

IMPACT ON QUALITY OF LIFE IN CHILDREN WITH MYELOMENINGOCELE AND BURDEN ON THEIR CAREGIVERS

Hypothesis / aims of study

The aim of this study is to evaluate the quality of life of children with myelomeningocele and work of their caregivers

Study design, materials and methods

Descriptive cross-sectional study that included children with myelomeningocele and the responsible researcher contacted the family at the time of medical or therapeutic consultation, inviting the caregiver and child to participate in the study, providing a prior explanation of the importance of all procedures. Thus, parents signed an informed consent and data collection was initiated. The data to characterize the sample was collected in an evaluation form prepared by the responsible researcher. For the assessment of overall quality of life of the population of children with myelomeningocele, AUQUEI and Qualiveen questionnaires was applied, and Qualiveen also evaluates the quality of life with emphasis on urinary dysfunction. The caregiver burden was also assessed by structured interview named Burden Interview. All the questionnaires were translated and validated for the Portuguese language. A graduate of the amount of urine leakage was measured by the 24 hours' pad test and urinary frequency measured over the three-day voiding diary. Two days were required to review such procedures could be performed.

On the first day of data collection, the form to characterize the sample were applied, and the Burden Interview with caregivers, as well as guidance on the procedures of the three-day voiding diary and the pad test, both assigned by the principal investigator procedure. The second day of evaluation was established by Qualiveen and AUQUEI answered by the children, in addition to collecting the results of the voiding diary and pad test related material.

Results

The interviewed population was 24 children with myelomeningocele of different levels of injury, they were divided into 2 groups, where Group 1 was made by children treated by clean intermittent catheterization (n=7), corresponding to 7 patients (29.17 % of the studied population) and Group 2 by children who used diapers as a method to contain urinary incontinence, totalizing 17 children (70.83 % of the population). Their ages ranged from 5 to 15 years, with a mean age of 11.28 years in Group 1 and 7.64 in Group 2. There was no significant difference in prevalence between the groups, considered homogeneous among them. Caregivers are mostly the mothers of the children themselves, only 4 caregivers of the sample (n=24) differ mothers, being a father, grandfather, grandmother and aunt.

The quality of life in general aspects measured by the AUQUEI showed no significant difference between groups (p=0.763), as well as the results of Qualiveen dimensions in the *Specific Impact Urinary Problems* with specific items related to the impact of urinary dysfunction (p=0.424) and also in the dimension of *Quality of Life*, in general aspects (p=0.882), and can then say that there is no difference between the two groups about the child's perception regarding urinary symptoms and the quality of life in general aspects.

The caregiver burden was assessed using the Burden Interview which shown that caregivers of Group 1 presented higher score (44.71 ± 4.49) and classified according to the scale as moderate to severe overload. The caregivers of Group 2 had lower scores (22.94 ± 2.88), ranked on the mean to moderate overload, demonstrating a significant difference between groups (p=0.0005) and featuring carers group that performs clean intermittent catheterization as more burdened in caring.

Children of Group 1 who perform clean intermittent catheterization were not considered continents because they have constant leakage of urine at intervals of probing through the 24 hours' pad test, which had a mean of 304.71 milliliters (ml) of loss. Thus, the Group 2 of the incontinents had a mean of 428.58 ml of loss, with no significant difference in urine loss between groups (p=0.142). However, there was a discrepancy in Group 1 of a child that lost 600 ml in pad test. If this individual was removed from the Group 1, the difference between urine loss between groups was statistically significant (p=0.04).

In voiding diary, there was no significant difference with regard to fluid intake between groups, being consumed a mean volume of 1674 ml per day. However, there was significant difference between the use of pads related groups in all the three-day voiding diary, with the lowest value observed on the third day (p=0.003), demonstrating that the Group 2 uses more pads in the period than the group that performs clean intermittent catheterization.

Interpretation of results

Children and adolescents with myelomeningocele have physical and psychosocial impairment compared with healthy individuals, however, the mobility factor has been touted as a determining factor in influencing of the quality of life of these patients, and hydrocephalus, orthopedic deformities and neurogenic bladder has lower impact, corroborating with the results in the present study because the urological treatment was different between the groups, and no significant difference with regard to the quality of life [1].

The care of the child with myelomeningocele requires reorganization of daily family life and new routines and procedures that require learning because of the congenital abnormality, in addition to coping with difficulties in social interaction, physical and emotional overload, which are present in such a situation. The present study showed that the caregivers are affected more strongly than children themselves, because spend more time for procedures such as administering medications continuous or prophylactic, completion of clean intermittent catheterization and prevention of skin lesions, use of orthosis, among others. This fact justifies the higher rank and greater overload on the Group 1 because catheterization is a procedure that needs to be filed, performed at specific times and cautela [2].

Incontinent patients using pads have worse prospects when compared to patients who perform clean intermittent catheterization. In the present study, only 29.175 % of the population carries the catheterization, demonstrating that improvement is needed in urology treatment of this population in order to prevent urological complications and impaired quality of life in Group 2 [3].

Concluding message

This study demonstrates that urinary incontinence does not directly affect the quality of life of the children with myelomeningocele, but using a smaller number of pads has a positive impact on this.

The clean intermittent catheterization is a factor of overwork, promoting negative impact on quality of life of caregivers and maybe that is the reason for the low adherence of this method. Being catheterization taught early to the children, the burden on caregivers should be lower, as well as urologic complications.

References

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Disclosures

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