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Original Article

# Quality of Life in Children and Adolescents With Cerebral Palsy and Myelomeningocele

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ABSTRACT

The aim of this study was to compare health-related quality of life in children with cerebral palsy and with myelomeningocele. Fifty-seven children with spastic cerebral palsy and 34 patients with myelomeningocele aged 5-16 years were included in the study. Their mothers completed standardized measures on the Revidierter Kinder Lebensqualitätsfragebogen (KINDL-R) parent questionnaire. The 2 groups were demographically comparable. The children with cerebral palsy were classified more frequently into levels II ($n = 24$) and III ($n = 18$) of the Gross Motor Function Classification System. Other patients were classified into levels IV ($n = 5$) and V ($n = 10$). Three patients with myelomeningocele were community walkers, 10 could walk with assistive devices, and 21 used a wheelchair. Lesion level was thoracic in 13 patients, lumbar in 17, and sacral in 4. Twenty-nine patients (85.3%) with myelomeningocele had hydrocephalus, and 27 had a shunt. Parents in the both studied groups reported similar overall quality of life of their children in the dimensions of physical and emotional well-being, self-esteem, family, friends, and school. No significant correlations between the quality-of-life scores and age, walking ability, and mental development of the studied groups were found.



## Introduction

Cerebral palsy is the most common childhood congenital disorder of movement and posture causing activity limitation attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain [1]. Cerebral palsy is a chronic condition occurring in 2-3 per 1,000 live births across Europe [2]. The prevalence of cerebral palsy in Poland is 3 per 1,000 live births [3].

Myelomeningocele is a serious congenital condition caused by incomplete neural tube closure during the third and fourth weeks of gestation and is frequently associated with other health conditions such as hydrocephalus, Chiari syndrome, and tethered cord syndrome [4,5]. The rates of myelomeningocele vary widely among countries and by geographic regions within countries. Neural tube defects occur at frequencies (per 10,000 births) ranging from 0.9 in Canada and 0.7 in central France, to 7.7 in the United Arab Emirates and 11.7 in South America [6]. The prevalence of myelomeningocele in Poland is 6.2 per 10,000 births [7].

Children with cerebral palsy or myelomeningocele are representative of many disabled children: they have a range of physical, intellectual, orthopedic, hearing, visual, and communication impairments, with a wide range of severity [8-11]. Almost all patients with myelomeningocele have significantly lower cognitive development compared to healthy children. Furthermore, early repair of the myelomeningocele, the presence of a shunt or shunt-related complications, and the spinal level of the lesion do not correlate with mental development [12]. Nearly all patients with myelomeningocele have bladder dysfunction (neurogenic bladder) [13]. Children with cerebral palsy and myelomeningocele experience various degrees of limited mobility and self-care capability, as well as restrictions in participation that threaten their health-related quality of life [14-19].

Health-related quality of life is a broad concept that refers to the assessment of various aspects of health from the patient's point of view and includes physical, mental, and social well-being and functioning [20,21]. The World Health Organization has recommended that measures of quality of life in children use self-reporting wherever possible. Although children with cerebral palsy or myelomeningocele often have intellectual impairment that

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renders them unable to self-report, the need to assess these children's quality of life is no less important [22,23]. Parents are often asked to report their children's quality of life, but previous work has indicated that parents and children frequently disagree [24,25]. Parent reports of child quality of life are influenced by the parents' own health and psychologic well-being [26].

To our knowledge, no comparative studies have been conducted in children with cerebral palsy and myelomeningocele. As has been suggested in children with other chronic conditions [27], we expected agreement between parent reports of children with cerebral palsy and myelomeningocele. The aim of this study was to compare the reports of parents of the quality of life of 5- to 16-year-old children with cerebral palsy and myelomeningocele.

## Patients and Methods

### *Patients*

Patients with cerebral palsy and myelomeningocele aged 5-16 years attending the outpatient clinic of the Department of Pediatric Rehabilitation and their mothers were eligible to participate in the study. The criteria for inclusion were age and the diagnosis of cerebral palsy or myelomeningocele. Children with postnatal meningitis, encephalitis, trauma, and metabolic or degenerative disorders were excluded from the study. Mothers with cognitive disabilities who were not able to complete self-report questionnaires were excluded from the study. Sociodemographic data included questions on the child's age, sex, type of school, parents' family status, and education.

