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Narrative Review

From fetal detection to lifelong congenital heart disease care: A narrative review of research progress

Muhammad Iqhrammullah[1*], Arga S. Adji[2] and Amos Dangana[3]

[1]Postgraduate Program of Public Health, Universitas Muhammadiyah Aceh, Banda Aceh, Indonesia; [2]Faculty of Medicine, Universitas Hang Tuah, Surabaya, Indonesia; [3]Department of Hematology, Faculty of Allied Health Sciences, University of Abuja, Abuja, Nigeria

*Corresponding author: m.iqhram@unmuha.ac.id

Abstract

Pediatric cardiology has shifted from survival-focused care toward earlier detection, timely intervention, individualized treatment pathways, and lifelong follow-up. Recent literature reflects major progress in fetal diagnosis, neonatal stabilization, surgical and catheter-based treatment, transition to adult congenital heart disease care, and long-term outcome surveillance. This review summarizes current research directions in congenital heart disease, with emphasis on the continuum from fetal detection to lifelong care. Recent studies on fetal echocardiography suggest that this modality is increasingly linked to delivery planning, neonatal stabilization, counseling, and prediction of postnatal needs. Early intervention has also become more pathway-based, involving stabilization, maintenance of ductal patency when needed, safe transfer, surgical or catheter-based treatment, and perioperative risk reduction. However, early treatment does not always mean immediate complete repair, as timing should be individualized according to lesion severity, clinical stability, anatomy, and institutional expertise. Surgical, catheter-based, and hybrid pathways have expanded treatment options, allowing definitive repair, staged palliation, bridge therapy, and reintervention. As survival improves, transition to adult congenital heart disease care has become a central issue. Structured transition programs, follow-up databases, lesion-complexity stratification, and active recall systems are needed to prevent loss to follow-up and support lifelong surveillance. Future research should move beyond mortality and procedural success alone by integrating patient-centered outcomes, registries, artificial intelligence-supported risk prediction, and implementation studies.

Keywords: Congenital heart disease, fetal echocardiography, pediatric cardiology, early intervention, adult congenital heart disease

Introduction

Pediatric cardiology has progressed rapidly over recent decades, with major improvements in the diagnosis, treatment, and long-term care of children with congenital heart disease (CHD). CHD remains the most common congenital anomaly worldwide and is usually reported at approximately 8–10 cases per 1,000 live births, although estimates vary by diagnostic method, case definition, and access to screening [1-3]. The global burden remains substantial, with mortality and disability concentrated in settings where fetal diagnosis, neonatal stabilization, surgery, catheter-based intervention, and long-term follow-up are limited [4]. CHD that was once associated with high early mortality are now increasingly survivable because of advances in

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healthcare. These improvements have changed the goal of pediatric cardiac care from early survival alone toward long-term cardiovascular health [5-7].

A major shift has occurred toward earlier detection and planned intervention. Prenatal screening and fetal cardiac imaging now allow many complex cardiac anomalies to be identified before birth when screening systems, trained personnel, and referral pathways are available [20-23]. Prenatal detection enables risk stratification, parental counseling, and delivery planning. As shown in published studies, early detection of specific lesions is associated with reduced preoperative compromise [24-26]. However, detection remains uneven across lesion types and health systems [27,29,30]. After birth, timely stabilization and intervention are critical, particularly for duct-dependent lesions, cyanotic heart disease, and lesions associated with early heart failure or pulmonary overcirculation. In parallel, catheter-based and hybrid procedures have expanded treatment options for selected patients, reducing the need for repeated open surgery in some cases [27,29,30]. This review highlights the evolving shift in pediatric cardiology toward viewing congenital heart disease as a continuum of care, extending from fetal detection and neonatal stabilization through pediatric treatment and lifelong follow-up into adulthood.

