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DELAYED DIAGNOSIS OF CHDS IN RURAL PAKISTAN AND ITS IMPACT ON SURVIVAL

Dr Waqas Ahmed[1*], Dr Bilal Sher Khan[2], Dr Sher Alam Khan[3], Khalida Shaheen[4], Dr Muhammad Fayaz[5], Farkhanda Jabeen[6]

[1*]Resident Paeditrician Ayub Teaching Hospital Abbottabad, Pakistan
Email: waqasamc@yahoo.com
[2]Speciality Training Officer Paediatrics Combined Military Hospital Abbottabad, Pakistan
Email: bilalsher777@gmail.com
[3]Resident Paediatrician, Combined Military Hospital Abbottabad, Pakistan
Email: doctorsheralamkhan@gmail.com
[4]Senior Head Nurse, Ayub Teaching Hospital Abbottabad, Email: khalidashaheen.2020@gmail.com
[5]Medical Officer, Ayub Teaching Hospital, Abbottabad, Email: muhammadfayaz795@gmail.com
[6]AFNS Officer, Combined Military Hospital Abbottabad, Email: farahaaman30@gmail.com

***Corresponding author:** Dr Waqas Ahmed
*Email: waqasamc@yahoo.com

ABSTRACT

Introduction: Congenital heart diseases (CHDs) lead to many deaths of infants in countries all over the world. It is common for CHDs in rural Pakistan to be diagnosed slowly, owing to limited healthcare facilities, a lack of understanding about the disease, and limitations in seeing a specialist.

Objective: To assess the impact of delayed diagnosis of CHDs on survival outcomes in children from rural Pakistan.

Materials and Method: The descriptive cross-sectional study was conducted at the Ayub Teaching Hospital Abbottabad, Pakistan from July 2021 to December 2021. The data came from examining the charts of 150 children with congenital heart disease. Among the patients in the study were children up to 12 years old who had heart defects determined by echocardiography. Criteria such as when the disease started, the initial symptoms, the time it took to receive a diagnosis, and treatment results were analyzed to review the data.

Results: Sixty-two percent of patients experienced a delayed diagnosis, and it was linked to more problems and risks of death. The social class, level of education, and neighborhood where the person lived all played a role in the process of diagnosis.

Conclusion: Detecting CHD early on improves the chances for a positive outcome. Each community should have greater access to healthcare and education about their health.

Keywords: Congenital heart disease, delayed diagnosis, rural Pakistan, pediatric cardiology, child survival.

INTRODUCTION

Congenital heart diseases (CHDs) affect many children worldwide, and a quick diagnosis helps decide how their condition turns out. For people living in rural Pakistan, many factors may cause the diagnosis of CHDs to be put off, including lack of knowledge, incomplete medical care, and socioeconomic challenges. Delay in pinpointing new diseases results in later treatment, which in turn increases the possible health complications and death rates among children (1). Iqbal et al. point out that because parents in rural Pakistan often do not realize the symptoms in their children and have limited access to cardiology services, they usually come for treatment late. Troubles with early recognition increase the probability of patients being treated less effectively and missing early opportunities for surgery or medicine. Detecting CHD early greatly benefits the child, as early care can often correct the abnormalities found in the heart. Atiq explains that quick diagnosis is essential as it can result in improved outcomes and a significant reduction in deaths, mainly in places where access to postnatal diagnostics is limited (2).

A further sign of why early detection matters is shown in the Glenn operation, where late diagnosis usually means a poor preoperative status and increased risks during the procedure (3). According to Tariq et al., late diagnoses result in more advanced complications, making it harder for surgery to be successful. As a result, even the most effective surgery is less reliable when the condition is discovered late. Many rural children in Pakistan have CHDs that are only found during adolescence or adulthood. According to Mughal et al., many GUCH patients returning to tertiary care centers were not correctly diagnosed or treated as children (4). Such a trend points to a serious healthcare issue that leads to poor results. People's cultural backgrounds influence their decisions about health care. In rural regions, people often rely on folk practices or delay seeking care from doctors because it is hard for them to visit faraway clinics or hospitals (5).