### *Cerebral palsy*

Fifty-seven children (33 boys and 24 girls, mean age 10.70 ± 3.47 years, range 5-16 years) with spastic diplegic cerebral palsy, tetraplegia, and hemiplegia were investigated. No significant difference ($P = 0.41$, $\chi^2$ test) was found between boys and girls. We confirmed the diagnosis of cerebral palsy in each case.

### *Myelomeningocele*

Thirty-four children (16 boys and 18 girls, mean age 10.85 ± 3.75 years, range 5-16 years) with myelomeningocele were investigated. We confirmed the diagnosis of myelomeningocele in each case. Clinical data included level of spinal cord lesion, number of operations in the past 12 months, ambulation ability, and management of neurogenic bladder.

### *Motor function*

The children with cerebral palsy were each assigned a score according to the Gross Motor Function Classification System [28] by an occupational therapist as follows: level I—walks without restrictions; II—walks without assistive devices, limitations in walking outdoor; III—walks with assistive devices; IV—self-mobility with limitations, children are transported or use powered mobility; V—self-mobility is severely limited.

The ambulatory function in patients with myelomeningocele was defined according to Hoffer et al. [29] as 4 categories—community, household, nonfunctional, and nonambulators—scored 4 to 1. The myelomeningocele level was defined as the lowest level on the better side at which the child was able to perform an antigravity movement through the available range of joint motion.

### *Cognitive function*

The patients were assigned to 1 of 3 groups, depending on their level of academic achievement, supplemented by the results of formal psychologic testing, as follows: (1) Normal—normal school performance to at least first-grade level, with no evidence of specific learning difficulties. All the children in this group had one or more formal psychologic assessments (the typical Wechsler Intelligence Scale for Children, Polish version, or Terman Merrill test). (2) Mentally handicapped—formal psychologic testing results indicated function in the mentally deficient range. (3) Mental retardation—divided into the following: mild, 70-84 intelligence quotient; moderate, 50-69 intelligence quotient; severe, <50 intelligence quotient. Normal children had an intelligence quotient of ≥85.

### *Health-related quality-of-life questionnaire*

Health-related quality of life was measured with the Revidierter Kinder Lebensqualitätsfragebogen (KINDL-R) questionnaire, a generic quality-of-life measure, Polish version.

**Table 1. Sociodemographic and clinical characteristics of 57 patients with cerebral palsy**

| Characteristic | Value* |
|---|---|
| Age | |
| Mean (S.D.) | 10.70 ± 3.47 |
| Range | 5-16 |
| Sex | |
| Female | 24 (42) |
| Male | 33 (58) |
| Residence | |
| Village | 38 (66.5) |
| City | 19 (33.3) |
| Type of school ($n = 50$) | |
| Kindergarten | 7 (12) |
| Primary school | 26 (46) |
| Secondary school | 14 (24.5) |
| Special needs school | 10 (17.5) |
| Family structure | |
| Full | 41 (72) |
| Single | 16 (28) |
| Type of spastic cerebral palsy | |
| Diplegia | 27 (47.4) |
| Hemiplegia | 15 (26.3) |
| Tetraplegia | 15 (26.3) |
| Ambulation, GMFCS level | |
| III | 1 (1.8) 24 (42) |
| III | 17 (29.8) |
| IV | 5 (8.8) |
| V | 10 (17.5) |
| Mental development | |
| Normal (≥85 IQ) | 9 (15.8) |
| Small delay (69-50 IQ) | 21 (36.8) |
| Mild (49-35 IQ) | 16 (28) |
| Severe (<35 IQ) | 11 (19.3) |
| Epilepsy | 9 (17.5) |

Abbreviations:
GMFCS = Gross Motor Function Classification System
IQ = Intelligence quotient
* Data are provided as *n* (%) unless otherwise indicated.

We asked 97 mothers to complete the KINDL-R parent questionnaire during a visit to the clinic. Mothers filled out the form at home. Parent reports of child quality of life were obtained for 91 children. Six mothers (93.8%) did not complete the questionnaire. This internationally well-established instrument provides 6 dimension scores as well as an index, with higher scores indicating better health-related quality of life [21,30]. The instrument has been psychometrically tested with good internal consistency (Cronbach's $\alpha > 0.80$) and convergent and discriminant validity [31].

