American Journal of Health Research
2022; 10(3): 51-62
http://www.sciencepublishinggroup.com/j/ajhr
doi: 10.11648/j.ajhr.20221003.12
ISSN: 2330-8788 (Print); ISSN: 2330-8796 (Online)

Delayed in Diagnosis of Congenital Heart Disease and Associated Factors Among Pediatric Patients in Cardiac Center Addis Ababa, Ethiopia, 2021/2022 G.C

Tesfaye Hurisa, Hirut Megersa, Tigist Tsegaye

Graduate Study Program, Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia

Email address:

tesfayehurisa12@gmail.com (T. Hurisa), yohbelay@gmail.com (H. Megersa), tigisttsegayebe@gmail.com (T. Tsegaye)

To cite this article:

Tesfaye Hurisa, Hirut Megersa, Tigist Tsegaye. Delayed in Diagnosis of Congenital Heart Disease and Associated Factors Among Pediatric Patients in Cardiac Center Addis Ababa, Ethiopia, 2021/2022 G.C. *American Journal of Health Research*. Vol. 10, No. 3, 2022, pp. 51-62. doi: 10.11648/j.ajhr.20221003.12

Received: April 19, 2022; **Accepted**: May 20, 2022; **Published**: May 31, 2022

Abstract: Morbidity and mortality due to congenital heart disease was primarily caused by delay in diagnosis. Early screening of neonates at birth identifies congenital heart disease and decreases complications related to delayed diagnosis. To assess delayed in diagnosis of congenital heart disease and associated factors among pediatric patients who were registered in Cardiac Center Ethiopia from January 1, 2018, to December 30, 2020. Institutional based cross-sectional study design was used to assess delayed in diagnosis of congenital heart disease and associated factors among pediatric patients in the cardiac center in Addis Ababa, Ethiopia and charts were selected using systematic random sampling out of 216 registered congenital heart disease pediatrics patients who fulfilled the inclusion criteria. The data was entered into Epi-data version 3.1 for cleaning and completeness and exported to SPSS version 23 for analysis. Then by binary logistic regression variables which p-value < 0.25 was identified and moved to multivariate logistic regression. Any statistical test with p-value < 0.05 at 95% CI was considered as statistically significant. In this study, 216 children were included, delayed diagnosis of CHD was identified in 206 (95.4%) record reviews. In multivariable logistic regression analysis, Maternal education for those who were illiterate mothers was 89.7% than delay in diagnosis of literate mother [AOR=0.103 (95% CI= (0.022-0.493)]. Place of child delivery in Health center about 97% delay in diagnosis of CHD than delivery in hospitals AOR=0.030 (95% CI= (0.003-0.293)]. Gestational age in weeks during delivery term baby 87.6% delay in diagnosis of CHD than preterm baby [AOR=0.124 (95% CI (0.020-0.758)]. The overall delay in the diagnosis of CHD was 95.4%. Maternal education, place of child delivery, and gestational age were independently associated with the delayed diagnosis of CHD. Health institutions are strongly recommended to give training to health care providers on screening of CHD during delivery.

Keywords: Delay Diagnosis, Congenital Heart Disease, Pediatrics

1. Introduction

1.1. Background

Congenital heart disease (CHD) is defined as an anatomic malformation of the heart or great vessels which occurs during intrauterine development, regardless of the age at presentation [1]. Ventricular Septal Defect (VSD), Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA), Coarctation of Aorta (CoA), Tetralogy of Fallot (TOF), Transposition of Great Arteries (TGA), Pulmonary Stenosis (PS), and Aortic Stenosis (AS) are common types of CHDs [2].

The prominent cause of morbidity and mortality due to congenital heart disease (CHD) was delayed in diagnosis. Congenital heart disease (CHD) is the most common congenital malformation worldwide. One in every 100 babies is born with CHD, with 1 in every 4 births having critical CHD. About 50,000 infants are born with CHD, and 12,500 are born with critical CHD. Although the fact those children with CHD have a better chance of survival remains a major health concern around the world [3]. A study that includes small muscular VSDs at birth and other small lesions in the western US indicates that the incidence of CHD reached 75/1,000 live births annually [4]. In Indonesia, 5 million

infants are born every year [5]. The incidence of moderate and severe forms of congenital heart disease is about 6/1,000 live births or 19/1,000 live births if the possibly severe bicuspid aortic valve is included [4].

Proper diagnosis of CHD is when the patient does not need emergency management at the onset of diagnosis, when treatment does not carry a high risk, when there is no need for different management, or when the patient has a good outcome if treated earlier [6]. On the other hand, advancing technology has improved the outcomes of children with these defects in developed countries. However, the financial impact of a child with CHD has exponentially increased over the last few decades. As such, in sub-Saharan Africa, the cost burden is significant and carries important implications for treating children with CHD [2]. Congenital deficiencies associated with monogenic and chromosomal abnormalities, environmental teratogenic substances, multifactorial inheritance, and micronutrient deficiency [7, 8]. Theoretically, clinical findings in cyanotic CHD should be more obvious than acyanotic CHD because of the bluish discoloration of children with cyanotic CHD due to the right-to-left shunt, which results from deoxygenated blood entering the circulation [9].

1.2. Statement of the Problem

Congenital heart disease is the major cause of birth defects and the second leading cause of death in the first year of life, after infectious diseases [10]. Study in the US shown that 3.6% pediatric hospitalizations treating children with CHD and greater than 15% were annual costs for pediatric hospitalizations [11]. A study shown in Florida that due to delayed diagnosis of congenital heart disease increased hospitalization by 52% more admissions, 18% hospitalized stay and 35% infancy hospitalization costs [12].

Delay in diagnosis of congenital heart disease is prevalent globally [13]. One study conducted in high-income countries were shown that 9% delay in diagnosis were 10.4% cyanotic CHD, 8.7% acyanotic CHD and 29.5% critical CHD were delay in diagnosis of CHD [13]. Similarly, a study conducted in low and middle-income countries showed a delay in diagnosis of congenital heart disease of 85.1% [14]. About 11.7% of the study cases died within 12 months of birth. Of these, 75.7% were diagnosed prenatally, 20.6% were diagnosed in the hospital, and 3.7% had delayed in diagnosis [15].

