

What We Choose to Fund Defines Who We Choose to Save: Pediatric Heart Failure in Emerging Economies

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Management of pediatric advanced heart failure (HF) in low- to middle-income countries faces substantial and interconnected challenges, including severely limited access to specialized care, a shortage of adequately trained healthcare professionals, delayed referrals, and high mortality rates. These systemic constraints significantly restrict both the availability and the effectiveness of life-saving therapies for children with end-stage HF.

A deeper understanding of mechanical circulatory support (MCS) in emerging economies – illustrated here through the Brazilian experience – provides a valuable foundation for identifying structural, logistical, and ethical barriers to care. Such analysis also informs the development of strategies aimed at the sustainable and equitable expansion of advanced HF therapies for children.

Brazil exemplifies the complexity of delivering high-cost, resource-intensive care in emerging economies. It is a vast and heterogeneous country, with an estimated population of 212 million people unevenly distributed across 8.5 million square kilometers. Nearly 30,000 children are born each year with congenital heart disease, many of whom will eventually require resource-intensive care and/or HF management.^{1,2}

Although Brazil has a mature heart transplantation network, the prevalence of advanced HF continues to rise, accompanied by increasing healthcare utilization, morbidity, and mortality.³ A persistent limitation – mirroring global trends – is the scarcity of size-matched donor organs. This challenge is further compounded by low pediatric organ donation rates, high family refusal rates (recently reported at approximately 46%), and systemic inconsistencies in donor management protocols and supportive infrastructure.⁴

These factors result in prolonged waiting times, with a median of 224 days for children weighing under 10 kg, and waitlist mortality reported to be as high as

45% for heart transplantation.⁵ Children who die while awaiting transplantation often experience severe clinical deterioration, frequently requiring advanced life support before an organ becomes available – a trajectory marked by profound suffering and burden for patients, families, and healthcare teams alike.⁶

Deployment of MCS in these high-risk populations has emerged as a transformative strategy to prevent multi-organ failure and improve survival during extended transplant waiting periods. It provides hemodynamic stabilization and preserves end-organ function, bridging critically ill children to transplant candidacy, transplantation itself, or – in select cases – myocardial recovery. Data from international registries such as the Advanced Cardiac Therapies Improving Outcomes Network (ACTION) and Pediatric Intermacs (Pedimacs) demonstrate that six-month favorable outcomes – defined as transplantation, recovery, or survival on device – now reach approximately 84% to 90% in high-income settings.^{7,8} Among children weighing under 10 kg, long-term MCS more than doubles the likelihood of receiving a transplant compared with medical therapy alone.⁵

Despite having one of the world's largest public transplant systems, Brazil still lacks an equitable and standardized approach to pediatric MCS, and the literature on the subject remains extremely limited.^{5,9-11} Most children with end-stage HF on the waitlist either die or reach transplantation in severely compromised clinical condition, reflecting a persistent misunderstanding that preemptive ventricular assist devices (VADs) and heart transplantation constitute a continuous therapeutic pathway rather than isolated interventions.

The expansion of pediatric MCS programs in Brazil faces significant financial and structural challenges. Although the Brazilian public health system provides universal coverage for heart transplantation, it does not fund the costs associated with pediatric MCS technology, despite healthcare being a universal right and a constitutional duty of the state. As access is often restricted to patients with private insurance or those supported by philanthropic “hub-and-spoke” models, substantial disparities arise from the system's own regulations, disproportionately affecting the poorest.¹²

Structurally, Brazil still lacks a broad distribution of healthcare centers capable of adequately performing pediatric MCS, leading to extremely late referrals – a critical determinant of outcomes in this population. Identifying patients before they progress to end-stage cardiogenic shock is essential, as the need for extracorporeal membrane oxygenation (ECMO) prior to VAD implantation or transplant surgery is associated with significantly worse outcomes.^{13,14}

Keywords

Heart Failure; Pediatrics; Extracorporeal Membrane Oxygenation; Heart Transplantation; Heart-Assist Devices

