

**Palliative care in pediatric cardiology – when should it be considered?**

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**Introduction:** Pediatric palliative care program started in 1994. Recently there is more discussion about the necessity of introducing the palliative care approach in pediatric cardiology. The aim of this study was to evaluate patients with congenital heart defects (CHD) who were under the hospice care in our institution between 1994 and 2013, and in the whole country in 2012.

**Material.** During 19 years, 63 children with CHD were under the home palliative care. There were 19 children with isolated CHD and 44 with chromosomal aberrations. in the whole country in 2012. In the whole country there were 80 patients with CHD, 28 with isolated and 52 with chromosomal aberrations

**Results:**

Period of palliative home care lasted from 3 to 1269 days, mean 161 days.

In our institution the diagnosis changed between 1994 – 2013. Until 2000 - 9 teenagers with complicated CHD who were not operated on due to pulmonary hypertension or severe pulmonary hypoplasia were admitted mainly due to possibility of home-based oxygen supply and hemodilutions. Since 2001: 10 children with post-operative complications, 3 after prenatal diagnosis, 4: T21 and pulmonary hypertension, 47 with lethal chromosomal aberrations, mainly T13, T18, and complicated T21. In the country the diagnosis were similar: single ventricle physiology after different stage of treatment (17), hypoplastic pulmonaty arteries (7), T13(7),T18(30) and complicated T21.

Since 1999 perinatal palliative care was established, for fetuses with lethal chromosomal aberrations complicated by congenital heart defects or with unoperable isolated CHD. 37 patients were admitted to the hospice program after prenatal diagnosis and consultation. None of those children was operated on. One newborn with HLHS diagnosed prenatally was under the hospice care for 35 days.

**Conclusions.** Palliative care should be considered in all children with life limiting conditions. In patients with complicated CHD in whom surgical treatment failed such options should be discussed with parents. Palliative care should be the method of choice for fetuses and neonates with lethal chromosomal disorders whose parents were against termination of pregnancy. Such approach should be discussed with parents if severe inoperable isolated CHD is diagnosed in fetuses.