Methods

This narrative review was based on a focused literature search in Scopus and targeted manual searching, conducted on 16 May 2026. The search was designed around two broad themes: screening/diagnosis and intervention/management in pediatric cardiology and congenital heart disease. For the screening and diagnosis theme, the following search strategy was used: (TITLE-ABS-KEY(neonatal) AND TITLE-ABS-KEY(diagnosis OR screening OR detection) AND TITLE-ABS-KEY(cardiology OR cardiac OR heart)) AND PUBYEAR > 2024 AND PUBYEAR < 2027. For the intervention theme, the following search strategy was used: (TITLE-ABS-KEY(neonatal OR early OR pediatric) AND TITLE-ABS-KEY(intervention OR management OR surgery OR treatment) AND TITLE-ABS-KEY(cardiology OR cardiac OR heart OR CHD)) AND PUBYEAR > 2024 AND PUBYEAR < 2027. The Scopus search was supplemented by manual screening through Google Scholar and publisher databases to identify additional relevant articles, recent reviews, society statements, guidelines, transition studies, registries, and digital health or artificial intelligence reviews that were not captured by the Scopus queries but were directly relevant to the review scope. Retrieved studies were screened for relevance to fetal and prenatal CHD diagnosis, neonatal and early intervention, surgical and catheter-based treatment, transition to adult congenital heart disease care, and long-term outcome surveillance. Priority was given to recent original studies and systematic reviews, while landmark epidemiological papers and consensus statements were included when they provided essential background for the continuum of CHD care.

Fetal and prenatal diagnosis of congenital heart disease

The current direction of research on fetal and prenatal CHD diagnosis is increasingly pathway-based, linking fetal echocardiography with delivery planning. For example, a study showed prenatal diagnosis to be especially valuable when the fetus is expected to require early catheterization or surgery, because the diagnosis allows delivery to be planned near specialized neonatal and cardiac services [8]. Further, a standardized clinical assessment and management plan for prenatally diagnosed CHD was reported to be associated with improved neonatal outcomes, suggesting that prenatal diagnosis should trigger a coordinated plan rather than remain an isolated imaging result [9]. In this context, fetal echocardiography functions as the starting point of a care pathway that includes maternal–fetal medicine, neonatology, pediatric cardiology, cardiac surgery, and catheterization teams. However, prenatal CHD diagnosis has been indicated to be affected by neighborhood socioeconomic status and geographic access [10,11]. Access to fetal echocardiography, distance from referral centers, availability of trained personnel, and screening infrastructure may determine whether CHD is detected before birth [10,11].

Lesion-specific studies have also demonstrated progress in prenatal risk stratification for functional and prognostic assessment. Recent research on transposition of the great arteries,

pulmonary stenosis, suspected coarctation of the aorta, and vascular rings indicates that fetal diagnosis is increasingly being used to anticipate postnatal clinical needs rather than merely to define cardiac anatomy [12-16]. For example, prenatal echocardiographic parameters may help identify pulmonary stenosis that will require infant surgery [13], while myocardial deformation and ventricular geometry are being explored in fetuses with suspected coarctation [14-15].

Another important development is the integration of fetal diagnosis with counseling and resource planning. Counseling studies emphasize that lesion severity affects how families understand prognosis and prepare for delivery and postnatal care [17]. Cost-analysis work also suggests that fetal echocardiography has implications for screening policy, especially in pregnancies with increased recurrence risk, such as offspring of adults with CHD [18]. In line with these advances, fetal cardiac screening guidelines increasingly emphasize standardized cardiac views, timely referral for fetal echocardiography, and multidisciplinary perinatal planning for lesions expected to be duct-dependent or clinically unstable after birth [20,21].

Recent literature continues to address the factors that limit prenatal CHD detection, including operator training, gestational age, imaging windows, lesion anatomy, and regional access to fetal cardiology services [22,23,27]. Contemporary meta-analytic and lesion-specific studies have also further examined the clinical value of prenatal diagnosis, suggesting that it may reduce cardiovascular compromise before planned neonatal surgery and improve early management for selected critical lesions, particularly transposition of the great arteries and hypoplastic left heart syndrome [24-26,28]. At the same time, ongoing evidence supports the continued use of newborn pulse oximetry because even well-established fetal screening programs do not identify all cases of critical CHD before delivery [29,30]. A summary of recent studies on fetal and prenatal diagnosis of CHD is presented in **Table 1**.

Early intervention on congenital heart disease

Recent advances in early intervention for congenital heart disease are summarized in **Table 2**. Collectively, these studies demonstrate substantial progress in prenatal management, neonatal stabilization, minimally invasive surgery, perioperative optimization, postoperative risk prediction, and artificial intelligence-assisted intensive care.

