Cardiology in the Young

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Access to healthcare for children with CHDs in middle and low-income countries: a systematic literature review

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Abstract

CHD includes a wide range of cardiac disorders present at birth. If appropriate care is delivered in time, the prognosis is relatively good. However, in many parts of the world, access to healthcare continues to be a problem for these patients, particularly in low- and middle-income countries. The aim of this study was to synthesise and analyse the available evidence to provide a deeper understanding of this problem. The literature search identified 1578 articles, and the final selection included 57 articles. Using the patient-centred healthcare access framework for identifying facilitators and barriers, issues were found at all levels of the health provision pathway, of which diagnosis, referral systems, lack of qualified institutions/health professionals, financing, inappropriate health insurance, and quality of care stand out. More evidence is needed to analyse the effect of potential barriers linked to acceptability. Given the nature of the barriers that this population faces, solutions depend on the health system and the local context.

Introduction

CHD refers to a wide range of cardiac disorders present at birth. The medical treatment for most of the children suffering from these conditions includes surgery, either corrective or palliative, within their first years of life.[1] If this is delivered in time, the prognosis is relatively good, and 85% of children may reach adulthood.[2] However, in many parts of the world, access to healthcare continues to be a problem for this patient population.[1]

Access to healthcare is a key building block of healthcare systems, which includes availability of facilities, resources and professionals, but also other aspects related to contact with the health system and the use of services, such as the delivery of information, financing and referral procedures. An adequate healthcare system that provides access to the population is crucial for achieving universal healthcare coverage,[3] which is a goal endorsed by many governments and international organisations such as the United Nations;[4] however, it is not available to all who need it. Furthermore, it is argued that access to healthcare is essential to protect human rights, as governments are obliged to "*adopt appropriate legal, budgetary, and other measures to ensure that individuals' human rights are fully realized*".[5] Ensuring proper access to healthcare requires not only the provision of sufficient healthcare by governments but also the participation of national stakeholders in the policy-making process, including civil society and non-governmental organisations.[6]

CHD affects children from all social groups in countries around the world,[7–9] and even though the incidence of CHD is relatively low—approximately 1% of newborn children[7]—it cannot be considered an orphan disease.[10] Consequently, it does not benefit from the policies designed to improve healthcare for diseases grouped in this category. There are a number of non-government organisations, scientific societies, and academic institutions providing support and advocacy, mostly in high-income countries but also in low- and middle-income countries. Nevertheless, they frequently tend to work without proper coordination,[1] leading to less social visibility.

Patients suffering from CHD frequently face significant barriers to accessing healthcare, particularly in low- and middle-income countries.[11–15] This means that care is not always provided, leading to more than 260,000 deaths each year worldwide, concentrated mostly in low- and middle-income countries.[16] Access to treatment for patients with CHD is of particular interest because there are features that make the treatment of these diseases different from other

conditions. As is the case of common paediatric cancers, CHD requires intensive use of healthcare resources, and many parents are not able to afford these costs when health insurance coverage is not available.[14,17] Furthermore, it is often the case that the provision of services is restricted to a limited number of facilities,[18] decreasing availability. Additionally, the CHD diagnosis is often difficult and many low- and middle-income countries do not have the resources or policies to carry it out and the referral process is not always well organised.

There is evidence of the barriers to access to treatment for children with CHD from high-income countries, which has been summarised in systematic and scoping reviews. In these studies, socio-economic and geographic issues[19] and non-reimbursement of some treatments[20] have been identified as barriers to access. A scoping review on a different population, namely children suffering from cancer in low- and middle-income countries, showed that factors such as misconception, stigma, and hierarchical relationships between parents and healthcare providers played a significant role in making communication and healthcare provision more difficult.[21] These factors may also thwart access to healthcare for children with CHD in low- and middle-income countries.

Synthesising and analysing the available evidence are needed to provide a deeper understanding of this problem. This information is vital to identify key barriers that explain the lack of access to healthcare for these children. This can help design and implement information-based policies to increase the provision of care for these children, and in this way reduce preventable deaths in this population. Consequently, this systematic literature review aims to systematically analyse the existing information on the key barriers to access to treatment for children with CHD, summarising the main reported findings and identifying factors that make access more difficult. Additionally, it is possible to identify potential knowledge gaps that may lead to further scientific research. Increasing the knowledge on this issue is a priority because CHD is a leading preventable cause of disability, and even death, for many children in low- and middle-income countries,[1] and informed and efficient healthcare policies could help to increase access and improve healthcare outcomes for these children in these countries.

Materials and methods

This review uses the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA; see checklist in Annex 1). A protocol was developed and registered in PROSPERO (ID number 470589).

The main outcome we focused upon in this study was access to healthcare for a specific population, namely children suffering from CHD. The context was low- and middle-income countries, defined by the World Bank as those countries having a gross national income per capita lower than US$13,205[22] (see Annex 2).

The PICOTS framework was used to define relevant inclusion and exclusion criteria, which included: (1) articles focused on children with CHD; (2) describing the process of healthcare access or concrete barriers to it; (3) published after 2000; (4) in low- and middle-income countries; (5) qualitative, quantitative, or mixed-methods studies; and (6) in English, French, Spanish, and Portuguese. Articles that did not meet the previously mentioned criteria were excluded. Annex 3 provides more information on the selection criteria.

The following databases were consulted for relevant academic literature: PubMed, Scopus, and Web of Science (WoS). Additionally, the reference lists of relevant articles were scanned to find studies not identified by the initial search.

