

P-298

Cardiac problems and palliative care in children with Trisomy 18

Szymkiewicz - Dangel J. (1), Ślęzak M. (2), Dangel T. (2)

Perinatal Cardiology and Congenital Anomalies Department, The Center of Postgraduate Medical Education, Warsaw, Poland (1); The Warsaw Hospice for Children, Warsaw, Poland (2)

Introduction: There are many controversies concerning type of treatment which should be implemented in children with Edwards syndrome (T18). The aim of our study was evaluation of type of cardiac problems and quality of pediatric palliative home care in children with T18.

Material and methods: The database of prenatal and home care program was used. For quality of home palliative care already describe questionnaire was applied.

Results: Data on 96 fetuses were obtained. There were 13 termination of pregnancy out of 48 diagnosed before 24 weeks (27%), 30 intrauterine deaths, 3 stillbirths and 50 live births. Among the live born: 34 died later in the hospital just after birth, 16 were discharged home under the care of the hospice. 42 children, 17 referred after prenatal diagnosis, were under home based palliative care program. 15 out of 17 (88%) with known T18 after prenatal karyotype were born at time by vaginal delivery, in contrary to 8 out of 25 (32%) without prenatal diagnosis. Birth weight was below normal in all. 38 children had septal defects, majority perimembranous inlet, 30 had primary pulmonary hypertension. One had palliative cardiac surgery. 37 children died at home, 2 at the hospital. 34 died in the first year of life. Time of palliative care lasted between 32 and 1730 days. Three different mechanisms of death were described. The parents highly rated the quality of home palliative care.

Conclusions: Prenatal diagnosis enables decision making about the type of delivery, palliative care and protection of the child against persistent therapy. Neonates born before 33 weeks and weighing <1300 g have no chance to survive. For the first time we proved, that majority of children with T18 have primary pulmonary hypertension, so cardiac surgery for closing the ventricular septal defect should not be performed. Home palliative care is a valuable alternative to hospital treatment in T18 children.