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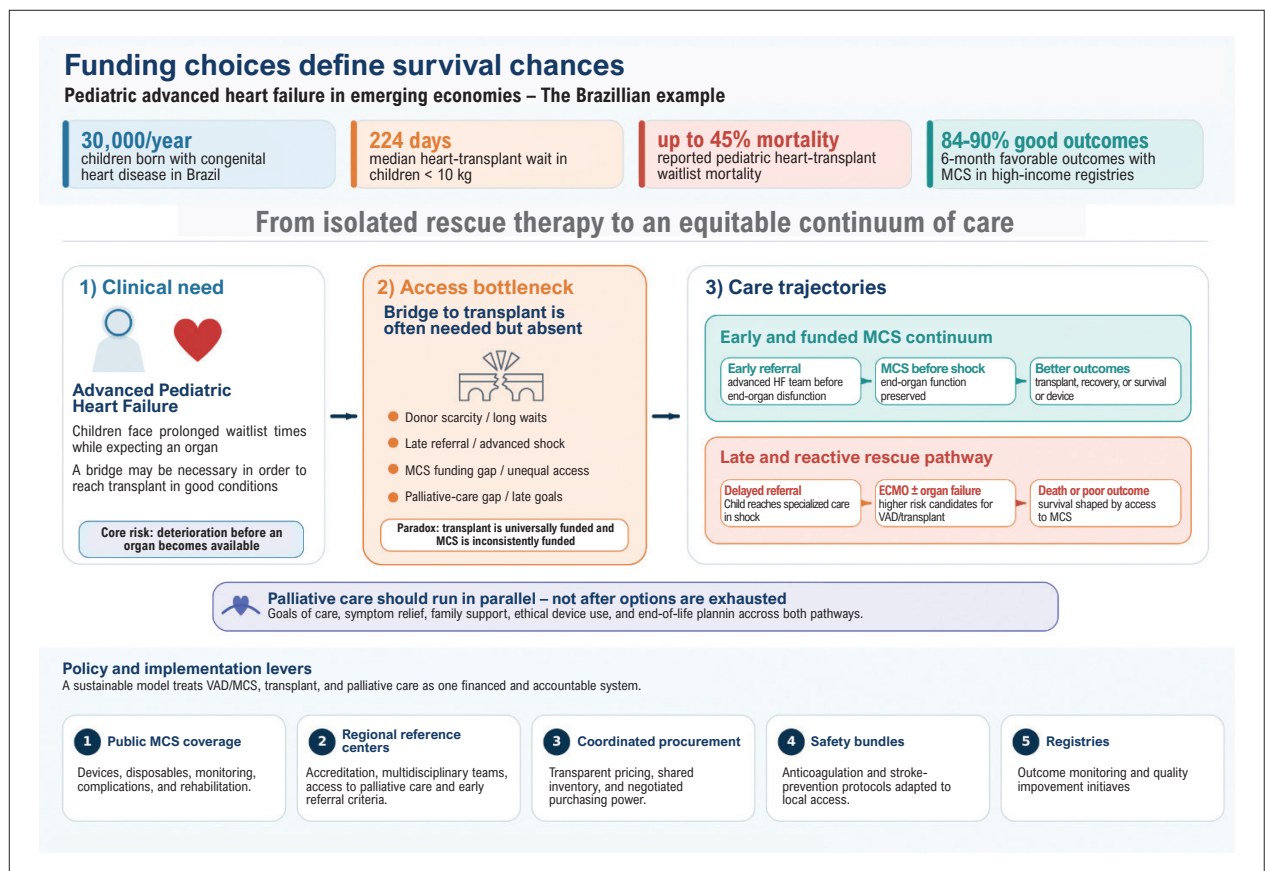


Figure 1 – Conceptual framework for pediatric heart failure. ECMO: extracorporeal membrane oxygenation; HF: heart failure; MCS: mechanical circulatory support; VAD: ventricular assist device.

Beyond economic barriers, the clinical management of VAD-related adverse events remains a major challenge in developing countries. Although international registries have reported an improvement in overall stroke incidence to 13.7%, rates remain higher in infants.^{7,8,15} In Brazil, single-center experience has shown even higher rates of neurological complications, with stroke affecting up to 57.1% of children supported by the Berlin Heart EXCOR, although a portion of these events occurred before device implantation.^{9,16}

Important factors potentially contributing to this disparity include delayed implementation of stroke-prevention bundles and, possibly, the unavailability of direct thrombin inhibitors such as bivalirudin – the cornerstone pharmacologic agent of the ACTION bundle, which has been shown to drastically reduce stroke rates in pediatric VAD patients.¹⁵ Reliance on heparin, the only intravenous anticoagulant available, increases the risk of both thrombotic and hemorrhagic events in infants due to the inherent challenges of monitoring and managing anticoagulation.¹⁷

