Assessment of mobility and quality of life of patients with myelomeningocele

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Summary

Introduction. The myelomeningocele is the most common defect of the central nervous system.
The aim of this study was to evaluate the motor activity and quality of life of patients with myelomeningocele and their families according to the epidemiologic factors, methods of rehabilitation, functional capacity, current deformation and musculoskeletal system.
Material and methods. The study was conducted within the group 19 children with myelomeningocele (11 girls, 8 boys) aged 2 to 16. Basic medical and motor assessments were performed. Modified questionnaires of PedsQL / Kidscreen / CPCHILD were analyzed.
Results. In the group, all the children had motor system deformity. Full independence mobility was observed in only one patient and 89% of children were able to move only with the use of orthopedic equipment. One patient was unable to move which correlated with the localization of myelomeningocele, hydrocephalus and decreased life quality.
Conclusions. The factors determining the life quality of children were: the ability of ambulation ability, the level of myelomeningocele and the age. The disease significantly reduced the quality of life of children.
Key words: myelomeningocele, the quality of life, rehabilitation, motor activity

Streszczenie

Wstęp. Przepuklina oponowo - rdzeniowa należy do najczęściej występujących wad wrodzonych ośrodkowego układu nerwowego.
Celem pracy była ocena sprawności ruchowej oraz jakości życia pacjentów po korekcji przepukliny oponowo-rdzeniowej w zależności od czynników demograficznych, poziomu przepukliny, obecnych deformacji narządu ruchu oraz od stosowanych metod rehabilitacji,
Materiał i metody. Badania objęły 19 dzieci z przepukliną oponowo-rdzeniową (11 dziewczynek, 8 chłopców) w wieku od 2 do 16 lat. U wszystkich pacjentów dokonano oceny klinicznej narządu ruchu oraz testy sprawności ruchowej. Przeprowadzono badanie ankietowe przy użyciu zmodyfikowanego kwestionariusza PedsQL/ Kidscreen/ CPCHILD.
Wyniki. Wszyscy pacjenci wykazywali deformacje narządu ruchu. Pełną samodzielność ruchową stwierdzono u jednego dziecka, 89% pacjentów poruszało się aktywnie za pomocą sprzętu ortopedycznego. U jednego pacjenta wykazano brak możliwości ruchu, co korelowało z wysokością przepukliny, wodogłowiem i obniżoną jakością życia.
Wnioski. Czynnikami determinującymi jakość życia dzieci są: zdolność lokomocji, poziom przepukliny oraz wiek dziecka. Choroba w znacznym stopniu obniża sprawność ruchową oraz jakość życia dzieci .
Słowa kluczowe: przepuklina oponowo-rdzeniowa, jakość życia, rehabilitacja, sprawność ruchowa

INTRODUCTION

Myelomeningocele is a congenital embryopathological malformation of the central nervous system formed in the womb. It is developed as a result of incorrect/improper or delayed closure of the neural tube and protrusion of the sac with its content through open vertebral arches or vertebral bodies. [1-5]

The development of the disease/disorder is determined by genetic predisposition and external factors. The deficiency of folic acid and vitamins B12 and B6 is the undeniable teratogenic factor. The other also many other factors like: taking anticonvulsants, retinoic acid, diuretics, antihistamines, sulfonamides and excessive use of zinc supplementation during the conceptual and first period of pregnancy. Similar effects may be caused by X-rays, chemicals and drugs [3,6-9].

The largest is the group of children with myelomeningocele in the lumbar (41%) and lumbosacral spine (23%) [6,10-13]. Moreover, it is reported that in families of lower socio-economic status and education level there are more defects developed. It is also more likely to develop in an unplanned than in planned pregnancy [3].