Ladak et al. believe that cultural differences and various environmental reasons bring added delays in finding a diagnosis and lessen the child's quality of life. Earlier diagnosis would be beneficial, as delayed diagnosis can affect someone even into adulthood. Often, children with CHD in Pakistan and other low and middle-income countries still live with poor health, limited activity, and heavy health problems from an early age because they do not receive early care (6). Ladak et al. reported that people with CHD who were diagnosed late and received treatment later also suffered from worsened health and lower mental health. It proves that how long it takes to make a diagnosis influences a patient's education, ability to work, and social life for a long time.

Delayed diagnosis is a problem that can be seen in Pakistan and many other places. Zhang et al., in their study from Beijing, point out that failure to find crucial congenital heart issues at birth can result in a lower chance of survival for newborns (7). Missing prenatal exams, the unavailability of trained pediatricians, and deficient postnatal care cause these delays. Murni et al. also pointed out that delayed diagnosis is a crucial concern caused by the lack of clear referral systems and heavy caregiver unawareness in Indonesia (8). This research applies to Pakistan, confirming that there are many reasons why patients take time to get diagnosed, mainly due to system issues. Recognizing that prenatal diagnosis has significantly contributed to better outcomes is also essential. While Vincenti et al. questioned if the benefits of prenatal care are being exaggerated, they still see its importance for management decisions (9).

According to Bonnet, prenatal diagnosis makes it possible for care to be organized immediately after childbirth, which helps patients survive and reduces the risk of complications (10). Even though maternal-fetal services and ultrasound are rare and limited in rural Pakistan, the benefits they could offer urgently require improving the training of primary health workers in maternal-fetal care services and ultrasound. Atiq underlines that identifying problems in their early stages has the most success and recommends spreading public awareness, advancing rural care provider education, and upgrading diagnostic resources (11). Global data reveals that early detection in the womb is very significant. After identifying complex CHDs in the early stages of pregnancy, babies were less likely to pass away, thanks to prompt treatment (12). Based on these findings, it is clear that enhancing diagnosis in rural Pakistan can be achieved through stronger policies and additional skills.

Further studies found that a late diagnosis can seriously affect a person's long-term survival. Uema et al. found that a late diagnosis of heart diseases, such as carcinoid heart disease, significantly lowered the survival rate of patients (13). The pathology details may vary, but the key idea of timely diagnosis is still the same. According to Khou et al., diagnosing pulmonary arterial hypertension in Australia was consistently delayed, suggesting this challenge is present in many different healthcare systems (14). In the study, the primary reasons for delays were the early symptoms and a shortage of experts, and these problems can be seen more clearly in remote areas of Pakistan. Additionally, Han et al. studied the outcomes of infants identified with Down syndrome early and those identified later. They noted a higher survival rate for those diagnosed before birth (15). It proves timely detection is crucial and pushes for better screening services worldwide before and after birth. Not discovering CHDs early in rural Pakistan means that most adults have a much lower chance of living in good health or even surviving.

Objective: To investigate the factors contributing to delayed diagnosis of congenital heart diseases (CHDs) in rural Pakistan and assess its impact on the survival outcomes of affected children.

MATERIALS AND METHODS

Design: Retrospective Cross-sectional Study.

Study setting: The study was done at the Ayub Teaching Hospital Abbottabad, Pakistan.

Duration: The process of collecting and analyzing data from six months, starting in July 2021 to December 2021.

Inclusion Criteria: The study included all patients in rural Pakistan who were 0 to 12 years old and were diagnosed with congenital heart disease during the study. Patients with records showing every procedure performed were included in this research. Infants diagnosed early and late were examined to compare their survival rates.

Exclusion Criteria: Anyone treated in urban hospitals who had acquired heart problems or whose records were not fully available was not included. Both children who were detected late during the study and those who did not have a clear rural residence status were not included in the study.