Early intervention in CHD has shifted from urgent rescue after postnatal deterioration toward structured stabilization and perioperative risk reduction. For critical CHD, intervention begins before the procedure itself. It includes rapid recognition, maintenance of ductal patency when needed, respiratory and circulatory stabilization, transfer planning, and preparation for the most appropriate definitive or staged treatment. A study showed that a prenatal–postnatal integrated management model was associated with earlier surgery that eventually improved preoperative status and lower operative mortality [33]. The intervention pathway, presented in **Figure 1**, emphasizes that postnatal treatment is only one part of a broader care trajectory, because risks originating from maternal health, fetal development, and prenatal stressors may influence short-term neonatal outcomes and long-term cardiovascular, metabolic, and neurodevelopmental consequences. A study from China demonstrated the increasing feasibility of early surgical intervention, with most neonates undergoing cardiopulmonary bypass for critical CHD surviving to hospital discharge [34]. Although early surgery is increasingly feasible, neonates remain particularly vulnerable during the postoperative period, as excessive FiO_2 after the Norwood procedure can increase Qp/Qs and reduce systemic blood flow [35].

Early intervention in CHD spans two closely connected phases: fetal management before birth and neonatal care after delivery. During the fetal phase, maternal and placental factors, including diabetes, obesity, preeclampsia, placental vascular malperfusion, fetal growth restriction, inflammation, and impaired oxygen or nutrient delivery, may worsen the effects of CHD [31,32]. Prenatal care should therefore include optimization of modifiable maternal risk factors where possible to improve fetal condition and subsequent neonatal outcomes (Figure 1). After birth, early intervention focuses on neonatal stabilization and definitive treatment. When immediate access to pediatric cardiac surgery is unavailable, stabilization before transfer becomes the priority. One study showed that most neonates with selected critical CHD could be safely stabilized at a Level-III perinatal center before transfer, with prostaglandin E1 used in many cases and no acute in-hospital mortality during stabilization [36].

Table 1. Selected recent studies on fetal and prenatal diagnosis of congenital heart disease

Authors, year (ref)	Design and research focus	Finding summary
Haxel *et al*., 2026 [8]	Regional study of liveborn infants with CHD requiring early catheterization or surgery	Prenatal diagnosis supported earlier referral and delivery planning for infants needing early cardiac intervention.
Ligumsky *et al*., 2026 [9]	Standardized clinical assessment and management pathway for prenatally diagnosed CHD	Structured prenatal-to-neonatal care planning improved neonatal management and outcomes.
Tran *et al*., 2026 [10]	Study of socioeconomic and geographic determinants of prenatal CHD diagnosis	Prenatal detection was influenced by neighborhood-level socioeconomic and geographic factors.
Trejo *et al*., 2026 [11]	Study of maternal residence and missed fetal CHD diagnosis	Geographic location was associated with failure to detect CHD before birth.
Lillitos *et al*., 2026 [12]	Long-term outcome study after prenatal diagnosis of transposition of the great arteries	Prenatal diagnosis helped guide early management, but long-term morbidity remained relevant after repair.
Wang *et al*., 2026 [13]	Prenatal echocardiographic prediction of postnatal pulmonary stenosis requiring surgery	Prenatal echo parameters helped predict postnatal pulmonary stenosis severity and surgical need.
Vigneswaran *et al*., 2026 [14]	Fetal myocardial deformation study in suspected coarctation of the aorta	Functional fetal cardiac markers may improve risk assessment in suspected coarctation.
Gungor *et al*., 2026 [15]	Fetal cardiac deformation study in persistent left-sided superior vena cava and suspected coarctation	Deformation imaging may support prenatal evaluation of fetuses at risk of coarctation.
Das *et al*., 2026 [16]	Postnatal outcome study of prenatally detected vascular rings	Prenatal detection helped guide postnatal assessment for airway and feeding-related complications.
Leone *et al*., 2026 [18]	Retrospective cost analysis of fetal echocardiography for offspring of adults with CHD	Fetal echocardiography has resource implications in recurrence-risk screening among adults with CHD.
Calzada-Lozada *et al*., 2026 [17]	Fetal cardiac counseling study based on lesion severity	Lesion severity shaped counseling needs and parental understanding of prognosis.
Rampengan *et al*., 2026 [19]	Scientometric review of prenatal CHD imaging research from 2000–2025	Fetal echocardiography was the dominant modality, with growing attention to genomics, AI, functional assessment, and LMIC equity gaps.

