

Transition from pediatric cardiology to GUCH - information from the Swedish National Registry SWEDCON

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Introduction: SWEDCON, a national registry for congenital heart disease, has been created in Sweden and includes data from pediatric cardiology, GUCH and congenital cardiac surgery. The registry has only been in use for 2 years but older data from extensive local registries have been imported to SWEDCON as well as data from the previous GUCH registry which was started in 1992.

Methods: Data from SWEDCON were analyzed concerning different aspects of the transition from pediatric cardiology to GUCH.

Results: At the start in February 2009 SWEDCON included a total of 21 387 patients, 6815 of these came from the GUCH registry. 5491 pts were older than 19 yrs but had not been registered as GUCH patients. To our surprise this group included some patients with transposition, single ventricle, Fallot etc. Partly this could maybe be explained by follow-up at non-GUCH clinics or missed registrations but it could also be an indication that follow-up had been missed.

VSD dominated as main diagnosis in the pediatric group and ASD/PFO in the GUCH group. In the group of patients that had actively been referred from pediatric cardiology for follow-up at a GUCH clinic (1759 pts) the dominating main diagnosis was aortic or pulmonary stenosis. In the referred group 32% had a complex malformation and 72% had been operated.

All registered deaths were analyzed and the age of death was noted for different diagnoses. Early death was noted more often for complex malformations. In a few cases death as late as after the age of 60 yrs was noted even for some patients with complex disease.

From the pediatric material the number of patients between 13-18 yrs was analyzed for some diagnostic groups, where follow-up at a GUCH clinic would be mandatory. This gave a good estimate of the needed GUCH capacity during the coming 5 years.

Conclusions: Data from a registry such as SWEDCON can be used to improve the transition from pediatric care to GUCH care and to detect changes in referral patterns early. Long-time survival can be studied and the future need for GUCH resources can be estimated.