Quality of life of children suffering from motor disabilities as evaluated by their parents

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ABSTRACT

Purpose: We assessed the quality of life of children with motor disabilities in comparison with healthy children, as evaluated by their parents, using the CHQ-PF28 questionnaire (*Child Health Questionnaire—Parent Form*).
Materials and methods: In a prospective study, we evaluated the quality of life of 105 children with motor disabilities.
Results: Our research showed lower quality of life in the group of children with motor disabilities compared with controls, both in terms of physical and psychosocial health. Significant correlations between independent walking and physical functioning, general behavior, and mental health of children suffering from motor disabilities were found. According to the average indices of quality of life of children suffering from motor disabilities, depending on sex, the greatest differences occurred in behavior and change of health status, while the smallest differences in self-esteem and parental involvement, compared with controls. In the case of healthy children, the largest differences appeared in the perception of pain, behavior, and self-esteem; whereas, the smallest variations occurred in the change of health status and physical activity.
Conclusion: Children suffering from motor disabilities demonstrate lower quality of life compared with healthy children.
Keywords: Quality of life; motor disability; children; parents

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INTRODUCTION

Quality of life is a multidimensional construct, involving the assessment of psychological, social, economic, physical, and other domains that may be targeted in rehabilitation counseling [2]. Nowadays, quality of life is a matter of interest to the fields of medicine, psychology, and sociology [4,5].

Assessment of the quality of life of children and adolescents with motor disabilities is influenced by the child's disability itself [6]. In the past decade, health status and health-related quality of life (HRQOL) instruments have been developed [7,8]. Some generic HRQOL questionnaires have already been used with cerebral palsy (CP) patients, and they have confirmed physical and psychosocial impairments [9].

The Child Health Questionnaire (CHQ-PF28) is a research tool designed to assess the quality of life of children and adolescents from the point of view of their parents. The CHQ was developed in the United States and has since been cross-culturally validated in 21 languages [8,9]. The CHQ-PF28 was developed specifically for children; therefore, it includes scales that consider the effects of the child's health on family functioning as well as specific scales such as behavior and self-esteem.

Motor disabilities include a variety of movement disorders that may be caused by many different factors and that always result in limitation of movement [10].

Research on quality of life enables us to detect abnormalities in the psychosocial development and functioning within a group and the family. The CHQ-PF28 has been used in populations of children with CP [11]. Children with CP have permanent and non-progressive developmental disorders. In spite of medical treatment and rehabilitation, several motor limitations can affect functionality and abilities required for activities of daily living [12].

CP occurs in 2 to 3 cases per 1,000 live births across Europe. Myelomeningocele (MMC) is the most common neurological congenital anomaly. The incidence is approximately 1 case per 1,000 in the US and ranges from 7.7 in the United Arab Emirates to 11.7 in South America [1]. The prevalence of MMC in Poland is 6.2 per 10,000 births [13].

In children with MMC, the level of the spinal lesion affects function, almost always leading to the impairment of the lower extremities, neurogenic bladder, and other orthopedic complications. Children with sacral MMC levels can usually move effectively in their surroundings and walk independently [14]. However, children with lumbar or thoracic MMC levels need walking aids and/or a wheelchair for mobility. In addition, in MMC, higher level defects are associated both with greater severity of brain malformations and poorer cognitive and motor outcomes, most likely because of greater impairment in the brain structure.

MMC is often associated with hydrocephalus that may require treatment with a diversionary shunt. Furthermore, children with severe hydrocephalus tend to have low IQs [15]. Almost all children with MMC have neurogenic bladder. Management of neurogenic bladder conditions requires patient education and may include interventions such as timed voiding, manual expression, medications, and intermittent catheterization [10].

From the literature, it is well known that many children with motor disabilities have poor hand function and visuospatial impairment [10]. Children with CP and MMC often also have a dysfunction of the bowels known as neurogenic bowels.

The ability to walk represents one of our most important skills. During the evaluation of CP or MMC, parents almost always ask doctors whether their child will walk independently. Children with motor disabilities are particularly vulnerable to lower quality of life [16]. Although children with motor disabilities often have intellectual impairments that render them unable to self-report, the need to assess these children's quality of life is no less important.

To our knowledge, no studies have been conducted in children with motor disabilities that evaluated their quality of life with the CHQ-PF28 in Poland.

The aim of this study was to present the parents' evaluations of the quality of life of their children suffering from the abovementioned motor disabilities in comparison with healthy children.