Table 2. Selected recent studies on early intervention in congenital heart disease

Authors, year (ref)	Design and research focus	Findings
Sun *et al*., 2026 [33]	Retrospective cohort study evaluating a prenatal–postnatal integrated management model in neonates with critical CHD	Integrated management was associated with earlier surgery, better preoperative status, lower operative mortality, and improved survival.
Zhang *et al*., 2026 [34]	Retrospective study of neonatal surgical outcomes for critical CHD in China	Among 234 neonates undergoing surgery with cardiopulmonary bypass, most were discharged after recovery, supporting the expanding feasibility of neonatal CHD surgery.
Brickmann *et al*., 2026 [36]	Retrospective cohort study on stabilization of neonates with critical CHD at a non-cardiac surgical center	Most neonates were safely stabilized before transfer; prostaglandin E1 was frequently used, and no acute in-house mortality occurred during stabilization.
Aronsson *et al*., 2026 [35]	Physiological study after Norwood procedure with RV-to-PA shunt in neonates with hypoplastic left heart syndrome	Higher FiO_2 increased Qp/Qs and reduced systemic blood flow, supporting careful oxygen titration after Norwood surgery.
Cai *et al*., 2026 [38]	Retrospective study of beating-heart ASD repair through right subaxillary mini-incision in children	The approach was safe across age groups, with children aged 12–60 months showing the most favorable perioperative outcomes.
Xie, 2026 [37]	Study of intraoperative hemodynamics and heart-rate variability during transcatheter VSD closure	Stable hemodynamics and higher heart-rate variability predicted better emergence quality after transcatheter VSD closure.

Authors, year (ref)	Design and research focus	Findings
Abdelazim *et al.*, 2026 [39]	Randomized noninferiority trial comparing hemofilters and hemodialyzers during pediatric cardiac surgery with CPB	High-flux hemodialyzers were noninferior to conventional hemofilters for cytokine control and showed comparable safety.
Wang *et al.*, 2026 [40]	Large retrospective study of blood conservation strategies during pediatric cardiac surgery with CPB	Patient blood management reduced transfusion requirements and lowered postoperative liver injury and acute kidney injury.
An *et al.*, 2026 [41]	Large-cohort prediction model for postoperative mortality in young children with CHD undergoing CPB surgery	A nomogram using routine clinical variables showed good discrimination and may support postoperative risk stratification.
Gerlach *et al.*, 2026 [42]	Longitudinal study of children after early surgical VSD repair	Surgery-related and postoperative variables were linked to later psychosocial adjustment and quality of life.
Yap *et al.*, 2026 [43]	Systematic review and single-arm meta-analysis of short-term VADs in pediatric heart transplant candidates	Short-term VADs were feasible as bridge-to-transplant support, but complications and waitlist mortality remained high.
Akbasli *et al.*, 2026 [44]	Review of AI applications in pediatric cardiac intensive care	AI-supported decision tools are emerging for early warning, low cardiac output, extubation readiness, and postoperative complication prediction.
Rampengan *et al.*, 2025 [45]	Meta-analysis comparing neonatal versus postneonatal complete repair for tetralogy of Fallot	More favorable outcomes in postneonatal repair, including lower mortality, fewer perioperative interventions, reduced arrhythmia, lower pacemaker implantation, and shorter ICU and hospital stays.

Progress in early CHD intervention has involved both less invasive procedures and improved perioperative care. Selected defects, including ventricular and atrial septal defects, can increasingly be managed through catheter-based or mini-incision approaches. One study found that intraoperative hemodynamic measures and heart-rate variability predicted postoperative emergence quality in children undergoing transcatheter ventricular septal defect closure [37], while another showed that beating-heart atrial septal defect repair through a right subaxillary mini-incision was safe across pediatric age groups, with the most favorable outcomes observed in children aged 12–60 months [38]. At the same time, perioperative optimization has become an important component of early intervention. One study found that high-flux hemodialyzers were noninferior to conventional hemofilters for cytokine control during pediatric cardiopulmonary bypass [39], and another showed that comprehensive blood conservation strategies reduced transfusion requirements and were associated with lower postoperative liver injury and acute kidney injury [40]. Together, these findings show that progress in early CHD treatment involves not only reducing procedural invasiveness but also improving perioperative safety and recovery.

