

MEASUREMENT OF HEALTH STATUS IN CHILDREN WITH SPINA BIFIDA USING PARENTAL CHILD HEALTH QUESTIONNAIRE (CHQ-PF 50)

Aims of Study

To assess the health-related Quality of Life (HRQoL) and disability in children with Spina Bifida (SB) and to correlate them with clinical picture using a Parental Child Health Questionnaire (CHQ-PF 50) (1,2).

Methods

29 consecutive children with SB (mean age 11 years, range 4-11) 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) parental-administered questionnaire for general health (CHQ-PF50); 3) standardised disability measurements (functional independence measure, Barthel Index, 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

Site of lesion was related to all main used disability scores and similarly main QoL measurements were related with the site of lesion. More proximal was the site of lesion, higher was the disability and lower the QoL. Deambulation Index ($r:0.59$, $p=0.05$) was related with physical aspects of QoL and was also correlated with parent's life domains. The same observation was noted with Barthel Index ($r:0.40$, $P=0.03$) and Functional Independence Measure(FIM) ($r:0.37$, $P=0.04$).

Unexpectedly, mental aspects of QoL were not related to disability measurements. Conversely, high physical disability was associated with frequent psychological distress, and severe role disability due to emotional problems only in patient's parents.

A significant difference was observed comparing the physical picture (PhS: $p=0.03$) between children who were supported by an assistant teacher for the handicapped at school and who were not. On the other hand no significant differences were noted analysing the mental picture. Children supported by an assistant teacher had higher disability and lower physical scores of QoL. The physical and the mental aspects of QoL were not related to age, sex or family educational level.

Conclusions

Spina Bifida (SB) is a congenital malformation of the neural tube, with impairment of growth, central nervous system, musculoskeletal and genitourinary systems. After shunt improvements and more aggressive treatment, survival increased. Traditional outcome assessment in neurological and rehabilitation fields had always been based on physician-derived and instrumental findings and recently researchers have underlined the need of a standardized evaluation of concepts such as QoL (3,4). This is the first study performed on a children SB population using a parental questionnaire for general health(5).

The multiperspective assessment showed that there is linear inverse correlation between disability and QoL in children with SB only for physical aspects. Conversely, there is linear inverse correlation between disability and QoL in patient's parents only for emotional aspects. This study provided useful information for clinical practice.

We hypothesise 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 and either continence, catheterisation and drug administration are important aspects regarding QoL in children with SB. This study also provided useful information regarding the importance of the presence of a teaching assistant at school underlined by the positive impact on emotional QoL.

References

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