Myelomeningocele is significantly affected by the location of the sac, spine level and the degree of damage of the nerve tissue. Weakness or paralysis of certain muscle groups of the lower limbs is typical. Meningomyelocele may be accompanied by distortion in the spine: kyphosis, lordosis or scoliosis which can occur separately or as a combination of these defects. Deformations and contractures in the lower extremities such as subluxation and dislocation of the hip, equinovarus, calcaneus and valgus foot are also characteristic. There is an increasing risk of pathological fractures of the paralyzed limbs and the development of osteoporosis. In these patients the studies have shown significantly reduced bone density which is caused by the reduction or the lack of ambulation. The majority of children, due to the damage of nerve pathways and centers responsible for bladder and bowel function, have problems with urination and bowel movements. Children have to face the problem of urine leakage or retention. Most of them require periodic catheterization every 3-4 hours (younger children) or every 4-6 hours (older children). Vesicoureteral reflux (VUR) and urinary tract infections that further lead to damage of the renal parenchyma and kidney failure occur frequently. Impaired intestinal motility and weakened muscles of anus and rectum lead to constipation and fecal stone formation. Laxity of the anal sphincter, which leads to so-called 'breathing/gaping anal' is characteristic for these children [4,14-18]. In most cases congenital meningomyelocele can cause coexisting defects like: hydrocephalus (90%), Arnold Chiarii type II malformation (80%) and tethered cord syndrome [3-5,10,14,15,19,20].

A child with myelomeningocele and hydrocephalus requires long-term treatment and comprehensive rehabilitation, which prevents development of deformities and contractures of the musculoskeletal system and helps maintain full range of motion in the joints of the lower extremities. The main rehabilitation methods are the concept of neurodevelopmental by Bertha and Karl Bobath and reflex locomotion by Vojta [5, 12, 21].

The sense of satisfaction resulting from the possibility of meeting individual needs defines the quality of life (QL). It is important that the evaluation of quality of life takes place on two levels - in objective (functional assessment of the child) and subjective terms (the expectations, dreams, ambitions, the child's emotional state). Questionnaires that were used to test the quality of life for children include the physical, mental and social factors. [22-24].

AIM OF THE STUDY

The aim of this study was to evaluate the mobility and quality of life of patients with meningomyelocele after surgical treatment, depending on:

- demographic factors,
- level of neurosegmental lesion/ level of spinal cord lesion,
- current musculoskeletal deformities,
- methods of rehabilitation.

MATERIAL AND METHODS

The study included 19 children with myelomeningocele, 11 girls (58%) and 8 boys (42%) at the age of 2 to 16 years and their families. The average age of the group was 9.8 years.

The quality of life test (QoL) of the children and their families in the clinical group was conducted according to the self-designed questionnaires based on: PedsQL Celebral Palsy Version 3.0, Kidscreen, CPCHILD (Caregiver Priorities and Child Health Index of Life with Disabilities) questionnaires, and survey on the quality of family life.

The quality of life questionnaire was adapted to the children age groups. The survey for children between 2 and 4 years was filled by their parents, for children above 5 years both children and parents were asked to answer the questions. All patients underwent clinical assessment of motion system and the test of their mobility.

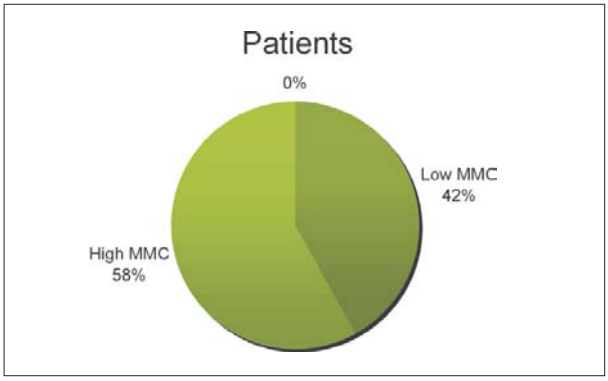


Fig. 1. Classification of spina bifida according to the location of the first opened vertebral arch

Statistical analysis, both descriptive and comparative, was based on computer programs Microsoft Office Excel 2007 and STATISTICA 10. The tests were checked accordingly to: t-test, Chi-square, post hoc univariate and multivariate analysis of variance and correlation analysis. The accepted statistically significant value was established at $p < 0.05$.

