Challenges in congenital heart disease in the Amazon region countries: A scoping review

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ABSTRACT

Introduction : **This study aimed to systematically analyze and describe the main challenges of congenital heart diseases (CHDs) in the countries in the Amazon region.**

Methods : **The methodology followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist utilizing the Medline, Embase, Lilacs, and Google Scholar databases. The inclusion criteria were articles addressing any topic involving CHD in the Amazon region. Incomplete articles, book chapters, lectures, conference abstracts, and editorials were excluded.**

Results : **Nine studies were identified, 7 of which were published in the last decade and were of Colombian and Brazilian origin. The methodology of the studies was cross-sectional and ecological, evaluating the regional and epidemiological factors, challenges to diagnosis and treatment, multidisciplinary team challenges, and the impact of the COVID-19 pandemic. Studies carried out by surgeons demonstrate more existing data regarding the challenges of the health-care system.**

Conclusions : **There is growing interest in analyzing the situation of CHD in the region. However, only a few studies are available, mostly on ecological and cross-sectional analysis. These records show the lack of hospital infrastructure and multidisciplinary teams for the diagnosis and treatment of CHD in the Amazon region; we see an initiative by specialists from two countries (Colombia and Brazil) to demonstrate the difficulties by seeking international training programs and government aid to improve the health system situation.**

Keywords : Developing countries, heart abnormality, heart surgery , low- and middle-income countries

INTRODUCTION

Congenital heart disease (CHD) presents with a wide range of clinical and anatomical variations, from asymptomatic to extremely severe, leading to an increase in infant mortality rates.[1,2] The global prevalence of CHD is about 1.8/100 live births;[1] considering 1% and

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the birth rate of the Brazilian Institute of Geography and Statistics (IBGE, about 2,89 million live births per year),[3] about 30,000 live births in Brazil have CHD, of which about 80% require cardiac surgery, half of them in the 1st year of life.[4,5]

In Brazil, congenital malformations are the second leading cause of mortality in children under 1 year of age, with CHD being the most common malformation, representing the highest mortality rate up to 1 year of age and the second cause of mortality up to 30 days of age.[6] In the past, few patients with complex CHD reached adulthood; however, this paradigm has changed over the years, especially in developed countries. Thus, the Brazilian national scenario requires more urgent measures to improve the survival of these children.

It is known that the comprehensive care of children with CHD in Brazil is still one of the significant challenges of the Unified Health System (SUS), with the continental dimension of our country being a considerable dilemma, where each region presents a reality check related to its technological development and human resources, with different public policies regarding the SUS.[7] A fundamental point in the context of the care of patients with CHD is access to the necessary health systems to allow timely diagnosis and treatment. Approximately 20%–30% of untreated children with cardiac disease die in the 1st month of life, making early diagnosis crucial to prevent and reduce morbidity and mortality associated with these diseases.[8]

Given the above and the scarcity of literature on CHD patients in the Amazon region, we saw the need to conduct a scoping review to systematically analyze and describe the main challenges of managing CHD in the Amazon region countries.

METHODS

Data sources

The chosen method was a scoping review synthesis based on the principles reported by Arksey and O'Malley[9] and supported by the principles of the Joanna Briggs Institute and following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews[10] checklist. A scoping review allows for evaluating new literature on the topic and provides an essential basis for future research. As this is a review, ethical committee approval is not required. Four databases were used: PubMed/Medline, Embase, Lilacs, and gray literature using Google Scholar. The systematic search was conducted during the month of January 2024. The descriptors used were CHD and developing countries. This methodology includes five stages: identification of the research question, identification of relevant studies, selection of studies, mapping of data, and presentation of results.

Research question identification

Given the limited data in the literature regarding the management of CHD in the Amazon region and the fact that it has not yet been summarized or synthesized, the research question is: What do we have in the literature about CHD in the Amazon region?