Based on the main objective of this study, the following key concepts were identified: healthcare access, healthcare barriers, CHDs, paediatric patients and low- and middle-income countries. These concepts were used with different syntaxes, according to each database's nomenclature, leading to different search strings for each database, which are available in Annex 4. References found were exported to EndNote and duplicates were removed using an internal algorithm and checked manually.

The selection of articles was done in three steps. First, titles and abstracts were screened to identify studies that met the inclusion criteria. A second researcher verified the selection of a sample of articles. All discrepancies were discussed by both researchers and a consensus was reached on the inclusion of each article. Agreement was reported appropriately. Then, full texts were screened to select articles that investigated access to healthcare for this population. Finally, the reference lists of the selected publications were reviewed using the same inclusion criteria. The relevance of the literature sources was judged according to the aforementioned inclusion and exclusion criteria.

The analysis used Lavesque's framework for identifying facilitators and barriers to patient-centred healthcare access,[23] which includes six steps for effective provision, and five healthcare features and five patients' skills that enhance or impede access. Based on this framework, an extraction matrix was developed in Microsoft Excel (v. 16.78.3). A summary of the main findings of each publication was included in the extraction matrix. One author (RL) charted the data, and this file was reviewed by another author (WS), discussing discrepancies. Information was then organised into tables and analysed using qualitative thematic analysis, using categories from Lavesque's framework.[23]

The quality of the scientific publications was assessed by means of standardised evaluation checklists based on the Critical Appraisal Skills Programme (CASP) quality appraisal tool checklists for qualitative[24] and quantitative[25] studies, paying particular attention to validity and reliability, i.e., where the source came from and whether it had been peer-reviewed.

Results

The literature search was conducted in October 2023 and yielded a total of 1,578 articles (1206 in PubMed, 167 in Scopus, and 205 in Web of Science). After eliminating duplications, a final list of 1,448 articles was screened by one author (RL), and a sample of articles was independently reviewed by another author (WS), according to the aforementioned stages. The agreement between them was 95.5% (kappa coefficient 0.7575; a sample of 35% of identified articles) for the title screening and 88.5% (kappa coefficient 0.7636; a sample of 30% of selected articles) for the abstract screening. The final selection of articles is depicted in Figure 1. Table 1 provides a summary of the 57 selected articles. Figure 2 shows countries where articles were selected from. See Annex 5 for publication details.

Studies have different sample sizes depending, among others, on the context and the approach, qualitative or quantitative. In addition to traditional clinical studies, we identified some reports describing the experience of a single centre or non-government organisation in a narrative way, while others used existing databases and estimates according to projections. The number of participants in articles included in this review ranged from 10 to 15,066. In terms of quality, quantitative studies obtained an average score of 7.9 points (out of 12), whereas qualitative studies

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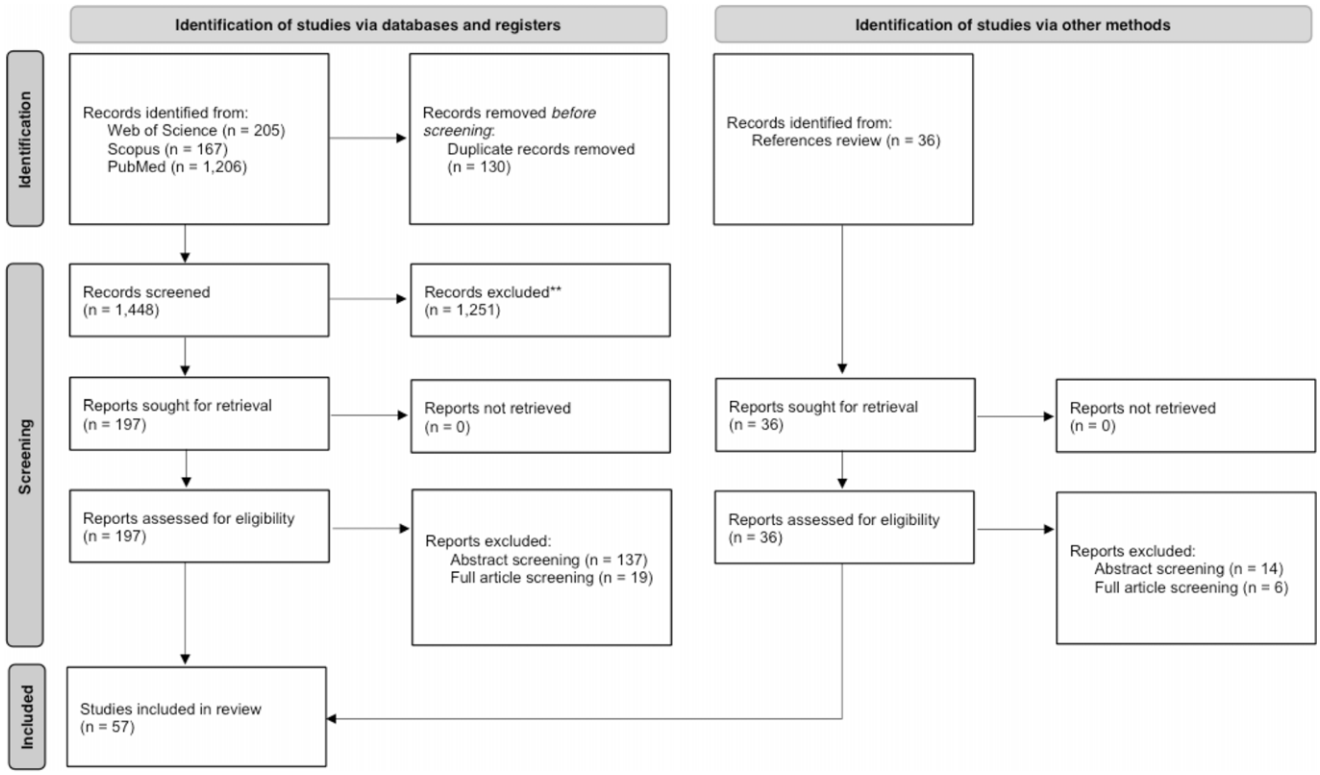

Figure 1. Flow diagram showing the identification and selection process of articles.

