Children with spina bifida and their mothers in Palestine
Lived experiences, self-perceived health and sense of coherence

Maha Hmeidan Nahal

Institute of Health and Care Sciences
Sahlgrenska Academy, University of Gothenburg

UNIVERSITY OF GOTHENBURG

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Sahlgrenska Academy, University of Gothenburg
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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. The lack of knowledge about health care needs of the child with SB had a true effect upon the mothers’ well-being, and increased their burden. 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 associated negatively with self-perceived health in children and adolescents with SB, while bladder dysfunction was negatively associated 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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