

The Diagnosis Is Not the Destination: Building a Foetal Heart Team in Pakistan

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A few months ago, I sat across from a family holding an ultrasound report that had, after weeks of uncertainty, finally given them an answer. Their unborn child had a critical heart defect. The relief of knowing lasted only a moment. Then the mother asked the question every parent in that chair eventually asks: "What happens now?" In much of Pakistan, the honest answer is still: it depends on where you live, and whom you happen to know.

That gap, between finding a diagnosis and knowing what to do with it, is where too many of our families are left standing.

Seeing Is Only the First Step

We have rightly spent the last decade pushing to close the detection gap. International guidance now recommends that routine screening go beyond the four-chamber view to include the outflow tracts, because the four-chamber view alone misses many conotruncal and outflow tract lesions, among them several of the defects most likely to cause a newborn to collapse in the first days of life.¹ That work matters, and it is not finished. But a diagnosis, on its own, changes nothing. What changes outcomes is what happens between the scan and the first breath.

The American Heart Association's scientific statement on foetal cardiac disease is explicit on this point: once a lesion is found, diagnosis and management become inseparable. Care passes to a multidisciplinary team, and every affected pregnancy is assigned an anticipated level of care at delivery, ranging from a routine birth to intervention in the delivery room itself.²

When Diagnosis Becomes Preparation

The evidence is not new. In a landmark series of newborns with transposition of the great arteries (TGA), no prenatally diagnosed baby died before surgery, compared with 6% of those diagnosed after birth; postoperative mortality was 0% versus 8.5%.³ A meta-analysis has since confirmed that, across critical congenital heart disease, prenatal diagnosis reduces the risk of death from cardiovascular compromise before planned neonatal surgery.⁴

These are observational data, and babies diagnosed before and after birth may differ in ways no study fully captures. But population-based data from Ontario, show the Department of Paediatric Cardiology, National Institute of Cardiovascular Diseases, Karachi, Pakistan.

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mechanism at work. Prenatally diagnosed babies with TGA reached tertiary care within 1.4 hours rather than 10.4, received prostaglandin within minutes rather than hours, and underwent balloon atrial septostomy nearly ten hours sooner, with significantly better one-year survival.⁵ The scan did not rescue those babies. The preparation it made possible did: the right hospital, prostaglandin at hand, and a team able to perform an urgent septostomy already waiting.

What Happens Without a Pathway

Pakistani data are limited, but they point the same way. In a Lahore study in which every enrolled newborn underwent echocardiography in the first week of life, only 3 of the 145 recruited had a prenatal cardiac diagnosis, whereas 21 critical lesions, most often transposition and tetralogy of Fallot, were found only after birth.⁶ Nationally, distance to a health facility is independently associated with neonatal death,⁷ a reminder that for a baby with a duct-dependent circulation, the journey itself carries risk. The experience of our region fills in the rest. Even at a leading paediatric cardiac centre in southern India, only 33 of 105 neonates with critical heart disease (31%) arrived with a prenatal diagnosis.⁸ In a second prospective study from the same region, 138 newborns with heart disease were transported a median of 138 km to a paediatric cardiac centre. Sixty per cent of those with duct-dependent circulation travelled without prostaglandin, and 42% arrived with end-organ injury.⁹ Referral networks and transport systems differ between our countries, but the constraints are much the same, and there is little reason to believe that Pakistani newborns fare better.

Pakistan already knows this story in its adult form. In our series of 129 adults with congenital heart disease at the National Institute of Cardiovascular Diseases, Karachi, 70.5% had been diagnosed late. The commonest reason was not the absence of a test but delayed referral (42.9%), and in almost a quarter of delayed cases the delay lay with the doctor.¹⁰ The same pattern is seen in childhood: at the Children's Hospital, Lahore, 85% of 354 children with congenital heart disease were diagnosed late, most often because of delayed first consultation, a missed diagnosis by a health professional or delayed referral.¹¹ The adults in our series were once children whose hearts someone, at some point, could have heard. The gap was never only in seeing. It was in what happened next.