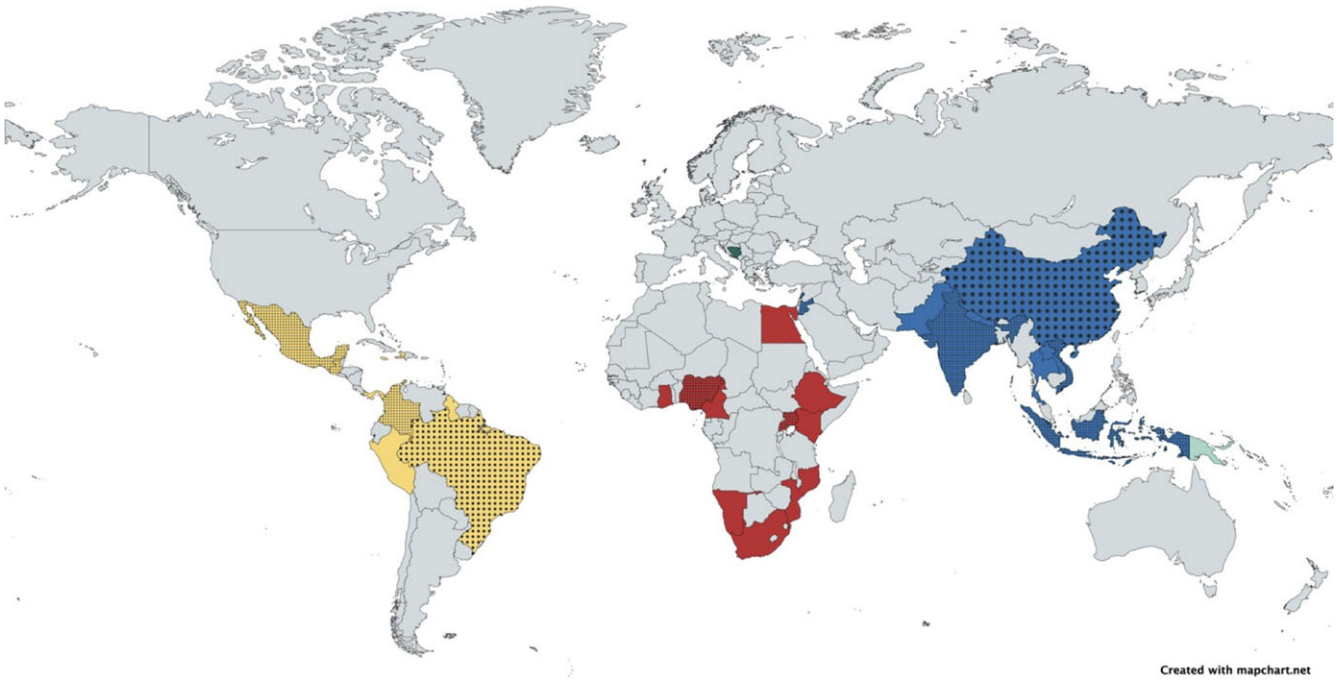

Figure 2. World map showing the countries from which articles were selected. If more than 1 article was selected, the country is dotted.

scored 5.7 (out of 10). However, not all studies could be assessed, given the different methodologies used.

To analyse the content of the publications further, we used Levesque's model, which distinguishes different types of access barriers for both the health system and patients, acting at different levels of the clinical encounter. Given that the barriers of the system and of the patients are closely related and in practice are the expression of the same phenomenon on one side or the other, it

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Table 1. Description of selected articles

Feature		Number of articles (%)
Publication year	2001–2005	4 (7.02)
	2006–2010	5 (8.77)
	2011–2015	14 (24.56)
	2016–2020	25 (43.86)
	2021–2023	9 (15.79)
Region	Asia	21 (36.84)
	Africa	17 (29.82)
	Americas	11 (19.3)
	Europe	1 (1.75)
	Pacific	1 (1.75)
	Mixed	6 (10.53)
Approach	Quantitative	32 (56.14)
	Qualitative	7 (12.28)
	Mixed-methods	4 (7.02)
	Experience description	14 (24.56)
Language	English	56 (98.25)
	Spanish	1 (1.75)

was decided to analyse the barriers in pairs. In this way, the stages of the medical care delivery process that present barriers are better illustrated (Table 2).

The selected articles revealed barriers in all stages of the medical care delivery process, with barriers being most reported in the *availability/ability to reach* stage, with 44 articles (78.6%), followed by *appropriateness/ability to engage* and *affordability/ability to pay*, mentioned in 43 articles (76.8%) each, then *approachability/ability to perceive*, with 38 articles (67.9%), and finally *acceptability/ability to seek*, which were reported in 21 articles (37.5%). A geographical analysis of the stages in which the barriers were described provides interesting results, which are depicted in Annex 6.