MATERIALS AND METHODS

The study included 105 parents of children and adolescents aged 5-18 years (48 girls and 57 boys) with motor disabilities (CP, MMC, erebro-cranial traumas) treated at the Department of Pediatric Rehabilitation. The study group consisted of 59 children (56.2%) suffering from CP, 35 children (33.3%) suffering from MMC, and 11 children (10.5%) suffering from traumatic brain injury. The age of the children ranged from 6 to 18 years (on average 13.2 ± 4 years old). Mean parental age

was 41.3 ± 1.8 years (range 24–72). Ninety-three percent were mothers and 7% were fathers; 56% had an elementary education, 8% had completed higher vocational education, and 36% had a university education. The control group comprised of research conducted on groups of healthy children (1718 children, 928 girls and 790 boys) by [16]. The age of the children ranged from 11 to 16 years (on average 13.5 ± 1.7 years old).

The children with CP were each assigned a score according to the Gross Motor Function Classification System (GMFCS) by an occupational therapist as follows: level I - walks without restrictions; II - walks without assistive devices, limitations in walking outdoors; III - walks with assistive devices; IV - self-mobility with limitations, children are transported or use powered mobility; V- self-mobility is severely limited. The motor function in patients with MMC was defined according to Hoffer et al. [17] as 4 categories - community, household, nonfunctional, and nonambulators - scored 4 to 1.

We used the Polish version of the CHQ-PF28 to assess the quality of life of children and adolescents with motor disabilities. CHQ-PF28 is a research tool designed to assess the quality of life of children and adolescents from the point of view of parents. It is used to measure health in the context of physical and psychosocial functioning. In this two-dimensional model of health, 10 sub-dimensions can be distinguished: General health perception, Physical fitness, Physical limitations in performing social roles, Emotional limitations in performing social roles, Feeling pain, Behavior, Mental health, Self-esteem (overall satisfaction), Parental involvement ― emotional dimension, and Parental involvement ― time management dimension. The questionnaire also includes questions concerning family functioning: Family activity and Family cohesion. It also contains a question relating to changes in the child's health in the last year. The individual sub-scales of the CHQ-PF28 questionnaire consist of one to five questions. The score of questions is positive: the higher the number of points, the better the parents' evaluation of the quality of life of a child in that particular area. Thus, a low score indicates parents' dissatisfaction with a child's quality of life in a given area.

We asked 130 parents to complete the CHQ-PF28 parent questionnaire during a visit to the clinic. Parents filled out the form at home. Parent reports of their child's quality of life were obtained for 105 children (80.7%). Twenty five parents did not complete the questionnaire (18 mothers and 7 fathers). The study of the quality of life of children and adolescents suffering from motor disabilities based on CHQ-PF28 questionnaires filled out by their parents received approval of the bioethics committee of the Medical University of Białystok, Poland.

Differences were measured by the level of significance p and the ratio of the size of the effect known as Cohen's d statistics. A Cohen's d value above 0.2 indicates a significant difference, a value from 0.5 to 0.8 denotes an average difference, and a value above 0.8 indicates a large difference between the averages. The differences between the groups were determined using the parametric *t*-test. Spearman's analysis was used to measure the interrelationships of the CHQ-PF28 subscales and the independent walking of children with motor disabilities. Statistical significance was defined as $p < 0.05$.

RESULTS

The studied groups were comparable (no significant difference) in terms of age, sex, residence, and family structure. Eighty-two percent of the children lived in two-parent families and 18% lived in single-parent families ($p<0.001$). Patients with CP were more frequently classified into levels II (n=25) and III (n=13) of the GMFCS; other patients were classified into levels IV (n=9) and V (n=12). None of the children was classified into level I. Three patients with MMC 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). Patients with other disorders were classified more often into levels II (n=7) and I (n=2); other patients were classified into levels III (n=1) and V (n=3).

Significant correlations between independent walking and physical functioning, general behavior, and mental health of children suffering from motor disabilities were found (Table 1).

Table 2 compares the average indices of the sub-scales of the CHQ-PF28 questionnaire and two dimensions of health: physical and psychosocial. Parents of healthy children evaluated family cohesion the lowest (59.56 (20.07)) and emotional limitations in performing social roles the highest (96.75 (12.88)). Parents of children with motor disabilities evaluated parental involvement ― emotional dimension the lowest (27.26 (29.56)) and mental health the highest (73.17 (19.51)).

The differences are significant in most of the sub-scales (<0.001).