Morbidity and mortality due to congenital heart disease was primarily caused by delay in diagnosis [16]. It is associated with cardiovascular compromise and organ dysfunction, leading to prolonged ventilation and mortality among neonates undergoing cardiac surgery [17]. Delay in diagnosis of cyanotic CHD occurs when children with CHD are diagnosed after being sent home from the birth clinic or hospital. Regarding acyanotic CHD, delay diagnosis is when the children are diagnosed during cardiac surgery or intervention that should have already been performed [18, 6].

In prior studies include inadequately trained health care providers in the health system and socioeconomic constraints in low and middle-income country [14]. Additionally, due to the high fertility rate and high neonatal mortality rate, the incidence of CHD in sub-Saharan Africa is greatly underestimated [19].

To my knowledge, there is no study conducted that aims to assess the magnitude of delay in diagnosis of congenital heart disease and associated factors among pediatric patients in the cardiac Centre Ethiopia.

1.3. Significance of the Study

To my knowledge, there is no study conducted on the delayed in diagnosis of congenital heart disease and associated factors among Pediatrics patients in the study area. It will also serve as baseline data for those who wish to conduct on the same topic. The finding of this study will help programmers and service providers in identifying areas where the emphasis has to be given to the development of strategies that will reduce delays in diagnosis of congenital heart disease.

2. Literature Review

2.1. Delayed in Diagnosis of Congenital Heart Disease

A delayed in diagnosis of acyanotic CHD, delayed diagnosis is the first diagnosis the defect at a time based on recommended standards and cyanotic congenital heart disease is a neonate with CHD at birth discharged from health institution without a diagnosis of congenital heart disease (20). Studies have shown in Eastern Europe 8.9% was delayed diagnosis (10). A study in India showed that treatment should already have taken place or if at the time of diagnosis, immediate therapeutic action was required. Also study shown in southern Asia were about 85.1% [14].

A study which was conducted in Pakistan showed that 58.9% of male and 40.1% of female patients had delayed in diagnosis of CHD. Regarding socio-demographic characteristics, 63.4% of children live in rural areas of residence and their Socio-economic status was low at 54.3%, middle at 37% and high 8.7%. A 43% of mothers were illiterate. For about 4.9% maternal fetal echocardiography was done and acyanotic CHD were identified in 67.9% of children and 32.1% had cyanotic CHD [21].

Another study conducted in southern Asia showed males 63.3% and females 36.7%. A 24 month was median age. The patients had a median weight of 13 kg with the majority of the patients weighing below the 3rd centile at the age of 56.8%. Approximately 60% of children come from rural areas. About 66% belonged to a poor socioeconomic class with an additional 30% from the middle income group. Illiteracy rate in parents was mothers 54%. Only 2% of mothers had a fetal echocardiography performed. Most babies were delivered at home or local maternity centers, 77%. The median distance the patient had to travel to reach the cardiac center was 32%, traveling more than 100 km. About 65.3% of children had acyanotic CHD [14]. Comorbid complications in delayed diagnosis of Congenital Heart Disease were prevalent [22]. If not diagnosed early, these

defects lead to significant morbidity and life threatening events [23].

In another study showed that in Kenya it was found that 60.6% of children have a delay in diagnosis of CHD [24]. Another study in Ethiopia reported that diagnosis of CHD were 35.8% [25].

2.2. Associated Factors of Delayed in Diagnosis of Congenital Heart Disease

As the Journal of the American Society of Echocardiography shows, Antenatal fetal echocardiography is considered to be a very supportive tool for the identification of CHD at earlier stages and can be useful in reducing the morbidity and mortality related to CHD [9]. Antenatal diagnosis of CHD is quite common in developed countries study conducted in London [16].

Findings that shown in Southern Asia reported most patients had delay in diagnosis of CHD due to the delayed diagnosis by health care providers 22.5%, delayed referral/follow-up 13.3%, social factors 13%, financial restrictions 12.3%, and religious beliefs 1.7% [14]. However, recent data shows that Antenatal fetal echocardiography is not routinely used for early identification of CHD in South Asia [14].

In other study shown in Southeast Asia diagnosis of CHD in most patients was delayed because of delayed diagnosis by doctor 57.5%, delays related to midwifery care 14.4%, financial factors 9.7%, delays in referral and follow-up 9.2%, and social factors 9.2% [20]. Most common factor contributing to found in delayed first consultation in 40.3% and by the doctor was the second most frequent to delayed diagnosis of CHD was 24.6% children [24].

Also, in another study shared in Indonesia on delayed diagnosis of CHD by doctors, it was identified to be the associated factors for delayed diagnosis of CHD in children among 57.5% cases [20]. Inadequate trained health system, lack of awareness and financial issues contributing to delay in diagnosis of CHD. Its diagnosis among health care provider could be one important reason behind missed diagnosis of CHD [14]. Studies have shown that delay in diagnosis of CHD is linked with severe complications and many times, complications have already occurred when the delay diagnosis is made [20, 21].

In Indonesia, a study showed in primary healthcare settings, lack of awareness about CHD by general practitioners might explain these delays. The clinical features of children with CHD are different, thus the diagnosis is challenging. These clinical signs, including cough, dyspnea, and failure to thrive, can be misinterpreted as symptoms of other diseases, and managed until an alternate diagnosis of CHD is established. Tuberculosis is one of the diseases reported in misdiagnoses of CHD in children due to its similar symptoms like failure to thrive, and its frequent incidence in Indonesia. These misdiagnoses lead to a lack of follow-up treatment since the physician's advice to give more feeding will not resolve the main problem [20].

The most common lesions found were PDA 29.2%, VSD 28%, ASD 17.7% and TOF 10.4%. Additionally, the most common clinical presentations were recurrent pneumonia 77.4%, murmur 76.6%, failure to thrive 24.1% and cyanosis 17% as study conducted in Kenya [22]. Advanced antenatal screening programs such as fetal echocardiography screening are well-established in high-income countries [23].

Studies shown in high-income countries reported the decline in delayed referrals of cyanotic CHD patients is attributable to national neonatal Pulse Oximetry Screening (POS) recommendations (26). Neonatal POS is a critical factor for screening of CHD in every newborn. Assessment timing ranges from less than 24-48 hours of age. Newborns should be referred for cardiology evaluation if oxygen saturation consistently falls below 95% [27].