In the first phase of the healthcare delivery process, which relates to *approachability* and the *ability to perceive*, the articles showed that there are several factors that make access a difficult task. In many contexts, a significant proportion of children are born at home, so they receive little or no neonatal medical care.[13,26–28] Furthermore, families do not know what symptoms could be explained by CHD, so they do not perceive the need for healthcare.[11,13,29–33] At the same time, health professionals themselves often do not have the necessary skills and resources for the screening of these diseases.[26,27,34–37] If despite these factors, the diagnosis is assumed, the referral process to a tertiary level facility is complex.[3,17,30,33,34,38–44] All these factors delay the diagnosis, often limiting the therapeutic options available.[45–48]

The second stage of the care delivery process was related to *acceptability* and the *ability to seek*. These were the least reported barriers in the selected articles. Among the cultural factors that could become barriers to access are gender biases,[26,28,49] the advice of traditional healers,[29,33,34,44] distrust of Western medicine,[11,13] long waiting lists,[50] and communication issues.[11,28,31–33,36,44,51,52] The latter factors contribute to increased anxiety and distress for families when dealing with healthcare institutions.[30,53]

Barriers related to *availability* and the *ability to reach* were the most common issues in the selected articles. The availability of care can be broken down into material and human resources,[29,34,40,41,45–48,50,54–66] but some articles point to more specific aspects, such as the possibility of receiving training in the care for these children,[35,36,54,67] the procedures for acquiring consumables,[40] and the availability of medications.[68] Regarding the ability to reach healthcare facilities, the most mentioned barrier was the distance to the centre where the surgery can be performed,[13,17,31,33,34,43,44,47,56,69–71] along with the costs of travel, which will be discussed later. This is why a number of authors advocate the establishment of more paediatric cardiac surgery centres.[34,50,56,61]

In terms of *affordability* and the *ability to pay*, the barriers detected in the selected articles recognise that these treatments have a high cost,[26,40,57,61,68] although this would be lower in some low- and middle-income countries.[50,65] The intensive use of resources that these pathologies imply constitutes a barrier in itself, particularly for low-income families.[27,37,47–49,53,60,66,70,72–74] Furthermore, governments in low- and middle-income countries do not always have the resources to deal with them, so treatment must often be paid for by the families themselves,[33,35] or is done in private centres.[34,40,56] It is noteworthy that people in many of these contexts lack appropriate health insurance,[13,17,26,28,30,38,41,42,54,55,57,60,72,74–76] which does not happen in all countries.[29] These facts would make financial matters a difficult barrier to overcome for many families. Furthermore, one of the aspects that is often not considered in the treatment of chronic diseases, is indirect costs, such as travel costs and loss of revenue,[13,31,34,44,50] which is partially mitigated in some contexts.[32]

As already mentioned, many children are born outside the hospital, so they are not evaluated by professional personnel immediately postpartum, limiting diagnostic options, but even if they are treated, the lack of awareness of health professionals makes the diagnosis a challenge for families.[34,41,45,47,48,64] Problems related to the *quality of care* are the lack of trained workforce, as commented in availability, and the lack of clinical records that allow evaluation of local protocols and resources.[51,56,58,77] In terms of quality of care, one author proposes that resources should be allocated "*to support regional centers of excellence*"[54,58] (p. 5). Another factor associated with the quality of care is poor communication between health professionals[29] and poor working conditions.[65,71] Communication is an important issue because the difficulties that families experience in understanding the situation have already been discussed, which is one of the factors that has been proposed as an explanation for the lack of follow-up,[38,43,47,54,70,75] an expression of the *ability to engage*. However, numerous experiences show that it is possible to engage families by means of tailored programmes.[30,31,33,44,52,67]

Discussion

This review analysed the evidence on the key barriers to access to treatment for children with CHD. The results show the wide range of obstacles that children suffering from CHD and their families face during their care journey to receive appropriate healthcare in low- and middle-income countries. Making the diagnosis is the first major issue, both due to lack of knowledge and cultural misconceptions of parents and lack of awareness from the health professionals' side. If CHD is suspected, access to healthcare and higher-level referral systems are often complex, and in some cases,

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Table 2. Barriers according to different stages of the healthcare provision

System	Approachability	Acceptability	Availability and accommodation	Affordability	Appropriateness
	Transparency	Professional values, norms, culture, gender	Geographic location	Direct costs	Technical and interpersonal quality
	Outreach		Accommodation	Indirect costs	Adequacy
	Information		Working hours	Opportunity costs	Coordination and continuity
	Screening		Appointment mechanisms		
Patients and families	**Ability to perceive**	**Ability to seek**	**Ability to reach**	**Ability to pay**	**Ability to engage**
	Health literacy	Personal and social values, culture, gender, autonomy	Living environments	Income	Empowerment
	Health beliefs		Transport	Assets	Information
	Trust and expectations		Mobility	Social capital	Adherence
			Social support	Health insurance	Caregiver support
Barriers	Home delivery	Gender biases	Lack of material resources	Treatment costs	Lack of clinical files
	Parents unawareness	Traditional healers	Lack of human resources	Lack of financing mechanisms	Paperwork
	Lack of healthcare professionals training	Communication issues	Lack of training programmes	Travel costs	Poor interprofessional communication
	Complex referral process	Anxiety		Loss of revenue	Poor communication with families

there are simply no institutions/health professionals capable of providing the necessary care. Another major problem is financing, since these conditions usually require intensive use of resources and, in many countries, health insurance has set limits, exclusions, or caps on the extent of the coverage of these costs. Moreover, the indirect costs of treatment are not covered. Finally, in cases where all these barriers have been successfully overcome, the quality of care may not be assured due to a lack of training programmes for health professionals, clinical records, or other administrative reasons.