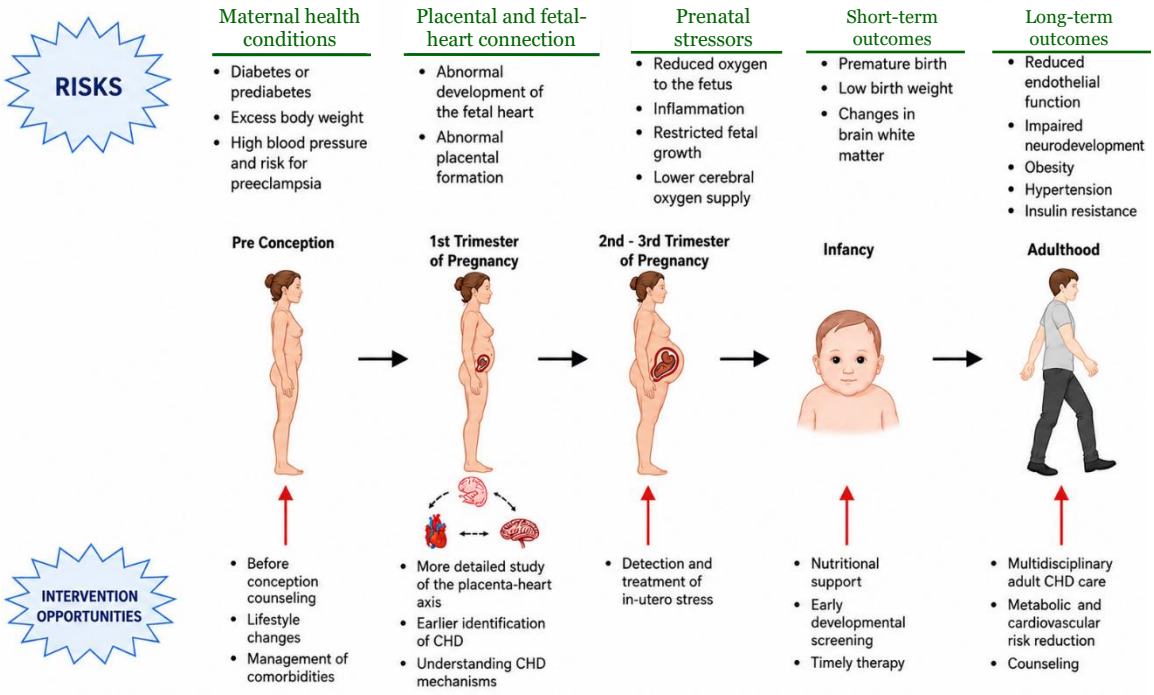

Figure 1. Early intervention framework in congenital heart disease across the maternal–fetal–infant–adult continuum. Adapted from Baldauf *et al.* [32], with conceptual support from the placenta–heart–brain framework of Leon *et al.* [31].

Extending beyond perioperative safety, recent research has increasingly focused on postoperative risk prediction. For instance, a mortality prediction nomogram for young children undergoing cardiopulmonary bypass has been developed to identify patients requiring closer surveillance after surgery [41]. Another study showed that outcomes after early ventricular septal defect repair were associated with later psychosocial functioning and quality of life, particularly through postoperative factors [42]. For critically ill children, early intervention may also include temporary circulatory support and intensive monitoring. Short-term ventricular assist devices can serve as a bridge to transplantation, although serious complications and waitlist mortality remain substantial [43]. AI-supported tools are also being developed for pediatric cardiac intensive care to predict hemodynamic decompensation, low cardiac output syndrome, extubation readiness, and postoperative complications [44].

Despite the improved outcomes of early intervention reported in recent studies, immediate definitive repair should not be considered universally appropriate. The optimal timing should instead be determined according to the lesion and the child's clinical condition. In a meta-analysis of 19 studies involving 28,968 patients with tetralogy of Fallot (TOF), neonatal repair was

associated with longer intensive care and hospital stays, higher mortality, more frequent delayed chest closure, and a greater need for pacemaker implantation than postneonatal repair [45]. Postneonatal repair may therefore be preferable when the infant can be safely stabilized, whereas neonatal repair remains necessary for unstable patients or when palliation is not feasible.

Surgical, catheter-based, and hybrid treatment pathways

Surgery remains the central treatment pathway for many congenital heart defects, but the route to definitive repair is increasingly individualized. Definitive surgery remains necessary for many structural lesions, including complex septal defects, outflow tract abnormalities, transposition of the great arteries, and TOF. At the same time, less invasive strategies are increasingly incorporated where anatomically appropriate, including catheter-based and hybrid procedures that may replace surgery in selected lesions, support staged management, or serve as bridge therapies before definitive repair [37,45,46]. Beating-heart atrial septal defect repair through a right subaxillary mini-incision has also been reported as safe across pediatric age groups, with particularly favorable outcomes in children aged 12–60 months [38].