Family history of CHD is an independent risk factor, particularly if one of the parents has CHD (20-25% recurrence in offspring).

2.3. Conceptual Framework

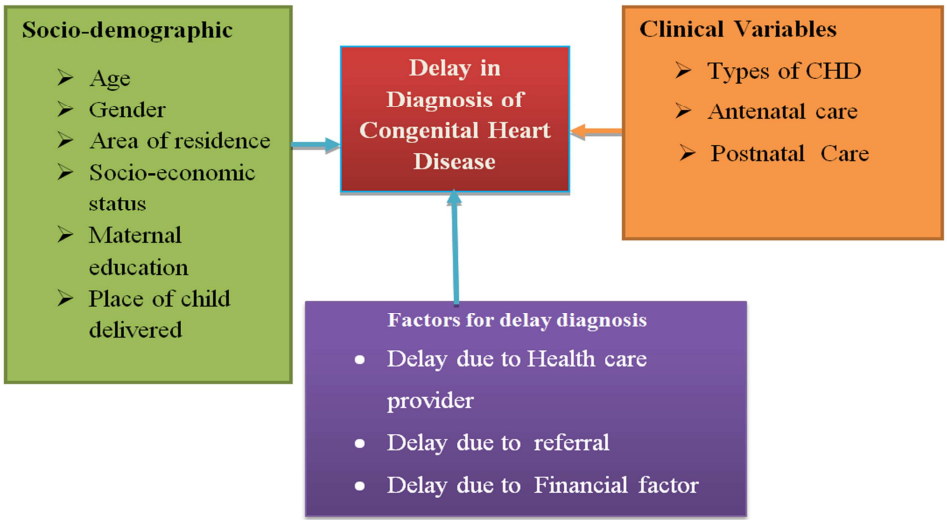

Figure 1. *Conceptual framework of study on delay diagnosis and associated factors of congenital heart disease [2, 6, 21, 22] (adapted from Literature).*

3. Objectives

3.1. General Objective

To assess delayed in diagnosis of congenital heart disease and associated factors among Pediatrics patients who were registered at Cardiac Center Ethiopia from January 1, 2018 to December 30, 2020.

3.2. Specific Objective

1) To identify the delayed in diagnosis of congenital heart disease among pediatric patients who were registered at Cardiac Center Ethiopia from January 1, 2018 to December 30, 2020.
2) To identify associated factors for delayed in diagnosis of congenital heart disease among pediatric patients who were registered at Cardiac Center Ethiopia from January 1, 2018 to December 30, 2020.

4. Methods and Materials

4.1. Study Area and Study Period

The study was conducted at Cardiac Center, Ethiopia (Children's Heart Fund of Ethiopia), located in Addis Ababa, which is the capital city of Ethiopia, established in 1992 inside Zewditu Memorial Hospital, Cardiac Center, Ethiopia, and is now located inside Black Lion specialized hospital in Addis Ababa. The idea of this cardiac center was conceived 30 years ago by Dr. Belay Abegaz but started functioning in 2009. It is a tertiary referral cardiac center for patients requiring cardiac intervention from all parts of the country. There are one hundred seventy-two (172) staff including supportive staff. It has a total of 13 heart team members that include six cardiologists, two cardiac surgeons, two cardiac anesthesiologists, one cardiac intensivist, and two per fusionist and trained nurses. Since the first date of its operation, it has provided services for about 10,000 patients free of charge, of which 5600 of them are Pediatrics. Cardiac catheterization, implanting peacemaker, coronary bypass surgery, coronary angiography, ECG, and Echocardiograph are some of the services given by the center. It also has facilities such as OPD, CCU, OR and Cardiac catheterization Laboratory (CathLab), which are the clinical departments. It has 30 beds and gives 24-hour services for both children and adults. It receives 150 new patients per month on average. These patients have follow-up depending on their condition at least once per month. Besides, patients can visit the clinic when he/she needs care [28].

A study was conducted from January 1, 2022 to January 30, 2022 G.C.

4.2. Study Design

Institutional based cross-sectional study design was used to assess delayed in diagnosis and associated factors among pediatric CHD patients at Cardiac Center Ethiopia.

4.3. Population

4.3.1. Source Population

All registered of pediatrics with congenital heart disease patients in Cardiac Center Ethiopia during study period.

4.3.2. Study Population

All congenital heart disease who attend in pediatrics cardiac clinic of cardiac center Ethiopia.

4.4. Eligibility Criteria

4.4.1. Inclusion Criteria

All charts who were diagnosed had confirmed CHD by echocardiography in the study hospital.

4.4.2. Exclusion Criteria

Records with incomplete data

Home delivery

4.5. Sample Size Determination and Sampling Technique

4.5.1. Sample Size Determination

The sample sizes in this study were determined using a single population proportion formula, where n =the required sample size

Z = a standard score corresponding to a 95% confidence interval of 1.96

P = the estimated proportion was take. One study in a low- and middle-income country in Pakistan found 85.1% or 0.85 of the children to have delayed diagnosis of CHD [14].

d = the margin of error (precision) 5% d- Is the desired degree of accuracy (taken as 0.05)

$$n = \frac{(Z\,\alpha/2)^2 \times P \times (1-P)}{d^2} = \frac{(1.96)^2 \times 0.85 \times (1-0.85)}{(0.05)^2} = 195.92 \sim 196$$

Therefore, n=196 since the data collection was based on the medical record number and interviewer administered method, the 10% non- response rate sample size was increased to 216.

4.5.2. Sampling Technique

Systematic random sampling technique was used to select CHD pediatrics charts. Sampling interval (k^{th}) was determined by dividing the total number of CHD patients that came within the study period (three Years) by the allocated sample size.

Total number of patients within 3 Years = 713 Sample size; 216

$$K = n/N$$

$$K = 713/216 = 3.3 \sim 3$$

The first patient was selected randomly, then every 3^{th} patient was selected from the patient registration list until the required sample was reached. Then, using the medical record number of selected; the patients' cards were retrieved from the card room.