Methods

A group of 150 children diagnosed with CHDs was selected by reviewing the medical records of the hospital. The data was extracted using a tool that captured the patient's age, symptoms, location, where CHD was diagnosed, diagnosis type, and whether they survived. Patients were sorted into two groups early diagnosis (property obtained in the first month) or delayed diagnosis (patient property received more than 1 month after birth). Chi-square tests and logistic regression were used to analyze the link between late diagnosis and survival. Barriers to spotting early signs, such as unawareness, having no easy way to get to healthcare facilities, and primary doctors taking too much time to refer people, were examined through interviews with ten caregivers. All the data were analyzed using SPSS version 25. TupleNet's review board approved, and consent from caregivers was obtained for them to participate in the interviews. The findings were considered concerning clinical and social factors.

RESULTS

Researchers studied 150 children affected by congenital heart disease (CHD) from rural areas in Pakistan. There were 88 male patients (58.7%) and 62 female patients (41.3%), and the average age at which the disease was diagnosed was 14.6 months. Ninety-three patients (62%) were diagnosed with RSV too late, after the first month of life, and only 57 patients (38%) were seen promptly in the first month of life. Table 1 outlines the demographic make-up of the participants. The leading group in this research (61.3%) came from low-income households. Most fathers (54%) and mothers (72%) in the families did not finish primary school. Also, most families were required to travel farther than 50 kilometers to get to a tertiary care center.

Table 1: Demographic Characteristics of Patients (n = 150)

Variable	Frequency (n)	Percentage (%)
Gender		
Male	88	58.7
Female	62	41.3
Age at Diagnosis		
≤1 month (Early)	57	38.0
>1 month (Delayed)	93	62.0
Household Income		
Low (< PKR 25,000/month)	92	61.3
Middle (PKR 25,000–50,000)	42	28.0
High (> PKR 50,000)	16	10.7
Maternal Education		
No Formal Education	64	42.7
Primary	44	29.3
Secondary or Higher	42	28.0
Distance to Hospital		
<25 km	28	18.7
25–50 km	21	14.0
>50 km	101	67.3

Among the 93 patients with late diagnosis, 51 (54.8%) faced serious consequences like congestive heart failure, episodes of cyanosis, or did not grow as expected. Furthermore, only 12 (21%) in the early-diagnosis group experienced complications. A statistically significant link was present between the timing of the diagnosis and how likely patients were to suffer complications ($p < 0.01$).

Table 2: Complications Based on Timing of Diagnosis

Diagnosis Timing	Patients with Complications (n)	Total Patients (n)	Percentage (%)
Early (≤1 month)	12	57	21.0
Delayed (>1 month)	51	93	54.8

The delay in diagnosis was linked to a higher rate of death, with 27 deaths (29%) observed in that group, compared to only four deaths (7%) in the fast diagnosis group. There was significant evidence that survival was influenced by when people were diagnosed ($p < 0.01$).

Table 3: Survival Outcome by Timing of Diagnosis

Diagnosis Timing	Survivors (n)	Deaths (n)	Total (n)	Mortality Rate (%)
Early (≤1 month)	53	4	57	7.0
Delayed (>1 month)	66	27	93	29.0

Most of the delays in diagnosis mentioned by parents were a result of parents not understanding heart symptoms, a misdiagnosis at a local center, problems finding pediatric cardiology services, and problems with money. Table 4 highlights the different barriers that have been reported.

Table 4: Reported Barriers to Early Diagnosis (n = 150)

Reported Barrier	Frequency (n)	Percentage (%)
Unawareness of symptoms	106	70.7
Lack of specialized healthcare services	88	58.7
Financial constraints	75	50.0
Transportation difficulties	61	40.7
Misdiagnosis at local healthcare centers	54	36.0

The findings revealed that people with CHD who are not diagnosed soon enough usually have more complications and worse survival chances. This finding is supported by literature stating that prompt detection and treatment of CHDs often lead to a better prognosis. It points out that better access to diagnosis, healthcare services, and information among parents in rural Pakistan is essential for better results in children with CHDs.

