

## HEALTH RELATED QUALITY OF LIFE AFTER SPINAL CORD INJURY: RESULTS OF AN ITALIAN SURVEY.

### Hypothesis / aims of study

Aims of the study were to investigate the major topics on the Quality of Life (QoL) of Spinal Cord Injury patients and to evaluate attitudes, experiences and behaviours concerning everyday activities, social life participation and familial relationship, the information needs and physical and psychological problems related to vesical and intestinal management (1). The components of QoL are five: a – physical and material well-being, b – relations with other people, c – social community and civic activities, d – personal development and e – recreation and fulfilment: a rehabilitation goal is to improve quality of life affected by illness, which is health-related quality of life (2).

### Study design, materials and methods

The research design was a retrospective and qualitative study, based on focus groups with patients, with a self-compiled questionnaire (some help by the parents being allowed), to obtain qualitative items. Statistical validation of the questionnaire was based on test-retest analysis (November 2002 – January 2003), alpha index of Cronbach and follow up (recall) on 15 patients. The self-questionnaires were anonymous and sent by mail (the whole Italian territory was represented).

### Results

Statistical analysis were elaborated on 949 patients (15% female and 85% male; age < 30 years in 15%, between 30 – 40 years in 44% and > 45 years in 41%) with an estimated number of prevalent cases of 50.000. The standard error was  $\pm 4,5\%$  and the confidence index 95%. Some subgroups were studied with test for trend.

Spinal cord lesion date from more than 10 years in 55%, from 2 to 10 years in 42% and less than 2 years in 3%. Traumatic spinal cord lesions were 60%; 61% WERE a.s.l.a. impairment Scale "A". The most important problems affecting the QoL were vesical management (11%), intestinal management (7%) or both (35%), followed by disability due to ambulatory impairment (33%) and sexual problems (8%). Management of urinary incontinence was based on CIC (4 – 5 CIC per day in 64%) and drugs (anticholinergics in 68%); no leakage in 23%, once per month in 21%, once per week in 13%, once per day in 16%, more than twice daily in 28%; urocondom was used in 54%. Stool leakage was absent in 56%, once in a month in 32%, once weekly in 8%, once daily in 2% and more than once in 2%; for bowel management 81% did not use any treatment, 8% enemas, 2% anal plugs, 7% drugs. Family condition, every day activities. Work and hobbies have been investigated. The majority of these patients showed a good autonomy about personal hygiene and dressing, less about housework.

### Interpretation of results

The most important problems affecting QoL were impairment in physical independence, mobility and occupation. Vesical management, intestinal management or both were referred as most important problems.

### Concluding message

Taken together, it seems that bladder and bowel dependence have a negative impact on several quality of life domains among individuals with non congenital SCI.

### References

- (1) Leduc B, Lepage Y. Health-related quality of life after spinal cord injury. Disability and Rehabilitation 2002;24:196-202.
- (2) De Lateur BJ. Quality of life: a patient-centred outcome. Arch Phys Med Rehab 1997;78: 237-239.