Distributions of variables are provided as means, standard deviations, and ranges. When comparing 2 groups, the chi-square test for nonordered categorical variables was used. Student's *t* test was used for comparison values of the quality of life between groups. Spearman's analysis was used to measure the dependence age, mental development, and motor function of cerebral palsy children and myelomeningocele patients. All tests were 2-tailed and conducted at the 5% significance level.

The study was approved by the ethics committee of the Medical University of Bialystok, Poland. Informed consent was obtained from the parents.

## Results

A full description of the groups of children under study are listed in Tables 1 and 2. Fifty-seven patients (33 boys, 24 girls) with cerebral palsy and 34 patients (18 boys, 16 girls) with myelomeningocele were recruited. Twenty-seven children had spastic diplegic cerebral palsy, 15 had spastic hemiplegic cerebral palsy, and 15 had spastic tetraplegic cerebral palsy.

Seventeen patients with myelomeningocele had lumbar myelomeningocele, 13 thoracic myelomeningocele, and 4 sacral myelomeningocele levels.

Of the cerebral palsy group, 26 children (46%) attended primary school, 14 (24.5%) attended secondary school, and 10 (17.5%) attended a special school for children with physical disabilities. In contrast, only a single child with myelomeningocele attended

**Table 2. Sociodemographic and clinical characteristics of 34 patients with myelomeningocele***

| Characteristic | Value |
|---|---|
| Age | |
| Mean ± S.D. | 10.85 ± 3.75 |
| Range | 5-16 |
| Sex | |
| Female | 16 (47) |
| Male | 18 (43) |
| Residence | |
| Village | 11 (32) |
| City | 23 (68) |
| Type of school | |
| Primary school | 19 (56) |
| Secondary school | 14 (41) |
| Special needs school | 1 (3.0) |
| Family structure | |
| Full | 26 (76.5) |
| Single | 8 (23.5) |
| Level of lesion | |
| Thoracic | 13(38) |
| Lumbar | 17 (50) |
| Sacral | 4 (12) |
| Operation past 12 months | 0 |
| CNS-related health problems | |
| Hydrocephalus | 29 (85.3) |
| Shunt | 27 (76.4) |
| Epilepsy | 14 (41) |
| Ambulation | |
| Community walker | 3 (9) |
| Household/near environment walker | 10 (29) |
| Wheelchair user | 21 (62) |
| Mental development | |
| Normal (≥85 IQ) | 49 (86) |
| Small delay (69-50 IQ) | 8 (14) |
| Mild (49-35 IQ) | 0 |
| Severe (<35 IQ) | 0 |
| Management of neurogenic bladder | |
| Flaccid bladder | 18 (43) |
| Spastic bladder | 16 (47) |
| Spontaneous control or SCIC | 14 (41) |
| CIC with need of assistance | 20 (59) |
| No bladder control | 0 |

Abbreviations:
CIC = Clean intermittent catheterization
CNS = Central nervous system
SCIC = Self-clean intermittent catheterization
* Data are provided as *n* (%) unless otherwise indicated.

a special school for children with physical disabilities. Nineteen patients (56%) with myelomeningocele attended primary school and 14 (41%) attended secondary school.

Twenty-nine patients (85.3%) with myelomeningocele had hydrocephalus and 27 had a shunt. More than 40% of children in the myelomeningocele study group had functional bladder control or were continent using clean intermittent self-catheterization; 20 patients (59%) needed assistance with clean intermittent catheterization; and none had no bladder control.

The studied groups were comparable (no significant difference) in terms of age, sex, residence, and family structure. More patients with myelomeningocele lived in the village than patients with cerebral palsy (no significant difference).

The main impairment variables (mental development, gross motor function, communication) differed significantly between the groups. Most children with cerebral palsy had motor and intellectual impairment (91%), and almost 20% of them could not communicate using speech. In contrast, most patients with myelomeningocele also had motor impairment, but only 14% had mental retardation (none had mild or severe mental retardation), and all could communicate using speech.

Of the parent respondents, all were mothers.

