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Mid-term follow-up and quality of life in patients after Fontan surgery

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Background: The Fontan procedure (atriopulmonary Fontan) and total cavo-pulmonary connection are designed to treat univentricular heart. Whereas peri-operative mortality has declined, the current challenge is mid and long-term outcome.

Objectives: To evaluate the outcome and quality of life of survivors with Fontan circulation.

Methods: This retrospective monocentric study aimed patients who had follow-up after Fontan surgery at the University Hospital of Lille. Data were collected on medical records. The quality of life was evaluated between June and October 2014 by two scales: Paediatric Quality of Life Inventory TM (PedsQL) before 26 years of age and Medical Outcome Study Short Form 36 (MOS SF 36) after 26 years.

Results: Among 96 patients who underwent Fontan procedure, median follow-up was 9.6 (6.1-12.5) years after the last intervention. Nine-year global survival was 93%. 95 % of patients had total cavo-pulmonary connection and 5 % had atrio-pulmonary connection. Arrhythmia occurred in 27.1%, single ventricle dysfunction in 87.4%, leak of the atrio-ventricular valve in 58.9%. Protein-losing enteropathy affected 4.2% of patients and thromboembolic events appeared in 17.7%. Total score of quality of life was 66.5 % according to the PedsQL and 62.5 % to the MOS SF36.

Conclusion: This French cohort of survivors with Fontan circulation has the same initial characteristics than which described in the literature. The level of quality of life was inferior to general population. The question of global rehabilitation of these patients must be raised.