Improving prenatal detection of major congenital heart disease

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National surgical registries in the UK and USA record surgical and interventional congenital heart disease (CHD) procedures. They are externally verified and indicate whether an infant had an antenatal diagnosis (AD). We distinguish antenatal diagnosis from prenatal detection, here, as the former only includes live born children surviving to reach a cardiac unit who are offered cardiac surgery or interventional catheter.

The UK database (NICOR-Congenital) publishes outcome data on a public portal and, since 2004, has published average AD data by healthcare region.¹ Several maternity hospitals lie within each region, but without maternity data to identify place of screening or feedback from cardiac centres, most maternity units and private obstetric practices do not know their individual screening performance.

Tiny Tickers training program

Tiny Tickers is a charity that was established in 1999 to improve prenatal detection of major CHD by promoting standards through education and training. At that time the average antenatal diagnosis rate for major CHD was 23% based on a nationwide study that relied on reporting from individual surgical centres.² A decade later, verified data from the national NICOR-Congenital database, shows a modest overall rise to 35%.

Since 2002, Tiny Tickers has provided on-site, hands-on training to maternity hospitals in obstetric ultrasound scanning to improve individual performance in detection of major CHD based on a 5 View protocol published by Yagel, *et al.*³

The five views were chosen to be comprehensive and practical, so that they would improve overall prenatal detection by including situs, 4 chambers, outflow tracts and 3 vessel and tracheal view and be readily included in the second trimester fetal anomaly screening scan. The sonographer trainer found the protocol was acceptable to sonographers and practical to incorporate into the limited time available (20–30 minutes). The five views has subsequently been adopted by ISUOG.⁴

Educational material to complement training was made available from the Tiny Tickers website and included a popular *aide memoir* poster to display in obstetric sonographers' rooms and a programme of case examples that could be downloaded

(<http://tinytickers.org/content/ultrasound-screening>).

However, assessing the impact of training proved more difficult. Despite the fact that audit has been strongly recommended in antenatal care guidelines,⁵ the resources to undertake verified audit were never provided at the maternity hospital level. Without prospective maternity audit, verified by the regional cardiac centre and by postmortem in cases undergoing termination, the true prenatal detection rate for a screening unit cannot be ascertained. This lack of feedback to screeners removes the ability to close the loop between training and performance.

It has been reported that one in three infants with a potentially life-threatening cardiovascular malformation left hospital undiagnosed⁶ and it is recognised that delayed diagnosis of CHD worsens preoperative condition and outcome of surgery in neonates,⁷ hence, the need to improve early detection.

Linking maternity and infant data

Individual children can only be identified in the surgical dataset of the treating hospital and may be linked to their mother through fields such as surname and postcode – provided these remain identical. Date of birth may assist in linkage if it is near the expected date of delivery.

However, submission to NICOR-Congenital involves an anonymisation process that removes these data fields and, although health region data can be presented centrally, prenatal screening performance for major CHD is not easily derived for an individual maternity hospital or private practice.

We have recently published data from the Tiny Tickers training experience by manually linking maternity, perinatal and infant data in 19 maternity hospitals referring pre- and post-natally to one cardiac surgical centre. Many were co-located with similar funding and training opportunities, yet there was wide inter-hospital performance. The units performing better received feedback from locally collected audit which we believe is an essential part of targeted training and quality improvement.⁸

Conclusion

Linking postnatal infant cardiac surgical data with prenatal and neonatal maternity and admissions data is time consuming, but can provide hospital and lesion-specific data allowing hospitals

to identify training needs and provide targeted support to improve individual and overall performance.

Diagnosis was not helpful due to the vagueness of prenatal reporting and we recommend that there is an agreed framework that can link prenatal suspicion to postnatal verification – using sophisticated coding systems such as ICD-10 that accommodate the complexity of CHD diagnoses. We further recommend that pre- and postnatal data sources be linked in the future to facilitate timely feedback on prenatal detection.

This is an opportunity for practitioners working in private offices or maternity hospitals to work with their cardiac centres to standardise practice and improve screening performance.

References

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