### *Motor function*

The children with cerebral palsy were classified more frequently into levels II ($n = 24$) and III ($n = 18$) of the Gross Motor Function Classification System; other patients were classified into levels IV ($n = 5$) and V ($n = 10$). None of patients was classified into level I (Table 1).

Three patients with myelomeningocele were able to walk in the community (score of 4), 10 were able to walk in the home and in the nearby environment (scores of 3 and 2), and 21 primarily used a wheelchair for ambulation (score of 1) (Table 2).

Ambulatory children with independent mobility were observed more often ($P = 0.019$) in the cerebral palsy group than in the myelomeningocele group (24, 42.1% vs 3, 8.8%) (Tables 1 and 2). Nonambulatory patients were found more frequently ($P = 0.006$) in the myelomeningocele group than in the cerebral palsy group (21, 61.7% vs 10, 29.4%).

### *Mental development*

Mental retardation was observed significantly more often ($P = 0.0048$) in children with cerebral palsy than in patients with myelomeningocele (48, 84.2% vs 8, 14%) (Tables 1 and 2).

### *Health-related quality of life*

Total values of health-related quality of life in patients with cerebral palsy (score of 64.2) and myelomeningocele (score of 61.6) were comparable (Table 3).

We found some differences in the domains of physical well-being, emotional well-being, self-esteem, and school in children with cerebral palsy compared to myelomeningocele patients (Table 3, Fig 1). These domains were not significantly different. School functioning was higher ($P < 0.058$) in patients with cerebral palsy compared to myelomeningocele patients.

No significant correlations between the quality-of-life scores and age, walking ability, and mental development of the studied groups were found (Table 4).

The Gross Motor Function Classification System level generally had a little effect on health-related quality-of-life differences. Interestingly, children with difficulties in independent walking had the highest values of the quality in their mothers' opinion. Children with cerebral palsy classified into level II had higher scores of quality of life in the domains of physical well-being, emotional well-being, and self-esteem compared to other children (data not shown).

**Table 3. Health-related quality of life in 57 patients with cerebral palsy and 34 patients with myelomeningocele**

| KINDL-R | CP ($n = 57$) | | MMC ($n = 34$) | | Mean Difference* | *P* Value |
|---|---|---|---|---|---|---|
| | Mean | S.D. | Mean | S.D. | | |
| Physical well-being | 57.0 | 12.8 | 53.2 | 12 | 3.8 | 0.168 |
| Emotional well-being | 53.8 | 11.9 | 50.6 | 10.5 | 3.2 | 0.203 |
| Self-esteem | 62.8 | 11.6 | 59.3 | 11.9 | 3.5 | 0.175 |
| Family | 71.6 | 9.6 | 70.6 | 8.0 | 1 | 0.732 |
| Friends | 71.1 | 11.9 | 72.8 | 11.1 | −1.7 | 0.505 |
| School | 68.7 | 13.1 | 63.1 | 13.7 | 5.6 | 0.058 |
| Total | 64.2 | 11.8 | 61.6 | 11.2 | 2.6 | 0.307 |

Abbreviations:
CP = Cerebral palsy
KINDL-R = Revidierter Kinder Lebensqualitätsfragebogen questionnaire
MMC = Myelomeningocele
* Comparison via *t*-test.

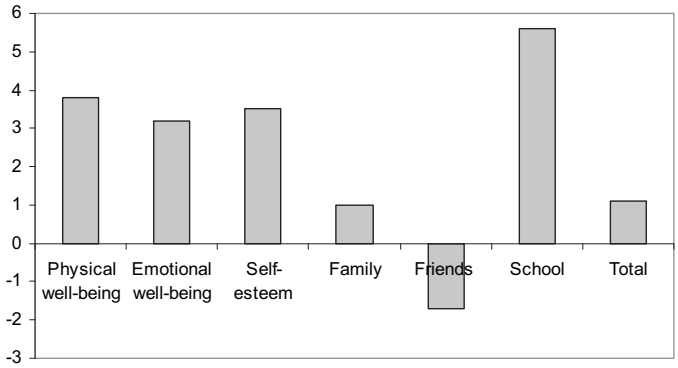


**Figure 1.** Box plots of KINDL-R quality of life mean differences by domain for children with cerebral palsy and children with myelomeningocele.