Within surgical, catheter-based, and hybrid treatment pathways, catheter-based interventions and mechanical circulatory support may serve as bridge strategies when definitive surgery or transplantation is not immediately feasible. Catheter-based procedures may stabilize circulation, relieve obstruction, preserve pulmonary or systemic blood flow, defer high-risk repair, or improve anatomical and physiological conditions before surgery. In selected lesions, they may also provide definitive treatment, as illustrated by transcatheter ventricular septal defect closure [37]. For children with severe circulatory failure, short-term ventricular assist devices may provide temporary support while awaiting heart transplantation, although serious complications and waitlist mortality remain substantial [43]. Together, these strategies can maintain clinical stability and provide time for recovery, growth, further assessment, or access to definitive treatment.

Hybrid treatment combines surgical and catheter-based techniques when neither approach alone is optimal. These strategies may be particularly valuable in small infants, patients with multiple lesions, or those with complex anatomy [46]. A recent pediatric case demonstrated successful hybrid management of a ruptured sinus of Valsalva aneurysm with coarctation of the aorta and a bicuspid aortic valve, illustrating how combined approaches can address several anatomical problems within a coordinated treatment plan [46]. Hybrid care therefore represents both a technical strategy and a multidisciplinary model involving pediatric cardiologists, interventional cardiologists, cardiac surgeons, anesthesiologists, intensivists, and imaging specialists.

Transition to adult congenital heart disease care

Transition to adult congenital heart disease care represents a continuation of lifelong management rather than the start of a separate treatment pathway. This process is influenced by multiple life-course factors, including early clinical experiences, neurodevelopment, emotional regulation, health behaviors, social support, resilience, and access to health services (**Figure 2**). Many patients and families may consider childhood repair the end of treatment. However, lifelong follow-up remains necessary because residual lesions, arrhythmias, ventricular dysfunction, valve disease, pulmonary hypertension, Fontan-related complications, pregnancy-related risks, and psychosocial problems may develop later in life. Transition planning should therefore begin before transfer to adult services and prepare patients to understand their condition, recognize warning symptoms, maintain follow-up, and engage effectively with adult congenital heart disease care.

It is worth noting that transfer and transition are not the same process. Transfer refers to the administrative move from a pediatric clinic to an adult clinic, whereas transition is a gradual preparation process that builds knowledge, autonomy, and self-management. This preparation should include education about the patient's diagnosis, previous surgery or catheter procedures, current medications, activity advice, endocarditis prevention, reproductive counseling, emergency care planning, and the need for lifelong surveillance. A transition service study

reported that structured transition care improved knowledge and self-care skills, including awareness of specialist follow-up, dental care, acute symptoms, contraception, and pregnancy safety [48]. This supports the need for transition programs that go beyond referral letters and include repeated education across adolescence.

