Short Communication

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Factors associated with clinical outcomes among children with delayed diagnosis of critical congenital heart disease: A cross-sectional study

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Abstract

Delayed detection of critical congenital heart disease (CHD) is associated with increased morbidity and mortality. Currently, there is a paucity of data on children with critical CHD in Indonesia. The aim of this study was to investigate the factors contributing to delayed diagnosis of critical CHD and its association with clinical outcomes such as mortality, heart failure, intensive care unit (ICU) admission, and ventilator use. A cross-sectional study was conducted using medical records from Haji Adam Malik Medan General Hospital. The study included all children aged 0 to 18 years diagnosed with critical CHD. The statistical analysis was performed by utilizing SPSS version 25.0. A total of 59 subjects were analyzed. The findings revealed a significant relationship between factors such as age, sex, respiratory tract infections, type of CHD, surgical interventions, and underlying syndromic abnormalities with various clinical outcomes. Delayed diagnosis of critical CHD was associated with increased mortality, heart failure, ICU admission, and ventilator use, with these outcomes influenced by the aforementioned factors.

Keywords: Delayed diagnosis, congenital heart disease, mortality, outcome, ICU admission

Introduction

Congenital heart disease (CHD) affects approximately 1 in 100 newborns, with about one in four cases classified as critical CHD in 2010 [1]. The current prevalence is about 8 per 1,000 live births, translating to roughly 40,000 affected infants annually as of 2021 [2]. Critical CHD conditions, such as coarctation of the aorta, truncus arteriosus, tetralogy of Fallot, interrupted aortic arch, and transposition of the great arteries, necessitate surgical or catheter-based intervention within the first year [3]. In Indonesia, 50,000 newborns are diagnosed with CHD each year, including 12,500 with critical CHD [1]. Although global mortality rates for CHD in children have decreased, the associated morbidity remains a major health concern [1,4]. Delayed diagnosis of CHD is a global issue, affecting both high-income and low- and middle-income countries [5,6]. In high-income countries, the rate of delayed diagnosis between 1995 and 2005 was 8.9% overall, with 10.4% for cyanotic CHD and 8.7% for acyanotic CHD. [7]. However, the delay rate rises to 29.5%. Early detection can be improved by recognizing clinical presentations of critical CHD and associated extracardiac conditions [8]. Conversely, low- and middle-income countries report an 85.1% rate of delayed diagnosis, largely due to inadequate healthcare resources and socio-economic barriers, leading to significant morbidity and mortality [9,10].

Received: January 8, 2025 - Accepted: August 13, 2025 - Published online: August 28, 2025

In Indonesia, there are limited data on late diagnosis of CHD in children. To address this issue, it is essential to evaluate the extent and causes of delayed diagnoses in low- and middle-income countries. The aim of this study was to investigate factors associated with delayed diagnosis of critical CHD and its effects on clinical outcomes, including mortality, heart failure, intensive care unit admission, and mechanical ventilator use.

Methods

Study design and sampling strategy

An observational study with cross-sectional design was conducted at Adam Malik Hospital, Medan, North Sumatera, Indonesia, from January 2021 to July 2023. Inclusion criteria for this study were children aged 0–18 years with delayed diagnosis of critical CHD at Adam Malik Hospital, Medan, North Sumatera, Indonesia. Exclusion criteria included incomplete medical records. We utilized a non-probability (judgment) sampling method to screen potential study populations to be included in the final analysis.

Data extraction and collection

Data were extracted from medical records of patients meeting inclusion criteria and excluding those with incomplete records. The collected data included age at presentation, sex, nutritional status, history of respiratory infections, echocardiography results, diagnosis, and type of intervention (or surgical procedures e.g., balloon atrial septostomy, catheterization, etc). Clinical outcomes such as in-hospital mortality, incidence of heart failure, intensive care admission, and use of ventilators were also documented to be correlated with initial risk factors. Microsoft Excel v.2021 (Microsoft, Redmond, Washington, USA) was used for data collection.

Statistical analysis

SPSS version 25.0 software (IBM SPSS, Chicago, Illinois, USA) was employed for data analysis, with $p \leq 0.05$ considered statistically significant. Continuous data were presented as mean and standard deviation (for normally distributed data) and median (minimum-maximum) for non-normally distributed data; categorical data were presented as frequency and percentages. Shapiro-Wilk test was utilized to assess data normality. Chi-square or Fisher's exact test was used to assess association between risk factors and clinical outcomes for normally distributed data, while Kruskal-Wallis test was used for non-normally distributed data. The statistical analysis was performed based on the appropriate methodological approach based on each data normality test and type (categorical or numerical) with $p<0.05$ considered statistically significant [11].