It is interesting to note that the distribution of these barriers shows differences depending on the geographical location of the countries. According to the articles included in this systematic review, in Asia, the barriers most frequently reported are mostly related to affordability/ability to pay and appropriateness/ability to engage. In Africa, it is mostly the availability/ability to reach and affordability/ability to pay, whereas in the Americas, appropriateness/ability to engage and approachability/ability to perceive account for more reported barriers. These differences could be linked to the level of development of paediatric cardiovascular surgery programmes in each continent, although the differences between countries within a continent are frequently as large as those between continents. In Latin America, for example, there are programmes that have been operational for several decades, while in Africa, many of the few centres have been developed relatively recently. However, these results should be interpreted with caution, given that the realities of the different countries in each continent can be very different. The health systems and resources available in Morocco are not similar to those of Mozambique (the former has centres that carry out surgical interventions for these children daily, while the latter depends on medical missions with health professionals from abroad), although both countries are in Africa. Unfortunately, it is not possible to perform a country-by-country analysis, since in most cases only one report is available for each context. For only two countries more evidence was available: India with 9 articles and Nigeria with 6. It is also important to highlight that the lesser expression of barriers is not necessarily linked to the non-existence of the problem but to underreporting. In Africa, not many barriers linked to the quality of healthcare are reported, but this could be because, in many African countries, the priority continues to be the availability of such care. In the same vein, barriers linked to acceptability/ability to seek were the least reported on all continents, but this is probably because such topics have not been explored in the academic studies included in this review and not because health systems are widely accepted in all contexts.

The following recommendations to reduce barriers to access to healthcare for this population can be drawn from our review findings:

- Strengthening the capacities of healthcare staff to diagnose these conditions is crucial because although there are simple screening protocols that require few resources, many professionals do not have the knowledge about these procedures.
- More resources for the treatment of these children should be provided, including indirect costs.
- Designing a sustainable strategy is essential and long-term financing strategies for this care must be considered, whether through health insurance, public spending, or some type of long-term public-private partnership.
- Having more paediatric cardiac surgery centres in underserved areas may seem to solve the problem of geographical availability; however, it could actually decrease the quality of care by diminishing the number of surgeries performed at each centre. The solution seems to be more along the lines of organising regional centres of excellence, capable of effectively resolving the pathologies of a given catchment area.
- In order to give these patients access to these centres, comprehensive and efficient transfer systems should be put in place to ensure the necessary conditions for the transfer of patients and their families.
- Additionally, advocacy groups could use this information, increasing coordination, and tailoring the message to specific audiences with data based on the most important issues of each region.

These results echo those reported in other similar studies. In a systematic review of CHDs with articles mainly from North America, Davey et al[19] reported that the social determinants of health (i.e. poverty/low socio-economic status, among others) were

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significantly associated with a lower probability of prenatal diagnosis and less use of healthcare resources, which was operationalised in a similar way to the ability to engage. Among the causal mechanisms proposed to explain this association would be transportation difficulties and lack of health insurance. In a scoping review focusing on a similar population, paediatric patients from low- and middle-income countries, but a different condition, paediatric cancer, Graetz et al[21] reported that communication barriers identified during the provision of healthcare services included misconceptions, stigma, and power relationships between parents and providers. Although in our findings, a number of communication problems between parents and health professionals are shown (which could be related to the ability to engage), findings in this dimension would probably fall into the acceptability/ability to seek category, for which we have less information. This is consistent with the research methodologies described in both systematic reviews because Greatz included 85% qualitative articles, while in our sample only 12.3% of the studies used such methodology.[21]

Recently, Cheng et al. published a systematic review of barriers to accessing congenital heart surgery in low- and middle-income countries.[79] The fact that there were two systematic reviews shows the high relevance of the topic and the different methodologies used for the search and analysis of results, as well as the different inclusion and exclusion criteria for the selection of articles, make these works complementary in nature. Despite the differences, both systematic reviews point to similar phenomena as possible causes of difficult access to healthcare for this population. In their systematic review, the barriers are temporally classified as pre-, peri-, and post-operative. However, as recognised in the article, many barriers interact with each other, so classification may be problematic. Using a structured approach, such as the categories proposed by Levesque, was useful in overcoming this problem in our case.

One of the main strengths of this systematic review is that it uses a validated framework, such as Levesque's, to analyse the barriers found in the included articles. In this way, it would not only be possible to compare the results with other contexts in which a similar approach is used, but it is also possible to identify dimensions in which there is less information available, such as acceptability, suggesting future areas for research.

Among the limitations inherent to this type of article, selection bias was managed by cross-checking two authors. Despite the high concordance between them, which speaks of good inclusion and exclusion criteria, some remaining biases cannot be ruled out. Due to the research team's experience conducting these types of studies, a medical librarian was not consulted, which could have led to a suboptimal search strategy. Publication biases must also be acknowledged. There may be studies that identify barriers but were not published in scientific journals indexed in the search engines used in this systematic review. Remarkably, even if the search criteria included articles in different languages, the vast majority of the selected studies are in English, which could be an expression of this issue. In this same vein, it is possible that there are barriers that have not yet been explored in medical research because researchers are not aware of them. This could be the case of barriers linked to acceptability, which were relatively underreported and might be a relevant knowledge gap to be filled. This study examines barriers to accessing health care for populations in low- and middle-income countries and the research team is made up of academics from high-income country, however, they have vast experience in similar contexts. Finally, the quality of the included studies was not optimal, limiting the validity of these findings.

In conclusion, there are several barriers for children affected by CHD to access healthcare, among which the following stand out: diagnosis, referral systems, lack of qualified institutions/health professionals, financing, inappropriate health insurance, and quality of care. There is no silver bullet to solve the problems, but the solution depends on the health system and the local context. More information is needed to propose solutions tailored to each context, as well as to analyse the effect of potential barriers linked to acceptability.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1047951124036485.