4.6. Measurement

4.6.1. Study Variables

(i). Dependent Variable

Delayed in diagnosis of Congenital Heart Disease

(ii). Independent Variables

Socio-Demographic Status

1) Age
2) Gender
3) Area of residence
4) Socio-economic status
5) Maternal education
6) Place of delivery

Clinical Variables

1) Types of congenital heart disease
2) Antenatal care
3) Postnatal care

Factors for delay in diagnosis

1) Delay due to health care provider,
2) Delay due to referral,
3) Delay due to financial factors and
4) Delay due to social factors

4.6.2. Instruments

The data was collected using a clinical card review checklist and telephone interview guide which is adapted from different literature on related topics by modifying the tools of previous studies and revising the literature of similar studies [14]. The check list includes socio-demographic characteristics, clinical variables and telephone interviews associated with delay in congenital heart disease and complication at the onset of diagnosis.

4.7. Data Collection and Procedures

The data was collected by using card review checklist and through telephone interviewing of patient's families retrospectively about associated factors related to delay in diagnosis of CHD. For this study, the three BSc nurses for data collection and one senior MSc nurse supervisor were recruited during data collection. The data collectors and supervisors were trained for 3 days about the objectives of the study and the data collection tools.

4.8. Operational Definition and Definition of Terms

Delay in diagnosis is newborns discharged from their birth clinic or hospital without a CHD diagnosis after 24 hours of postnatal time [29].

Delay diagnosis due to health care provider: never suspected of CHD by the health care providers after discharging a child from a health facility.

Delay due to referral is the time from the health care provider for a definite diagnosis, or suspected of CHD to be referred to tertiary health care.

Delay related to social factors: any personal, cultural, and spiritual beliefs that influenced the delayed in diagnosis.

Delay related to financial factor: economic factors that influence delayed diagnosis or treatment of CHD after seeking medical attention [14].

Pediatrics age range is defined as ages 0-18 (birth to 18 years of age) [28].

Incomplete data if there is not available echocardiography result and at least 2 phone numbers on patients' cards.

Socio-economic status: - families monthly income.

4.9. Data Quality Control and Management

To assure the quality of data, the data collection instrument was developed in the English version using different literature. The data collection format was pretest on 5% of the sample size to check for uniformity and understandability of the checklist in Black Lion Specialized Hospital before the actual data collection. During the data collection procedures, all the collected data was revised and checked daily for its completeness, accuracy and clarity by the supervisor and principal investigator.

4.10. Data Analysis Procedure and Ethical Consideration

4.10.1. Data Analysis Procedure

The data was compiled, entered into Epi-data version 3.1, and then cleaned, explored, standardized, and exported to SPSS windows version 23 for summarization and further analysis. Bivariable analysis was carried out to assess the association between the dependent and all the independent variables and to identify the candidate for multivariate analysis. Variables having a p-value < 0.25 were a candidate for multivariable analysis. Then multivariable analysis was performed to determine the associated independent factors of the dependent variable. Statistical significance was considered at p-values < 0.05 and the Adjusted Odds Ratio (AOR) at 95% confidence interval (95% CI). The result was presented using COR and adjusted OR. Finally, the result was presented in tables, graphs, and statements.

4.10.2. Ethical Consideration

An ethical approval letter was obtained from St. Paul's Hospital Millennium Medical College Institution review board (IRB). Then the official letter was written to Cardiac Center Ethiopia Telephone consent was obtained from their families of study participants before they were briefly informed about the objectives and the aim of the study before taking a full telephone interview. Confidentiality was maintained at all levels of the study by not writing the respondent's name on the checklist and the information which was gotten from the respondent was not shared with other persons and was used only for the purpose of the study. Ethical issues dealing with respondents, techniques of supervision and how to handle data collection instruments were discussed.

5. Results

5.1. Demographic Characteristics of Patients

In this study, 216 chart were included, 83 (38.4%) were male and 133 (61.6%) were female, majority of the

participants age is found in (12 month - 5 years) 85 (39.4%) and mean age and SD 58 ± 50 month. One hundred and seventy-five (81%) children were from rural areas. Regarding maternal education status, 54 (25%) were illiterate and 162 (75.0%) was literate. Concerning participants' economic status, the majority, 144 (66.7%), categorized as Low socioeconomic status there monthly family income less than or equal to 4000 ETB [30]. (Table 1)

Table 1. *Socio demographic characteristics of the patients.*

Variables		Delayed in diagnosis	
		Yes	No
Age	0-1 month	1 (0.5%)	0 (0.0%)
	1-12 month	34 (16.5%)	9 (90.0%)
	12 month - 5 year	84 (40.8%)	1 (10.0%)
	5-10 year	54 (26.2%)	0 (0.0%)
	10-18 year	33 (16.0%)	0 (0.0%)
Gender	Male	78 (37.9%)	5 (50.0%)
	Female	128 (62.1%)	5 (50.0%)
Area of residence	Urban	36 (17.5%)	5 (50.0%)
	Rural	170 (82.5%)	5 (50.0%)
Maternal education	Illiterate	48 (23.3%)	6 (60.0%)
	Literate	158 (76.7%)	4 (40.0%)
Socio-economic status	Low <4000	135 (65.5%)	9 (90.0%)
	Middle 4001- 7000	59 (28.6%)	1 (10.0%)
	High >7000	12 (5.8%)	0 (0.0%)

5.2. Clinical Variables of Patients

Maternal fetal echocardiography was done in 2 (0.9%). Acyanotic CHD was noted in 205 (94.9%) children while the remaining had cyanotic CHD 11 (5.1%). Delayed diagnosis of CHD was identified in 206 (95.4%) children. One hundred twenty-seven (33.8%) of children under 5-their body weight was below 3rd-centile. During the ANC follow-up, maternal fetal echocardiography for about 2 (0.9%) was done for the mother of children. (Table 2)

Table 2. *Clinical Variables related to delayed in diagnosis of congenital heart disease patients attending at cardiac center Ethiopia, Addis Ababa, Ethiopia, January 1, 2018, to December 30, 2020.*