Results

Baseline characteristics

The present study included 59 children, comprising 32 males (54.2%) with an average age of 45.44 months. Most children were under two years old (61%). The mean weight and height were 11.2 kg and 84.21 cm, respectively. The majority had a gestational age of 35–38 weeks (64.4%), and 35.6% were well-nourished. Duct-dependent pulmonary circulation was the most common CHD type (55.9%). Underlying syndromes were present in 33.9% of cases. Respiratory infections and heart failure were observed in 57.6% and 49.2% of children, respectively. Intensive care was required in 67.8%, and 45.8% needed ventilatory support. The mortality rate was 25.4% (**Table 1**).

Table 1. Characteristics of children

Characteristics	n (%)
Sex	
Male	32 (54.2)
Female	27 (45.8)
Age	
Mean (SD)	45.44 (58.35)
Median (min-max)	14 (0.2–191)
<2 years	36 (61)
≥2 years	23 (39)
Body weight (kg)	

Characteristics	n (%)
Mean (SD)	11.20 (10.22)
Median (min-max)	6.2 (2.4–44)
Body height (cm)	
Mean (SD)	84.21 (34.56)
Median (min-max)	69 (47–163)
Gestational age	
32–34 weeks	21 (35.6)
35–38 weeks	38 (64.4)
Nutritional status	
Severe malnutrition	20 (33.9)
Malnutrition	18 (30.5)
Well-nourished	21 (35.6)
Congenital heart disease (CHD) type	
CHD with systemic circulation	12 (20.3)
CHD with pulmonary circulation	33 (55.9)
CHD with parallel circulation	10 (16.9)
CHD with complete mixing circulation	4 (6.8)
Type of surgery	
Balloon atrial septostomy	3 (5.1)
Catheterization	33 (55.9)
Catheterization with patent ductus arteriosus (PDA) stenting	2 (3.4)
Pulmonary artery (PA) banding	1 (1.7)
PDA stenting	9(15.3)
Percutaneous transluminal balloon valvuloplasty (PTBV)	3 (5.1)
No intervention	8 (13.6)
Underlying abnormal syndrome	
Yes	20 (33.9)
No	39 (66.1)
Respiratory tract infection	
Yes	34 (57.6)
No	25 (42.4)
Heart failure	
Yes	29 (49.2)
No	30 (50.8)
Mechanical ventilator use	
Yes	34 (57.6)
No	25 (42.4)
In-hospital ward	
Intensive care unit	40 (67.8)
General ward	19 (32.2)
Deceased	
Yes	3 (7.1)
No	39 (92.9)

Factors associated with clinical outcomes

Among 59 children with delayed diagnosis of critical CHD, mortality was significantly associated with sex (p=0.013), surgical intervention (p<0.001), and underlying syndromes (p=0.051) (**Table 2**). Most deaths occurred in males and in those without surgical intervention. Heart failure incidence was higher in children under two years (p=0.049) and those with respiratory tract infections (p=0.024). ICU admission was significantly linked to age (p=0.009), CHD type (p=0.025), and underlying syndromes (p=0.036), with younger children and those with systemic circulation CHD more frequently admitted. Mechanical ventilator use was significantly higher in children under two years (p=0.015) and those with systemic circulation CHD (p=0.017). Gestational age and nutritional status showed no significant associations with any clinical outcomes.

The absence of intervention emerged as the most significant determinant of death (odds ratio (OR)=82.332; 95% confidence interval (CI): 4.390–1544.174; p=0.003), followed by underlying abnormal syndrome (OR=20.965; 95%CI: 1.358–323.633; p=0.029), CHD type (OR=17.321; 95%CI: 1.527–196.423; p=0.021), and female sex (OR=16.124; 95%CI: 1.525–167.591; p=0.020).

Fachrozi et al. Narra X 2025; 3 (2): e191 - http://doi.org/10.52225/narrax.v3i2.191

Table 2. Factors associated with mortality, incidence of heart failure, ICU admission, and mechanical ventilator use in children with delayed diagnosis of critical congenital heart disease

