

Self-perceived health among children with spina bifida in the West Bank: a cross-sectional study

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Abstract

Background Children born with spina bifida endure constant physical disability, which is challenging for themselves and their families. To date, the impact of spina bifida on the health-related quality of life (HRQOL; eg, physical, psychological, and social wellbeing) of these children has been assessed mainly through parent proxy reports, and self-perceived health among these children is rarely measured. This study aimed to measure self-perceived health in children with spina bifida in the West Bank, to compare this with that in a healthy reference group also from the West Bank, and to assess the potential association between self-perceived health and the level of disability in children with spina bifida.

Methods A cross-sectional study was conducted in the West Bank. The Paediatric Quality of Life Inventory (PedsQL) was administered to a convenience sample of 200 children aged 8–12 years, of whom 50 have spina bifida and 150 are healthy. For the children with spina bifida, their disability was categorised and ranked according to four aspects of impairment (mobility, bowel function, bladder function, and hydrocephaly). Data were analysed with SPSS version 24. Difference in PedsQL scores between the two groups of children was tested with the Mann-Whitney U-test. The Spearman's rank correlation coefficient was used to evaluate the association between the level of physical impairment in children with spina bifida and their self-perceived health. Written informed consent was obtained from the children's parents. The children's verbal assent was also obtained, and their right to withdraw from the study at any time was emphasised.

Findings Children with spina bifida had lower overall PedsQL scores (mean 45·5, SD 14·5) than those reported by the reference group of healthy children (mean 80·0, SD 12·8). For children with spina bifida, social functioning had the lowest mean score (30·5, SD 20·8), followed by physical functioning (37·5, SD 16·6), emotional functioning (56·0, SD 17·2), and school functioning (62·6, SD 17·8), whereas the range for all of the PedsQL scores in the reference group was 71·7–84·5. The results demonstrate significant inverse associations between self-perceived health (overall PedsQL score) in children with spina bifida and both the level of mobility impairment ($r_s = -0·65$, $p < 0·0001$) and the presence of hydrocephalus ($r_s = -0·53$, $p < 0·0001$). A weak inverse association was found between self-perceived health and both bladder and bowel dysfunction. For both groups, no associations were found between demographic characteristics (age, gender, type of settlement of residence [city, village, camp]) and self-perceived health.

Interpretation The findings provide insights into the importance of social support and rehabilitation services for children with spina bifida in the occupied Palestinian territory. In particular, community awareness, and education of health care providers and family members, may be important.

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Contributors

MN carried out data collection and statistical analysis, and wrote the abstract with input from ÅBA. AI, HW, and ÅBA reviewed the results. All authors have seen and approved the final version of the Abstract for publication.

Declaration of interests

We declare no competing interests.

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