

Oral Presentation

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Quality of life in spina bifida patients: results of an Italian survey

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Background

The objectives were: 1. to investigate the major topics on the Quality of Life (QOL) of Spina Bifida patients; 2. to evaluate attitudes, the experienced and the behaviours concerning everyday activities, social life participation and familial relationship; 3. to evaluate the information needs; 4. to evaluate the physical and psychological problems related to vesical and intestinal management.

Materials and Methods

1. Qualitative study based on focus groups with parents of patients < 18 years, adult spina bifida patients and care givers (2001); 2. Statistical validation of the questionnaire was based on test-retest analysis (Nov. 2002–Jan. 2003), alpha index of Cronbach and follow up (recall) on 15 patients; 3. The questionnaires were anonymous, self compiled (some help by the parents being allowed) and sent by mail (the whole Italian territory was represented); 4. Statistical analysis of the results was made.

The sample was of 173 patients (51% female and 49% male) with an estimated number of prevalent cases of 4000. The standard error was $\pm 10\%$ and the confidence index 95%. Some subgroups were studied with test for trend.

Results

Open spina bifida were 83% (of which 88% of myelomeningocele); 91% had VP shunt (>40% had had more than 1 procedure). The most important problems affecting the QOL were vesical management (26%), intestinal management (11%) or both (20%), followed by disability due to ambulatory impairment (25%) and sexual problems (15%). Management of urinary incontinence was based on CIC (96% of the sample, started at an early age and self managed in 82%) and drugs (anticholinergics in 53%); 74% wear diapers (no leakage in 19%, once per

month in 19%, once per week in 11%, once per day in 17%, more than twice daily in 35%). Stool leakage was absent in 46%, once in a month in 34%, once weekly in 11%, once daily in 4 % and more than once in 5%); for bowel management 68% did not use any treatment, 16% enemas, 4% anal plug, 9% drugs). Everyday activities, school attendance, work and hobbies have been investigated: 73% have a computer (versus 9% of Italian population) and 63% access to the internet (versus 18%). The majority of these patients showed a good autonomy about personal hygiene and dressing, less about housework. Decisional autonomy and familial dialogue were poor with excessive protection by the family or care givers.