DOI: https://doi.org/10.53350/pjmhs211551488

ORIGINAL ARTICLE

Factors Contributing to Delayed Diagnosis of Congenital Heart Disease in Pediatric Population

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ABSTRACT

Objective: To analyze various factors contributing to delayed diagnosis of congenital heart disease (CHD) in pediatric population.

Study Design: Cross-sectional study.

Place and Duration of the Study: Department of Pediatrics and Department of Cardiology, Sheikh Khalifa Bin Zayed Al Nahyan Hospital, Rawalakot from January to December 2020.

Material and Methods: A total of 265 children of both genders aged up to 15 years and presenting for the 1st time with the echocardiography confirmed diagnosis of CHD were enrolled. A special proforma was designed and questions were asked from parents/guardians of all study participants. Socio-demographic profile along with improper referral status and inadequate health facilities were noted. SPSS version 26.0 was used for statistical analysis. Qualitative variables like gender, area of residence, literacy status, socio-economic status, types of CHDs, delayed diagnosis (yes/no) and reasons for delayed diagnosis were represented as frequency and percentages.

Results: In a total of 265 children included in the study, there were 156 (58.9%) male. Majority of the children, 184 (69.4%) were less than 2 years of age. Body weight below 3rd centile was noted in 164 (61.9%) children. Maternal fetal echocardiography was done in 13 (4.9%). Acyanotic CHD was noted in 180 (67.9%) children while remaining had cyanotic CHD 85 (32.1%). Delayed diagnosis of CHD was noticed in 211 (79.6%) children. Most common factor contributing to delayed diagnosis of CHD was found to be delayed 1st consultation in 85 (40.3%). Delayed or missed diagnosis by the doctor was the 2nd most frequent factor contributing to delayed diagnosis of CHD noted in 52 (24.6%) children. Delayed referrals were observed in 42 (19.9%) children.

Conclusion: Delayed diagnosis of CHD was noted among 79.6% cases. Acyanotic CHD was the commonest type of CHD in the present study. Most common factors contributing to delayed diagnosis of CHD were delayed 1st consultation, delayed diagnosis by the doctor and delayed referrals.

Keywords: Congenital heart disease, fetal echocardiography, delayed referrals.

INTRODUCTION

Heart disease in children contributes significantly to morbidity and mortality.[1] Congenital heart disease (CHD) are common types of heart diseases seen among children and adults.[2] CHD is considered to form major proportion of all types of major congenital malformations and estimated to affect 2 to 3% neonates while overall prevalence vary between 3 to 10 per 1000 live births worldwide.[3,4] Around 40,000 children are calculated to born with CHDs in Pakistan every year.[5] Data from the west has revealed that burden of CHD is increasing because of escalation in etiological risk factors.[1]

One of the major reasons behind high mortality rates among children with CHDs is that many of these cases present late in cardiac healthcare facilities while complications have already developed that further add to mortality rates liked to CHDs.[6,7] Improvement in early identification as well as timely management have contributed significantly to decline in mortality rates among cases suffering with CHDs.[8,9] Data from Pakistan reveals ventricular septal defect (VSD) and tetralogy of fallot (TOF) to be the most frequency types of CHDs found among 27% and 11% CHD cases respectively.[10]

Antenatal identification of CHDs is now considered as standard care among developed countries that have been found to lead to significantly better outcomes.[11] In a developing country like Pakistan, facilities like antenatal detection of CHDs are not always accessible while most of the patients present late. Such types of delays can result in substandard treatment and poor outcomes as complications may already have occurred in those cases.

This study was aimed at analyzing various factors contributing to delayed diagnosis of CHD in pediatric population. The findings of this study are thought to identify factors delaying diagnosis of CHDs which can further help in planning of awareness and screening programs for the early and timely detection of CHDs.

MATERNAL AND METHODS

This was a cross-sectional study conducted at Department of Pediatrics and Department of Cardiology, Sheikh Khalifa Bin Zayed Al Nahyan Hospital, Rawalakot from January to December 2020. Approval from Institutional Ethical

Committee was taken and informed consent was sought from parents/guardians of all study participants. Inclusion criteria was children of both genders aged up to 15 years and presenting for the 1st time with the echocardiography confirmed diagnosis of CHD. All children presenting with acquired heart disease including acute viral myocarditis or post-viral cardiomyotpahy or those with rheumatic heart disease were not included in this study.

A special proforma was designed and questions were asked from parents/guardians of all study participants. Socio-demographic profile along with improper referral status and inadequate health facilities were noted. Improper referral was labeled as health worker at a level not having sufficient resources like drugs, skills or equipment to manage a clinical condition and does not seek assistance of a better resourced setting. Inadequate health facility was labeled as absence of required diagnostic tools like equipment, drugs or skills at health setting to fully manage a case of heart disease. Social factors were labeled as discrepancy between the culture and society that endanger the life a social group.

Any children diagnosed having cyanotic CHD but with history of getting discharged from a birth clinic was described as delayed diagnosis. Children with acyanotic CHD were considered to have delayed diagnosis if they presented at a time when elective cardiac repair should have already been performed as per contemporary standards of paediatric cardiology.[12]

SPSS version 26.0 was used for statistical analysis. Qualitative variables like gender, area of residence, literacy status, socio-economic status, types of CHDs, delayed diagnosis (yes/no) and reasons for delayed diagnosis were represented as frequency and percentages.