Children with cerebral palsy and myelomeningocele had epilepsy. Frequency of epilepsy was not significantly ($P = 0.07$) higher in the myelomeningocele group (14, 41%) than the cerebral palsy group (9, 17.5%) (Tables 1 and 2).

## Discussion

To our knowledge, this is the first study on children with cerebral palsy and myelomeningocele that compares parent reports of the children's quality of life. The study of the characteristics of the children in both populations (cerebral palsy of myelomeningocele) indicates that they are broadly comparable. Our findings are partially in agreement with previous reports on the quality-of-life studies in patients with cerebral palsy [9,15,22] and myelomeningocele [27,30].

In the present study, only mothers reported their child's quality of life. We did not use the patient form of the KINDL-R questionnaire. Previous reports have indicated that parents and children frequently disagree in the assessment of quality of life [20-22,25]. Thus, parent reports should not be considered as substitutes for child self-reports but rather as complementary information. It has been suggested that other proxies be sought to complement parent reports [20]. Guyatt et al. [32] found that proxy vs patient evaluations of quality of life frequently indicated about a 50% correlation, varying with the domains assessed and the relationship of the proxy. Proxy reports of more easily observed domains (i.e., physical functioning, cognition) correlated better with patient reports. In general, patients reported higher function, while proxies, especially close contacts, reported more impairment. For psychologic and emotional morbidities, patients generally reported more problems.

In a European generic health-related quality-of-life questionnaire (KIDSCREEN), results indicated discordance in scores and reasoning for answers between parents and children aged 8 to 12 years. The children tended to provide extreme scores and base responses on single examples [16].

Danielsson et al. [18] found patients with myelomeningocele with hip dislocation and spinal deformity, or those who were mentally retarded also had significantly worse functional mobility. General health-related quality of life was significantly lower in patient with myelomeningocele than for control patients. Non-ambulatory and mentally retarded patients had a significantly lower physical function of their quality of life.

In a large-sample study ($n = 1{,}174$), Dickinson et al. [16] assessed the quality of life in cerebral palsy by KIDSCREEN. They found that severely limited self-mobility was significantly associated with reduced mean score for physical well-being; intellectual impairment with reduced mean for moods and emotions and autonomy; and speech difficulties with reduced mean for relationships with parents. Furthermore, pain was common and associated with lower quality of life in all domains. In the present study, we did not evaluate pain intensity. Dickinson et al. concluded that children with cerebral palsy had a similar quality of life to children in the general population in all domains except schooling.

Our findings indicate that myelomeningocele may not affect all domains of health-related quality of life equally. We found some differences in the domains of physical well-being, emotional well-being, self-esteem, and school compared to children with cerebral palsy.

The Gross Motor Function Classification System level generally had little effect on health-related quality-of-life differences [33]. Gates et al. [33] determined whether there was a difference between perspectives of functioning and health-related quality of life of parents and adolescents with spastic cerebral palsy. They found that parents and adolescents agreed more on functioning than health-related quality of life. Parents and adolescents both recognized significant comorbidities, but adolescents saw themselves as less limited than their parents did. Age, parent well-being, and parent sex had a little effect, and comorbidities had no effect. The greatest differences between parents and adolescents were in the health-related quality-of-life scales for male adolescents.

Children and adolescents with cerebral palsy and myelomeningocele have a range of type and severity of impairments in addition to problems with posture or walking. They usually have one or more additional impairments of vision, hearing, intellect, communication, or behavior [6,8,34,35].

In our study, most patients with cerebral palsy could walk, but patients with myelomeningocele used wheelchairs. Nearly all

