

**Responsibility, knowledge and trust
– Important aspects in the preparation to the transfer to adult care**

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Introduction

For a majority of children born with Congenital Heart Disease (CHD) the medical and surgical progress has resulted in increased lifetime expectancy. To maximize the potential and lifetime functioning of this growing group of adolescents, lifelong care is needed. In order to ensure a lifetime follow-up, the Paediatric-to-adult transfer of care should be preceded by a preparatory transitional phase for the adolescents. During the transition process the young persons need to learn about their health and step by step take over responsibility for their own health care. However, this transition is also a part of a wider developmental transition process for the young person, which includes occupational choices, personal, family and social aspects.

Objective

The objective was to describe how to prepare adolescents born with CHD before adult care.

Methods

Data was collected through four group interviews. The participants were adolescents between 14 – 18 years old born with CHD from four paediatric cardiology centres in Sweden. The interviews were transcribed verbatim and analysed with content analysis.

Results

Three categories were revealed, Responsibility, Knowledge and Trust. The adolescents emphasised that the responsibility for their health situation had to be shared between themselves, the parents and the paediatric caregivers. Further they wanted to learn about the new adult caregiver, their health, their health situation and how to communicate their health with others. Finally, continuity and a trustful relation to the paediatric health care team were important aspects during the preparation for transfer. The adolescents requested to be included in the transition planning and receive relevant information. Important aspects to consider for the paediatric health care team when giving information and meeting adolescents are maturity and age. These factors are crucial in how adolescents handle different situations related to the transition process.

Conclusion

A trusting relation to the paediatric health care team is a prerequisite for a successful transfer for the adolescents with CHD. Further, maturity and age are other essential aspects to consider when meeting the adolescents need of increased knowledge and the shared responsibility in the transition process.