RESULTS

The children were divided into two groups: children with high hernia (T6-L1) and low hernia (L2-L5) depending on the location of the first opened vertebral arch. The division was based on both physical examination and medical records. Children with high hernia were accounted for 58% (11 cases) and children with low hernia were accounted for 42% (8 cases).

Tab. 1. Correlation between motor capabilities of children and spina bifida level (high, low)

	CORRELATIONS	
	Chi^2 Pearsona	*Chi^2 NW*
The ability of locomotion and the spina bifida level	9,552341	11,61377
	p = 0,049	p = 0,020
The ability to maintain in standing position and the spina bifida level	5,126860	6,242846
	p = 0,077	p = 0,044
The ability to transition into a sitting position and the spina bifida level	5,858586	8,117432
	p = 0,119	p = 0,044
The ability to transition to a four-point kneeling position and the spina bifida level	11,82102	15,82006
	p = 0,019	p = 0,003

Tab. 2. The strength of separate muscle groups depending on to the spina bifida level

CORRELATIONS	*P value*
spina bifida level and hip flexors	p = 0,000
spina bifida level and hip adductor	p = 0,003
spina bifida level and hip abductor	p = 0,003
spina bifida level and external rotators of the femur	p = 0,002
spina bifida level and internal rotators of the femur	p = 0,014
spina bifida level of and knee extensors	p = 0,000
spina bifida level of and knee flexors	p = 0,000
spina bifida level and dorsal flexors and pronators	p = 0,017

Fig. 2. Deformities of trunk in the assessed group

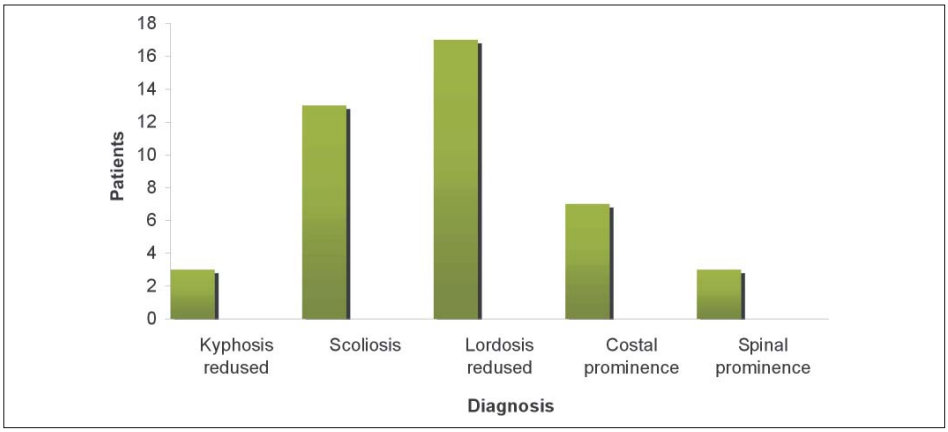
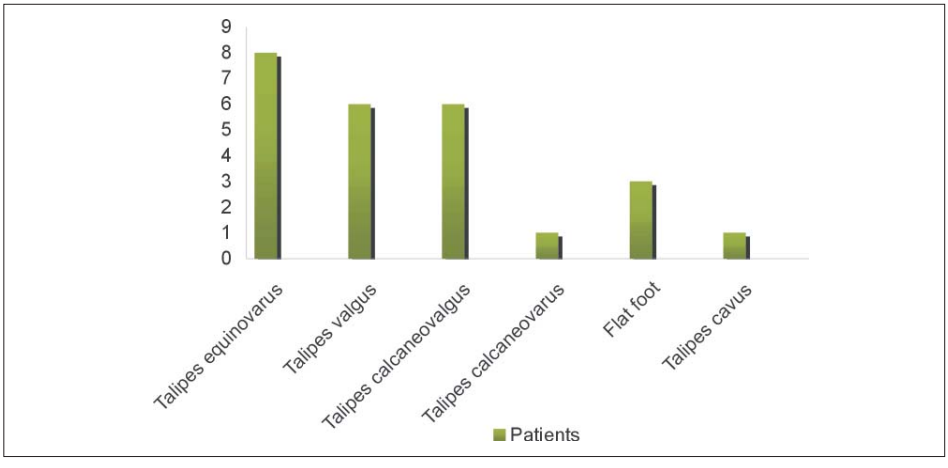


Fig. 3. Deformations of ankle joints in the studied group



The children mobility was evaluated according to the level of meningomyelocele. That correlation was checked with the Chi-square test and is presented in table 1.

