

# Patient empowerment during the transition to adulthood in young persons with chronic conditions

Akademisk avhandling

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Medicinaregatan 3, den 15 januari, klockan 13:00

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Fakultetsopponent:

Professor Deborah Christie, University College London, United Kingdom

## Avhandlingen baseras på följande delarbeten

- I. Acuña Mora M, Sparud-Lundin C, Moons P, Bratt EL. Definitions, instruments and correlates of patient empowerment: a descriptive review. *Submitted*.
- II. Acuña Mora M, Luyckx K, Sparud-Lundin C, Peeters M, van Staa A, et al. Patient empowerment in young persons with chronic conditions: psychometric properties of the Gothenburg Young Persons Empowerment Scale (GYPES). *PLoS One*. 2018; 13(7): e0201007.
- III. Acuña Mora M, Sparud-Lundin C, Burström Å, Hanseus Å, Rydberg A, Moons P, Bratt EL. Patient empowerment and its correlates in young persons with congenital heart disease. *European Journal of Cardiovascular Nursing*. 2019; 18(5): 389-398.
- IV. Acuña Mora M, Sparud-Lundin C, Moons P, Bratt EL. Patient empowerment and patient-reported outcomes: what is the direction of effect? *In manuscript*

# Patient empowerment during the transition to adulthood in young persons with chronic conditions

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## Abstract

During the transition to adulthood and adult care young persons with chronic conditions (CCs) are in need of developing the skills necessary to manage their condition, communicate with the healthcare provider, participate in the decision-making process and become autonomous. In order to help them develop such skills, patient empowerment has been suggested as a relevant approach. Through patient empowerment, young persons can become active partners in care and mobilize the resources they need to achieve their goals. Despite its relevance in adolescent health and care, patient empowerment has not been investigated thoroughly in this group. The aim of this doctoral thesis was to explore patient empowerment in young persons with CCs during the transition to adulthood.

Study I was a descriptive review that aimed to inventory the definitions and measurements of patient empowerment, appraise the conceptual and methodological rigor of published studies and to identify correlates of patient empowerment in persons with CCs. Study II was a cross-sectional study that described the development and psychometric evaluation of the Gothenburg Young Persons Empowerment Scale (GYPES). Study III was also a cross-sectional study measuring the level of patient empowerment in young persons with congenital heart disease (CHD) and examining potential correlates of patient empowerment. Study IV was a longitudinal study that aimed to examine the direction of effects between patient empowerment and other patient-reported outcomes.

The findings in this thesis show that there is no consensus on a definition of patient empowerment and available studies have used instruments that on occasion are not meant to measure patient empowerment. Given the limitations of previous instruments, GYPES was developed to measure patient empowerment. Results show the scale is valid and reliable in a sample of young persons with CHD and diabetes mellitus. Research has assessed a broad scope of correlates of patient empowerment, but most of this research has been in cross-sectional studies and the direction of the investigated associations is not yet clear from the available evidence. In young persons with CHD, patient empowerment was correlated with transition readiness and communication skills. Moreover, results from this doctoral thesis indicate that patient empowerment leads to improved communication skills in young persons with CHD.

From the findings of this thesis, it is possible to conclude that patient empowerment is relevant in improving communication skills. These skills are fundamental, as they are an initial step in becoming an active partner of the care process. Additionally, GYPES can be used to compare the level of patient empowerment across different CCs and contexts. Researchers should make an effort to achieve more consensus on definitions and dimensions that comprise patient empowerment to facilitate the comparison of the available evidence.

**Keywords:** chronic conditions, cross-sectional study, descriptive review, instrument development, longitudinal research, patient empowerment, transition, young persons