Mortality in Congenital Heart Disease: Are Governmental Registries Reliable for Cause of Death?

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Background: Statistics on mortality are of great importance for prognostic research. Therefore, the aim of this study was to assess the reliability and utility of the governmental mortality registry in research on causes of death in adult patients with congenital heart disease (CHD).

Methods: A nationwide registry of over 10,000 adults with CHD was used to verify the causes of death provided by the governmental mortality registry, by linkage of the two registries.

Results: Of our nationwide registry (n=7277, on date of linkage) we could link 95% (n=6933) to the governmental mortality registry. In the governmental mortality registry 196 patients (2.4%) were found and recorded deceased, versus 228 deceased patients (3.1%) recorded in our nationwide registry, during a follow up of 18,100 patient years. Median age at death was 49 years (range 20 to 91 years). Of all deaths in our registry, 77% had a cardiovascular origin; nearly 50% were due to progressive heart failure and arrhythmias. The governmental mortality registry recorded death due to progressive heart failure and arrhythmias in only 8.5%. Moreover, this registry recorded death with an 'unspecified' cause in approximately 30%, primarily containing patients who died from progressive heart failure and arrhythmias according to their medical records.

Conclusions: The governmental mortality registry lacks the specificity and completeness needed for accurate research on causes of death in adult patients with CHD, and should not be used for this purpose.