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Survival Prospects and Circumstance of Death in Contemporary Adult Patients with Congenital Heart Disease: The Shifting Focus of Mortality from the Perioperative Period to Long-Term Complications

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Background: In the current era, over 90% of children born with congenital heart disease survive to adulthood. However, adult congenital heart disease (ACHD) patients have ongoing morbidity and reduced long-term survival. Recently the importance of specialized follow-up at tertiary ACHD centres has been highlighted. We aimed to assess survival prospects and clarify causes of death in a large cohort of patients at a single, tertiary centre.

Methods and results: We have included 6,969 adult patients (age 29.9±15.4 years, 49.9% female) under follow-up at our institution between 1991 and 2013. Causes of death were ascertained from official death certificates. Survival was compared with the expected survival in the general age and gender matched English population and standardized mortality rates (SMRs) were calculated. Over a median follow-up time of 9.1 years (IQR 5.2–14.5), 524 patients died. Leading causes of death were chronic cardiac failure (44%), pneumonia (10%), sudden-cardiac death (7%), cancer (6%) and haemorrhage (6%), while perioperative mortality was low. Isolated simple defects (ASD, VSD or PDA) exhibited mortality rates similar to those in the general population, while patients with Eisenmenger syndrome (SMR 12.8), complex congenital heart disease (SMR 14.1) and Fontan physiology (SMR 23.4) had much poorer long-term survival ($P<0.0001$ for all). The probability of cardiac death decreased with increasing patient's age (OR 0.90/decade [95% CI 0.82–0.98], $P=0.02$) whereas the proportion of patients dying from non-cardiac causes, such as cancer, increased (OR 1.34, [95% CI 1.1.2–1.63], $P=0.002$).

Conclusions: ACHD patients, as a whole, continue to be afflicted by increased mortality, as they grow older, compared to general population. Highest mortality rates were observed amongst patients with complex ACHD, Fontan physiology an Eisenmenger syndrome. Our contemporary data show a clear shift from perioperative to chronic cardiac mortality and non-cardiac death.