

Effectiveness of a transition program to empower adolescents with congenital heart disease in the transition to adulthood: Rationale and methods of the STEPSTONES-ConHD project

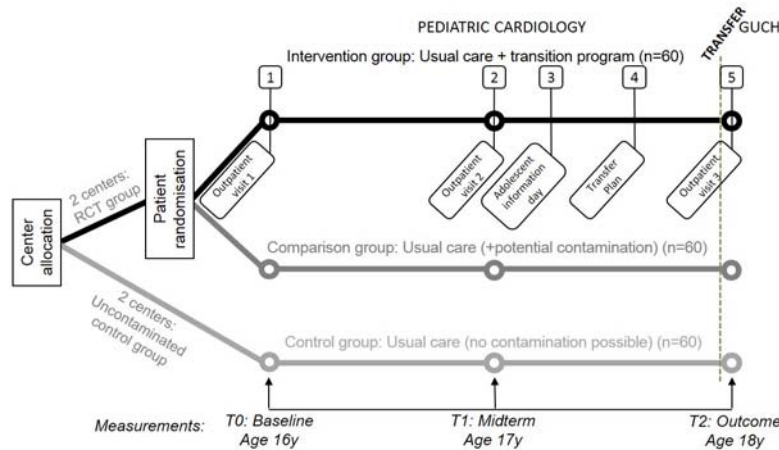
Moons P. (1,2), Sparud-Lundin C.(1), Acuña Mora M.(1), Bratt E.L.(1)
 Institute of Health and Care Sciences, University of Gothenburg, Gothenburg, Sweden (1); Academic Center for Nursing and Midwifery, KU Leuven - University of Leuven, Leuven, Belgium (2)

Introduction:

Ninety percent of children born with congenital heart disease (ConHD) survive into adulthood. To prepare adolescents with ConHD to take on new responsibilities for their health and to anticipate a transfer to adult care, transition programs have been developed. However, hard evidence on the effectiveness of transition programs is lacking. In STEPSTONES-ConHD (Swedish Transition Effects Project Supporting Teenagers with chrONic mEdical conditionS – Congenital Heart Disease), we test the hypothesis that adolescents with ConHD who receive a structured, person-centered transition program over a 2-year period have a higher patient empowerment score than adolescents who receive usual care. This abstract describes the rationale and design of STEPSTONES-ConHD.

Methods:

We employ a hybrid experimental design, in which a randomized controlled trial (RCT) is embedded in a longitudinal, observational study. This design allows to account for potential contamination of the comparison group. The study is conducted in 4 centers in Sweden (Gothenburg, Lund, Stockholm, Umeå). Two centers are assigned to the RCT group and two centers to the control group (see figure).



Literate, Swedish-speaking adolescents with ConHD, aged 16 years, and their parents are eligible for inclusion. A multi-component intervention, comprising 8 key components, is implemented: These components are implemented in five steps (see figure). The intervention is performed by specialized nurses at the outpatient clinic of pediatric cardiology, after being trained to become transition coordinator. Sample size calculation indicated that 60 patients are needed in each arm of the study. Interim analyses will be undertaken during the project, to check if adjustments to the sample size are needed. The primary outcome is Patient Empowerment, as measured with the Gothenburg Young Persons Empowerment Scale (GYPES). The secondary outcomes are transition readiness; knowledge; health behavior; patient-reported health; quality of life; illness perception and parental uncertainty. Data are collected at baseline (T0); midterm (T1); and after transfer (T2). Recruitment of patients starts in May 2016, and will last until the end of 2017. The study will be completed in 2019.

Conclusion

The STEPSTONES-ConHD project is designed to provide evidence on the effectiveness of a transition program for young people with ConHD.