

Children with Congenital Heart Defects Intellectual Functioning and Family Impact

Carmen Ryberg

Avhandling för avläggande av filosofie doktorsexamen i psykologi, som med vederbörligt tillstånd av Samhällsvetenskapliga fakulteten vid Göteborgs universitet kommer att offentligens försvaras fredagen den 24 maj 2019, kl. 10.00, Sal F1, Psykologiska institutionen, Haraldsgatan 1, Göteborg.

Opponent är professor Elisabeth Utens, Faculty of Social and Behavioral Sciences, University of Amsterdam.

The dissertation is based on the following studies:

- I. Ryberg, C., Sunnegårdh, J., Thorson, M., & Broberg, M. (2016). Intellectual Functioning in Children with Congenital Heart Defects Treated with Surgery or by Catheter Interventions. *Frontiers in Pediatrics*, 4(113). doi:10.3389/fped.2016.00113.
- II. Buratti, S., Ryberg, C., Broberg, M., & Sunnegårdh, J. (2016). Do Self- and Proxy Reports of Cognitive Problems Reflect Intellectual Functioning in Children and Adolescents with Congenital Heart Defects? *Frontiers in Pediatrics*, 4(127). doi:10.3389/fped.2016.00127.
- III. Ryberg, C., Sunnegårdh, J., & Broberg, M. (Submitted). The Impact of Children with Congenital Heart Defects on their Families according to Mothers' and Fathers' reports.



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Abstract

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The purpose of the present doctoral thesis was to investigate intellectual functioning and the influence of the children with congenital heart defects in their families. We analyzed how the severity of the heart defect, the child's age, and the socio-economic status of the child's family were related to the intellectual functioning of the children and to the impact on the family. A scale from a screening tool, the PedsQL 3.0 Cardiac module, was also tested to identify children and adolescents at risk of intellectual problems. A psychological model for understanding the development of children was used in discussing how physical and psychosocial factors affect each other and how parents, healthcare professionals, and the child's environment influence children's development.

This thesis is based in three empirical studies. Studies I and II deal with intellectual functioning in children with CHD in Sweden, and suggest a screening instrument to detect early intellectual difficulties in children. Children with a broad spectrum of congenital heart defects, different ages, different intellectually functioning and from families with different socio-economic backgrounds were investigated. Study I found out that children with CHD treated with surgery or by catheter interventions as a group performed within the normal range on overall intellectual functioning and identified severity of the heart diagnosis and SES as important factors related to increased risk for lower FSIQ. Study II found that the use of the Self-report and the Proxy-reports of PedsQL Subscale Cognitive Problems was valid as a screening tool for identifying children who need to undergo further cognitive evaluation. Study III investigate the influence of a child with CHD in the family and showed that in families of children with CHD mothers reported higher levels of negative impact than fathers, that severity of the CHD was significantly related to parental stress for both fathers and mothers, that mothers with low and medium SES reported higher stress than mothers in the high SES groups and that the strongest predictor for negative impact for both mothers and fathers was the presence of multiple risk factors. Our results show that children and parents of children with CHD are a heterogenous group and that we need longitudinal studies to help us understand how children with congenital heart defects develop over time and how their families experience the impact of having a child with CHD.

Key words: Intellectual functioning, self-reports, proxy reports, congenital heart defects, neurodevelopment, congenital heart defects, mothers and fathers of children with congenital heart defects.