The Economics of Preparation

The honest question in any resource-limited setting is cost, and here too the regional evidence points the other way. In the southern Indian cohort, prenatal diagnosis with planned peripartum care was associated with 16% lower total costs of neonatal cardiac care and a significantly smaller burden relative to family income.⁸ A foetal heart team does not add an expense to the system. It moves the expense earlier, to a phone call and a case conference, instead of later, to an ambulance without prostaglandin and a longer, sicker admission.

A Diagnosis That Was Allowed to Matter

I have seen what the other path looks like. During my congenital cardiac imaging fellowship in Malaysia, a 23-year-old mother was referred at 25 weeks with a suspected foetal cardiac tumour. Foetal echocardiography told a different story. TGA with a large ventricular septal defect, a small left ventricle, and a pseudoaneurysm of the mitral–pulmonary intervalvular fibrosa causing severe subpulmonary obstruction, a lesion so rare that no routine scan could have been expected to name it (Figure 1).¹²

The finding was not the achievement. What mattered was what it set in motion: counselling for the parents weeks before birth, delivery planned at a tertiary cardiac centre, prostaglandin prepared for a circulation that might depend on the duct, and surgical evaluation arranged in advance.¹² That mother did not have to ask “What happens now?” Someone had already written it down.

Counselling in Our Own Context

A pathway imported without adaptation will not work here. In Pakistan, a foetal cardiac diagnosis is rarely received by a couple alone. It is often shared with an extended family,

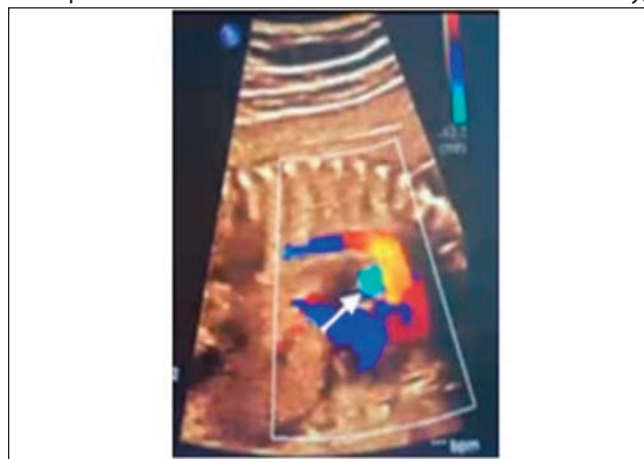


Figure-1: Foetal colour Doppler echocardiography at 25 weeks' gestation in a foetus with transposition of the great arteries, showing flow into a mitral–pulmonary intervalvular fibrosa pseudoaneurysm (arrow). The prenatal finding directly shaped counselling and delivery planning. Reproduced from the author's own published case report (Ahsan AK, Yubbu P, Rosli AA. *J Cardiol Cases* 2026).¹²

frequently after 20 weeks' gestation, and within religious and legal frameworks that shape which choices are considered. The pregnant woman's own preferences and consent must remain at the centre: she should decide who joins the conversation and how decisions are made. Counselling must therefore be unhurried, repeated, and offered in the family's own language. It must be honest about prognosis, about the treatment actually available in this country, and about its cost, and it must present every lawful option without steering the family towards any of them. This is a clinical skill, and it deserves to be taught as one.

