcomes and access to care. As social determinants of health are closely associated with CHD risks and outcomes, a patient-centered and holistic approach is ultimately necessary [23]. Diagonal approaches, while focused on single disease populations, strengthen the health system overall by building capacity in cross-cutting areas such as human resources, data collection, financing, and supply chains. In this manner, diagonal approaches leverage the diagonal nature of integrated care approaches, whilst also emphasizing political, economic, and social factors [24]. Because of its lifelong nature, CHD is particularly well-suited for this approach. For example, CHD newborn screening programs save the lives of many vulnerable newborns [25,26]. In hospitals, services necessary for congenital heart surgery, such as blood banking, tight infection control and prevention policies, respiratory therapy, pharmacy, laboratory medicine and many more, have a positive spillover effect on other patients and services [27,28].

In the real world, a diagonal approach to CHD has been shown to be successful in different settings. A population-based program addressing the care continuum for CHD in Kerala, India, proved effective in increasing congenital heart surgery volumes and reducing overall and CHD-related infant mortality [29]. Key to the success of the program were political support and government financing, important aspects of diagonal approaches to care delivery. Similarly, in the state of West Bengal, a public-private partnership between the government and public and private hospitals has been ensuring free cardiac care for children with CHD for more than ten years [30]. Furthermore, in Johor, Malaysia, quality improvement efforts supported referral to and care delivery at the sole cardiac center in the state, now enabling over 80% of children with CHD to survive into adulthood [31]. Children with less complex or non-surgical forms of CHD are managed in-state, whereas those requiring more complex interventions are referred to the

National Heart Institute (Institut Jantung Negara) in Kuala Lumpur, the country's capital. This hospital has been supported by Children's HeartLink since 2008 and is named a Pediatric Cardiac Care Centre of Excellence. Practically, diagonal approaches may not require greater funding compared to vertical approaches, as existing health systems and stakeholders are engaged, thereby reducing redundancy. Nevertheless, diagonal approaches require the engagement of a multitude of multidisciplinary stakeholders, and thus increase workforce and time needs, but improve need-based, contextual, and patient-centered program development and care pathways. Recently, a comprehensive framework to embed pediatric heart disease and CHD services in public health systems in LMICs was proposed by a multidisciplinary group of experts from around the world [32]. This framework and accompanying recommendations across different levels of care may guide policymakers to integrate CHD care in health policies. However, the framework did not include population need-based policymaking for CHD, an aspect that still needs development in all LMICs.

4 Challenges and Opportunities

While promising, the practical implementation of diagonal approaches is still limited by several challenges. First, a change in mindset is required to move away from vertical silos. For organizations, this will require a recognition that indirect spending on CHD care (e.g., investments in primary care) will still benefit CHD services (e.g., community-based screening and follow-up) [28]. For funders, this means a shift away from earmarking of funds, which has been the bedrock of global health financing to date. For governments, this necessitates a greater focus on health systems strengthening as opposed to "quick fixes" that may be more politically appealing to garner votes. Second, increasing care capacity must go hand in hand with improved surveillance for case detection. Many children are still born at home, in the community, or at low-resource health clinics where newborn screening for CHD is generally absent [33]. Where possible, prenatal diagnosis is preferred to reduce healthcare costs and improve outcomes [34]. Third, political prioritization is a complex process whereby certain areas of health are prioritized over others beyond mere disease burden considerations. To date, CHD care has been poorly prioritized consistent with other cardiovascular and surgical conditions [35,36]. Political buy-in is necessary to truly move the needle. Fourth, the surgical and non-surgical workforce involved with CHD care is limited, especially in LMICs [37]. Upscaling the CHD workforce will require considerable time and investments. Fifth, diagonal approaches, unlike vertical ones, are centered around financial sustainability. This requires a baseline increase in allocated funding as well as leveraging novel and innovative financing instruments to ensure fiscal sustainability. These may include but are not limited to levies placed on airline tickets (e.g., similar to UNITAID) or social impact bonds (as explored for non-communicable diseases) [38,39]. Furthermore, this requires careful and transparent costing over time to ensure adequate financial planning (e.g., health budgets) and resource allocation (e.g., based on economic evaluations) [24].

Nevertheless, several opportunities exist. The Global Alliance for Rheumatic and Congenital Hearts (Global ARCH) unites patient-family organizations across the globe, with roughly half of these organizations based in LMICs. Accordingly, patients and families–those truly at the heart of global health–are provided a platform to voice their experiences and wishes. Policymakers, funders, and researchers are encouraged to ensure that such voices are at the table to avoid historical academic and policy ivory towers from persisting; indeed, policy change frequently happens as a result of patient advocacy. Similarly, NGOs have a key role to play in advocating for greater inclusion of CHD care in global and national health agendas [40]. Many NGOs involved with CHD care do so at their respective local and national levels, albeit commonly alone or with few partners. The even greater impact may come from the unification of voices, a lack of which has been a root cause of the low levels of political prioritization for rheumatic heart disease and global surgery [35,36]. Furthermore, innovative educational models have grown in recent years to scale open-access online learning. For example, Heart University and SURGhub are examples of widely supported e-learning platforms that can greatly support continued

medical education [41,42]. These efforts should be accompanied by engaging LMIC voices in program development to meet local capacity-building needs as well as avoid historical inequities in academic deliverables. Lastly, at the health systems level, comprehensive lifespan outcomes for individuals with CHD can help inform the quality of and gaps in care [43]. These outcomes reflect both clinical and patient-reported outcomes, recognizing the need to improve hard clinical outcomes and patient-centered outcomes globally.

5 Conclusions

Conventional vertical approaches have narrow and often short-term disease-specific foci, whereas horizontal approaches address entire health systems but can come at the cost of efficiency and disease-specific progress. Lifespan and health systems-wide approaches combining the advantages of vertical and horizontal approaches are necessary to ensure appropriate and comprehensive care for people living with CHD and avert preventable morbidity, mortality, healthcare spending, and socioeconomic losses. Opportunities exist to sustainably embed CHD care within health systems through a diagonal approach, benefiting both CHD services and other parts of the health system.

Acknowledgement: DV is supported by the Canadian Institutes of Health Research (CIHR) Vanier Canada Graduate Scholarship.

Funding Statement: None.

Author Contributions: Conceptualization: DV, BZ; Original draft/writing: DV, AV, SMN, CCE, BZ; Critical review/revisions: DV, AV, SMN, CCE, BZ; Approval: DV, AV, SMN, CCE, BZ.

Availability of Data and Materials: No datasets or materials were generated or analyzed for this study.

Ethics Approval: Not applicable.

Conflicts of Interest: The authors declare that they have no conflicts of interest to report regarding the present study.

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