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References

1. Vervoort D, Zheleva B, Jenkins KJ, Dearani JA. Children at the heart of global cardiac surgery: an advocacy stakeholder analysis. World J Pediatr Congenit Heart Surg 2021; 12: 48–54.
2. Bhat AH, Sahn DJ. Congenital heart disease never goes away, even when it has been 'treated': the adult with congenital heart disease. Curr Opin Pediatr 2004; 16: 500–507.
3. Mills A. Health care systems in low- and middle- income countries. NEJM 2014; 370: 552–557.
4. United Nations General Assembly. Resolution A/74/L.4, 2019. Political declaration of the high-level political forum onsustainable development convened under the auspicesof the General Assembly. Available at https://documents.un.org/doc/undoc/gen/n19/318/21/pdf/n1931821.pdf. Published on October 2019. Accessed on December 2022.
5. Global Network of WHO Collaborating Centres for Bioethics. Global Health Ethics. Key Issues. World Health Organization, Geneva, 2015. Available at https://iris.who.int/bitstream/handle/10665/164576/9789240694033_eng.pdf?sequence=1. Accessed on December 2022.
6. Office of the United Nations High Commissioner for Human Rights & World Health Organization. The Right to Health, United Nations, Geneva, 2008.
7. Moller JH, Taubert KA, Allen HD, Clark EB, Lauer RM. Cardiovascular health and disease in children: current status. a special writing group from the task force on children a youth, American Heart Association. Circulation 1994; 89: 923–930.
8. Armstrong BJ, Dolk H, Pattenden S et al. Geographic variation and localized clustering of congenital anomalies in Great Britain. Emerg Themes Epidemiol 2007; 4: 14.
9. Mulder BJM. Epidemiology of adult congenital heart disease: demographic variations worldwide. Neth Heart J 2012; 20: 505–508.
10. United States Congress. H.R.4013 – Rare Diseases Act of 2002, 107th Congress (2001-2002). Available at https://www.congress.gov/bill/107th-congress/house-bill/4013. Published on June 2002. Accessed on December 2022.
11. Salgado CL, Lamy ZC, Nina RV, Melo LA, Lamy Filho F, Nina VJ. Pediatric cardiac surgery under the parents' view: a qualitative study. Rev Bras Cir Cardiovasc 2011; 16: 36–42.
12. Elissa K, Sparud-Lundin C, Axelsson Å.B, Khatib S, Bratt EL. Struggling and overcoming daily life barriers among children with congenital heart disease and their parents in the West Bank, Palestine. J Fam Nurs 2018; 24: 585–611.
13. Choi S, Shin H, Heo J et al. How do caregivers of children with congenital heart diseases access and navigate the healthcare system in Ethiopia? BMC Health Serv Res 2021; 21: 110.

