Welcome to half-time review
for the degree of Doctor in Clinical Medicine

Friday 16th of February at 9-11 AM

Birgitta Svensson

Health-Related Quality of Life in Children With Right Ventricular Outflow Tract Anomalies

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Main Supervisor
Associate Professor Petru Liuba
Department of Pediatrics/Pediatric Cardiology, Clinical Sciences, Lund University

Co-supervisor
Professor Ewa Idvall
Faculty of Health and Society, Malmö University

Opponents
Associated Professor Ulf Thilén
Department of Cardiology, Clinical Sciences, Lund University

Professor Anna Forsberg
Department of Health Sciences, Lund University

Location
Segerfalksalen
Sölvegatan 17, Lund
Skåne University Hospital

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Välkommen till halvtidskontroll
för Doktorsexamen i klinisk medicin

Fredag 16:e februari kl. 9-11

Birgitta Svensson

Health-Related Quality of Life in Children With Right Ventricular Outflow Tract Anomalies

Handledare
Docent, Univ. Lektor Petru Liuba
Avd. för Pediatrik, Inst. för Kliniska Vetenskaper, Lunds Universitet

Granskare
Docent Ulf Thilén
Kardiologi, Inst. för Kliniska Vetenskaper, Lunds Universitet

Professor Anna Forsberg
Inst. för hälsovetenskaper, Lunds Universitet

Lokal
Segerfalksalen
Sölvegatan 17, Lund
Skånes Universitetssjukhus

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Abstract for half-time review | Birgitta Svensson, PhD candidate

Health-Related Quality of Life in Children With Right Ventricular Outflow Tract Anomalies

PhD student:
Birgitta Svensson, reg. nurse

Main scientific adviser:
Petru Liuba
Assoc. Professor
Pediatric Heart Center, Skåne University Hospital and Lund University

Scientific Co-adviser:
Ewa Idvall
Professor
Faculty of Health and Society, Malmö University

Background
Right ventricular outflow tract (RVOT) anomalies include a heterogeneous group of congenital heart defects that often need at least one cardiac surgery during childhood. Careful clinical and imaging assessment of especially those children that would require re-intervention at some point is crucial in the therapeutic decision making. Health-related quality of life (HRQoL) has been increasingly used in the past decade as patient-related outcome (PRO) in order to better understand the impact of a certain disease on the individual’s health status.

Aims
To describe the HRQoL in children with previous cardiac surgeries and in children with RVOT anomalies from the age of 8 years.

Method
Study I was based on registry data from the Swedish National Registry for Congenital Heart Disease (SWEDCON) and aimed to describe the association between cardiac surgery and HRQoL using the DISABKIDS chronic generic measure-short version (DCMG-12) in 337 children with congenital heart disease (CHD). Study II included children with previous surgical repair for several types of RVOT anomalies.
anomalies in whom HRQoL was assessed at both item and domain levels using 3 earlier validated questionnaires (PedsQL 4.0, PedsQL Cardiac Module and DCMG-12) completed by both children and their parents (n=97). Studies III and IV are under way, and include qualitative longitudinal interviews of 9 children with RVOT anomalies and their parents who are interviewed separately at three occasions (54 interviews). The PedsQL Cardiac Module was completed on every occasion.

**Preliminary results**

In study I, there was an inverse correlation between the number of cardiac surgeries and the HRQoL total score. Children with ≥ 3 cardiac surgeries appear to have lower HRQoL than children with other chronic diseases. The results of this study are published in British journal “Cardiology in the Young” (2016). In study II, children with RVOT anomalies had decreased HRQoL in cognitive and physical functioning, with almost 50 % of children reporting problems due to breathlessness during physical activities. The agreement between the child and parent report using the PedsQL Cardiac Module was strong in 13 of 22 items.

**Significance**

Further understanding of HRQoL in children with complex CHD such as those with previous surgical repair of RVOT anomalies, is expected to aid to the clinical decision making during follow-up.

**Publications**