Identification of relevant studies

The review methodology used four databases: PubMed/Medline, Embase, Lilacs, and gray literature, including Google Scholar. The systematic search was conducted throughout January 2024, using descriptors such as CHD, children, and developing countries [Table 1]. The methodological process included five steps: Identification of the research question, identification of relevant

Table 1: Descriptors used in each database

Database (portal)	Search	Filter	Items found	Search date
Medline (PubMed)	("Developing Countries"[Mesh]) AND "Heart Defects, Congenital"[Mesh]	Humans	193	January/2024
Embase	'congenital heart disease'/exp OR 'congenital heart disease' OR 'heart defects, congenital'/exp OR 'heart defects, congenital' OR 'congenital heart malformations'/exp OR 'congenital heart malformations') AND ('Amazon region' OR 'Amazon' OR 'Brazil'/exp OR 'Brazil' OR 'South America'/exp OR 'South America')	Humans	466	January/2024
Lilacs	(mh: "Cardiopatias Congênitas" OR (cardiopatías congénitas) OR (heart defects, congenital) OR (malformação cardiovascular) OR (defeitos cardiovasculares congênitos) OR (anormalidades cardíacas) OR mh: c14.240.400* OR mh: c14.280.400* OR mh: c16.131.240.400*) AND (mh:"Países em Desenvolvimento" OR (países en desarrollo) OR (developing countries) OR (países subdesenvolvidos) OR (países do terceiro mundo) OR (países menos desenvolvidos) OR (nações em desenvolvimento) OR (países de baixa e média renda) OR (países de renda baixa) OR (país de renda baixa) OR (país de baixa renda) OR (países de baixa renda) OR (países de renda média) OR (países de média renda) OR (país de média renda) OR (países emergentes) OR (país de renda média-baixa) OR (países de renda média-baixa) OR mh: i01.615.500.300*) AND (db:("LILACS"))	Humans	26	January/2024
Google Scholar	"congenital heart disease fetal" and "developing countries"	Humans	103	January/2024

studies, selection of studies, mapping, and presentation of results. All identified studies were transferred into the Rayyan system and analyzed in an organized manner. The protocol for this scoping review was registered in the Open Science Framework on October 18, 2023 (https://doi.org/10.17605/OSFIO/7WK45).

Study eligibility criteria

The inclusion criteria were articles addressing any topic involving CHD in the Amazon region. Incomplete articles, book chapters, lectures, conference abstracts, and editorials were excluded. The initial screening included the removal of duplicate articles. Subsequently, two reviewers, working in pairs, analyzed the titles and abstracts of all publications according to the eligibility criteria. Later, the full texts were read in the final screening phase. Doubts and discrepancies were resolved by consensus and, if necessary, by discussion with a third reviewer. Cross-referencing and active searches for articles on the topic were also performed.

Data mapping

The following variables were collected from the included studies: author details, year of publication, study location, objectives, methodology, multidisciplinary team, and principal conclusions. We made an Excel data extraction form to collect relevant information from the studies in a systematic manner [Table 2].

Presentation of selected studies

The results of this scoping review were presented using narratives, tables, and graphs.

RESULTS

The initial search of the four databases PubMed/Medline (193), Embase (466), Lilacs (26), and gray literature through Google Scholar (102) yielded 787 articles. After 265 duplicate articles were removed and titles and abstracts evaluated, 513 articles were excluded. Cross-referencing analysis was performed, and at the end of the screening process, 9 articles remained for in-depth review. This final number represents the eligible studies for inclusion in the review [Figure 1].

Table 2 provides a detailed overview of the 9 eligible articles,[11-19] including author details, year of publication, study location, objectives, methodology, multidisciplinary team, and critical findings.

In Figure 2, we provide a comprehensive overview of studies on challenges in managing CHD in the countries that make up the Amazon region. Most of the studies have been reported in the last 10 years,[11,13-16,18,19] thus demonstrating the paradigm shift in these countries, with greater concern in managing children with CHD. Among the 9 included studies, we observed that 2 are Colombian[12,15] and 7 are Brazilian,[11,13,14,16-19] 4 of which are from the Brazilian Amazon region.[11,13,18,19] It is observed that there is still a lack of data, especially in other countries in the Amazon region where no studies have been found [Figure 2].

