

## ABSTRACT

## Developing a modified 'quality of life' questionnaire for children with spina bifida

S. Vande Velde, J. Laridaen\*, J. Daelman, S. Van Biervliet, M. Van Winckel, H. Verhelst<sup>o</sup>,

Department of Pediatric Gastroenterology, Coordinator Spina bifida reference centre<sup>o</sup>, Child  
Psychologist Spina bifida reference centre\*, University Hospital Ghent (UZG), Belgium

**Background:** In order to develop a 'quality of life' (QoL) questionnaire, adapted to the specific needs of the population of children with spina bifida (SB), a pilot study is presented.

**Methods:** Three versions were made: a parent-scale, an 'adolescent'-scale (11-18 yrs) and a 'child-scale' (5-10 yrs). Questions are answered on a Likert-scale. Questions were based on previous quality of life-scales, especially the standardised and frequently used paediatric QoL 4.0, and missing items relevant to the SB-population.

10 SB patients attending their six monthly consultation to the multidisciplinary SB reference centre, were asked to fill in an 'extended pilot questionnaire'. After completing the questionnaire, child and parent were asked to comment how they experienced it, which questions were relevant to them and which questions were too vague or difficult.

**Results:** Given the wide diversity of mental abilities in patients with SB, the division in age-dependent scales appeared not useful. The mental age and not the real age was an indicator of the abilities of a child. Several questions were deleted in being unnecessary, too vague or confusing.

One questionnaire was developed for all children, regardless of age. Each question was formulated in a simple way, accompanied by a short clarification. Younger children and children with limited mental abilities were interviewed, showing an adapted picture illustrating each question. Answers were given on a visual 3-points Likert-scale (☺ ☹ ☹). Parents, older children and children with enough mental abilities filled the questionnaire themselves, answering on a 5-points Likert-scale.

**Conclusion:** A quality of life questionnaire was developed, adapted to SB patients. Validation of this questionnaire is in progress.