DISCUSSION

The study reveals that both rural children and their health in Pakistan are at risk due to late diagnosis of congenital heart disease (CHD) and the resulting high rates of morbidity and mortality. 62% of the participants from the study were diagnosed with CHD beyond the neonatal period, suggesting that cases are often missed early. It is alarming since research clearly shows that early diagnosis helps improve the outcomes of congenital heart defects. Delaying the detection of the disease causes children to face more severe illnesses, such as heart failure, decreased oxygen in blood, and slow growth, and it also increases their risk of death, as confirmed by the difference in death rate between the two groups (29% versus 7%). The main issues that cause CHD to be diagnosed late in rural regions were found in quantity-based studies and conversations with parents. Some parents were not informed enough to notice if their children had heart disease.

Most parents assumed their child's illness was due to general weakness, common infections, or malnutrition something often reported in rural regions where awareness about medical matters is low. The shortage of awareness becomes even more serious as most of the mothers in the study (72%) did not complete primary school, suggesting that completing primary schooling can help people seek medical care promptly. This aligns with previous studies, demonstrating that a higher maternal education level helps identify illness early and get needed care. It was also found that many people have limited access to specialized healthcare. More than two-thirds of families had to go more than 50 kilometers to find a medical center where CHD could be diagnosed and treated.

A lack of pediatric cardiologists and lab equipment in the community makes it hard for primary providers to spot congenital heart flaws early. In 36% of cases, the condition was not identified accurately or at all in nearby clinics, which delayed the situation further. The same happens in low- and middle-income countries, where problems with resources and personnel often prevent early diagnosis. Many people faced serious obstacles because of a lack of money. Many families in the study mentioned that struggling financially prevented them from using specialized services. The majority of participants coming from low-income homes mean travel fees, outpatient tests, and the risk of surgery are a significant challenge for them. Because health insurance is not standard and many costs are paid directly, getting medical treatment early is often difficult for most in Pakistan.

Moreover, cultural values about gender and reliance on men for medical decisions can cause the process of seeking health advice to be delayed if the mother is the primary caregiver and cannot independently make financial choices. The outcomes demonstrate the impact that delayed diagnosis can have on clinical care. Almost 55% of the children with late diagnosis suffered from complications, while early detection meant only 21% experienced any. This problem's steep difference points to the fact that early diagnosis may prevent death. Early identification allows prompt medical care, surgeries when required and a better chance for the pet to have a good quality of life. A late diagnosis often means that damage cannot be reversed, and patients are more susceptible to dangerous diseases.

Looking at mortality data makes the issue even more serious. When it comes to the delay in diagnoses, a tripling of deaths suggests that problems exist in medical care and health education.

The results suggest that immediate improvements are needed in handling neonatal screening, especially in rural and other disadvantaged places. Carrying out screening with pulse oximetry for newborns and granting access to echocardiography in secondary health care could decrease the number of late-detected CHDs. Public health professionals can gain insights from this study about how important it is to conduct initiatives within communities. Educating the public using community health workers, organizing campaigns, and involving congenital heart disease in maternal and child health measures can raise awareness. Ensuring doctors and other healthcare staff in rural areas can recognize warning symptoms and refer patients immediately is just as necessary. Using telemedicine and portable health units with testing equipment in remote areas gives people there easier access to healthcare.

Crucial points about CHD diagnosis in rural Pakistan can be found in this study, but some limitations should be noted. The research was carried out in a single tertiary hospital so that the results may differ everywhere. Also, sometimes parents may remember certain aspects incorrectly, creating recall bias. Despite these obstacles, having a large sample and reasonable trends helps support the recommendations and further research.

CONCLUSION

This study points out that late diagnosis of CHD in children in rural Pakistan is due in large part to low awareness, inefficient healthcare services, and financial issues. These findings point out that a late diagnosis leads to more complications and higher death rates, so timely service should be prioritized. Most of the families involved faced significant difficulties, such as needing to go far to get care and not knowing enough about CHD, especially the less-educated mothers. As a result, it is essential to launch neonatal screening programs, improve education about healthcare in communities, and make primary healthcare more effective. Additional training for rural healthcare staff and telemedicine can improve the early detection and management of diseases. Working on these issues is necessary for improving how many children live and helping prevent morbidity and mortality in less served communities due to CHD. Changing the system requires the cooperation of the health, education and policy sectors.

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