The physical examination of muscle strength in the lower limbs was evaluated with the Lovett scale. Chi-square test was used to explore the correlation between the strength of muscle parts and the hernia level and is presented in the table 2.

There was no significant correlation between the strength of extensor hip muscles and the spina bifida level (p = 0,073.)

Tab. 3. The impact of functional ambulation on life quality of children with myelomeningocele

FUNCTIONAL AMBULATION	Average number of points in QoL Questionnaire
nonambulation	140
ambulation with wheelchair	248
ambulation with crutches	283
community ambulation	267

Tab. 4. Correlations between functional ambulations

CORRELATIONS	p *value*
nonambulation and ambulation with wheelchair	p = 0,003
nonambulation and ambulation with crutches	p = 0,000
nonambulation and community ambulation	p = 0,001
ambulation with wheelchair and ambulation with crutches	p = 0,119
ambulation with crutches and community ambulation	p = 0,946

Tab. 5. Children's life quality depends on gender/sex

Sex/ Gender	Average number of points in QoL Questionnaire	Number of patients
Female	206,55	11
Male	204,50	8
p = 0,924		

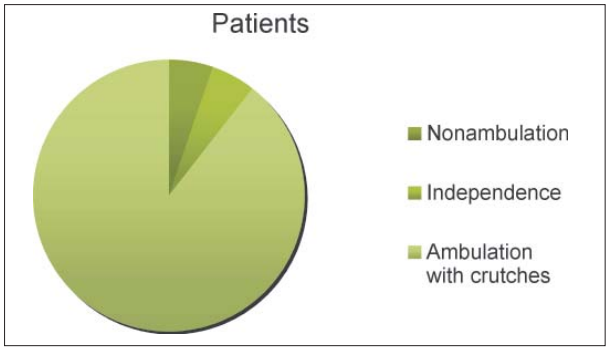


Fig. 4. Functional ambulation in studied group of patients

The evaluation of mobility range and the presence of deformations and contractures of body structures is presented in the tables below [fig. 2-3].

All children in the study group had deformities of the trunk and ankle joints.

In the physical examination 84% of children had a flexion contracture of the knee. Full extension was noted in 16% of patients, including one child with hyperextension of the knee.

Full mobility independence was observed in case of one child, 89% of patients were actively moving with use of orthopedic equipment. One patient was nonambulatory. Patients in the last group had hydrocephalus, high level lesion and significantly lower quality of life scores.

In this study we examined the impact of the functional ambulation on the quality of life of children with myelomeningocele. The parents and children report was used for the analysis [Table 3]. Statistical analysis was performed using post hoc test.

Correlation analysis between the different variables of motor skills was performed, taking an average number of points obtained in the questionnaire, depending on the capabilities of motor [Table 4].

Statistically significant differences in the life quality of children who were community walkers, with the help of crutches or a wheelchair, compared to nonambulatory patients.

The study group showed no statistically significant correlation between the quality of life of children and the gender of the respondents (p = 0.924) [Table 5].

An analysis of the impact of age and spina bifida level on child's life quality was performed, taken into account the assessment of children and their parents - the results are shown in table VI. A statistically significant difference between the group of children younger and older with a high myelomeningocele was proved (p = 0.02).

All 19 patients in the study group were under rehabilitation treatment. Eight children in first year of life were treated by NDT Bobath method, six by Vojta method. Both methods were applied to 5 children.

The influence of both rehabilitation methods used in 1 year of age on the life quality of children with myelomeningocele was analyzed. No statistically significant difference in the life quality and the methods of rehabilitation (p = 0.412) was shown. However, the children treated by NDT Bobath method had higher average quality of life scores compared to children treated with Vojta method. The children rehabilitated by both methods had lower quality of life than those treated only with NDT Bobath.

