

**Ready for the transfer to the adult care
- factors associated with transition readiness in adolescents with congenital heart disease**

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Introduction

Transfer to adult care for adolescents with Congenital Heart Disease (CHD) is predominantly determined by age even though international guidelines recommend taking self-management skills, maturity and transition readiness into consideration. To improve preparation for transfer to adult care transition readiness is essential to scrutinize. The aim of this study was to (i) describe the level of readiness for transition in adolescents with CHD, (ii) to compare the level of readiness for transition assessed by the adolescents with parental assessments, and (iii) to study potential correlates of transition readiness in adolescents with CHD.

Methods

A cross-sectional questionnaire study was conducted. Adolescents aged 14-18y with a CHD and their parents were invited. Data collected: Sociodemographic information, CHD-complexity, Readiness for Transition (RTQ), Empowerment (GYPES), Knowledge (KnoComh), Quality of life (LAS), Illness Perception (IPQ), Health status (PedsQL) and Health Behavior (HBS). Parents filled out RTQ-proxy version.

Results

Data from 157 triads (adolescents, mothers and fathers) were included. Mean age was 15.7y, and 45.9% were females. Adolescent overall readiness (A-OR) and adolescent responsibility (A-AR) increased with age (A-OR $p=0.03$, A-AR $p=0.002$). Parental involvement assessed by adolescents (A-PI) decreased with increasing age ($p=0.045$). Adolescent scored their A-OR higher than parents ($p=0.001$). Fathers scored PI lower than the mothers and adolescents (father-PI mean 3.2 ± 0.8 , mother-PI mean 3.6 ± 0.5 , adolescent-PI mean 3.6 ± 0.6 ; $p<0.001$). A-OR was associated with mother-OR ($p=0.002$) and father-OR ($p=0.001$). A higher level of empowerment ($p=0.03$) and lower IPQ-score ($p=0.047$) predicted a higher level of A-OR. A higher level of A-AR was associated with increased age ($p=0.04$), mother-AR ($p=0.003$) and father-AR ($p=0.02$). The A-PI was predicted by the mothers-PI ($p=0.023$) and adolescents age ($p=0.025$).

Conclusion

Age was associated with transition readiness and increased adolescent responsibility as well decreased parental involvement. Age in itself does not solely determine when adolescents are ready for transfer. Empowerment and illness perception also are related to transition readiness. Therefore, emphasis should be given to empowering adolescents, increase awareness about their condition to promote self-management during transition to adulthood and transfer to adult care.