Adolescents with Congenital Heart Disease and their parents
-needs before transfer to adult care

Burström Á., Öjmyr-Joelsson M. (1); Bratt E-L. (3); Lundell B. (1); Nisell M. (1,2)
Karolinska Institute, Inst for Women and Children’s Health Stockholm, Sweden (1); Institute of Health and Care Sciences, University of Gothenburg, Sweden (2); The Red Cross Nursing College Stockholm, Sweden (3)

Introduction
Young people with Congenital Heart Disease (CHD) undergo different stages during their life. One of the many important phenomena that occur includes a developmental transition into adulthood, a phase during which young people evolve from being a dependent child to becoming an independent adult. Another important phenomenon is that their setting of care is transferring from a paediatric context to an adult-focused environment. Indeed, a timely and well-prepared transfer to adult-centred care is advocated. For adolescents with CHD and their parents the transfer from paediatric health care to an adult care can be difficult.

Objective
To identify and describe the needs of adolescents with CHD and their parents during the transition before transfer from paediatric cardiology to adult cardiology health care.

Methods
This study has an exploratory design with a qualitative approach, where 13 adolescents with moderate to complex CHD and their parents (12) were individually interviewed. The interviews were analysed with qualitative content analysis.

Results
The analysis of the adolescents' interviews resulted in three categories: Change of relations, Knowledge and information and Daily living. The theme that emerged depicting the meaning of the categories found in the responses was Safety and Control, indicating needs of continuity, knowledge and taking responsibility. Analysis of the parents' answers gave two categories: Change of relations and Daily living. The theme that emerged was Safety and Trust indicating needs of continuity and shifting responsibility.

Conclusions
The transition is a process that must be carefully planned to ensure that adolescents with CHD and their parents can master new skills to manage the transfer to ACHD (Adult with Congenital Heart Disease). A structured programme may facilitate and fulfill the needs of the adolescents and their parents, taking into consideration the aspects of trust, safety and control. However the content and performance of such a program must also be examined. The results from present study will serve as baseline for further intervention studies.