An additional structural issue requires urgent attention. In Brazil, the market for SCM therapies is characterized by low implant volumes and sales through distributors—factors that directly impact total costs.¹⁸ Moreover, in many institutions, short- and long-term devices are not maintained as in-house inventory, and investment in scalable programs remains

low – extending the problem beyond distributor margins. Instead, technologies are frequently acquired on an as-needed basis, shifting logistical risk to distributors and reinforcing a fragmented, just-in-time procurement model. Institutional surcharges can further increase final costs. Together, these factors sustain high prices, weaken negotiation leverage, and restrict program growth, placing a substantial burden on both the public and private sectors.

Despite its profound implications for equity and sustainability, this financial architecture remains largely absent from academic and policy discussions. Greater transparency, regulatory oversight, and coordinated procurement strategies are urgently needed. Addressing these issues is essential if equitable access to advanced HF therapies is to progress beyond rhetoric and become a tangible reality.

Important aspects of clinical care also demand renewed scrutiny. Barriers to the early integration of palliative care for children with advanced HF remain substantial (Figure 1). Historically, the suffering experienced by pediatric HF patients has been underrecognized, only gaining visibility over the past decade. It is now well established that suffering in this population is multifactorial—spanning physical, psychological, social, and spiritual domains throughout the disease trajectory—and that early palliative care plays a crucial role in mitigating disease burden.^{19,20}

However, as survival improves and disease complexity increases, unmet needs specific to pediatric HF have become increasingly apparent, yet literature addressing the integration of palliative care in this population remains scarce.²¹⁻²³ Recent guidelines from the American Heart Association reinforce the role of pediatric palliative care as a core component of best practice in advanced HF, mirroring earlier recommendations in adult care.²⁴

Palliative care is a growing field in Brazil, but its application in the pediatric population remains incipient. Only in 2018 did the Ministry of Health formally mandate the integration of palliative care into the Brazilian public health system. Currently, according to the Brazilian Academy of Palliative Care, 234 teams operate nationwide; however, fewer than half provide pediatric services, and none offer directives specifically tailored to children with advanced cardiac disease.²⁵ Addressing this gap is essential for enabling early definition of goals of care and mitigating disease burden – tasks for which pediatric cardiologists and cardiac surgeons often feel unprepared.^{26,27}

Integrating palliative care frameworks for children with advanced HF may further refine the appropriateness of complex therapies on an individual basis, contributing to more efficient resource allocation – a key aspect of the sustainable expansion of these costly technologies. Because some of these children will face death even while supported by MCS, preparing healthcare professionals for end-of-life care in the context of mechanical circulatory support is imperative for the ethical expansion of the therapy. Therefore, properly structuring access to pediatric palliative care must advance in parallel with the expansion of MCS for this population.

The mismatch between clinical need and available resources underscores the profound implications of funding priorities and health policy decisions, ultimately determining which children gain access to life-saving therapies. Paradoxically, while heart transplantation is publicly funded and institutionally supported, mechanical circulatory support (MCS) strategies – often decisive in whether a child survives to transplant and in what condition – remain inconsistently incorporated and financed. Disseminating advanced therapies for pediatric heart failure in low- to middle-income countries such as Brazil must be regarded not only as a clinical goal but also as a moral imperative. The healthcare community, policymakers, and public health authorities must actively collaborate to bridge the gap between technological potential and systemic realities, ensuring that every child has a fair chance at survival regardless of socioeconomic status. Stakeholders must advocate for accessible, equitable, and high-quality MCS programs across diverse healthcare settings, grounded in the accreditation of multidisciplinary reference centers, publicly funded initiatives, and the establishment

of regional registries to monitor outcomes and drive quality improvement.

The goal should extend beyond improving waitlist survival to ensuring that every child reaches transplantation in the best possible clinical condition. Achieving this requires more than fragmented or reactive measures – it demands a coordinated, system-wide approach that fully integrates early MCS strategies, sustained multidisciplinary expertise, regulated access to equipment, and early pediatric palliative care as foundational components of standardized practice. At this stage, failure to implement such a framework reflects not only limited resources but also a lack of collective commitment to equitable, evidence-based, and ethically sound care.

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During the preparation of this work, the author(s) used Grammarly to improve english version. After using this tool/service, the author(s) reviewed and edited the content as needed and take full responsibility for the content of the published article.

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