25

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HEALTH-RELATED QUALITY OF LIFE IN ADOLESCENTS WITH SPINA BIFIDA: A PROSPECTIVE MULTIDIMENSIONAL STUDY

Aim of the study

In order to assess the Quality of Life (QoL) in young Spina Bifida (SB) patients and to correlate it with conventional disability measures and clinical picture, we performed a prospective multidimensional study, according to the outcome research methodology, using the most used general health status questionnaire and validated conventional clinical and disability measurements.

Methods

30 consecutive young patients with Spina Bifida (mean age 16.4, range 14-18 years) were evaluated with a

prospective multidimensional study by means of: 1) clinical assessment: we acquired personal data concerning educational level ,urological aspects etc through a case form and after we performed a detailed clinical examination (neurological and physical rehabilitation); 2) self-administred questionnaire for general health (SF-36 Short-Form Health Survey)(1); 3) standardised disability measurements (FIM:functional independence Measure, BI:Barthel Index,DI: Deambulation Index). Relationships between disability measurement, patient-oriented picture and conventional clinical assessment were evaluated. Statistical analysis was performed using the STAT-SOFT (OK, USA) package.

Results

As expected, the disability was inversely related only (r: 0.50, p=0.006) to the physical aspect of QoL of patients. Similarly, the disability was inversely related (r:0.35, p=0.005) to the emotional aspect of QoL of patient's parents. Unexpectedly, the mental aspects of QoL of patients were inversely related to disability, in fact severe disability was not associated with higher psychological distress and patients with less disability had difficulty in daily activity due to emotional problems. The findings at clinical examination, especially proximal deficit of inferior limbs (r: 0.75, $p<0.04$), were usually related to higher disability and lower physical aspects of QoL.

Conclusions

Spina Bifida (SB) is a congenital malformation of the neural tube, and accounts for as many as 4,7 in 10000 live births (2). SB affects the growth and development of the central nervous system, and the musculoskeletal and genitourinary systems. We performed a study to assess QoL and disability in young patients with SB and to correlate it with the clinical picture.

In our SB sample, as expected, disability is strongly associated with clinical impairment of the proximal muscles of the lower limbs. In fact, proximal muscles are mainly involved in walking and generally in the motor functions of the lower limbs. With regard to QoL, the pattern appears more complex. Expectely, higher disability and severe muscle deficit of the lower limbs are associated with a reduction in the physical aspect of QoL.

On the contrary, unexpectedly, mental aspects of QoL is inversely related to disability: patients with low disability, for example normal walking ability or total autonomy, presented emotional problems higher than patients with severe disability. When we analysed which emotive aspect is mainly involved, evaluating the subscores, we observed that the patients with low disability have difficulty in daily activity due to emotional problems.

Conversely, patients with high disability , referred that the inability to perform daily activity was due to physical problems and they had a good quality of life from an emotional point of view. We observed that greater feelings of global self esteem in physical appearance were associated with greater severity of disability.

We hypothesize that the sfincterial problem plays a key role in this QoL pattern, in fact it must be noted that even patients with low disability have severe sfincterial problems. Probably the patients with lower disability have more social activity and spend most of their time among healthy people, but they know their disease and hide their severe urological problems.

Conversely, patients with severe disability perceive that the limitations are not due to emotional problems but mainly to physical and they accept their condition emotively.

Regarding the emotional picture, we believe that parents may greatly influence this aspect of patient's QoL. Some studies assess parents' perception of QoL and perception of youth but the relationship is complex and still matter of debate (3-6). The main lack of this study is the small sample studied. Notwithstanding, the study of this comprehensive and multiperspective assessment of the disease provided several significant results.

In conclusion, our results provide data against an easy and linear inverse correlation between disability and QoL in SB adolescent patients. Assessment of QoL, and particularly the emotional results, give us useful information for clinical practice: patients with mild disability concerning inferior limbs (patients who are able to walk, run and have total autonomy) but urological problems need psychological support more than patients with severe whole disability.

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