

Valvular aortic stenosis in children Outcome, physical activity and health-related quality of life

Akademisk avhandling

Som för avläggande av medicine doktorexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i föreläsningssalen Tallen, Drottning Silvias Barn- och ungdomssjukhus, den 4 maj 2022, klockan 13.00.

av Cecilia Kjellberg Olofsson

Fakultetsopponent:

Professor Daniël De Wolf, MD, PhD, FESC

Ghent University, Faculty of Medicine and Health Sciences, Ghent, Belgium

Avhandlingen baseras på följande delarbeten

- I. Kjellberg-Olofsson C, Berggren H, Söderberg B, Sunnegårdh J. Treatment of valvular aortic stenosis in children: a 20-year experience in a single institution. *Interact Cardiovasc Thorac Surg.* 2018 Sep 1;27(3):410-416. doi: 10.1093/icvts/ivy078
- II. Kjellberg Olofsson C, Hanseus K, Johansson Ramgren J, Johansson Synnergren M, Sunnegårdh J. A national study of the outcome after treatment of critical aortic stenosis in the neonate. *Cardiol Young.* 2020 Sep;30(9):1321-1327. doi: 10.1017/S1047951120002036
- III. Skovdahl P*, Kjellberg Olofsson C*, Sunnegardh J, Fridolfsson J, Börjesson M, Buratti S. Children and Adolescents Treated for Valvular Aortic Stenosis Have Different Physical Activity Patterns Compared to Healthy Controls: A Methodological Study in a National Cohort. *Pediatr Cardiol.* 2021 Apr;42(4):774-783. doi: 10.1007/s00246-021-02540-1. *Equal contribution
- IV. Kjellberg Olofsson C, Hanseus K, Johansson Ramgren J, Johansson Synnergren M, Sunnegårdh J. Outcomes in neonatal critical and non-critical aortic stenosis: a retrospective cohort study. *Submitted*
- V. Kjellberg Olofsson C, Skovdahl P, Fridolfsson J, Arvidsson D, Börjesson M, Sunnegårdh J, Buratti S. Life Satisfaction, Health-Related Quality of Life and Physical Activity After Treatment for Valvular Aortic Stenosis. *Accepted for publication in Cardiology in the Young*

**SAHLGRENKA AKADEMIN
INSTITUTIONEN FÖR KLINISKA VETENSKAPER**



Valvular aortic stenosis in children Outcome, physical activity and health-related quality of life

Cecilia Kjellberg Olofsson

Avdelningen för pediatrik, Institutionen för kliniska vetenskaper, Sahlgrenska akademien, Göteborgs universitet, Sverige, 2022.

Abstract

Introduction: Isolated valvular aortic stenosis (VAS) accounts for 3–5% of congenital heart disease and presents with a wide spectrum of severity. Critical VAS in the neonate is the most severe form, fatal in the absence of treatment. Physical activity is essential for normal development and is a prerequisite for long-term cardiovascular health. Health-related quality of life (HRQoL) and life satisfaction are important subjective outcome factors.

Aim: To investigate survival and treatment outcome in neonates, children and adolescents treated for isolated VAS and in the children and adolescents, to study physical activity, HRQoL and life satisfaction.

Methods: All patients were treated for VAS with surgical valvotomy as the preferred primary intervention. Patients were identified in surgical registries at the two Swedish paediatric surgical heart centres. A distinction was made between neonatal critical VAS (severe stenosis, with duct-dependent systemic circulation and/or depressed left ventricular function) and neonatal non-critical VAS. Data were collected from patient files and echocardiograms, with survival data from the Swedish Population Registry for long-term follow-up. Physical activity was measured objectively with accelerometry. HRQoL was measured with KIDSCREEN-52, and life satisfaction was measured with the Satisfaction With Life Scale. Patients were matched with controls from the Swedish Population Registry.

Results and conclusions: Mortality after treatment for VAS in neonates and children was low. Transplant-free survival was 96% in the paediatric cohort (n=113), 91% in neonates with critical VAS (n=65) and 98% in neonates with non-critical VAS (n=42) with median follow-up between 11 and 14 years. Reinterventions were common and performed in 38% of the paediatric patients, 58% of neonates with critical VAS and 33% of neonates with non-critical VAS (p=0.008). Both patients and controls fulfilled the WHO recommendations for physical activity to a high degree. Accelerometry revealed a different physical activity pattern in patients compared to controls. Patients rated their HRQoL and life satisfaction as similar to healthy controls. An unexpected finding was a negative association between high-intensity physical activity and psychological well-being and life satisfaction in adolescent patients.

Keywords: Valvular aortic stenosis, critical aortic stenosis, neonate, child, outcome, surgical valvotomy, physical activity, health-related quality of life, life satisfaction