

Quality of life and long-term follow-up after stenting of Coarctation of the Aorta.

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Background: Stenting of coarctation of the aorta (CA) requires life-long medical follow-up for late complications, hypertension sequelae and treatment (including reinterventions). Lack of adequate care is a frequent problem with Grown-up congenital heart defect (GUCH) patients.

Objective: To evaluate the long-term clinical condition and quality of life (QoL) after stenting for CA in tertiary heart center.

Methods and patients: QoL was assessed with a custom-made questionnaire through direct contact during regular visit or phone call. The main topics include self-assessment, arterial hypertension, medication, symptoms, follow-up and demographics. A comparison with official statistical analysis was performed. Hospital database was used to assess health care accessibility, insurance, specific diagnostics and treatment.

41 patients underwent CA stenting between 2003 and 03.2017. Procedure related complications were observed in 8 cases (19%). The patients were followed-up for a mean of 3.2 ± 2.8 years (0.1 to 10.2 years). Six patients were excluded from the study (2 urgent operations and 4 foreigners). During follow-up 10 additional interventional procedures were conducted (all of them in children).

Results: There is no regular follow-up for more than 4 years in 52% of GUCH. By October 2017 nine patients (26.5%) are children and 26 patients (74.3%) are GUCH. 26 responded to the questionnaire; 9 (34.6%) of the adults did not due to inactive phone number/refusal to participate. There is significant difference in follow-up free period - mean 1.86 years for children versus 5.86 years for adults ($p=0.003$). Educational level corresponds to the general population. Follow-up is performed in secondary (37.5%) or a tertiary center (56.3%) by cardiologist (43.8%) or pediatric cardiologist (50%). 25% of GUCH are not followed up at all. 11 % are unemployed with no insurance. All but 5 patients report good general health and 13 (50 %) take antihypertensive therapy.

Conclusion: There is clear lapse in the care for GUCH with stented CA. QoL for these patients is not significantly different from the general population. There is a discrepancy between general self-assessment as being "cured" and symptomatic findings. GUCH with stented CA need proactive care with multimodality imaging methods and timely solution of potential complications.