Building It Within Our Means

We must also be honest about capacity. Neonatal cardiac surgery in Pakistan is concentrated in a small number of centres in a few cities, and a delivery plan is only as good as the service that receives the baby. Clinicians in Khyber Pakhtunkhwa describe newborn cardiac screening held back by limited resources, fragmented referral and sociocultural barriers.¹³ This argues for a hub-and-spoke model: tele-consultation linking district obstetric units to regional foetal cardiology hubs; planned in-utero transfer, so that the mother rather than a sick newborn makes the journey; and a palliative care pathway, planned with the same care, for lesions that cannot be treated locally. Within that model, five steps are achievable with the resources we already have (Figure 2):

1. Detect: extend routine anomaly scans to include the

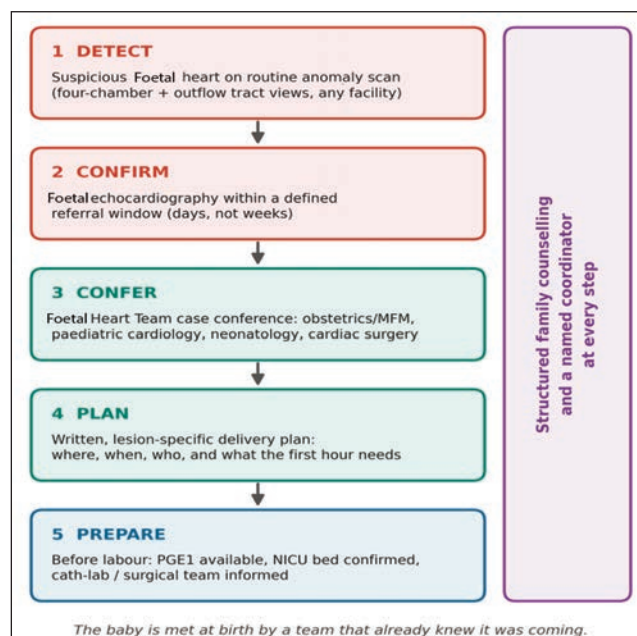


Figure-2: A proposed Foetal Heart Team pathway for Pakistan, from detection at any facility to a lesion-specific delivery plan with resources in place before birth. MFM: maternal-foetal medicine; PGE1: prostaglandin E1; NICU: neonatal intensive care unit.

outflow tract views recommended internationally.¹

2. Confirm: a defined referral window, so that a suspicious scan anywhere in the country reaches a foetal echocardiographer within days, not whenever a family finds its own way.
3. Confer: a standing Foetal Heart Team of obstetrics and maternal-foetal medicine, paediatric cardiology, neonatology and cardiac surgery, reviewing every confirmed diagnosis together.
4. Plan: a written, lesion-specific delivery plan, so that a duct-dependent lesion and a well-tolerated shunt are never funnelled into the same reflexive pathway.²
5. Prepare: prostaglandin available, a neonatal bed confirmed, and the catheter or surgical team informed before labour begins.

Running through all five is something no guideline can manufacture. One named person who picks up the phone, and a conversation that treats a frightened family as partners in the plan rather than recipients of a report.

This need not begin nationally. A pilot at two or three regional hubs, with a simple audit, would show whether the pathway works: the time from a suspicious scan to foetal echocardiography, the proportion of confirmed cases with a documented delivery plan, delivery at the designated centre, deterioration before intervention, neonatal mortality, and out-of-pocket cost to families. These are measures any hub can collect, and they would give us the Pakistani outcome data on referral and transport that we still lack.

Met, Not Merely Seen

Too many of the adults in our clinics carry the consequences of diagnoses that came too late to matter.¹⁰ A foetal heart team is our chance to stop writing that story one generation earlier. It will not be built by a single institution or a single specialty. It will be built when obstetricians, sonologists, paediatric cardiologists, neonatologists and surgeons agree that a foetal cardiac diagnosis is not the end of their involvement, but the beginning of a shared plan. The first step is modest: agree on the pathway at a few hubs, measure what happens and let the results guide its expansion.

Detection in Pakistan is still incomplete, and improving it remains a priority. But each time a heart is found before birth, we should be ready, with equal seriousness, for what happens next. Every Pakistani baby found to have a critical heart defect deserves not only to be seen, but to be met at birth by a team that already knew it was coming.

Disclaimer: None.

Conflict of interest: The author is the first author of references 10 and 12.

Source of funding: None.

DOI:<https://doi.org/10.47391/JPMA.26-88>

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