The STEPSTONES transition program for adolescents with congenital heart disease is effective in improving patient empowerment: a randomized controlled trial

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Background: Congenital heart disease (CHD) is the most common birth defect, with a global birth prevalence of 8.2 per 1000 new-borns. Improvements in the diagnosis and treatment of children with CHD have resulted in increasing life prospects, with more than 90% surviving into adulthood today. To ensure expert lifetime care, patients need to transfer from paediatric-oriented care to adult-oriented care. At the same time, they need to transition from a dependent child with CHD to an independent adult who can manage living with CHD. Thus, during adolescence, patients with CHD need to acquire knowledge and skills to independently manage their health, while simultaneously experiencing a series of physical, cognitive and social changes. To facilitate this phase, transitional care is needed. However, high-level empirical evidence on the effectiveness of transitional care is scarce.

Purpose: To investigate the empowering effect (primary outcome) of a structured person-centred transition programme for adolescents with CHD, and to study the effectiveness on transition readiness, patient-reported health, quality of life, health behaviours, disease-related knowledge, parental uncertainty, and parental perception of transition readiness (secondary outcomes).

Methods: The STEPSTONES-CHD trial comprised a hybrid experimental design, in which a randomized controlled trial (RCT) was embedded in a longitudinal, observational study. The trial was conducted in seven CHD centres in Sweden. Two centres were allocated to the RCT-arm, randomising participants to intervention (IG) or control group (CG). The other five centres were intervention-naïve centres and served as contamination check control group (CCCG). Outcomes were measured at the age of 16 y (T0; baseline), 17 y (T1) and 18.5 y (T2).

Results: The change in empowerment from T0 to T2 differed significantly between the IG and CG (mean difference=3.44; 95% CI: 0.27–6.65; p=0.036) in favour for IG. For the secondary outcomes, significant differences in change over time were found in parental involvement (p=0.008), CHD-specific knowledge (p=0.0002), and satisfaction with physical appearance (p=0.039). No differences in primary or secondary outcomes were detected between CG and CCCG, indicating that there was no contamination in the CG.

Conclusion: The STEPSTONES-CHD trial demonstrated the effectiveness of a person-centred transition programme in empowering adolescents with CHD. Furthermore, parental involvement, satisfaction with physical appearance and CHD-related knowledge were positively influenced. This trial provides empirical underpinnings for the implementation of transition programmes for afflicted adolescents.