RESULTS

In a total of 265 children included in the study, there were 156 (58.9%) male. Majority of the children, 184 (69.4%) were less than 2 years of age. Body weight below 3rd centile was noted in 164 (61.9%) children. There were 168 (63.4%) children who belonged to rural areas of residence. Socio-economic status was poor (monthly family income below PKR.20000) in 144 (54.3%), middle (monthly family income between PKR. 20000 to 40000) in 98 (37.0%) and upper (monthly family income above PKR. 40000) in remaining 23 (8.7%). Maternal education status as illiterate was noticed among 114 (43.0%) cases. Maternal fetal echocardiography was done in 13 (4.9%). Acyanotic CHD was noted in 180 (67.9%) children while remaining had cyanotic CHD 85 (32.1%). Delayed diagnosis of CHD was noticed in 211 (79.6%) children. Characteristics of children enrolled in the present study are shown in table 1.

Among 211 children with delayed diagnosis of CHD, possible factors for delayed diagnosis were recorded. Most common factor contributing to delayed diagnosis of CHD was found to be delayed 1st consultation in 85 (40.3%). Delayed or missed diagnosis by the doctor was the 2nd most frequent factor contributing to delayed diagnosis of CHD noted in 52 (24.6%) children. Delayed referrals were observed in 42 (19.9%) children. Table 2 shows possible factors for delayed diagnosis of CHD.

Table 1: Characteristics of Children (n=265)

Characteristics		Number (%)
Gender	Male	156 (58.9%)
	Female	109 (41.1%)
Age (Years)	<2	184 (69.4%)
	2-5	58 (21.9%)
	>5	23 (8.7%)
Body Weight < 3rd Centile		164 (61.9%)
Area of Residence	Rural	168 (63.4%)
	Urban	97 (36.6%)
Socio-economic Status	Poor	144 (54.3%)
	Middle	98 (37.0%)
	Upper	23 (8.7%)
Maternal Education	Illiterate	114 (43.0%)
	Literate	151 (57.0%)
Maternal Fetal Echocardiography Done		13 (4.9%)
Types of CHD	Cyanotic	85 (32.1%)
	Acyanotic	180 (67.9%)
Delayed Diagnosis of CHD		211 (79.6%)

Table 2: Possible Factors for Delayed Diagnosis of CHD (n=211)

Factors for Delayed Diagnosis of CHD	Number (%)
Delayed 1st Consultation	85 (40.3%)
Delayed or Missed Diagnosis by the Doctor	52 (24.6%)
Delayed Referral	42 (19.9%)
Social Factors	20 (9.5%)
Financial Factors	12 (5.7%)

DISCUSSION

Although the burden of CHD in terms of morbidity and mortality has decreased significantly in the recent decades but is still a major health problem. Delay in diagnosis of CHD is linked with cardiovascular related compromise as well as organ dysfunction that can further lead to prolonged ventilation and mortality among individuals undergoing cardiac interventions.[13]

In the present study, it was revealed that 79.6% children were having delayed diagnosis of CHD. Delayed diagnosis of CHD is observed both in developing and developed countries. Local study done by Rashid U et al from Lahore Pakistan found 85.1% of the children to have delayed diagnosis of CHD.[14] Data from Belgium reported 8.9% of children had delayed diagnosis of CHD.[12] Data from USA showed that out of 3746 live-births with non-syndromic critical CHD, late detection occurred among 1106 (29.5%) infants.[15]

Researchers have revealed that types of CHD or the existence of extra-cardiac defect are linked with less likely delayed diagnosis of CHD.[15] Local data in the past revealed inadequate trained health system and financial issues contributing to delay in diagnosis of CHD.[14] We found that most common factor contributing to delayed diagnosis of CHD was found to be delayed 1st consultation in 85 (40.3%). Delayed or missed diagnosis by the doctor was the 2nd most frequent factor contributing to delayed diagnosis of CHD noted in 52 (24.6%) children. We observed that delayed referrals were noted in 42 (19.9%) children with delayed diagnosis of CHD. Recent data from Indonesia shared that delayed diagnosis of CHD by doctors was noted to be the reason for delayed diagnosis of CHD in children among 57.5% cases.[16] Lack of awareness about CHD and its diagnosis among general practitioners could be one important reason behind missed diagnosis of CHD. Studies have revealed that delay in diagnosis of CHD is

linked with severe complications and many a times, complications have already occurred when the diagnosis (late) is made.[16,17]

We found that 61.9% children were having malnutrition as well. Regional data suggests that malnutrition is noted have prevalence around 26% among children[18] but in the present study it was noted in much higher proportion highlighting the fact that children with delayed diagnosis of CHD are much more exposed to malnutrition than other children. Children with malnutrition are found to have increased rates of morbidity and mortality when undergoing cardiac surgeries so early identification of CHD for timely intervention is much more important to save these children from complications related to delay and management of CHD.

In the present study, we found that maternal fetal echocardiography was done in only 4.9% cases. Antenatal fetal echocardiography is considered to be a very helpful tool for the identification of CHD at earlier stages and can be useful in minimizing the morbidity and mortality related with CHD.[19] Antenatal diagnosis of CHD is quite common in developed countries[20] but recent data revealed that it is missing in our local population[14] so sources should be allocated and efforts should be made to make it possible in maximum number of cases to diagnosis CHD during antenatal check-ups.

Our study had some limitations as well. As this was a single center study with limited duration of data, our findings cannot be generalized. Definition and interpretation of delay in diagnosis can itself pose some ambiguity so further studies are required to further refine these concepts. Further studies finding out correlation of specific types of CHD with delayed diagnosis should be done. More research is required to correlate complications linked with delay in diagnosis of CHD.

CONCLUSION

Delayed diagnosis of CHD was noted among 79.6% cases. Acyanotic CHD was the commonest type of CHD in the present study. Most common factors contributing to delayed diagnosis of CHD were delayed 1st consultation, delayed diagnosis by the doctor and delayed referrals.

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