14. vervoort D, Vinck EE, Kishore Tiwari K, Tapaua N et al. Cardiac surgery and Small Island States: a bridge too far? Ann Thorac Surg 2021; 111: 931–936.
15. Sabatino ME, Dennis RJ, Sandoval-Trujillo P, et al. Access to paediatric cardiac surgery in Colombia: a population-based study. Eur J Cardiothorac Surg 2022; 61: 320–327.
16. Zimmerman MS, Smith AG, Sable CA et al. Global, regional, and national burden of congenital heart disease, 1990–2017: a systematic analysis for the global burden of disease study 2017. Lancet Child Adolesc Health 2020; 4: 185–200.
17. Kowalsky RH, Newburger JW, Rand WM, Castañeda AR. Factors determining access to surgery for children with congenital cardiac disease in Guatemala, Central America. Cardiol Young 2006; 16: 385–391.
18. Salciccioli KB, Oluyomi A, Lupo PJ, Ermis PR, Lopez KN. A model for geographic and sociodemographic access to care disparities for adults with congenital heart disease. Congenit Heart Dis 2019; 14: 752–759.
19. Davey B, Sinha R, Lee JH, Gauthier M, Flores G. Socioeconomic determinants of health and outcomes for children and adults with congenital heart disease: a systematic review. Pediatr Res 2021; 89: 275–294.
20. Dold SK, Hass NA, Apitz C. Effects of sport, exercise training, and physical activity in children with congenital heart disease – a review of the published evidence. Children 2023; 10: 296.
21. Graetz DE, Garza M, Rodrigguez-Galindo C, Mack JW. Pediatric cancer communication in low- and middle-income countries: a scoping review. Ann Ny Acad Sci 2020; 126: 5030–5039.
22. World Bank. World bank country and lending groups, 2023. [online]. Available at: https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups. Accessed on March 2023.
23. Levesque JF, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. Int J Equity Health 2013; 12: 18.
24. Critical Appraisal Skills Programme. CASP Qualitative Checklist, 2018. [online] Available at: https://casp-uk.net/checklists/casp-qualitative-studies-checklist-fillable.pdf. Accessed on November 2023.
25. Critical Appraisal Skills Programme. CASP Cohort Study Checklist, 2018. [online] Available at: Critical Appraisal Skills Programme (2018). CASP Qualitative Checklist. [online] Available at: https://casp-uk.net/checklists/casp-qualitative-studies-checklist-fillable.pdf. Accessed on November 2023.
26. Kiran VS, Nath PP, Maheshwari S. Spectrum of paediatric cardiac diseases: a study of 15,066 children undergoing cardiac intervention at a tertiary care centre in India with special emphasis on gender. Cardiol Young 2011; 21: 19–25.
27. Rashid U, Qureshi AU, Hyder SN, Sadiq M. Pattern of congenital heart disease in a developing country tertiary care center: factors associated with delayed diagnosis. Ann Pediatr Cardiol 2016; 9: 210–215.
28. Saxena A. Congenital heart disease in India: a status report. Indian Pediatr 2018; 55: 1075–1082.
29. Phuc VM, Tin DN, Cam Giang DT. Challenges in the management of congenital heart disease in Vietnam: a single center experience. Ann Pediatr Cardiol 2015; 8: 44–46.
30. Ezzat S, Saeedi O, Saleh DA et al. Parental perceptions of congenital cardiovascular malformations in their children. Cardiol Young 2016; 266: 1158–1167.
31. Olarte-Sierra MF, Suarez R, Rubio MA. Brigadas de salud en cardiología pediátrica: del triaje médico al triaje social. Salud Colect 2018; 4: 531–544.
32. Vivan L, Comitis G, Naidu C, Hunter C, Lawrenson J. A first qualitative snapshot: cardiac surgery and recovery in 10 children in the red cross war memorial children's hospital, Cape Town, South Africa (2011–2016. Cardiol Young 2018; 28: 322–328.
33. Bansal E, Patel K, Lacossade S et al. Population health and socio-demographic variables as predictors of access to cardiac medicine and surgery in Haiti. Glob Health Res Policy 2023; 8: 27.
34. Saxena A. Congenital heart disease in India: a status report. Indian J Pediatr 2005; 72: 595–598.
35. Hwang IC, Sisavanh M, Billamay S et al. Congenital heart disease at Laos children's hospital: two year experience. Pediatr Int 2017; 59: 271–279.
36. Isaac D, Nagesh V, Bell A et al. Impact of a pediatric cardiology clinical program on congenital heart disease outcomes in Guyana. Glob Pediatr Health 2017; 4: 1–6.
37. Murni IK, Wibowo T, Arafuri N et al. Feasibility of screening for critical congenital heart disease using pulse oximetry in Indonesia. BMC Pediatr 2022; 22: 369.
38. Al-Ammouri I, Ayoub F. Heart disease in Syrian refugee children: experience at Jordan university hospital. Ann Glob Health 2016; 86: 300–306.
39. Ekure EN, Bode-Thomas F, Sadoh WE et al. Audit of availability and distribution of paediatric cardiology services and facilities in Nigeria. World J Pediatr Congenit Heart Surg 2017; 8: 699–706.
40. Aliku TO, Lubega S, Namuyonga J et al. Pediatric cardiovascular care in Uganda: current status, challenges, and opportunities for the future. Ann Pediatr Cardiol 2017; 10: 50–57.
41. Altamirano-Diaz L, Norozi K, Seabrook JA, Welisch E. Lack of access to paediatric cardiology services in the public health system in four major urban centres in Perú. Cardiol Young 2018; 28: 1452–1456.
42. Palacios-Macedo A, Merz CM, Cabrera AG et al. A novel private-public hybrid model for treatment of congenital heart disease in Mexico. World J Pediatr Congenit Heart Surg 2019; 10: 206–213.
43. Shidhika FF, Hugo-Hamman CT, Lawrenson JB et al. The Namibian children's heart project: a south-south partnership to provide cardiac care. Cardiol Young 2019; 29: 206–213.
44. Ibbotson JL, Luitel B, Adhikari B et al. Overcoming barriers to accessing surgery and rehabilitation in low and middle-income countries: an innovative model of patient navigation in Nepal. World J Surg 2021; 45: 2347–2356.
45. Tefuarani N, Hawker R, Vince J, Sleigh A, Williams G et al. Congenital heart disease in Papua New Guinean children. Ann Trop Paediatr 2001; 21: 285–292.
46. Begic H, Tahirovic H, Mesihovic-Dinarevic S, Ferkovic V, Atic N, Latifagic A. Epidemiological and clinical aspects of congenital heart disease in children in Tuzla Canton, Bosnia-Herzegovina. Eur J Pediatr 2003; 162: 191–193.
47. Awori MN, Ogendo SWO, Gitome SW, Ong'uti SK, Obonyo NG. Management pathway for congenital heart disease at Kenyatta national hospital, Nairobi. East Afr Med J 2007; 84: 312–317.
48. Edwin F, Entsua-Mensah K, Sereboe LA et al. Conotruncal heart defect repair in Sub-Saharan Africa: remarkable outcomes despite poor access to treatment. World J Pediatr Congenit Heart Surg 2016; 7: 592–599.
49. Ramakrishnan S, Khera R, Jain S et al. Gender differences in the utilisation of surgery for congenital heart disease in India. Heart 2011; 97: 1920–1925.
50. Maheshwari S, Animasahun BA, Njokanma OF. International patients with congenital heart disease: what brings them to India? Indian Heart J 2012; 6401: 50–53.
51. Jenkins KJ, Castaneda AR, Cherian KM et al. Reducing mortality and infections after congenital heart surgery in the developing world. Pediatrics 2014; 134: e1422–e1430.
52. Staveski SL, Parveen VP, Madathil SB, Kools S, Franck LS. Parent education discharge instruction program for care of children at home after cardiac surgery in Southern India. Cardiol Young 2016; 26: 1213–1220.
53. Xianf L, Su Z, Liu Y et al. Impact of family socioeconomic status on health-related quality of life in children with critical congenital heart disease. J Am Heart Assoc 2019; 8: e010616.
54. Kumar RK, Shrivastava S. Paediatric heart care in India. Heart 2008; 94: 984–990.
55. Macumbi AO. African experiences of humanitarian cardiovascular medicine: the Mozambican experience. Cardiovas Diagn Ther 2012; 2: 246–251.
56. Aliku TO, Lubega S, Lwabi P, Oketcho M, Omagino JO, Mwambu T. Outcome of patients undergoing open heart surgery at the Uganda heart institute, Mulago hospital complex. Afr Health Sci 2014; 14: 946–952.

