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Late causes of death after congenital cardiac surgery - a population-based six-decade study with 98% follow-up

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Introduction (or Basis or Objectives): Survival after paediatric congenital cardiac surgery is lower than the general population, but has improved significantly during recent decades. Consequently, the number of adults with congenital heart defects (CHD) has surpassed paediatric patients. The majority of patients require life-long follow-up. Information regarding causes of death late after surgery would benefit follow-up among these patients. We investigated whether late modes of death after surgery for CHD's have changed in recent years and how they compare to rates among the general population.

Methods: We obtained data retrospectively from a nation-wide CHD database, including paediatric patients who underwent cardiac surgery at <15 years of age at one of five university– or one district hospital in Finland 1953-–2009. The Finnish population registry supplied patient survival status. We categorised modes of death into CHD-related and non-CHD-related deaths using ICD diagnostic codes. Modes of death among the study population were compared to those among a sex-, age-, birth-time-, and hospital district-matched control population supplied by Statistics Finland.

Results: Between 1953 and 2009, 10,964 patients underwent 13,876 operations, with 98% follow-up (10,692). The longest follow-up was 60 years. Early (<30 days) and late mortality were 5.7% (612 patients) and 11% (1,130 patients), respectively. The incidence of CHD-related death correlated with defect severity. Fatal heart failure (17% with pulmonary hypertension) was the most common mode of CHD-related death, but decreased among those undergoing surgery 1990–2009 (Table 1). The incidence of sudden death was zero after surgery for ASD, VSD, TOF, and TGA 1990–2009 (Table 1). Deaths due to respiratory, neurological, endocrine and metabolic disease were significantly more common among study patients than the general population. Pneumonia constituted the majority of non-CHD-related deaths among the study population.

Conclusions: Sudden death and fatal heart failure after congenital cardiac surgery decreased markedly among study patients, but remained a significant cause of death among patients operated for severe cardiac defects, warranting life-long surveillance. Pneumonia requires immediate diagnosis and treatment among these patients.

	Cardiovascular incidence / 1000 PY		***Heart failure incidence / 1000 PY***		***Sudden death incidence / 1000 PY***		***Perioperative incidence / 1000 PY***	
Defect	**1953–1989**	**1990–2010**	**1953–1989**	**1990–2010**	**1953–1989**	**1990–2010**	**1953–1989**	**1990–2010**
PDA	0.07	0	0.31	0	0.03	0.13	0.04	0
ASD	0.08	0	0.11	0	0.23	0	0.04	0
COA	0.17	0	0.64	0.58	0.64	0.14	0.20	0.29
VSD	0.33	0.08*	1.42	0.84*	0.61	0**	1.13	0.34***
TOF	0.85	0.26	1.94	0.78	1.94	0	1.55	0.78*
TGA	1.12	0.95	4.65	2.21**	3.53	0***	2.41	2.52
UVH	3.50	3.47	11.51	8.69	4.50	4.63	9.01	6.95

Table 1 – Incidence of CHD-related deaths among different defect groups by era of operation.
PY = Person years; *p<0.05; **p<0.01, ***p<0.0001 PDA patent ductus arteriosus; ASD atrial septal defect; COA coarctation of the aorta; VSD ventricular septal defect; TOF tetralogy of Fallot; TGA transposition of the great arteries; UVH univentricular heart