Survivorship in children and young adults with congenital heart disease in Sweden.

The mortality in patients with congenital heart disease has markedly decreased during the last

decades because of advancement in pediatric care. Nevertheless, there are limited data on

survival trends in children and young adults with CHD compared with the general population.

We linked data from the Swedish Patient and Cause of Death Registers to study all patients who

were diagnosed with CHD and born between January 1, 1970 and December 31, 1993. Follow-up

and comorbidity data were collected until December 31, 2011.

We identified 21,892 patients (48.5% women) with CHD in Sweden with a mean follow-up of 27

years. Controls (n= 219,816, 10 for each patient) matched for birth year, sex, and county were

randomly selected from the general population. The survivorship among children aged younger

than 5 years was increased by two thirds in those born in 1990–1993 compared with those born in

1970–1979. Furthermore, the group of patients with the most severe complex defects had the

highest risk for death, with HR of 64.1 (95% CI 53.4 – 76.9).

According to this large registry study from Sweden, the absolute and relative survivorship

increased substantially but mortality remains high in young patients with congenital heart disease

compared with matched controls, in particular in subsets of great complexity.

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For further information, please contact:

Zacharias Mandalenakis MD, PhD

Department of Molecular and Clinical Medicine/Cardiology

Sahlgrenska University Hospital/Östra

Diagnosvägen 11, SE-416 50 Gothenburg, Sweden

E-mail: zacharias.mandalenakis@gu.se

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