Variables		Delayed in diagnosis	
		Yes	No
Place of child delivery	Hospital	77 (37.4%)	9 (90.0%)
	Health Center	129 (62.6%)	1 (10.0%)
Body weight of child during diagnosis	<16 Kg	110 (53.4%)	9 (90.0%)
	>/= 16	96 (46.6%)	1 (10.0%)
Maternal Fetal Echocardiography	Yes	1 (0.5%)	1 (10.0%)
	No	205 (99.5%)	9 (90.0%)
Diabetes mellitus dx before or during pregnancy	Yes	4 (1.9%)	0 (0.0%)
	No	202 (98.1%)	10 (100.0%)
History of maternal Hypertension	Yes	34 (16.5%)	0 (0.0%)
	No	172 (83.5%)	10 (100.0%)
First prenatal care visit	First trimester	46 (22.3%)	3 (30.0%)
	Second trimester	113 (54.9%)	4 (40.0%)
	Third trimester	38 (18.4%)	3 (30.0%)
	Unknown	9 (4.4%)	0 (0.0%)
Family history of Congenital Heart Disease	Yes	16 (7.8%)	4 (40.0%)
	No	190 (92.2%)	6 (60.0%)
Plurality	Singleton	200 (97.1%)	10 (100.0%)
	Twins or Above	6 (2.9%)	0 (0.0%)
Gestational age in weeks during delivery	32-36 (Preterm)	10 (4.9%)	3 (30.0%)
	37-42 (Term)	196 (95.1%)	7 (70.0%)
Types of Congenital Heart Disease	Acyanotic CHD	198 (96.1%)	7 (70.0%)
	Cyanotic CHD	8 (3.9%)	3 (30.0%)

About 216 children were included, delayed in diagnosis of CHD was identified in 206 (95.4%) and 10 (4.6%) were no delay in diagnosis children.

Among 206 children with a delayed diagnosis of CHD, possible factors for delayed diagnosis were recorded. The most common factor contributing to delayed diagnosis of CHD was found to be delayed due to health care providers at 193 (89.4%). Delayed in referral was the second most frequent factor contributing to delayed diagnosis of CHD in about 13 (6%) children. Delayed in finances were observed in 5 (2.3%) children. (Figure 2)

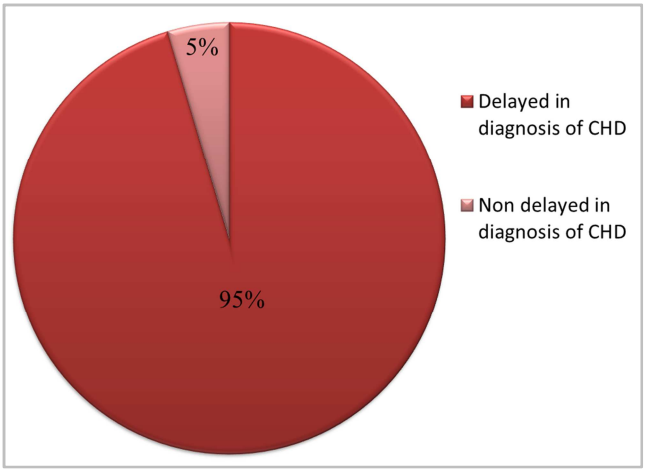

Figure 2. *Delayed and non-delayed in diagnosis of congenital heart disease patients attending at cardiac center Ethiopia, Addis Ababa, Ethiopia January 1, 2018, to December 30, 2020.*

Table 3. *Factors for delayed in diagnosis of congenital heart disease patients attending at cardiac center Ethiopia, Addis Ababa, Ethiopia, January 1, 2018, to December 30, 2020.*

Factors	Frequency	%
Delay due to Health care provider	189	91.7%
Delay in referral	8	3.9%
Financial factors	5	2.4%
Unknown	4	1.9%

5.3. Complication at the Onset of Diagnosis

The common complications at the onset of diagnosis among children with delay in diagnosis of congenital heart disease patients attending at cardiac center Ethiopia are congestive heart failure, pulmonary hypertension, heart rhythm problem, repeated attach of respiratory tract infection and failure to thrive. About 88 (41%) of children were repeated attach of respiratory tract infection is a major complication during this study. (Figure 3)

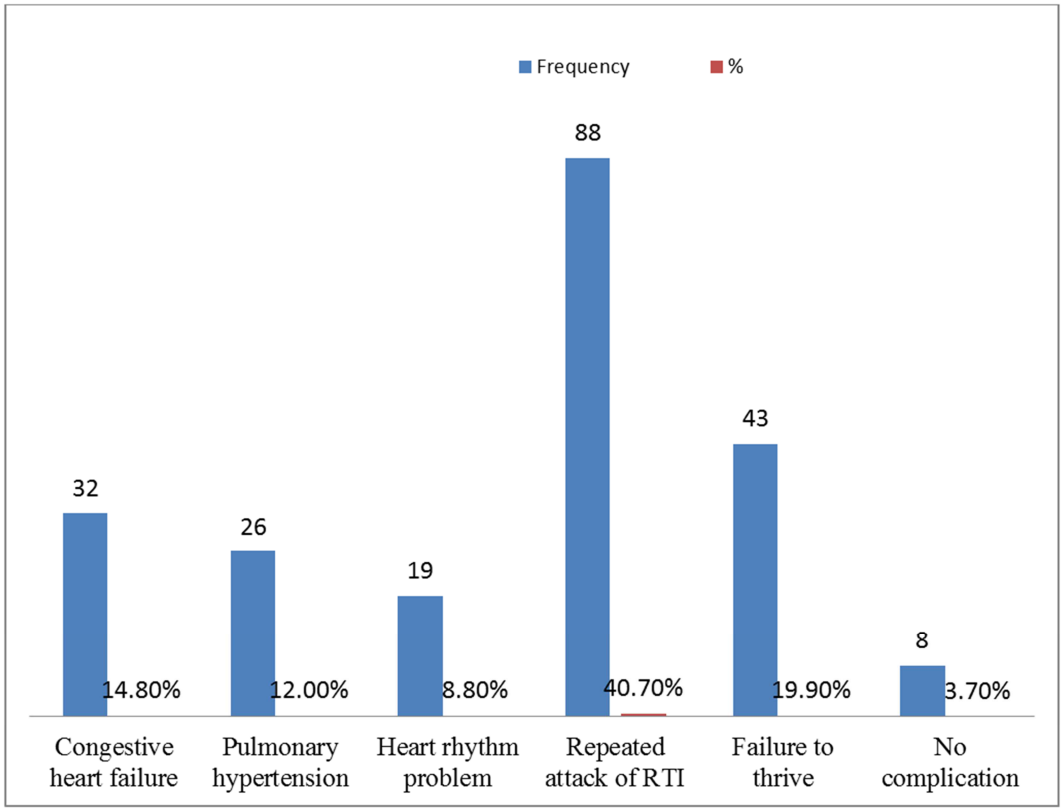

Figure 3. *Complications at the onset of diagnosis among children with delay in diagnosis of congenital heart disease patients attending at cardiac center Ethiopia, Addis Ababa, Ethiopia, January 1, 2018, to December 30, 2020.*