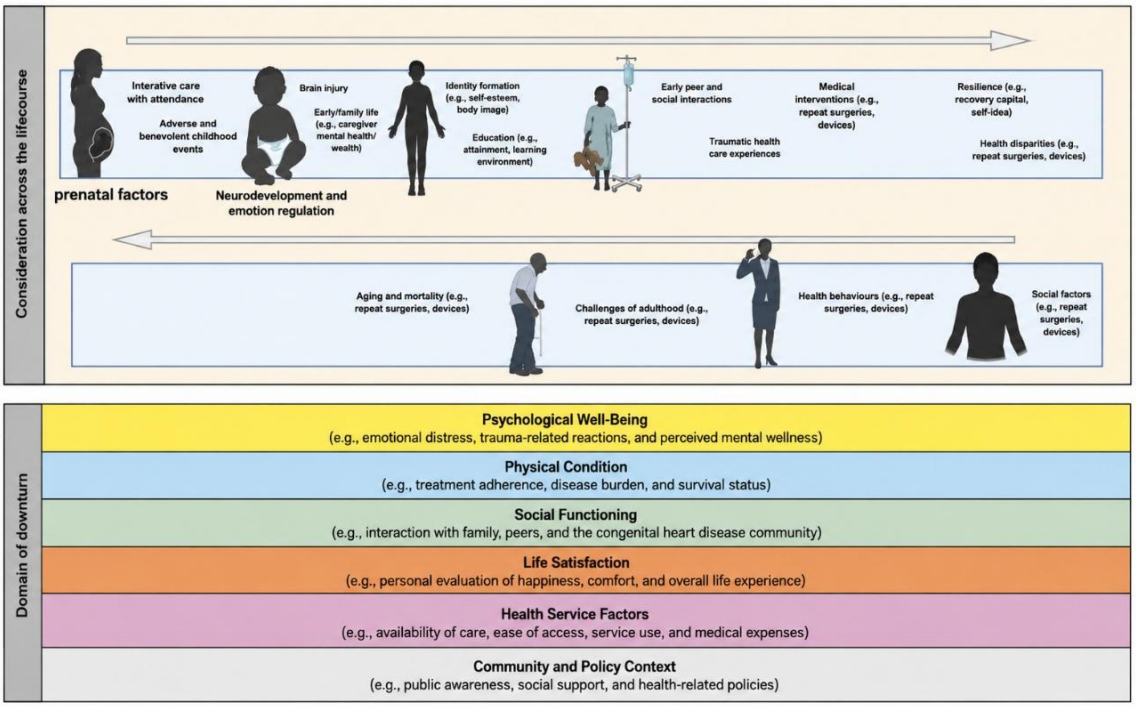

Figure 2. Life-course framework for transition to adult congenital heart disease care. Adapted from the American Heart Association scientific statement on psychological outcomes in congenital heart disease by Kovacs et al. [47].

A practical transition strategy is to establish a minimum follow-up database for adolescents approaching transfer to adult care. The database should record the diagnosis and CHD complexity, previous surgical and catheter-based procedures, residual lesions, current medications, recent and planned visits, transition readiness, ACHD referral status, and attendance at the first adult clinic appointment. It should also include updated contact information and risk flags for patients with Fontan circulation, repaired tetralogy of Fallot, pulmonary hypertension, complex valve disease, implanted cardiac devices, pregnancy-related risks, or repeated missed appointments. Such active tracking is important because young people with CHD may disengage from care owing to weak handover, limited disease knowledge and autonomy, loss of trust during provider changes, and socioeconomic disadvantage [49,50]. Patients who miss appointments should therefore be identified and contacted, while those with complex CHD should have a confirmed adult clinic appointment before leaving pediatric services. This approach can identify patients at risk of loss to follow-up before they become disconnected from care.

To support a smooth transition, programs may include joint pediatric–adult CHD clinics, transition coordinators or nurse-led services, written care summaries, patient-held care passports, digital reminders, and family meetings that gradually transfer responsibility from parents to the adolescent. A randomized controlled trial of a structured transition program in adolescents and young adults with CHD aimed to improve autonomy and reduce disruption in care, reflecting the growing use of formal transition interventions rather than usual care alone [51]. Similarly, a systematic review identified patient education, self-management support, appointment coordination, and communication with healthcare providers as common components of effective transition programs [52].

Transition planning should also prepare patients for the long-term systemic consequences of complex CHD. Fontan circulation illustrates why adult follow-up cannot focus solely on cardiac anatomy. A meta-analysis reported a pooled prevalence of vitamin D deficiency of 51% among

individuals with Fontan palliation [53]. This deficiency may be related to chronic venous hypertension, impaired gastrointestinal perfusion, intestinal inflammation, nutrient malabsorption, and protein-losing enteropathy [53]. Therefore, follow-up for patients with complex palliated circulation should extend beyond cardiac assessment to include nutrition, bone health, exercise capacity, liver and renal function, psychosocial well-being, reproductive health, and quality of life.

Consensus and guideline documents increasingly define transition as a planned developmental process rather than a single transfer between clinics. Recommended components include early preparation, written care summaries, education about the specific cardiac diagnosis, self-management training, reproductive and genetic counseling when relevant, and confirmed linkage with an adult congenital heart disease service [54,55]. The required follow-up should also be tailored to lesion complexity, as imaging schedules, arrhythmia surveillance, exercise recommendations, endocarditis prevention, pregnancy counseling, and thresholds for reintervention differ substantially between simple repaired defects and complex palliated physiology [56-58].

As illustrated by the life-course framework in Figure 2, adult outcomes are influenced not only by cardiac anatomy but also by neurodevelopment, psychological well-being, family support, education, employment, health literacy, and access to healthcare [47,59,60,66-68]. Patients with Fontan circulation, cyanotic disease, pulmonary hypertension, complex valve disease, or pregnancy potential require broader surveillance that may include hepatic, renal, nutritional, endocrine, reproductive, and mental health assessment [61,62]. Preventive care should also include appropriate dental care, endocarditis prevention when indicated, and individualized physical activity guidance rather than routine restriction [63-65].