Regarding methodology, we included 2 ecological studies, 6 cross-sectional studies, and 1 review article [Table 2]. The two ecological studies are Brazilian and evaluated the situation of congenital surgery in each Brazilian region[14] and how a regionalization program can reverse the critical situation in the Amazon region (North of Brazil).[17] Among the cross-sectional studies, we find the description of clinical and epidemiological characteristics,[11,13,19] the presentation of the results of a social program in children's cardiac surgery in Colombia,[15] the evaluation of the consequences of the COVID-19 pandemic in CHD surgery centers[16] and the analysis of waiting time for cardiac surgery.[18] It was observed that 5 studies were conducted in the presence of a cardiac surgeon or a hemodynamics expert.[14-18] These are the studies that most commented on the surgical conditions of these patients, the waiting time for surgery, the multidisciplinary team and limited resources, and the need to implement effective public policies to optimize the management of these patients. The other studies comment on the high mortality

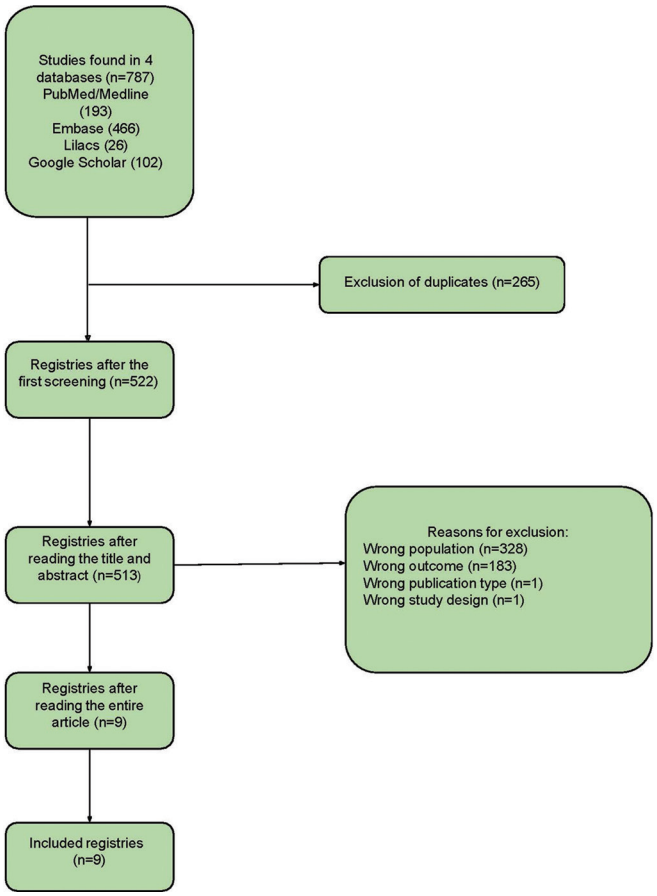

Figure 1: Flowchart of the included studies

Table 2: Main results of the included studies

References	Objective	Methodology	Health team	Main findings
Alves *et al.*, 2022[11] Brazil	Describe the clinical-epidemiological profile of cases of CHD treated at a referral hospital in the state of Pará, Brazil	Cross-sectional	Nephrologist, biologist, nurse, physiotherapist, biomedical, and technologist	There are difficulties in access to diagnosis and treatment, especially in communities further away from the state capital. 52% were older than 1 year at diagnosis, and 75.1% had acyanotic heart disease, with ventricular septal defect being the most common (21%). Tetralogy of Fallot was the most common cyanotic heart disease (12%). There was no gender predominance. At the time of evaluation, 55.7% of patients were awaiting treatment. The mortality rate during the study period was 9.61%, of which 83.9% were treated surgically
Araujo, 2019[12]	To explain why CHD in adults is actually a heterogeneous specialty	Review article	Cardiologist	Adult CHD is a heterogeneous group in which different adult specialties (cardiologic and non-cardiologic) should participate–the creation of the Colombian Adult CHD Chapter
Cappellesso and De Aguiar, 2017[13]	Investigate the epidemiologic and clinical characteristics of children and teenagers from a children's hospital in Manaus - Amazonas	Cross-sectional	Nurse	There are difficulties in accessing diagnosis and treatment, especially in municipalities further away from the state capital. There is a high rate of CHD among children belonging to families with unfavorable socio-economic conditions, with complications in most cases, requiring high-complexity services
Pinto *et al.*, 2004[14] Brazil	Describe the situation of congenital heart surgeries in Brazil	Ecological	Vascular Surgeon	The situation is more critical in the Northern and Northeastern regions of Brazil
Sandoval *et al.*, 2023[15] Colombia	To present the experience of a social program in pediatric cardiac surgery in a country of medium income	Cross-sectional	Pediatric cardiac surgeon	Highly effective, reproducible, and self-sustainable social responsibility program
