

Children living with type 1 diabetes and congenital heart disease in the West Bank, Palestine

Self-perceived health status, sense of coherence, and the daily life experiences of these children and their parents

Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i 2118, Hälsovetarbacken, Hus 2, Arvid Wallgrens backe, torsdag den 26 april, klockan 13.00.

Av Kawther Elissa

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Hälsö högskolan, Jönköpings Universitet, Sverige

Avhandlingen baseras på följande delarbeten

- I. Elissa, K., Bratt, E.-L., Axelsson, A. B., Khatib, S., & Sparud-Lundin, C. (2017). Societal Norms and Conditions and Their Influence on Daily Life in Children with Type 1 Diabetes in the West Bank in Palestine. *Journal of Pediatric Nursing*, 33, 16-22. [https://doi: 10.1016/j.pedn.2016.12.005](https://doi.org/10.1016/j.pedn.2016.12.005)
- II. Elissa, K., Sparud-Lundin, C., Axelsson, Å. B., Khatib, S., & Bratt, E.-L. (2018). Struggling and Overcoming Daily Life Barriers Among Children With Congenital Heart Disease and Their Parents in the West Bank, Palestine. *Journal of Family Nursing*, 24, 585-611. [https://doi: org.ezproxy.ub.gu.se/1074840718809710](https://doi.org/10.1016/j.jfn.2017.07.001).
- III. Elissa, K., Bratt, E.-L., Axelsson, Å. B., Khatib, S., & Sparud-Lundin, C. Self-perceived health status and sense of coherence in children with type 1 diabetes in the West Bank, Palestine. Submitted
- IV. Elissa, K., Sparud-Lundin, C., Axelsson, Å. B., Khatib, S., & Bratt, E.-L. Living with congenital heart disease under challenging conditions in the West Bank, Palestine: self-perceived health status and sense of coherence. In manuscript.

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*Self-perceived health status, sense of coherence, and the daily life experiences
of these children and their parents*

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Abstract

Chronic diseases such as type 1 diabetes (T1D) and congenital heart disease (CHD) are lifelong conditions, need regular treatment, self-management, and follow-ups. Growing up with these conditions affects the children's and their parents' lives at various levels, because of the increased burden and responsibilities imposed on them. In addition, the particular socio-cultural conditions in the Palestinian West Bank can also be assumed to influence their daily life. The overall aim was to explore the experiences of daily life in children and adolescents with T1D and CHD and their parents living in the West Bank, Palestine, and to describe self-perceived health status and sense of coherence (SOC) in these children compared with a healthy reference group. In Study I and II, a qualitative descriptive design based on individual interviews was used to explore daily life experiences in children with T1D or CHD and their parents. Study III and IV employed a quantitative approach with a cross-sectional design to measure self-perceived health status and SOC in children with T1D or CHD and to compare them with a healthy reference group. In Study I and II, children with T1D and CHD and their parents were highly impacted by stigma, societal stereotyping, their perception of their chronic illness, and political conflict. Although this affected every aspect of their lives, they explained that their reliance on God facilitated their acceptance of their fate and lives. The results of Study III and IV showed comparable self-perceived health status in children with T1D and the reference group, whereas the children with CHD had lower self-perceived health status. SOC was low in both groups and no differences between the groups were found. In adolescents with T1D, a strong SOC was correlated with better self-perceived health status and more optimal glycemic control. Boys with T1D reported higher self-perceived health status than girls. Children with complex heart disease and those who had undergone heart surgery scored lower on self-perceived health status. Furthermore, a stronger SOC was associated with higher self-perceived health status in children with T1D and CHD. To provide optimum care for children with T1D and CHD and their parents, health care providers need to understand the negative consequences associated with sociocultural conditions and beliefs about chronic illness. Monitoring self-perceived health status and taking the role of SOC into consideration in children with T1D and CHD may form the basis for future health care interventions for these children.

Keywords: Adolescent, child, diabetes mellitus type 1, experiences, health status, heart defects, congenital, parents, sense of coherence

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