

Developmental Pediatrics

Title: QUALITY OF LIFE OF YOUNG CHILDREN WITH SPINA BIFIDA: DIFFERENCES BASED ON BOWEL AND BLADDER CONTINENCE STATUS

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Background: Spina Bifida (SB) is a chronic condition that includes a host of sequelae that may adversely impact a person's quality of life (QOL). Incontinence issues are ubiquitous in SB; in fact, up to 90% of individuals with SB have significant urologic dysfunction. Further, incontinence can limit participation in typical activities, potentially affecting QOL. However, limited research exists investigating continence status and QOL among younger children with SB. The purpose of this study was to investigate whether QOL differed given child's bowel and bladder continence status based on both parent and child report.

Method: As part of a larger study investigating the effectiveness of interventions for incontinence problems, 108 children with SB ages 5 to 12 years and their parents completed appropriate versions of the Pediatric Quality of Life Inventory (PedsQL; Varni, 1999), a 23-item questionnaire that provides both global and domain specific assessment of QOL. Chart review was used to classify child bowel and bladder continence status (i.e., continent vs. incontinent).

Results: Parent-rated Overall, School, Physical, and Social PedsQL scores were significantly lower for children with bowel incontinence (all p values < 0.05; ANOVA). Only parent-rated Social PedsQL scores were significantly lower for children with bladder incontinence (p = 0.046). Based on child ratings, PedsQL Physical scores were significantly lower for children with bowel incontinence (p = 0.026); no between group differences in PedsQL scores were obtained based on child report given bladder continence status.

Conclusion: Findings suggest differences in QOL given bowel continence status, and to a lesser extent bladder continence status, based on parent report, with minimal differences based on child report. Results suggest the importance of attending to the impact that continence status can have on participation in meaningful life activities for children with SB and how parents' views of about continence are addressed.