5.4. Factors Associated with Delayed in Diagnosis of Congenital Heart Disease

In the bivariable logistic regression, it was conducted to identify associated variables with delay in diagnosis of congenital heart disease of the study participants. Area of residence, maternal education, place of child delivery and gestational age in weeks. Accordingly, four variables had a significant level of less than 0.25 with delay in diagnosis of congenital heart disease. All four variables were entered into multivariable logistic regression for identifying significant variables, of which three variables had an association with delay in diagnosis of CHD with a significance value of p-value less than 0.05.

Maternal education, Place of child delivery and Gestational age in weeks during delivery were found to be independent predictors of delay in diagnosis in multi variable regression analysis at p-value<0.05.

Table 4. *Bivariable and Multivariable analysis of factors associated with delayed diagnosis of congenital heart disease cardiac centre Ethiopia, Addis Ababa Ethiopia January 1, 2018 to December 30, 2020.*

Variables		Delay in diagnosis		COR (95%CI)	AOR (CI 95%)	P-value
		Yes	No			
Area of residence	Urban	36 (17.5%)	5 (50.0%)	0.212 (0.058-0.770)	0.273 (0.061-1.229)	0.091*
	Rural	170 (82.5%)	5 (50.0%)	1	1	
Maternal education	Illiterate	158 (76.7%)	4 (40.0%)	0.203 (0.055-0.747)	0.103 (0.022-0.493)	0.004**
	Literate	48 (23.3%)	6 (60.0%)	1	1	
Place of child delivery	Hospital	77 (37.4%)	9 (90.0%)	0.066 (0.008-0.534)	0.030 (0.003-0.293)	0.003**
	Health Center	129 (62.6%)	1 (10.0%)	1	1	
Gestational age in weeks during delivery	32-36 (Preterm)	10 (4.9%)	3 (30.0%)	0.119 (0.027-0.531)	0.124 (0.020-0.758)	0.024**
	37-42 (Term)	196 (95.1%)	7 (70.0%)	1	1	

Notes: **at P <0.05 *at P <0.25
Abbreviations: COR- Crude odd ratio, AOR- adjusted odds ratio, CI- Confidence interval.

In multivariable logistic regression analysis, Maternal education those who were illiterate mothers 89.7% than delay in diagnosis of literate mother [AOR=0.103 (95% CI= (0.022-0.493)].

Place of child delivery in Health center about 97% delay in diagnosis of CHD than delivery in hospitals AOR=0.030 (95% CI= (0.003-0.293)].

Gestational age in weeks during delivery term baby 87.6% delay in diagnosis of CHD than preterm baby [AOR=0.124 (95% CI (0.020-0.758)].

6. Discussion

In this study, it was shown that 95.4% of children had a delayed diagnosis of congenital heart disease. In a previous study in southern Asia showed that about 85.1% were delayed diagnosis of CHD (14). The finding shows that the higher delayed diagnosis than the previous study. This difference might be due to health care delivery system of the study area.

In this study, Maternal education those who were illiterate mothers 89.7% than delay in diagnosis of literate mother [AOR=0.103 (95% CI= (0.022-0.493)].

This difference may be due to information found from written materials. Educated mothers may got idea from written materials like newspapers, leaflets, pamphlets and etc than non-educated mother doesn't get the information. Increase in maternal education will lead to an increase in health care access for her children.

Place of child delivery in Health center about 97% delay in diagnosis of CHD than delivery in hospitals AOR=0.030 (95% CI= (0.003-0.293)]. This difference may be due to health service taken in those institutions. In health center there is no echocardiography available for confirmatory diagnosis but in hospitals there is material for confirmation and trained professionals.

Gestational age in weeks during delivery term baby 87.6% delay in diagnosis of CHD than preterm baby [AOR=0.124 (95% CI (0.020-0.758)]. This difference may be due to preterm babies were more symptomatic than term babies. Since, preterm babies were cyanotic which gives clue for health professionals to diagnosis CHD early. This justify that delayed diagnosis is prevalent in term babies.

7. Conclusion and Recommendation

7.1. Conclusion

Delay in the diagnosis of CHD was identified among 95.4% of CHD cases. Acyanotic CHD was the most common and had a more delay in diagnosis than cyanotic CHD. Maternal education, place of child delivery, and gestational age during delivery of children were independently associated with the delayed diagnosis of congenital heart disease. The most common factors contributing to delay in diagnosis of CHD was delayed due to the Health care provider. The most common complication in this study was repeated attach of respiratory tract infection due to delayed diagnosis of CHD.

7.2. Recommendation

7.2.1. For Health Institution

Health institutions are strongly recommended to follow the health care providers on screening of CHD during delivery.

7.2.2. For Health Professionals

Health professionals at different levels should have adequate knowledge about screening of children during birth attending especially those who are at risk mothers.

7.2.3. For Policymakers

Policymakers must include congenital heart disease assessment on antenatal and postnatal care of maternal and child health training on assessments of newborn after delivery and maternal fetal Echocardiography during ANC follow-up and postnatal care.

7.2.4. For Researchers

Researchers will use prospective study design for the delay in the diagnosis of CHD because this study for the first time in this county Ethiopia.

So, it will be an extra need further study related on this topic doing.

The variables associated in this study were maternal education,

place of delivery and gestational age of the child during delivery were no associated in prior study, so the researcher will recommend do on this topic by adding sample size.

8. Strength and Limitation of the Study

8.1. Strength

The strength of this study was done for the first time in our country

8.2. Limitation

Limitation of this study was limited literature related to this study and shortage of time during data collection.

Being analytic cross-sectional study design that doesn't show cause-effect relationship.

