

## Functional aspects of spina bifida in childhood: a cross-sectional analysis of a nationally represented sample

Indre Bakaniene, Audrone Prasauskiene

Lopselio g. 10, Kaunas, LT-47180, Lithuania

indre.bakaniene@kaunoklinikos.lt

### Background

The aim of the study was to investigate the clinical and psychosocial outcomes of spina bifida (SB), as well as relationships between pathology, participation, environment, and health-related quality of life (HRQOL).

### Materials

A cross-sectional study of a nationally representative sample of 99 children with SB aged 5 to 18 years. Methods. The questionnaires used in the study were the Spina Bifida HRQOL instrument, developed by Parkin et al. (1997), and the Participation and Environment Measure for Children and Youth. Clinical data related to SB were obtained from the medical files and the clinical examination.

### Results

Children with SB were experiencing a high number of secondary health conditions (mean  $\pm$  SD =  $6.23 \pm 3.316$ ). Participation restrictions were found mostly in school and the community. The environmental factors consistently explained at least one dimension of participation across all settings. Cognitive abilities had a significant impact on participation at home and school, while bowel incontinence influenced participation in school. The most potent predictors of the HRQOL in children aged 5 to 12 years were the community overall environmental supports, a number of health conditions, access to personal transportation, and supplies, explaining 80% of the variance in the SB-HRQOL scores. The most significant predictors of the HRQOL in adolescents aged 13 to 18 years were a number of health conditions, cognitive demands of activities at home, supplies, money, physical layout at school, and access to public transportation, explaining 90% of the variance in the SB-HRQOL scores.

### Conclusions

Our findings highlight the role of the neuropsychological functioning and environment in explaining participation and the HRQOL of children with SB and, therefore, support the development of interventions to train executive functions, as well as the development of compensatory strategies and environmental modifications.