Using correlation analysis, the authors examined the effect of rehabilitation frequency on the life quality among younger and older children [Table 8]. In the younger group, where life quality was assessed primarily by a parent, only negative correlation was revealed. The assessment of life quality was affected by parent difficulties with intense rehabilitation program, rather than the fact of the presence of rehabilitation in a child's life. In

the group of older children, where quality of life was reported by the child and the parent, a positive correlation was obtained. This means that the frequency of weekly rehabilitation increases the life quality of the patient.

DISCUSSION

Beside movement limitations children with myelomeningocele cope with everyday life challenges. It is a problem for them to function in kindergarten, schools because of their emotional problems. The disease significantly reduces quality of life the children and their families. [25,26] Our study confirmed the influence of myelomenongocele on motor function abilities of children. Higher localization of the congenital mielomeningocele reduces the mobility. Statistically significant differences in the variables: the ability of the transition to a four-point kneeling position ($p = 0.019$), the ability of locomotion ($p = 0.049$) were found. Many authors proved also that the mobility of children depends on the localization of myelomeningocele [27-33].

The study confirmed the correlation between motor abilities and life quality of patients. Assessment of life quality was significantly lower in children unable to move even with orthopedics equipment. Children in wheelchairs and patients moving with crutches had similar scores but lower then community walkers. Danielsson at al. described similar results [29]. Król at al. compared the QL in younger and older children. The QL scores in younger group were lower than in older because the survey was only done by their parents [30]. Similar results were described in our study. Many authors correlate the QL of children with myelomeningocele to the level of spinal defect and movement activity [31-35]. Flanagan using PedsQL questionnaire showed higher QL scores in children with localization of spinal defect over L2 [31]. Also Schoenmakes et al. indicated that the community motor ability has the biggest influence on the QL of a child [32]. Similar data was confirmed in our research. According to Buffart female QL scores were lower. In our study there was no correlation between gender and QL [33].

Motor function and quality of life in children with myelomeningocele were analyzed in correlation with the methods of rehabilitation and level of the spinal defect. Methods of Vojta and NDT Bobath were commonly used in children with neuronal defects. [34,35] There were no significant results found between methods of Vojta and NDT Bobath p=0,49. Okurska- Zawada et al. confirmed also no evidence between this methods and psychomotor development of children. They assumed that the methods influence not only the final effects of rehabilitation but inhibit pathologic motor movements and stimulate the children's development [27]. According to Jozwiak there were no differences between the methods of rehabilitation of children with myelomeningocele. Final effects of therapy mostly depended on the level of spinal defect [36].

Summarizing, the quality of life of children with neural tube defects is a very complicated topic. Interdisciplinary model of therapy and psychosocial treatment involves the patient, his emotional and social aspects. QL research revealed the patient's needs, allowed not only to assess the treatment and rehabilitation satisfaction but also to individually organize the program of motor improvement.

CONCLUSION

1. Most of patients with mielomeningocelce despite of motor abilities limitation were able to move with orthopedics' equipment support.
2. Quality of life in children with mielomeningocele was determined by: age, level of the defect and ability of locomotion with or without orthopedics' equipment.
3. There were no significant influences of rehabilitation methods and frequency on quality of life.
4. Quality of life in children with mielomeningocele was significantly decreased.

Tab. 6. Life quality depends on myelomeningocele level in younger and older group of patients

	High level of spina bifida	Low level of spina bifida
Younger group	184,667	208,250
Older group	246,667	267,500
P value	**p=0,029**	**p=0,215**

Tab. 7. The life quality depending on the rehabilitation method

REHABILITATION METHOD	Average number of points in QoL Questionnaire	N
NDT Bobath	245	8
Vojta	207	6
NDT Bobath + Vojta	218	5
p = 0,412		

Tab. 8. Correlation between quality of life and frequency of rehabilitation in younger and older groups of patients

Age	Correlation coefficient	*n*	*P value*
younger group	- 0,6620	7	**p = 0,037**
older group	0,2798	12	**p = 0,207**

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