Göteborg, 2022

Process and economic evaluation of a transition program for adolescents with congenital heart disease: the STEPSTONES project

Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademin, Göteborgs universitet kommer att offentligen försvaras i hörsal Arvid Carlsson, Academicum, Medicinaregatan 3, den 18 februari, klockan 13.00.

Av Markus Saarijärvi

Fakultetsopponent: Professor Graham Moore, Cardiff University, United Kingdom

Avhandlingen baseras på följande delarbeten

I. Saarijärvi M, Wallin L, Moons P, Gyllensten H, Bratt E-L. Factors affecting adolescents' participation in randomized controlled trials evaluating the effectiveness of healthcare interventions: the case of the STEPSTONES project. *BMC Medical Research Methodology* 2020; 20: 205.

II. Saarijärvi M, Wallin L, Moons P, Gyllensten H, Bratt E-L. Implementation fidelity of a transition program for adolescents with congenital heart disease: the STEPSTONES project. *Submitted.*

III. Saarijärvi M, Wallin L, Moons P, Gyllensten H, Bratt E-L. Mechanisms of impact and experiences of a person-centred transition programme for adolescents with CHD: the STEPSTONES project. *BMC Health Services Research* 2021; 21: 573.

IV. Saarijärvi M, Bratt E-L, Moons P, Wallin L, Gyllensten, H. Cost-effectiveness of a transition program for adolescents with congenital heart disease: the STEPSTONES project. *In manuscript.*

SAHLGRENSKA AKADEMIN
INSTITUTIONEN FÖR VÅRDVETENSKAP OCH HÄLSA

GÖTEBORGS UNIVERSITET

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Process and economic evaluation of a transition program for adolescents with congenital heart disease: the STEPSTONES project

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2022

Abstract

Transition programs have been developed for adolescents with chronic conditions and evaluated through randomized controlled trials. However, knowledge is lacking on what barriers and facilitators to implementation exist, how change is created, and the cost-effectiveness of these programs. The **overall aim** of this thesis was to perform a process evaluation and health economic analysis of the STEPSTONES transition program for adolescents with congenital heart disease in transition to adulthood and transfer to adult care. The **methods** used in this thesis were process evaluations (Studies I – III) and a health economic evaluation (Study IV). Mixed methods were used to design, collect, and analyze data according to the methodological guidance for process evaluation of complex interventions by Moore et al (2015). The **findings** showed that the transition program was implemented with high fidelity, although some components were more difficult to implement. Factors affecting the implementation process were the participants' and healthcare professionals' responsiveness and willingness to engage in the program, organizational factors, recruitment and retention, and the parents' process of achieving balance between becoming a support system and managing their own information and support needs. Key change mechanisms were the opportunity to meet a transition coordinator trained in person-centered care and adolescent-friendly communication, the creation of a safe space that was built on confidentiality, a learning process starting from the adolescents' needs, and goal setting beyond the heart defect. The health economic evaluations showed that the intervention group had higher costs due to receiving the transition program. No differences in health outcomes with the EQ-5D were observed in this study. The **conclusion** is that the transition program was largely implemented as it was intended. Implications from these findings are that transition programs have prerequisites for implementation but tailoring to other conditions and contexts needs to be taken into consideration. Knowledge is needed on the longitudinal impact of transition programs to provide decision makers with evidence on the future benefits of transition programs for adolescents with chronic conditions.

Keywords: adolescents, health economic evaluations, heart defect; congenital, mixed methods, process evaluation, randomized controlled trial, transition

ISBN 978-91-8009-592-1 (PRINT) http://hdl.handle.net/2077/69806
ISBN 978-91-8009-593-8 (PDF)