Miana *et al.*, 2022[16] Brazil	To study the COVID-19 pandemic implications in Brazilian pediatric and congenital heart surgery programs	Cross-sectional	Physician and vascular surgeon	In general, Brazilian pediatric and congenital cardiac surgery programs have been seriously affected by the decrease in surgical volume, unbalanced case mix towards more complex cases, and increased mortality. Almost half of the programs are related to postoperative COVID-19 contamination with high mortality
Pinto *et al.*, 2013[17] Brazil	Describe the national panorama about the distribution of pediatric cardiovascular surgery centers, with speeches and concepts about regionalization	Ecological	Vascular surgeon	Demonstrated the building of a regionalized network of assistance, equitably distributed in all regions of Brazil; promoted a supraregional reference center; and created centers tutors for multidisciplinary training. It also reports a need for government interest in implementing effective public policies
Jesus *et al.*, 2018[18] Brazil	Analyze the waiting time for elective surgical treatment and/or intervention in children with CHD in a cardiology referral center	Cross-sectional	Pediatric cardiologists, hemodynamics	Most of the children waiting for cardiac procedures come from outside the metropolitan area and have malformations that can potentially be treated by catheterization
Freitas *et al.*, 2024[19] Brazil	To describe the incidence and different clinical manifestations of CHD cases in newborns from referral hospitals in Manaus, Amazonas	Cross-sectional	Pharmaceutical, biomedical	The study suggests a close relationship between CHD and a systemic impact, including a profile of chronic inflammation, chronic/acute renal failure, and liver disease

CHD: Congenital heart disease, NGO: Nongovernmental organization

rate due to CHD in the region,[11] higher frequency of CHD in the population with unfavorable socioeconomic conditions,[11,13] difficulties in accessing the diagnosis and treatment,[11,13] systemic involvement of the heart disease, considering the need for a multidisciplinary group, with the presence of cardiological and non-cardiological specialists, mainly in the adult population with CHD.[12,19]

DISCUSSION

In this scoping review, our aim was to systematically analyze and describe the main challenges of managing CHD in the Amazon region countries. We identified only 9 studies, highlighting the lack of literature on this important subject. Identifying a lack of research on this topic in the Amazon region underscores the need for more investment and effort to understand and address the specific challenges in this area. Dissemination of the knowledge generated by these studies can contribute to a better understanding of diagnosis, treatment, follow-up, and other aspects of CHD.

The diagnosis and treatment of CHD have evolved significantly over the past 80 years, but this evolution

Figure 2: Geographical overview of the included articles

has occurred satisfactorily in high-income countries. The findings of the articles included in this scoping review are consistent with literature data that demonstrate the difficulties in access to diagnosis and effective treatment of these patients in low- and middle-income countries, where many tend to die before their 5 years for lack of access to surgical treatment.[1]

We found that 9 included articles addressed some common themes: regional characteristics and epidemiologic factors, challenges to diagnosis and treatment, challenges to multidisciplinary teams, and impact of the COVID-19 pandemic. Each of these themes is discussed below.

