

CONTINUED FOLLOW-UP CARE

- DURING TRANSITION AND TRANSFER OF YOUNG PEOPLE WITH CONGENITAL HEART DISEASE

Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentlig försvaras i Arvid Carlsson, Academicum, Medicinaregatan 3, Göteborg, den 16 december, klockan 09.00

av Sandra Skogby

Fakultetsopponent: Professor Walter Sermeus, KU Leuven, Belgien.

Avhandlingen baseras på följande delarbeten

- I. Skogby S, Moons P, Johansson B, Sunnegårdh J, Christersson C, Nagy E, Winberg P, Hanséus K, Trzebiatowska-Krzynska A, Fadl S, Fernlund E, Kazamia K, Rydberg A, Zühlke L, Goossens E, Bratt E-L.
Outpatient volumes and medical staffing resources as predictors for continuity of follow-up care during transfer of adolescents with congenital heart disease. *International journal of cardiology*. 2020;310:51-7.
- II. Skogby S, Goossens E, Johansson B, Moons P, Bratt E-L.
Qualitative study of facilitators and barriers for continued follow-up care as perceived and experienced by young people with congenital heart disease in Sweden. *BMJ Open*. 2021;11:e049556.
- III. Skogby S, Goossens E, Johansson B, Moons P, Bratt E-L.
Facilitators and barriers for continued follow-up care after transfer - from a healthcare providers' perspective.
Manuscript.
- IV. Skogby S, Bratt E-L, Johansson B, Moons P, Goossens E.
Discontinuation of follow-up care for young people with complex chronic conditions: conceptual definitions and operational components.
BMC Health Services Research. 2021;21:1343.

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Abstract

Although life-long follow-up care and transfer from paediatric to adult facilities are recommended for most young people with congenital heart disease, a substantial proportion present with discontinued follow-up care, which is associated with adverse outcomes and requires active prevention. **The overall aim** of this thesis was to scrutinize discontinuation of follow-up care among youths with congenital heart disease and gain a deeper understanding of associated factors on patient, hospital, and healthcare system levels, as well as provide increased clarity around the concept of discontinuation of follow-up care. **The methods** applied include register and survey-based statistical analyses (I & III), individual semi-structured interviews with patients and healthcare providers subjected to qualitative content analysis (II & III) and a conceptual inquiry of the concept of discontinuation in published literature using a modified summative content analysis and a Delphi-inspired expert evaluation (IV). **Findings:** Study I showed a relatively low proportion of discontinuation in the included centres, clear differences in proportions of discontinuation across hospitals and an association between paediatric outpatient volumes and continued follow-up care after transfer. The difference in proportions of discontinuation across the hospitals indicates the relevance of hospital-related factors influencing discontinuation of follow-up care. In Study II, patients' perceptions and experiences of factors affecting continued follow-up care after transfer included three main categories, "Motivation for follow-up care", "Participation in care and sense of connectedness with health care provider" and "Care accessibility". Study III showed a low proportion of no follow-up at two Belgian centres. Furthermore, healthcare providers' perceptions and experiences of factors perceived to affect continued follow-up care after transfer included the categories "Care structure", "Care processes" and "Patients' characteristics and circumstances". In Study IV, three different types of discontinuation of follow-up care emerged from the analysis of published literature, including "Untraceability", "Lost to follow-up care" and "Gap(s) in follow-up care", the latter two being distinguished from one another through time intervals versus time periods and whether patients were currently engaged in care or not. **In conclusion**, a plethora of factors affecting continuity of patient care was raised, including patient, hospital, and healthcare system factors, which likely trigger each other, creating synergetic effects. Agreement between patients and health care providers regarding relevant factors was high and many of the factors raised could possibly be tackled through clear structures, provision of sufficient health care provider resources, competencies, and skills, as well as transitional care interventions. Furthermore, expansion of the concept of discontinuation of follow-up care to include personal experiences as well as informational and relation aspects, is deemed mandatory.

Keywords: adolescent; continuity of patient care; cross-sectional study; expert evaluation; heart defects, congenital; individual interviews; logistic regression; patient transfer; qualitative descriptive study; qualitative content analysis; summative content analysis; young adult

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