For these reasons, a passive referral letter is insufficient, particularly for high-risk patients. Young adults with CHD may experience prolonged gaps in follow-up after leaving pediatric services, especially when they do not understand the need for lifelong surveillance or face geographic and financial barriers to adult care [69-71]. Structured education and nurse- or coordinator-supported transition programs have therefore been evaluated to improve disease knowledge, self-efficacy, and continuity of appointments [72,73]. The success of transition should be measured by confirmed attendance at the first and subsequent adult congenital heart disease visits, rather than merely by completion of a referral.

In resource-limited settings, the main challenge is often not the absence of advanced ACHD services alone, but the absence of a reliable system to identify who needs follow-up, who has transferred, and who has been lost from care. This gap is important because congenital cardiac conditions differ widely in long-term risk, and aggregated reporting may obscure the needs of patients with complex lesions. For this reason, a minimum follow-up database may be one of the most feasible first steps. It can be started as a simple institutional registry before being expanded into a regional or national ACHD registry.

Future trajectories in congenital heart disease research

Current CHD research is moving toward more individualized and pathway-based care, although personalization remains less advanced than in many other clinical fields. Existing risk-adjustment systems, including RACHS-1, the STAT categories, and the Society of Thoracic Surgeons congenital heart surgery models, already demonstrate the importance of accounting for lesion complexity, procedure type, age, comorbidities, and institutional case mix when evaluating outcomes [74-77]. The next step is to move beyond population-level risk classification toward integrated clinical pathways that combine prenatal and postoperative risk stratification, timing of early intervention, bridge strategies, catheter-based treatment, hybrid procedures, and long-term follow-up. Future studies should determine how these components can be combined to guide the safest sequence and timing of care for individual patients, rather than evaluating each intervention in isolation.

A major future priority is to close the evidence and infrastructure gaps in low- and middle-income countries. Longitudinal CHD registries should be established to capture lesion type, complexity, intervention history, residual disease, reintervention, transition to adult care, and patient-centered outcomes across the life course [78-81]. Multicenter collaboration will also be

essential to include more diverse populations, improve generalizability, and allow comparison across health systems with different levels of resources. Digital health and artificial intelligence may support fetal imaging, risk prediction, remote counseling, clinical monitoring, and continuity of follow-up [82-84]. However, future evaluations should focus not only on technical accuracy but also on practicality, affordability, cost-effectiveness, workflow integration, equity, and clinical benefit in resource-constrained settings. The central research question should therefore be whether these technologies can improve access and outcomes without creating additional financial or organizational burdens.

Conclusions

Pediatric cardiology has entered a stage in which progress is no longer defined only by early survival. Advances in fetal echocardiography, prenatal risk stratification, neonatal stabilization, surgery, catheter-based treatment, hybrid procedures, and intensive care have improved the ability to detect and manage CHD across the earliest stages of life. However, these advances are most meaningful when they are connected within a coordinated care pathway. Prenatal diagnosis should lead to appropriate counseling, delivery planning, and neonatal readiness. Early intervention should be based on timely decision-making rather than the assumption that earlier repair is always superior. Surgical, catheter-based, and hybrid treatments should also be selected with attention to anatomy, physiology, durability, and the likelihood of future reintervention.

As more children with CHD survive into adolescence and adulthood, lifelong care has become a central priority. Many patients continue to face residual lesions, arrhythmia, ventricular dysfunction, pulmonary hypertension, Fontan-related complications, nutritional and metabolic problems, psychosocial concerns, and reduced quality of life. Therefore, transition to adult CHD care should be planned as a structured process rather than a simple referral. Minimum follow-up databases, lesion-complexity classification, transition readiness assessment, and active tracking systems are practical strategies to reduce loss to follow-up, especially in resource-limited settings where services are fragmented.

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Competing interests

The authors declare that there are no conflicts of interest.

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Underlying data

No new datasets were generated or analyzed in this narrative review.

Declaration of artificial intelligence use

An artificial intelligence (AI) tool, ChatGPT, was used for language refinement and manuscript formatting. All AI-assisted outputs were critically reviewed by the authors to ensure the integrity and reliability of the manuscript. The final decisions and interpretations presented in this article remain the responsibility of the authors.

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