The data were collected from a single tertiary hospital, which included only patients treated in this referral facility.

Abbreviations and Acronmys

AOR -Adjusted Odds Ratio
AS - Aortic Stenosis
ASD- Atrial Septal Defect
CCU- Cardiac care unit
CHD- Congenital Heart Disease
CI – Confidence Interval
CoA- Coarctation of Aorta
COR-Crude Odds Ratio
ECG- Electrocardiography
IRB-Institution Review Board
LMICS - Low-Middle Income Countries
OPD- Out patient Department
OR- Odds Ratio
OR -Operation Room
PDA- Patent Ductus Arteriosus
POS -Pulse Oximetry Screening
PS- Pulmonary Stenosis
RTI –Respiratory Tract Infection
SPHMMC –Saint Paul's Hospital Millennium Medical College
TGA- Transposition of Great Arteries
TOF-Tetralogy of Fallot
US - United States
VSD-Ventricular Septal Defect

Declaration

A Thesis submitted to Saint Paul's Hospital Millennium Medical College, Nursing school directorate, as partial fulfillment of the requirement for the degree of Master of Cardiovascular Nursing Practitioner.

Assurance of Principal Investigator

I the undersigned agree to accept all responsibilities for the scientific and ethical conduct of the research project. I was providing timely progress reports to my advisor and sought the necessary advice and approval from my primary advisors in the course of the research. I was communicating timely to my advisors all stakeholders involved in the study including any source of funding for this research.

Name of the student: Tesfaye Hurisa (BSc. Nurse)
Signature: _____
Date: _____
Approval of the Primary Advisor
Name of the primary advisor: -
Signature: _____
Date: _____
Approval of the Co-Advisor
Name of the primary advisor: -
Signature: _____
Date: _____
Approval of the Examiner
Name of the Examiner: -
Signature: _____
Date: _____

Acknowledgements

I want to express my great thanks to SPHMMC, the Department of Medical-Surgical Nursing, and Postgraduates Cardiovascular Nursing Programs for its usual facilities and outstanding opportunity to attend a master's program in Cardiovascular Nursing. My deepest heartfelt gratitude goes to my advisors Sr. Hirut Megersa (MSc, Ph.D. Fellow) and Sr. Tigist Tsegaye (BSc. MSc.) who have been a great help to develop this Thesis paper. In addition, I would like to extend my appreciation to those who have helped me a lot by giving additional advice.

Finally, I would like to thank the data collector and supervisor who participated in this thesis.

Appendix

Appendix 1. Telephone Consent

Basic Elements of Informed Consent:

1) A statement that the study involves research 2) Research purpose and procedures 3) Duration subjects' expected participation in the research 4) Risks 5) Benefits 6) Alternative to participation (if any) 7) Contact name and contact information 8) Voluntary participation 9) Privacy and Confidentiality

Hello, my name is_____. I am a student St. Paul's Hospital Millennium Medical College Department of Medical Surgical Nursing post graduate program conducting research titled delayed in diagnosis of congenital heart disease and associated factors among pediatric patients in Cardiac Center Addis Ababa, Ethiopia.

I am calling to ask you if you are interested in participating in this research study. Your participation is completely voluntary. This means that you do not have to participate in this study unless you want to.

Your decision whether or not to participate in this study will not affect your relationship with your (medical providers, university, community leaders, etc., as applicable). If you do not agree to verbally consent to participating in this study, you will continue to receive appropriate medical care. Would you be willing to hear more information about this study? (If yes, continue with below. If no, thank them for their time and end the call.)

I appreciate your time. Thank you for agreeing to continue. Let me tell you more about this study and what will be required of you.

Appendix 2. English Version of Informed Consent Form

The study is being conducted by Mr. Tesfaye Hurisa from St. Paul's Hospital Millennium Medical College Department of Medical Surgical Nursing post graduate program. The study will be conducted by reviewing your medical chart and telephone interviewing. Therefore, I am kindly requesting you to take part in this study by allowing your medical data to be included in the study. The interview will take 10-15 minutes. Your name will not be written in the data collection form and will never be used in connection with any information you tell us. There is no risk associated with participating in this study. All information regarding your medical condition will be kept strictly confidential. Your participation is voluntary, and you are not obligated to participate in the study. If you feel discomfort with study, it is your right to drop it anytime you want. If you have questions regarding this study, please feel free to contact the principal investigator via his e-mail address: tesfayehurisa12@gmail.com.

So, do you agree to respond? 1. Yes 2. No

Thanks for your time

Appendix 3. Check List/Data Abstraction Format from Patient Medical Chart

Code № _____ Date _____ Phone№

Part I- Socio-demographic characteristics

S. no	Question	Answer	Remark
1	Age	In year_____	
2	Sex	1. Male 2. Female	
3	Area of residence	1. Urban 2. Rural	
4	Maternal education	1. Illiterate 2. Writing and reading 3. College or university	
5	Socio- economic status	1. Low<4000 2. Middle 4001-7000 3. High>7000	

Part II -Clinical Variables and Telephone Interviews associated with delay in congenital heart disease

S. no	Question	Answer	Remark
1	Delay in diagnosis	1. Yes 2. No	
2	Place of child delivered	1. Hospital 2. Health center	
3	Body Weight of child	In Kg	
4	Maternal fetal Echocardiography	1. Yes 2. No	
5	Diabetes Mellitus diagnosis before or during index pregnancy	1. Yes 2. No	
6	History of maternal Hypertension	1. Yes 2. No	
7	First prenatal care visit	1. First trimester 2. Second trimester 3. Third trimester 4. Unknown	
8	Family history of congenital heart disease	1. Yes 2. No	
9	Plurality	1. Singleton 2. Twins or above	
10	Gestational age in weeks	1. 32-36 (preterm) 2. 37-45 (Full term)	
11	Types CHD of patients with delay diagnosis	1. Acyanotic CHD 2. Cyanotic CHD	
12	Factors of delayed in diagnosis CHD	1. Delay due to Health care provider 2. Delayed in referral 3. Financial factor 4. Social factor 5. Unknown	

Appendix 4. Complications at the Onset of Diagnosis Among Pediatrics with CHD

	Complications
1	Congestive heart failure
2	Pulmonary hypertension
3	Heart rhythm problems
4	Repeated attack of RTI
5	Failure to thrive
6	No complication

Thank you for your cooperation
Data collector name_____ Supervisor Name_____
Date Signature _____ Date Signature_____

References

[1] Rao PS. Congenital heart defects–A review. Congenital heart disease-Selected aspects. 2012: 3-44.