Regional characteristics and epidemiological factors

The study area encompasses the vast Amazon River basin, the largest hydrographic basin on the planet. This region consists of 25 thousand kilometers of navigable rivers, which poses a significant challenge for access to referral hospitals, as the rivers serve as the main transportation routes in the area.[20]

This vast geographic area, characterized by an extensive river network, underscores the logistical complexity and challenges of access to health services, especially for diagnosing and treating medical conditions such as CHDs.[11,13,18,20] In addition to the geographical characteristics, we also have the unfavorable socioeconomic level of this location.[11,13] These characteristics pose challenges in the diagnostic and therapeutic management of these cases due to the educational, socioeconomic, and even cultural differences within this population.

Access to health care in the Amazon region faces significant challenges due to its vast geographic expanse and lack of infrastructure. A lack of the Internet access hampered the implementation of telemedicine, especially in remote towns. Many areas far from major urban centers experience connectivity difficulties, affecting telemedicine's feasibility as an effective solution to improve medical care in these regions.[1,11,20,21] This limitation highlights the need for innovative approaches that address connectivity barriers when implementing health-care solutions in the Amazon region.

The increasing private sector involvement in health care reinforces the concentration of specialized services in large cities where wealthier families reside. This exacerbates limitations in access to care, infrastructure deficiencies, and treatment effectiveness due to challenges in attracting and retaining health professionals, especially physicians.[18] This centralization significantly hinders access to health services for populations in remote or economically disadvantaged areas, exacerbating the shortage of health workers.[19] Therefore, strategies should address health infrastructure and the equitable distribution of resources and professionals to ensure adequate access to care throughout the Amazon region.[20]

Challenges to diagnosis and treatment

The complexity of CHD often requires surgical correction, and early diagnosis during prenatal care is crucial.[11] Delayed diagnosis of CHD and the extensive waiting time for surgical correction turn pediatric patients into adults with CHD, increasing the need for lifelong health care.[12,15] It is estimated that a significant proportion of CHD are diagnosed and treated in adulthood (10%–15%), particularly in Latin American countries. This finding is likely due to underdiagnosis and undertreatment in the region, making the clinical picture and natural history more severe.[12] These findings contradict current data from around the world, where we already have an adult population undergoing surgery and requiring later postoperative care after the asymptomatic "honeymoon" period of surgical correction.[12,22] In any case, a multidisciplinary team is always necessary to care for people with CHD, whether children or adults.[1,12,20]

In the Brazilian studies, we observed the establishment of specialized centers capable of performing congenital heart surgery. This initiative began in 2004 after the realization of the critical situation of these patients in the North and Northeast regions.[14] The average number of cardiovascular surgeries for CHD that were necessary in Brazil was in the order of 23,077 procedures per year, including newborns with CHD and cases requiring reoperation. In 2002, 8092 procedures were performed, representing a deficit of 65%, with the highest deficit in the Northern region (93.5%) and the lowest in the Southern and Central-Western regions (46.4% and 57.4%, respectively).[14] These services were strategically created to ensure one service per 800,000 inhabitants under the age

of 18 years, with the proposal to develop approximately 90 specialized CHD services nationwide. This register aims to analyze the quality of services and provide opportunities for the sector to be optimized and restructured. The last published report on the performance of congenital heart surgery in Brazil is from 2010, with a deficit reduction from 93.5% to 89% after creating two qualified centers in the North region.[17] We note the need for greater control in implementing, training, and evaluating the process.

Multidisciplinary team challenges

Demographic realities and a lack of medical support in diagnosis can hinder access to treatment.[11,12,17] Furthermore, there is a highlighted need for health-care professionals to receive training in pediatric cardiac intensive care, especially in resource-limited settings.[16] The lack of early diagnosis and treatment contributes to significant demand, as many patients rely on a single referral hospital in the area, making regionalization of care and patient arrival at the diagnostic center very challenging.[14,17]

Given the infrastructure challenges and limited access to health care, we recognize that the effectiveness of CHD treatment in the Amazon region is critical. It would be very interesting for the Amazon region to participate in global initiatives such as the IQIC (International Quality Improvement Collaborative for Congenital Heart Surgery in Developing Countries) as it is a promising strategy.[23,24] Brazil is part of the IQIC; however, this support has not yet been offered to any other state in the Amazon region. This global collaboration could strengthen local capacity, providing more efficient and comprehensive care for patients with CHD in the Amazon region.[21,23] The unequal distribution of specialized services, especially pediatric cardiac surgeons, contributes to disparities in care in the Amazon region, with the area having a significantly lower number compared to other regions with more than one referral center.[11,14,17]

