Young people with Congenital Heart Disease – how to prepare for adult care -their own perspective

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Introduction
For many adolescents with Congenital Heart Disease (CHD) medical and surgical progress has resulted in an increased life expectancy. Lifetime care should be provided in order to maximize their potential and lifetime functioning. Paediatric-to-adult transfer of care should be preceded by a preparatory transitional phase. Transition in this respect is defined as a process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood. During adolescence they need to get prepared to take over the responsibility of their health and to adopt good health behaviour in order to prevent late complications.

Objective
To describe young people’s perception on what is essential for the transfer to adult care and what they consider to be important to know.

Method
Four group interviews were performed with adolescents aged 14-18 years (n=18), they had moderate to complex CHD. The participants came from 4 different paediatric cardiology centres in Sweden. The transcribed interviews was analysed with qualitative content analysis.

Result
The analysis revealed in two categories: “an on-going process” and “not being distressed”. The adolescents described the transition as a natural process that has to go stepwise. Further, the adolescents expressed that they had no specific concerns about the transfer while; it was difficult to have an opinion when they did not know what the difference would be. Additional, the responsibility for the process was shared between the cardiology team and the parents.

Conclusion
Young people with CHD have poor knowledge about their diagnosis and what they need to know about the transfer. The transfer procedure is unfamiliar and they are unaware with where their medical check up will continue after leaving paediatric care. The cardiology team should successively introduce and teach young people with CHD how to handle their health and treatment. The parents need to give more responsibility to their child and promote their independence.