**Table 4. Correlations between health-related quality-of-life scores and age, walking, and mental development in 57 patients with cerebral palsy and 34 patients with myelomeningocele**

| KINDL-R | Age | | Walking Ability | | Mental Development | |
|---|---|---|---|---|---|---|
| | CP ($R$) | MMC ($R$) | CP ($R$) | MMC ($R$) | CP ($R$) | MMC ($R$) |
| Physical well-being | 0.089 NS | 0.099 NS | −0.036 NS | 0.197 NS | 0.015 NS | 0.142 NS |
| Emotional well-being | 0.167 NS | −0.258 NS | 0.043 NS | 0.257 NS | 0.065 NS | 0.085 NS |
| Self-esteem | −0.104 NS | −0.200 NS | −0.041 NS | −0.010 NS | −0.003 NS | −0.053 NS |
| Family | −0.008 NS | 0.036 NS | 0.049 NS | −0.096 NS | −0.025 NS | 0.057 NS |
| Friends | 0.077 NS | 0.157 NS | 0.183 NS | 0.048 NS | 0.154 NS | −0.082 NS |
| School | −0.043 NS | −0.053 NS | 0.123 NS | −0.187 NS | −0.016 NS | 0.094 NS |
| Total | 0.029 NS | −0,036 NS | 0.053 NS | 0,034 NS | 0.031 NS | 0,040 NS |

Abbreviations:
CP = Cerebral palsy
KINDL-R = Revidierter Kinder Lebensqualitätsfragebogen questionnaire
MMC = Myelomeningocele
NS = Not significant
*R* = Spearman rank correlation coefficient

patients with myelomeningocele have bladder dysfunction (neurogenic bladder) [4]. Almost half of these patients used clean intermittent catheterization. Most patients with myelomeningocele have a flaccid paraparesis below the spinal cord lesion; in contrast, most patients with cerebral palsy have a spastic paraparesis [18,29].

In recent years, there has been discussion about whether the parent, patient, or both should report on functioning and quality of life in cerebral palsy [15,36-38] and myelomeningocele [19,27,30]. Other studies concerning parent reports of quality of life for children with cerebral palsy also found that the more severely physically impaired children had lower quality of life in areas of physical functioning [9,33]. Livingston and Rosenbaum [38] reported that because adolescents with cerebral palsy have different life issues than adults or children, individuals should self-report well-being whenever possible. Müller-Godeffroy et al. [19] investigated the self-reported health-related quality of life in children and adolescents with myelomeningocele. Patients in the study group reported diminished overall health-related quality of life compared to norm data, specifically in the dimensions of emotional well-being, self-esteem, and peer relations. Adolescents reported diminished health-related quality of life in the dimension of peer relations. These findings are partially in agreement with our results.

Children with cerebral palsy expend up to 3 times the energy required for ambulation as compared to typically developed children of the same age [39]. Johnston et al. [40] compared the energy cost of walking in children with cerebral palsy classified at different levels of the Gross Motor Function Classification System with that in children with typical development. A difference in energy cost of walking across the Gross Motor Function Classification System levels was found. This difference is important because it reflects a difference in metabolic demand during walking: the more impaired children with higher Gross Motor Function Classification System levels place a greater metabolic demand on their systems while walking.

In our study, most of the patients with cerebral palsy were frequently classified into levels II and III of the Gross Motor Function Classification System, so they had lower metabolic demand while walking. On the other hand, only 3 patients with myelomeningocele were community walkers, 10 could walk with assistive devices, and 21 used a wheelchair. It is known that the physical strain is 1.4 to 2 times higher in patients with myelomeningocele than in healthy subjects. Nonambulatory patients with myelomeningocele have lower energy cost (per unit time and per meter) during wheelchair use than comparison participants during walking [41]. We think that both the studied groups had comparable metabolic demands while walking.

Neural tube defects can be prevented by periconceptional folic acid supplementation. The risk for incidence of cerebral palsy can also be reduced by women's engaging in healthy habits, including eating healthy food, avoiding smoking and harmful substances, and visiting the doctor regularly. Early diagnosis and intervention intensity are the most important factors in cerebral palsy and myelomeningocele treatment. Active rehabilitation and treatment of associated disorders can improve quality of life in these children.

The main limitations of the study are the lack of the comparison groups and the small sample size. Effects tend to be larger compared to norm data than to matched comparisons, and the sample size limits the precision of the results and the statistical power of the tests. We did not evaluate patient-reported quality of life; only mothers reported on functioning and quality of life in children and adolescents with cerebral palsy and myelomeningocele.

Our results may be of clinical interest. They warrant further prospective studies to shed light on the relation between functional independence and mobility; children's, parents', and clinicians' expectations; and health-related quality of life in children with cerebral palsy and myelomeningocele.

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