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57. Animasahun BA, Johnson A, Ogunkunle OO et al. Transcatheter closure of patent ductus arteriosus and atrial septal defect without on-site surgical backup: a two-year experience in an African community. Pediatr Cardiol 2014; 35: 149–154.
58. Nguyen N, Jacobs JP, Dearani JA et al. Survey of nongovernmental organizations providing pediatric cardiovascular care in low- and middle-income countries. World J Pediatr Congenit Heart Surg 2014; 5: 248–255.
59. Lapao LV, Correia A. Impact of family socioeconomic status on health-related quality of life in children with critical congenital heart disease. In: Gillis G, Newsham D, Maeder AJ (eds). Global Telehealth 2015: Integrating Technology and Information for Better Healthcare. IOS Press, Amsterdam, 2015, pp 51–57.
60. Raj M, Paul M, Sudhakar A et al. Micro-economic impact of congenital heart surgery: results of a prospective study from a limited-resource setting. PLoS ONE 2015; 10: e0131348.
61. Ekure EN, Sadoh WE, Bode-Thomas F et al. Congenital heart defects in Nigerian children: preliminary data from the national pediatric cardiac registry. Cardiovasc J Afr 2017; 28: 54–59.
62. Giambeti A, Butera G, Mvondo CMVE et al. The Shisong cardiac center in Cameroon: an example of a long-term collaboration/Cooperation toward autonomy. Front Pediatr 2018; 6: 188.
63. Wallen TJ, Arnaoutakis GJ, Blenden R, Soto R. Programmatic changes to reduce mortality and morbidity in humanitarian congenital cardiac surgery. World J Pediatr Congenit Heart Surg 2018; 9: 47–53.
64. Murni IK, Wirawan MT, Patmasari L, Sativa ER, Arafuri N, Nugroho Noormanto S. Delayed diagnosis in children with congenital heart disease: a mixed-method study. BMC Pediatr 2021; 21: 191.
65. Kim S, Seshadrinathan S, Jenkins KJ, Murala JS. Can the public-private business model provide a sustainable quality pediatric cardiac surgery program in low- and middle-income countries? World J Pediatr Congenit Heart Surg 2023; 14: 316–325.
66. Castro F, Zuniga J, Higuera G, Carrion Donderis M, Gomez B, Motta J. Indigenous ethnicity and low maternal education are associated with delayed diagnosis and mortality in infants with congenital heart defects in Panama. Plos ONE 2016; 11: e0163168.
67. Bastero P, Staveski SL, Zheleva B et al. Partnership models for the establishment of sustainable paediatric cardiac surgical and cardiac intensive care programmes in low- and middle-income countries. Cardiol Young 2017; 27: S55–S60.
68. Orubu ESF, Robert FO, Samuel M, Megbule D. Access to essential cardiovascular medicines for children: a pilot study of availability, price and affordability in Nigeria. Health Policy Plan 2019; 34: 20–26.
69. Khongphatthanayothin A, Layangool T, Sittiwangkul R, Pongprot Y, Lertsapcharoen P, Mokarapong P. Pediatric heart surgery waiting time in Thailand and its effect on mortality: a cooperative study from Chulalongkorn, Children and Chiang Mai University Hospitals. J Med Assoc Thai 2005; 88: S23–S29.
70. Sadoh WE, Nwaneri DU, Owobu AC. The cost of out-patient management of chronic heart failure in children with congenital heart disease. Niger J Clin Pract 2011; 14: 65–69.
71. Mattos Sda S, Hazin SM, Regis CT et al. A telemedicine network for remote paediatric cardiology services in north-east Brazil. Bull World Health Organ 2015; 93: 881–887.
72. Okonta KE, Tobin-West C. Challenges with the establishment of congenital cardiac surgery centers in Nigeria: survey of cardiothoracic surgeons and residents. J Surg Res 2016; 202: 177–181.
73. El Rassi I, Assy J, Arabi M et al. Establishing a high-quality congenital cardiac surgery program in a developing country: lessons learned. Front Pediatr 2020; 8: 357.
74. Zhang XE, Geng Z, Shao J et al. The heartguard: a humanitarian pediatric cardiac surgery program in rural China. Thorac Cardiovasc Surg 2021; 69: 723–728.
75. Leon-Wyss JR, Veshti A, Veras O et al. Pediatric cardiac surgery: a challenge and outcome analysis of the Guatemala effort. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu 2009; 1: 8–11.
76. Al-Ammouri I, Daher A, Tutunji L et al. Outcome of heart disease in syrian refugee children: insights into crisis. Pediatr Cardiol 2020; 41: 877–884.
77. Sandoval N, Kreutzer C, Jatene M et al. Pediatric cardiovascular surgery in south America: current status and regional differences. World J Pediatr Congenit Heart Surg 2010; 1: 321–327.
78. Wamala I, Gongwer R, Doherty-Schmeck K et al. Infrastructure availability for the care of congenital heart disease patients and its influence on case volume, complexity and access among healthcare institutions in 17 middle-income countries. Glob Heart 2021; 16: 75.
79. Cheng SPS, Heo K, Joos E, Vervoort D, Joharifard S. Barriers to accessing congenital heart surgery in low- and Middel-income countries: a systematic review. World J Pediatr Congenit Heart Surg 2024; 15: 94–103.

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