

## **VESICAL AND BOWEL MANAGEMENT AND QUALITY OF LIFE IN SPINA BIFIDA ADULT PATIENTS: RESULTS OF A MULTICENTER ITALIAN SURVEY**

### **Hypothesis / aims of study**

To evaluate vesical and bowel management, continence status and their interference on Quality of Life in adult subjects with Spina Bifida. To obtain a representative sample of the Italian population, the multicentric study was started in five third-level Institutions, with patients referred from several areas.

### **Study design, materials and methods**

An Italian multicentric study in adult subjects with spina bifida was started in November 2002. The study was based on an anonymous, self-administered mailed questionnaire. The questionnaire was previously validated on 15 subjects using: test-re-test and missing items analysis; internal consistency analysis, through  $\alpha$  index of Cronbach; follow-up (recall).

173 (51% female and 49% male) adult patients with spina bifida answered. The sample was representative of the whole Italian territory (prevalent cases estimated: 4000; SEM  $\pm$  10%; CI 95%). Attention was directed to: type of spina bifida, associated neurological anomalies as well as major clinical problems related to bladder and bowel dysfunction. Interference of bladder and bowel status on quality of life (QoL) were investigated. The behaviours concerning everyday activities, social life and familial relationship were evaluated.

### **Results**

Spina bifida was open in 83% of subjects (88% myelomeningocele), associated to hydrocephalus in 91% of cases. Non-walking subjects were 62%. Urinary incontinence ( $\geq 2$  episodes/day in 35%, 1 episode/day in 17%, 1 episode/week in 11%) was present in 62% of cases, urinary tract infections occurred in 72% of cases, renal failure in 14%, constipation in 68%, soiling in 54%. Different devices were used: fluff-pulps (31%), pads (43%), drip collectors (8%) and urisheaths (8%). Bladder and bowel dysfunction were self-managed in 61% and 68% of cases, respectively. Bladder management was based on clean intermittent catheterization (CIC) in 96% of subjects (self-catheterisation in 82%). CIC was started before 10 years of age in 57% of individuals and anticholinergic agents were associated in 53% of cases. Ninety-one percent of patients were satisfied of CIC. Reasons for satisfaction were: autonomy (61%), easy performance (65%) in different situations (56%), facilitated social life (59%), achieved complete continence (27%). The unsatisfied patients complaining of: pain (9%), persistence of incontinence (36%), lack of autonomy (25%), difficulty (25%). 53% of the unsatisfied patients consider urinary tract infection as a consequence of CIC. Thirty-two percent of individuals were on bowel management program for constipation and soiling using diet (30%), enemas (16%), drugs (9%), anal plugs (4%), others (7%). Satisfaction of bowel management program was reported by 72% of subjects, related to normal bowel movements (59%), easy performance in different situation (31%), facilitated social life (38%), assured continence (17%). The lack of bowel regulation (51%), persistent incontinence (28%), dependence from others (41%), pain (22%), inadequate drugs (62%) and difficulties to perform (6%) were the motivations of patients unsatisfied of their bowel management. Sex, age, social and cultural status were comparable between satisfied and unsatisfied subjects. The major perceived disability affecting QoL was bladder and bowel dysfunction (57% of cases), 26% due to bladder, 11% to bowel and 11% to both dysfunction; while ambulatory impairment was considered the major disability in 25%, sexual problems in 15% and other problems in 3%. Problems arising from bladder versus bowel control interfered differently into the various everyday activities, except for domestic activities (4%) and family life (10%); travel by public transport (18% bladder versus 19% bowel), nocturnal sleep (20% vs 18%), shopping (26% vs 24%), choice of type of clothes (30% vs 19%), decreased general health (38% vs 39%), sports (46% vs 37%), sexual life (45% vs 37%), mood (48% vs 45%), holidays

(47% vs 48%), social outing (49% vs 45%), leisure (51% vs 40%), inability to use public restrooms (57% vs 52%) and travelling (59% vs 53%).

### **Interpretation of results**

Bladder and bowel dysfunction are relevant clinical and self-perceived problems in subjects with spina bifida and significantly affect QoL. CIC is performed in the great majority of these patients, starting at different ages. Most patients are satisfied with CIC, but complaints have been referred, mainly about infection and difficult prevention of leakage, with still too frequent use of diapers. Unlike bladder dysfunction, bowel management programs have not been popular so far. Old protocols and scarce attention by physicians and patients to bowel dysfunction might play a role. Moreover, constipation is more easily dealt with by the subjects with different personal strategies.

### **Concluding message**

Bladder and bowel status with strong implications on QoL are reported in adult population with spina bifida. However, there is evidence that younger patients could greatly benefit from earlier and more careful treatment protocols, with particular regard to bowel dysfunction, which appears undertreated and poorly considered, compared to patient's perception of disability.