Table 1. Correlations between independent walking and the CHQ-PF28 dimensions of children suffering from motor disabilities

CHQ-PF28 dimensions	**R**	**P value**
Physical functioning	0.288	0.003
Role functioning: emotional/behaviour	-0.02	0.818
Role functioning: physical	-0.110	0.259
Bodily pain	-0.049	0.615
General behaviour	-0.262	0.007
Mental health	-0.209	0.031
Self-esteem	-0.143	0.145
General health perception	-0.123	0.210
Change in health	-0.006	0.954
Parental impact: emotional	-0.099	0.310
Parental impact: time	-0.068	0.4873
Family activities	-0.003	0.9710
Family cohesion	0.0761	0.4401
Physical health	-0.193	0.0483
Psychosocial health	0.0854	0.4918

R- Spearman rank correlation coefficient

Table 2. Differences in the average assessment of CHQ-PF28 dimensions of children suffering from motor disabilities to healthy children

CHQ-PF28 dimensions	**Children suffering from motor disabilities**		**Control group**		**P value**	**Cohen's d value**
	Mean	**SD**	**Mean**	**SD**		
Physical fitness	36.83	33.56	92.05	18.20	<0.001	**-2.134**
Emotional limitations in performing social roles	68.57	35.75	96.75	12.88	<0.001	-1.159
Physical limitations in performing social roles	72.70	33.26	94.13	17.13	<0.001	-0.851
Feeling pain	66.10	27.89	79.85	18.67	<0.001	-0.591
Behaviour	55.58	19.56	67.07	16.68	<0.001	-0.634
Mental health	73.17	19.51	70.6	15.09	0.049	0.149
Self-esteem (overall satisfaction)	71.27	16.90	78.2	13.42	<0.001	-0.457
General health perception	32.07	13.59	61.64	19.75	<0.001	-1.774
Change of health status	59.76	26.96	61.66	20.90	0.552	-0.079
Parental involvement: emotional dimension	27.26	29.56	79.58	21.13	<0.001	**-2.064**
Parental involvement: time management dimension	60.48	30.77	68.09	12.61	<0.001	-0.351
Family activity	70.36	26.47	85.70	18.59	<0.001	-0.681
Family cohesion	51.90	17.91	59.56	20.07	0.004	-0.403
Physical health	49.24	28.11	79.69	13.18	<0.001	-1.475
Psychosocial health	59.39	25.34	74.37	12.23	<0.001	-0.797

The obtained results proved that the biggest differences in the case of children suffering from motor disabilities occurred in behavior and change of health status, while the smallest differences were seen in self-esteem (overall satisfaction) and parental involvement — emotional dimension. Details are shown in Table 3. In the case of the healthy children, the biggest differences occurred in feeling pain, behavior, and self-esteem, while the smallest ones can be found in the change of health status and physical activity.

Table 3. The average indices of the quality of life of children suffering from motor disabilities in comparison to the control group

CHQ-PF28 dimension	Group of children suffering from motor disabilities			Control group		
	Girls	Boys	P value	Girls	Boys	P value
	Mean/SD	Mean/SD		Mean/SD	Mean/SD	
Physical fitness	30.50/30.07	41.95 /35.57	0.082	91.16 /19.29	93.03 /16.87	0.038
Emotional limitations in performing social roles	73.76 /32.55	64.37 /37.91	0.182	69.93 /13.21	96.54 /12.51	0.538
Physical limitations in performing social roles	78.01 /29.71	68.39 /35.55	0.141	93.94 /18.06	94.33 /16.05	0.646
Feeling pain	63.83 /28.48	67.93 /27.51	0.456	77.51 /19.38	82.42 /17.52	<0.001
Behavior	61.76 /18.69	50.58 /18.97	0.003	68.80 /15.72	65.15 /17.50	<0.001
Mental health	70.92 /19.57	75.00 /19.43	0.289	69.85 /15.07	71.43 /15.09	0.033
Self-esteem (overall satisfaction)	71.63 /17.08	70.98 /16.90	0.845	79.50 /13.33	76.75 /13.39	<0.001
General health perception	31.49 /13.03	32.54 /14.12	0.695	62.15 /19.56	61.06 /19.96	0.274
Change of health status	65.96 /24.69	54.74 /27.88	0.033	61.58 /21.69	61.74/ 20.01	0.870
Parental involvement: emotional dimension	27.93 /29.97	26.72 /29.47	0.837	79.95 /21.20	79.18 /21.06	0.458
Parental involvement: time management dimension	65.96 /30.69	56.03 /30.38	0.101	68.41 /12.59	67.72 /12.65	0.268
Family activity	73.40 /22.36	67.69 /29.35	0.291	85.78 /18.88	85.60 /18.29	0.843
Family cohesion	53.72 /18.04	50.43 /17.83	0.352	60.24 /19.16	58.81 /21.01	0.150
Physical health	49.62 /6.88	48.93 /7.89	0.800	79.18 /13.61	80.27 /12.65	0.103
Psychosocial health	61.99 /7.01	57.28 /8.33	0.054	75.19 /11.86	73.49 /12.57	0.006

Table 4. The average indices of the quality of life of children suffering from motor disabilities dependent on residence

