Time and method of diagnosis of severe congenital heart defects

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Background: Congenital heart defects (CHD) are the most common birth defects worldwide and are an important cause of morbidity and early death. The time of diagnosis may have impact on treatment and outcome. The objective of this study was to investigate the time and method of diagnosis in children with severe CHDs.

Methods: Data concerning all pregnancies and children with severe CHD in Norway in 2016 were retrieved from the Norwegian Registry of Pregnancy Termination and the Oslo University Hospital’s Clinical Registry for Congenital Heart Defects.

Results: In this nationwide register-based cohort study, which included all 60528 live births, stillbirths and late terminated pregnancies in Norway in 2016, 181 (0.3%) fetuses with severe CHDs was identified. The severe CHD was identified before birth in 105 (58%) fetuses. A total of 51 (49%) pregnancies with severe CHD were terminated. In most children without prenatal diagnosis, the CHD was identified during the birth hospitalization, however, in nine (12%) children without a prenatal diagnosis, the heart defects were discovered after discharge from hospital. The method of CHD detection in live born children without prenatal diagnosis is presented in figure 1.

Conclusions: Most children with severe CHDs were detected by ultrasound examination during pregnancy or routine examinations prior to maternity leave. However, almost half of the children diagnosed with severe CHD after birth were found outside of routine examinations and in some children the diagnosis was not recognized until after hospitalization. The importance of immediate assessment by a cardiologist of small children with suspected severe CHD has to be emphasized.

Figure 1. The method of CHD detection in live born children without prenatal diagnosis