Characteristics	Mortality, n (%)			Incidence of heart failure, n (%)			ICU admission, n (%)			Mechanical ventilator use, n (%)		
	Deceased	Survived	*p*-value	Yes	No	*p*-value	Yes	No	*p*-value	Yes	No	*p*-value
Sex												
Male	11 (40.7)	16 (59.3)	0.013[a]	13 (48.1)	14 (51.9)	0.887[a]	16 (59.3)	11 (40.7)	0.197[a]	13 (48.1)	14 (51.9)	0.735[a]
Female	4 (12.5)	28 (87.5)		16 (50.0)	16 (50.0)		24 (75.0)	8 (25.0)		14 (43.8)	18 (56.2)	
Age												
<2 years	12 (33.3)	24 (66.7)	0.081[a]	14 (38.9)	22 (61.1)	0.049[a]	29 (80.6)	7 (19.4)	0.009[a]	21 (58.3)	15 (41.7)	0.015[a]
≥2 years	3 (13.0)	20 (87.0)		15 (65.2)	8 (34.8)		11 (47.8)	12 (52.2)		6 (26.1)	17 (73.9)	
Gestational age												
32–34 weeks	3 (14.3)	18 (85.7)	0.144[a]	17 (44.7)	21 (55.3)	0.361[a]	13 (61.9)	8 (38.1)	0.472[a]	7 (33.3)	14 (66.7)	0.154[a]
35–38 weeks	12 (31.6)	26 (68.4)		12 (44.7)	9 (42.9)		27 (71.1)	11 (28.9)		20 (52.6)	18 (47.4)	
Nutritional status												
Severe malnutrition	7 (35.0)	13 (65.0)	0.422[a]	10 (50.0)	10 (50.0)	0.728[a]	15 (75.0)	5 (25.0)	0.652[a]	10 (50.0)	10 (50.0)	0.166[a]
Malnutrition	3 (16.7)	15 (83.3)		10 (55.6)	8 (44.4)		11 (61.1)	7 (38.9)		5 (27.8)	13 (72.2)	
Well-nourished	5 (23.8)	16 (76.2)		9 (42.9)	12 (57.1)		14 (66.7)	7 (33.3)		12 (57.1)	9 (42.9)	
CHD type												
CHD with systemic circulation	6 (50.0)	6 (50.0)	0.107[c]	4 (33.3)	8 (66.7)	0.154[b]	11 (91.7)	1 (8.3)	0.025[b]	9 (75.0)	3 (25.0)	0.017[b]
CHD with pulmonary circulation	6 (18.2)	27 (81.8)		16 (48.5)	17 (51.5)		17 (51.5)	16 (48.5)		10 (30.3)	23 (69.7)	
CHD with parallel circulation	3 (30.0)	7 (70.0)		5 (50.0)	5 (50.0)		9 (90.0)	1 (10.0)		7 (70.0)	3 (30.0)	
CHD with complete mixing circulation	0 (0)	4 (100)		4 (100)	0 (0)		3 (75.0)	1 (25.0)		1 (25.0)	3 (75.0)	
Surgical intervention												
No	7 (87.5)	1 (12.5)	<0.001[b]	5 (62.5)	3 (37.5)	0.472[c]	7 (87.5)	1 (12.5)	0.416[c]	6 (75.0)	2 (25.0)	0.126[c]
Yes	8 (15.7)	43 (84.3)		24 (47.1)	27 (52.9)		33 (64.7)	18 (35.3)		21 (41.2)	30 (58.8)	
Respiratory tract infection												
Yes	8 (23.5)	26 (76.5)	0.697[a]	21 (61.8)	13 (38.2)	0.024[a]	23 (67.6)	11 (32.4)	0.977[a]	18 (52.9)	16 (47.1)	0.197[a]
No	7 (28.0)	18 (72.0)		8 (32.0)	17 (68.0)		17 (68.0)	8 (32.0)		9 (36.0)	16 (64.0)	
Underlying abnormal syndrome												
Yes	13 (33.3)	26 (66.7)	0.051[a]	16 (41.0)	23 (59.0)	0.081[a]	30 (76.9)	9 (23.1)	0.036[a]	18 (46.2)	21 (53.8)	0.933[a]
No	2 (10.0)	18 (90.0)		13 (65.0)	7 (35.0)		10 (50.0)	10 (50.0)		9 (45.0)	11 (55.0)	

CHD: congenital heart disease; ICU: intensive care unit
[a]Analyzed using Chi Square
[b]Analyzed using Fischer's Exact
[c]Analyzed using Kruskal Wallis

Multivariate analysis of factors associated with clinical outcomes

Multivariate analysis of heart failure (**Table 2**), including age, CHD type, and respiratory tract infection, found that only respiratory tract infection had a significant impact on heart failure (OR=3.433; 95%CI: 1.156–10.193; p=0.026). For intensive care admission, the analysis of sex, age, CHD type, and underlying syndrome identified age as a significant factor. Children under two years old are notably more likely to require intensive care (OR=4.519; 95%CI: 1.414–14.448; p=0.011).

Multivariate analysis of mechanical ventilator use, considering age, gestational age, nutritional status, CHD type, surgery type, and respiratory tract infections, indicated that children under two years old and those with critical CHD affecting systemic circulation had significantly higher risks of requiring a ventilator. Specifically, the risk was 5.219 times higher for critical CHD types (OR=5.219; 95%CI: 1.139–23.915; p=0.033) and 4.212 times higher for children under two years old (OR=4.212; 95%CI: 1.253–14.156; p=0.020).

