The Incidence of Unrecognised Life-Threatening Congenital Heart Disease in Newborns Discharged from Hospital in Scotland

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Aims: To determine the proportion of infants with life-threatening congenital heart defects being discharged from hospital before diagnosis, over a 10 year study period in Scotland.

Methods: Retrospective data analysis of all infants born from 1st January 2001 to 31st December 2010 in Scotland with prenatal, postpartum, postdischarge or post-mortem diagnosis of life-threatening congenital heart disease.

Results: 491 infants were born with life-threatening congenital heart defects in Scotland from 2001-2010. In 98 cases the diagnosis was made after the infant was discharged from hospital, equating to 20.0% of all diagnoses. Of these 98 infants, 6 (6.1%) were dead, 30 (30.6%) were critically ill, 60 (61.2%) were unwell and only 2 (2.0%) were well at the time of presentation.

Conclusions: 20.0% of all diagnoses of life-threatening congenital heart disease in Scotland from 1st January 2001 to 31st December 2010 were made after the infant was discharged from hospital. In 98% of these cases, the infant was either unwell, critically unwell or deceased at presentation. As clinical examination of newborns continues to perform poorly in identifying infants with life-threatening congenital heart disease, improvement in detection is likely to come from other sources: increasing antenatal diagnoses, educating health professionals about the limits of physical examination and implementing routine pulse oximetry in the postnatal period.