CHQ-PF28 dimension	Group of children suffering from motor disabilities		
	City	Village	P value
	Mean/ SD	Mean/ SD	
Physical fitness	40.30 /33.01	32.37 /34.09	0.231
Emotional limitations in performing social roles	70.06 /35.93	66.67 /35.83	0.632
Physical limitations in performing social roles	72.32 /34.55	73.19 /31.91	0.895
Feeling pain	66.44 /27.90	65.65 /28.18	0.887
Behavior	53.86 /19.61	57.80 /19.50	0.308
Mental health	70.90 /20.08	76.09 /18.56	0.178
Self-esteem (overall satisfaction)	70.76 /18.98	71.92 /13.99	0.730
General health perception	30.87 /13.48	33.61 /13.72	0.307
Change of health status	61.44 /26.80	97.61 /27.32	0.473
Parental involvement: emotional dimension	24.58 /29.17	30.71 /30.01	0.294
Parental involvement: time management dimension	62.71 /31.92	57.61 /29.34	0.402
Family activity	69.49 /26.70	71.47 /26.44	0.706
Family cohesion	51.69 /19.62	51.17 /15.66	0.893
Physical health	49.54 /7.68	48.86 /7.24	0.803
Psychosocial health	58.81 /7.33	60.13 /8.40	0.590

Table 4 illustrates that no substantial differences were observed in the assessment of quality of life. The biggest difference occurred in the assessment of mental health while the smallest in physical limitations in performing social roles, family cohesion, and feeling pain.

DISCUSSION

Our results showed considerable differences in feeling pain among children with motor disabilities and healthy children. Our findings are in agreement with previous reports on quality-of life studies in children and adolescents with motor disabilities [9]. Disabled children require constant appointments at specialist clinics and frequent rehabilitation that takes many hours. This may be sometimes unpleasant and painful, which translates into a lowered quality of life of a disabled child [18]. It is worth remembering how crucial the individual approach towards a child that tries to

regain physical fitness is. The fact that a child accepts a set of exercises contributes to a successful therapeutic process. The lack of acceptance of a child's disease by his/her parents, though, often delays the process of proper rehabilitation [19].

In the current study, more than 90 percent of mothers and only 7% of fathers reported their child's quality of life. We did not use the patient form of the CHQ-PF28 questionnaire. Earlier reports have indicated that parents and children frequently disagree in the assessment of quality of life [20]. Therefore, parent reports should not be considered substitutes for children's self-reports but rather as complementary information. It has been suggested that other proxies be sought to complement parent reports.

Flangan et al. [8] found that patients with MMC with worse functional mobility and a shunt had lower health-related quality of life than patients with better motor activity. Similarly, Danielsson et al. [3] found that nonambulatory patients with MMC had a significantly lower quality of life. In our study, most patients could walk, but patients with MMC used wheelchairs.

Patients with motor disabilities usually have one or more additional impairment. In a study by Stacin et al. [20], adolescents who sustained severe traumatic brain injury had lower HRQL related to overall psychosocial functioning and in the domains of behavior, mental health, general health, and family impact.

The GMFCS level generally had little effect on health-related quality-of-life differences. Gates et al. [9] determined whether there was a difference between perspectives of functioning and health-related quality of life of parents and adolescents with spastic CP. 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.

In contrast, Vargus-Adams [21] demonstrated the CHQ physical functioning subscale was correlated with severity of CP, as reflected by the GMFCS, which supports the overall validity of the physical functioning subscale, because GMFCS is by definition a ranking of physical functioning. These findings are partially in agreement with our results. Quality of life largely increases with the adjustment of housing conditions to the needs of a disabled child. However, difficulty in using public transport and architectural barriers become more likely to reduces the willingness to participate actively in social life and significantly reduces participation in sports, recreation, and rehabilitation [13,15]. Our findings confirm a reduction in performing social roles of children with disabilities compared with healthy children.. One of the biggest concerns of children with motor disabilities is the fear of being rejected by their peers because of their abnormalities [22]. The self-esteem of a child isolated from his peers is significantly reduced. In our study, we also confirmed reduced self-esteem of disabled children compared with healthy children. Having a disabled child in a family causes many problems of an educational, emotional, and social nature.

Current research shows that parental involvement is significantly higher among parents of disabled children than parents of healthy children. Difficult situations lead to high levels of emotional tension. Parents are worried that they will not be able to handle problems that arise from the need to care for and rehabilitate a child and the difficulties of everyday life. The data from the literature [15,23,24] show that families of children suffering from motor disabilities battle with a number of problems, for example, the necessity for one parent to give up their job, medicines, and rehabilitation. These data are in agreement with our results. The Parental impact ― time management dimension was lower in parents of disabled children [25].

The limitations of the study include lack of examination of economic status of the families, rehabilitation success, and heterogeneous patients with motor disabilities.

Conflicts of interest

There is no conflicts of interest.

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