Impact of the COVID-19 pandemic

Understandably, the COVID-19 pandemic has had a negative impact on global health, including pediatric and congenital heart surgery programs in the Amazon region. Disruptions caused by the pandemic, such as mobility restrictions, health system overload, and reallocation of resources to fight COVID-19, may have affected the ability to perform medical and surgical procedures unrelated to the pandemic.[16]

Difficulties may have been exacerbated in remote areas, such as the Amazon, where access is already challenging. The need to prioritize COVID-19 care may have postponed nonurgent procedures, including pediatric and congenital heart surgery. This underscores the importance of addressing not only existing challenges in medical conditions but also the resilience of health systems in the face of disruptive events such as a pandemic.[2,16] There is an urgent need to explore future research or specific interventions to mitigate the impact of the pandemic on health-care delivery, especially for critical conditions such as CHD in the Amazon region.[16]

Comparing the challenges faced in the Amazon region with global data reveals common barriers in low- and middle-income countries such as India, sub-Saharan Africa, and Southeast Asia.[1,25] Multicenter studies show that infant mortality from CHD remains high in these regions due to a lack of access to early diagnosis and specialized treatment.[1] In addition, socioeconomic and cultural differences, such as low family income and inadequate maternal education, exacerbate health challenges similar to those observed in India, where the centralization of health services in urban areas limits access for rural populations.[25] Therefore, strategies such as strengthening multidisciplinary teams, implementing telemedicine, and improving the training of health-care professionals are critical to improving the care of patients with CHD in remote and underdeveloped regions.

Strengths and limitations

This scoping review explored the multifaceted challenges of CHD in the Amazon region countries, addressing a significant gap in the current medical literature. Using a structured methodology helped to search for data in a comprehensive and organized manner. The findings highlight the urgent need for context-specific health interventions that could significantly influence the Amazon region's public health policy and resource allocation. Including evidence from diverse fields such as cardiology, public health, and epidemiology provides a well-rounded understanding of the complexities of managing CHD in under-resourced settings.

The specific focus on the Amazon region may limit the applicability of the findings to other areas with different socioeconomic and environmental contexts. The reliance on existing literature may introduce bias due to the uneven quality and depth of research on CHD in the Amazon, reflecting the broader issue of data scarcity in developing regions. As a scoping review, this study does not provide a quantitative synthesis of data, which may be necessary to inform specific clinical or policy recommendations. The unique geographic and infrastructural challenges of the Amazon region may impede the implementation of proposed interventions, a factor that must be considered when translating research into practice.

Future perspectives

As for future research perspectives, it would be valuable to explore ideas for studies addressing the following points: to investigate the specific prevalence of CHD in different areas and all the countries of the Amazon region; to evaluate the particular barriers that communities

face in accessing diagnostic, treatment, and follow-up services for CHD; to assess the effectiveness of specific interventions in improving early diagnosis, treatment, and quality of life of patients with CHD in the Amazon region; to analyze the economic and social impact of CHD in the area; and to identify strategies to mitigate these impacts. With more detailed research in this region, we can propose redirecting public policies to reduce mortality and improve the overall quality of life for those affected.

CONCLUSIONS

This scoping review provided a comprehensive overview of the challenges faced in the Amazon region regarding CHD. There is growing interest in analyzing the situation of CHD in the region. However, there are only a few studies on ecological and cross-sectional analysis. We observed a need for more data in the region, where only two countries have published records. Through these records, we can see the lack of hospital infrastructure and multidisciplinary teams for the diagnosis and treatment of CHD in the Amazon region; we know an initiative by specialists from these two countries to demonstrate the difficulties by seeking international training programs and government aid to improve this situation.

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Conflicts of interest

There are no conflicts of interest.

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