[2] Al-Hamash SM. Pattern of congenital heart disease: a hospitalbased study. Al Kindy College Medical Journal. 2006; 3: 44-8.

[3] Van Der Linde D, Konings EE, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJ, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. Journal of the American College of Cardiology. 2011; 58 (21): 2241-7.

[4] Hoffman JI, Kaplan S. The incidence of congenital heart disease. Journal of the American college of cardiology. 2002; 39 (12): 1890-900.

[5] Statistik-Bps SI-BP. National Population and Family Planning Board-BKKBN/Indonesia, Kementerian Kesehatan-Kemenkes-Ministry of Health/Indonesia, ICF International. Indonesia Demographic and Health Survey (IDHS). 2017; 2018: 1-606.

[6] Massin M, Dessy H. Delayed recognition of congenital heart disease. Postgraduate medical journal. 2006; 82 (969): 468-70.

[7] Rapoff MA. Adherence to pediatric medical regimens: Springer Science & Business Media; 2009.

[8] Bruneau BG, Srivastava D. Congenital heart disease: entering a new era of human genetics. Circulation research. 2014; 114 (4): 598-9.

[9] Rychik J, Ayres N, Cuneo B, Gotteiner N, Hornberger L, Spevak PJ, et al. American Society of Echocardiography guidelines and standards for performance of the fetal echocardiogram. Journal of the American Society of Echocardiography. 2004; 17 (7): 803-10.

[10] Troeger C, Forouzanfar M, Rao PC, Khalil I, Brown A, Reiner Jr RC, et al. Estimates of global, regional, and national morbidity, mortality, and aetiologies of diarrhoeal diseases: a systematic analysis for the Global Burden of Disease Study 2015. The Lancet Infectious Diseases. 2017; 17 (9): 909-48.

[11] Simeone RM, Oster ME, Cassell CH, Armour BS, Gray DT, Honein MA. Pediatric inpatient hospital resource use for congenital heart defects. Birth Defects Research Part A: Clinical and Molecular Teratology. 2014; 100 (12): 934-43.

[12] Peterson C, Dawson A, Grosse SD, Riehle-Colarusso T, Olney RS, Tanner JP, et al. Hospitalizations, costs, and mortality among infants with critical congenital heart disease: how important is timely detection? Birth Defects Research Part A: Clinical and Molecular Teratology. 2013; 97 (10): 664-72.

[13] Peterson C, Ailes E, Riehle-Colarusso T, Oster ME, Olney RS, Cassell CH, et al. Late detection of critical congenital heart disease among US infants: estimation of the potential impact of proposed universal screening using pulse oximetry. JAMA pediatrics. 2014; 168 (4): 361-70.

[14] 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. Annals of pediatric cardiology. 2016; 9 (3): 210.

[15] Liberman RF, Getz KD, Lin AE, Higgins CA, Sekhavat S, Markenson GR, et al. Delayed diagnosis of critical congenital heart defects: trends and associated factors. Pediatrics. 2014; 134 (2): e373-e81.

[16] Iyer PU, Moreno GE, Caneo LF, Faiz T, Shekerdemian LS, Iyer KS. Management of late presentation congenital heart disease. Cardiology in the Young. 2017; 27 (S6): S31-S9.

[17] Brown KL, Ridout DA, Hoskote A, Verhulst L, Ricci M, Bull C. Delayed diagnosis of congenital heart disease worsens preoperative condition and outcome of surgery in neonates. Heart. 2006; 92 (9): 1298-302.

[18] Pfammatter J-P, Stocker F. Delayed recognition of haemodynamically relevant congenital heart disease. European journal of pediatrics. 2001; 160 (4): 231-4.

[19] Hoffman JI. The global burden of congenital heart disease. Cardiovascular journal of Africa. 2013; 24 (4): 141-5.

[20] Rao PS. Consensus on timing of intervention for common congenital heart diseases: part I-acyanotic heart defects. The Indian Journal of Pediatrics. 2013; 80 (1): 32-8.

[21] Iqbal S, Saidullah S, Ahmed RI, Khan MAA, Ahmed N, KHAN MF. Factors Contributing to Delayed Diagnosis of Congenital Heart Disease in Pediatric Population. Age (Years). 2021; 2 (184): 69.4.

[22] Murni IK, Wirawan MT, Patmasari L, Sativa ER, Arafuri N, Nugroho S. Delayed diagnosis in children with congenital heart disease: a mixed-method study. BMC pediatrics. 2021; 21 (1): 1-7.

[23] Mocumbi AO, Lameira E, Yaksh A, Paul L, Ferreira MB, Sidi D. Challenges on the management of congenital heart disease in developing countries. International journal of cardiology. 2011; 148 (3): 285-8.

[24] Ng'eno-Owino MC. Factors associated with late diagnosis of Congenital Heart Disease in Kenya. 2018.

[25] Talarge F, Seyoum G, Tamirat M. Congenital heart defects and associated factors in children with congenital anomalies. Ethiop Med J. 2018; 56 (4): 335-42.

[26] Sawyer DB, Vasan RS. Encyclopedia of Cardiovascular Research and Medicine: Elsevier; 2017.

[27] Pfammatter J-P, Keuffer A. Timely diagnosis of congenital heart disease-did we improve? Cardiovascular medicine. 2015; 18 (10): 282-4.

[28] Parker NP, Walner DL. Trends in the indications for pediatric tonsillectomy or adenotonsillectomy. International journal of pediatric otorhinolaryngology. 2011; 75 (2): 282-5.

[29] Organization WH. WHO recommendations on postnatal care of the mother and newborn: World Health Organization; 2014.

[30] Melkamu AW, Bitew BD, Muhammad EA, Hunegnaw MT. Prevalence of growth monitoring practice and its associated factors at public health facilities of North Gondar zone, northwest Ethiopia: an institution-based mixed study. BMC pediatrics. 2019; 19 (1): 1-8.