

Göteborg, 2019

Children with spina bifida and their mothers in Palestine

Lived experiences, self-perceived health and sense of
coherence

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 11 april, klockan 13.00

Av Maha Hmeidan Nahal

Fakultetsopponent: Professor emeritus Anders Möller
Ersta Sköndal högskola, Sverige

Avhandlingen baseras på följande delarbeten

- I. Nahal, M. S. H., Wigert, H., Imam, A., & Axelsson, Å. B. (2017). From feeling broken to looking beyond broken: Palestinian mothers' experiences of having a child with spina bifida. *Journal of Family Nursing*, 23(2), 226-251.
- II. Nahal, M. S., Axelsson, A. B., Imam, A., & Wigert, H. (2019). Palestinian children's narratives about living with spina bifida: Stigma, vulnerability, and social exclusion. *Child: Care, Health and Development*, 45(1), 54.
- III. Nahal, M. S. H., Wigert, H., Imam, A., & Axelsson, Å. B. (2019). Self-perceived health among children with spina bifida in the West Bank, Palestine. Manuscript.
- IV. Nahal, M. S. H., Wigert, H., Imam, A., & Axelsson, Å. B. (2019). Assessment of health status in adolescents with spina bifida in the West Bank: Sense of coherence and self-perceived health. Manuscript.

SAHLGRENSKA AKADEMIN
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Abstract

The overall aim in this thesis was to describe the lived experiences of children with spina bifida (SB) and their mothers while living under specific social and cultural conditions in West Bank, Palestine. A further aim was to gain knowledge about the impact of SB on self-perceived health and sense of coherence (SOC) among a group of children and adolescents with SB in comparison to their healthy peers.

Study I and II involved narrative interviews with 20 mothers and 10 children, respectively, which were analysed with the phenomenological-hermeneutical method. Study III and IV involved self-reported questionnaires. The Pediatric Quality of Life Inventory (PedsQL™ 4.0) was used in Study III to assess self-perceived health in 50 children with SB in comparison with 150 healthy children. In Study IV, the PedsQL™ 4.0 and SOC scales were used to assess self-perceived health and SOC in 50 adolescents with SB in comparison with 150 healthy adolescents. The association between self-perceived health, SOC and levels of impairment in children and adolescents with SB was also investigated. The findings in this thesis show that children with SB, their mothers and other family members were struggling with negative sociocultural beliefs about the disability. Stigmatisation, political conflict and consequent poor health care services were shaping the daily life experiences of the children and their families. Children with SB were struggling with social exclusion and seemed to possess a negative self-concept. Children and adolescents with SB perceived their health to be worse than the health of their peers. SOC was lower in adolescents with SB than it was in their healthy peers. Levels of impairment in mobility and hydrocephaly correlated negatively with self-perceived health in children and adolescents with SB, while bladder dysfunction was negatively correlated with SOC only among the adolescents. In conclusion, stakeholders, policy makers, health care providers and educators in Palestine must be aware of the extent of the burden and suffering experienced by children with SB and their families. Health promotion and social support for this group of children and their families can be achieved through the development and implementation of effective policies and strategies, such as a family-centred care (FCC) approach, within health care systems and rehabilitative practices in the Palestinian context.

Keywords: Childhood, Disability, Experience, Family, Mother, Palestine, Perceived health, Phenomenological-hermeneutical, Spina bifida, Stigma, Sense of Coherence

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