

QUALITY OF LIFE MEASUREMENT IN CHILDREN WITH MYELOMENINGOCELE AND INCONTINENCE TREATED WITH THE PIPPI-SALLE TECHNIQUE.

Hypothesis / aims of study

Spinal dysrafism is the most common neural tube defect, affecting 10-15% of the population.[1] Myelomeningocele can impair adequate bladder storage and voiding functions, causing in some of the patients continuous urinary incontinence. The treatment of this entity may require bladder augmentation associated with correction of incompetent urethral closure mechanism. These patient can be treated with artificial urinary sphincter, with satisfactory long term results. In our country, though, the artificial sphincter has a prohibitive cost, making its use unaffordable. One treatment proposed for the correction of this type of incontinence in pediatric population was the Pippi-Salle technique, which provides a continence mechanism by lengthening the urethra through a bladder wall flap.[2] The Qualiveen questionnaire is a specific questionnaire used for evaluation of urinary and general quality of life(QoL)[3]. It is divided in two parts: Specific Impact of Urinary Problems (SIUP) , that has four domains (Inconvenience, Restrictions, Fears and Impact on Daily Life) and General QoL. We aim to present the long-term results of Pippi-Salle technique, as well as evaluate these patients Quality of Life using the Qualiveen questionnaire.

Study design, materials and methods

Records of 15 patients previously treated according to the Pippi-Salle technique were reviewed and then they were invited to answer the Qualiveen questionnaire. They were seen in medical appointment, history and physical examination were performed and the questionnaire answered. Data were analyzed for demographics and the comparison of SIUP and QoL was performed utilizing the Spearman's correlation coefficient.

Results

Of 15 patients, only 10 (66%) were available for quality of life evaluation. The other five were excluded because three were operated due to incontinent epispadia while the other two patients with myelomeningocele were lost during follow-up. Their age at questionnaire evaluation varied from 8 to 23 years, mean 16±4.62 years. The mean interval between surgery and questionnaire evaluation was 84.6±22.9 months, ranging from 22.4 to 100.2 months. Seven patients were male. Five patients are able to walk and five are wheel-chair users. Six patients still use pads (60%), being five patients because of fear of loss and only one due to continuous urinary incontinence. All patients perform clean intermittent catheterization, but three patients need a caregiver to perform the intermittent catheterization. Sixty percent of the patients (6) complained of fecal incontinence, but only 4 of them use pads due to fecal loss. The results of SIUP and QoL for each patient are shown on table 1.

Interpretation of results

This technique is an interesting alternative to artificial urinary sphincter, yielding satisfactory results in the long-term follow up. Out of 10 patients, only one patient presents continuous urinary incontinence, while five patients use pads for precaution, with infrequent urinary loss if catheterization id delayed for too long or fecal loss. Patients that use pads for fecal or urinary incontinence had lower QoL results, but without significance. Correlation between SIUP and QoL did not achieve statistical significance, but correlation was positive (p=0.058). The comparison of the four domains of SIUP with the general QoL section has demonstrated inverse correlation, because of contrary scaling of results (SIUP is graded from 0 to 4, being 4 the worst, while QoL varies from -2 to +2, being -2 the worst).

Concluding message

The Qualiveen questionnaire can be use in patients with myelomeningocele yielding good results, allowing urinary and general QoL measurement. Despite the lack of a pre-operative version of the questionnaire, post-operative questionnaire data demonstrated that urinary problems (SIUP) are not the sole complaints of this group of patients.

1. Paediatr Neurol. 1998; 2(4):179-85
2. J Urol 1994;152(2 Pt 2):803-6.
3. Eur Urol. 2001; 39(1):107-13.

Patient	Inconvenience	Restrictions	Fears	Impact on daily life	SIUP	QoL
1	2,67	1,88	1,63	3,00	2,30	-0,78
2	1,33	1,88	1,13	2,60	1,74	-0,33
3	0,89	2,75	1,38	1,20	1,56	0,00
4	1,78	1,63	1,25	1,00	1,42	0,44
5	0,11	1,00	0,38	0,60	0,52	1,56

6	0,00	1,50	0,50	0,40	0,60	1,11
7	0,56	3,38	0,50	0,80	1,35	0,00
8	0,44	0,63	1,13	1,60	0,95	0,89
9	2,20	3,00	1,38	0,40	1,75	1,22
10	0,44	1,00	0,63	3,00	1,25	1,11
Mean±SD	0.86±0.76	1.86±1.00	0.92±0.41	1.46±1.04	1.34±0.55	0.52±0.77

Table 1. Qualiveen questionnaire – SIUP domains and QoL score.

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HUMAN SUBJECTS: This study was approved by the CEP - FCM - UNICAMP and followed the Declaration of Helsinki Informed consent was obtained from the patients.