

**Living with a congenital heart disease:  
Adolescents' and young adults' experiences**

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Belgium

This thesis is based on the following papers, referred to in the text by their Roman numerals.

- I Berghammer M., Dellborg M., Ekman I. Young adults experiences of living with congenital heart disease.  
*International Journal of Cardiology 2006; 110:340-347.*
- II Berghammer M., Karlsson J., Ekman I., Eriksson P., Dellborg M. Self-reported health status (EQ-5D) in adults with congenital heart disease.  
*International Journal of Cardiology 2011 Nov 1.*  
Doi nr. 10.1016/j.ijcard.2011.10.002 [Epub ahead of print]
- III Berghammer M., Brink E., Rydberg A., Dellborg M., Ekman I. Committed to life - adolescents and young adults experiences from living with Fontan circulation.  
*Submitted*
- IV Berghammer M., Rydberg A., Ekman I., Hanseus K., Karlsson J. Sense of coherence, health perception, satisfaction with life in adolescents' and young adults' living with Fontan circulation.  
*In manuscript*



UNIVERSITY OF GOTHENBURG

# **LIVING WITH A CONGENITAL HEART DISEASE: ADOLESCENTS' AND YOUNG ADULTS' EXPERIENCES**

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## **Abstract**

Adolescents and young adults with a congenital heart disease (CHD) belong to a new and in several respects unexplored population within health research. They represent a diversity of heart defects requiring different surgical procedures and interventions that create different physiological and anatomical structures, with various impacts on life. Extensive improvements in congenital cardiology and heart surgery have created new groups of children surviving into adolescence and adulthood. One of these new groups comprises adolescents and young adults living with a surgically palliated univentricular heart. The overall aim in this thesis was to illuminate how adolescents and young adults with a CHD experience life and their life situation. Furthermore, the thesis aims to describe the impact of a CHD on health perception, sense of coherence, quality of life and satisfaction with life in adolescents and young adults with a CHD or, in particular, a surgically palliated univentricular heart.

A multi-method approach was used, consisting of in-depth interviews and surveys. The first two studies involved adults with various kinds of CHD. Study I involved six in-depth interviews, analysed with the phenomenological-hermeneutical method. Study II consisted of statistical analysis of EQ-5D questionnaire data from 1435 adults included in the GUCH registry. The last two studies involved adolescents and young adults living with a surgically palliated univentricular heart. Seven in-depth interviews in Study III were complemented by a survey in Study IV using the Sense of Coherence scale and the modified study-specific Essence of Existence questionnaire. The 33 responses were analysed with a combination of content analysis and descriptive statistics.

The results show that adolescents and adults with a CHD in most cases perceive their health to be good, and the same as their peers. Pain or discomfort and anxiety or depression were found to be prevalent health problems, but adults with a CHD reported less pain or discomfort than a general population. It was further shown that symptoms may occur even if the adult with a CHD reports himself/herself to be asymptomatic. Despite limitations in everyday life, adolescents and young adults with a surgically palliated univentricular heart experience satisfaction with their lives and see themselves as exceptional, strong and healthy. This indicates that there is no direct association between the severity of the heart defect and the experience of satisfaction with life. The findings suggest that the existential maturity they had developed, along with their experienced happiness over "being me", may promote a stronger sense of coherence.

The conclusion from this thesis was that, through a process of adaptation, the CHD becomes integrated and a normal part of life. However, adolescents and young adults could at the same time be seen as "walking a fine line" when balancing the aspects of health and disease that co-exist in the life of a person with a CHD. Thus, the concept of "health within disease" (as opposed to "health within illness") emerges to describe this population, since they experience themselves most of the time as healthy.

**Key words:** congenital heart disease, health, hermeneutics, interviews, quality of life, sense of coherence