Discussion

The study included 59 children, mostly male, with late-diagnosed critical CHD at H. Adam Malik's Hospital. Similar findings were found in a Beijing study, which found that 59.1% of the total 1,851 patients with CHD were male, followed by 38.84% of female and 2.05% of unknown [12]. According to a Pakistani study, 58.9% of delayed diagnosis of CHD were male [13]. Nonetheless, two Indonesian investigations found that the frequency of CHD patients was higher in female than in male (51–53.5% vs 46.5–49%) [14,15]. Variations in the study's location, duration, and sample count could account for discrepancies in the findings of this investigation compared to earlier research. Majority of included participants were aged under two years old (61%), with mean body height and weight being 84.21 cm, and 11.2 kg. These findings align with previous study, which involved 141 children with CHD, in which more than half of participants (57.4%) were under the age of 12 months [16]. Additionally, research conducted in Indonesia reveals that 62.2% of pediatric CHD cases were identified in the 0–1 age range [12]. The distribution of CHD, with the majority occurring in the first few years of life, may suggest that efforts have been implemented to enforce early CHD diagnosis and that the system of reference for case management has improved [17].

The present study found that surgical intervention is significantly associated with mortality in children with critical CHD and delayed diagnosis (p<0.001). Approximately 80% of deaths occur before surgery, with 95% of these deaths happening at home and 63% attributed to univentricular heart disease. The mortality rate post-intervention is 7.5%, compared to 2.5% in other studies 30 days after the intervention [18]. Other studies indicate a 9.1% mortality rate for newborns undergoing surgical intervention or catheterization, with 68% of deaths occurring before surgery, highlighting potentially modifiable factors that could improve clinical outcomes [19]. The type of critical CHD is associated with intensive care admission in cases with delayed diagnosis. Previous studies report a 4–4.5% incidence of CHD in neonates treated in neonatal intensive care units (NICUs) [20,21], while a one-year prospective study indicates a prevalence of 3.49% for CHD among all neonates treated at the NICUs [22].

The study identified four significant independent variables associated with mortality: sex (p=0.020), type of CHD (p=0.021), type of surgery (p=0.003), and underlying abnormal syndrome (p=0.029). Surgical intervention emerged as the most critical factor, with an OR of 82.332 (95%CI: 4.390–1544.174), indicating that untreated critical CHD significantly increases mortality risk. This finding aligns with previous research showing that 40–50% of newborns with left ventricular outflow tract obstruction and duct-dependent systemic circulation (DDSC) were diagnosed post-hospitalization, with high perioperative mortality and poor pre-operative clinical status impacting survival [23-25].

This study has several limitations. The cross-sectional design limits the ability to establish causal relationships between risk factors and clinical outcomes. The use of retrospective medical records may have introduced information bias due to incomplete or inconsistent documentation. As a single-center study with a relatively small sample size (n=59), the generalizability of findings may be limited. Moreover, potentially relevant variables such as socioeconomic status and referral timing were not assessed. Future research should involve multicenter prospective studies with larger sample sizes and include broader sociodemographic and clinical variables to better understand the impact of delayed diagnosis on critical CHD outcomes.

Conclusion

Mortality, heart failure, ICU admission, and mechanical ventilator use in critical CHD patients with delayed diagnosis are influenced by age, sex, respiratory tract infections, type of CHD, type of surgery, and underlying syndrome. These findings highlight the importance of early detection, timely referral, and appropriate surgical intervention to reduce the risk of adverse clinical outcomes. Strengthening early screening programs and improving access to pediatric cardiac care, particularly for high-risk groups such as infants and those with syndromic conditions, are essential steps toward improving survival and quality of care for children with critical CHD.

Ethics approval

Ethical approval was granted by Ethical Committee for Health Research, Adam Malik Hospital, Medan, North Sumatera, Indonesia (No: LB.02.02/D.XXVIII.III.2.2.2/4427/2023).

Acknowledgments

The authors would like to acknowledge all of individuals who contributed to the research.

Competing interests

Authors have no known conflict of interest in relation to the publication of this work.

Funding

This study received no external funding.

Underlying data

Data underlying this study can be requested from the corresponding authors upon reasonable requests.

Declaration of artificial intelligence use

We hereby confirm that no artificial intelligence (AI) tools or methodologies were employed at any stage of this study, including data collection, analysis, visualization, or manuscript preparation. All work presented herein was conducted entirely by the authors without the assistance of AI-based tools or systems.

How to cite

Fachrozi MR, Adriansyah R, Pratita W, *et al*. Factors associated with clinical outcomes among children with delayed diagnosis of critical congenital heart disease: A cross-sectional study. Narra X 2025; 3 (2): e191 - https://doi.org/10.52225/narrax.v3i2.191.

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