

Improving the perspectives on quality of life for adolescents with cerebral palsy by medical textile

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ABSTRACT – REZUMAT

Improving the perspectives on quality of life for adolescents with cerebral palsy by medical textile

The quality of life (QoL) can be defined as the individual's perception of his own existence, both from the point of view of the physical integrity of the body's structures and of functionality too, as well as of the activity, respectively the capability of performing tasks, and of the participation, regarded as the involvement in the life situations.

From a medical perspective, the quality of life assessment is an indicator that provides important information, closely related to the improvement of the health status and the effectiveness of the therapeutic-rehabilitative interventions. The textile sector by research-development activities and by its numerous projects and accomplishments in the bio-materials, biotechnologies and medical device, showed a steady focus, in close relation to the medical field, on disabled persons' quality of life and on the facilitation of their social and professional integration.

The aim of rehabilitative interventions is to obtain the best possible physical and mental health, allowing each patient to build social relationships with family and community and, on the other hand, to acquire professional skills for being able to find a suitable job which will improve his wellbeing and quality of life.

This paper presents how adolescents with cerebral palsy and their parents/caregivers perceive the quality of life of the adolescent taking into consideration the activity limitations and the participation restrictions.

The results of the study showed the existence of discrepancies between adolescents' and parents' reports regarding the QoL, with adolescents' reporting a higher QoL than did their parents.

Optimism and positive thinking can be seen as augmentation factors of the therapeutic interventions' effects by increasing the adolescent's involvement in the rehabilitation process, having as direct benefit early and better results.

Keywords: health, education, participation, social inclusion, wellbeing

Îmbunătățirea percepțiilor asupra calității vieții adolescenților cu paralizie cerebrală prin textile medicale

Calitatea vieții poate fi definită ca percepția individului asupra propriei existențe, atât din punct de vedere al integrității fizice a structurilor organismului și al funcționalității corpului, cât și al activității, respectiv al capacității de a îndeplini sarcini, și al participării, privită ca implicare în situațiile de viață.

Din perspectivă medicală, evaluarea calității vieții reprezintă un indicator care furnizează informații importante, strâns legate de îmbunătățirea stării de sănătate și de eficacitatea intervențiilor terapeutice de recuperare. Sectorul textil, prin activitățile sale de cercetare-dezvoltare și numeroase proiecte și realizări în domeniul biomaterialelor, biotehnologiilor și dispozitivelor medicale, a arătat un interes permanent, în strânsă legătură cu domeniul medical, pentru a îmbunătăți calitatea vieții persoanelor cu dizabilități și pentru a le facilita incluziunea socială și profesională.

Scopul tratamentului de recuperare este de a obține cea mai bună stare de sănătate fizică și psihică posibilă, care să permită fiecărui pacient, pe de o parte, să construiască relații sociale cu familia și cu comunitatea și, pe de altă parte, să dobândească abilități profesionale pentru a putea găsi un loc de muncă adecvat, care să ducă la o creștere a prosperității și calității vieții.

Acest articol prezintă modul în care adolescenții cu paralizie cerebrală și părinții/apartinătorii acestora percep calitatea vieții adolescentului luând în considerare limitările activității și restricțiile de participare. Rezultatele studiului au arătat că adolescenții, spre deosebire de părinții/apartinătorii lor, sunt mai optimiști în ceea ce privește percepția calității vieții lor. În același timp, există diferențe semnificative ale valorilor indicatorilor de percepție cu privire la calitatea vieții, atunci când luăm în considerare tipologia afecțiunilor cerebrale investigate. Optimismul și gândirea pozitivă pot fi priviți ca factori de amplificare a efectelor intervențiilor terapeutice prin creșterea implicării adolescentului în procesul de recuperare, având ca beneficiu direct apariția precoce a unor rezultate mai bune.

Cuvinte-cheie: sănătate, educație, participare, incluziune socială, bunăstare

INTRODUCTION

International Classification of Functioning, Disability and Health – Children & Youth Version (ICF-CY) defines “mental functions of attention, memory and perception... activities involving play, learning, family life and education” as “components of health and

health-related components of well-being (o.n.HRQoL)” [1]. Thus, health refers not only to Body Functions and Structures (physiological functions of body systems and, respectively anatomical components of the body), but to Activities (execution of tasks) and Participation (involvement in life situations), too.

World Health Organization (WHO) defines health as "... state of complete physical, mental, and social well-being not merely the absence of disease..." and QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live ... in relation to their goals, expectations ... concerns" [2].

A new and very humane vision of WHO – according to the level and expectations of a developed and civilized society – considers that the problematic situational ensemble represented by the handicap of a disabled person is primarily a result of the society/community's (for now) inability to have compensate the individual for invalidity so that, their activity and participation, socio-economic, are (almost) unchanged. In this respect, some authors recommend to use the term "disabled child" instead of "child with a disability", considering that society and environment are the ones that disables them [3].

Information technology (IT) field/tech sector/tech industry, represented by the virtual infrastructure and the related communication possibilities, is an opportunity to implement this humanitarian vision of non-discrimination and social inclusion of persons with physical disabilities, and consequently mobility limitations, helping them to overcome barriers constituted by physical distances between individuals, communities and institutions.

In addition to this, the European Union's strategies included the development of digital services, based on, along with the specific infrastructure of communications services, human capital. Thus, the European Disability Strategy (2010–2020) highlighted among the priority areas for joint action between the EU and EU countries – accessibility, participation, education and training, employment – in order to empower people with disabilities so that they can fully enjoy their rights and participate in society and the economy on an equal basis with others [4]. Two EU's priorities in the field of education are reducing early school leaving to less than 10% across EU member states [5] and reaching the target that 40% of young Europeans have a higher education qualification [6].

The textile sector by research-development activities and by its numerous projects and accomplishments in the bio-materials, biotechnologies and medical device, showed a steady focus, in close relation to the medical field, on disabled persons' quality of life and on the facilitation of their social and professional integration [7–8]. The textile materials used for healthcare and hygiene products are those commonly used on hospital wards for the care and hygiene of the patient and includes bedding, clothing, mattress covers, incontinence products, cloths and wipes.

Cerebral palsy (CP) is a group of non-progressive abnormalities of movement and posture, which results from an aggression on the brain during its developmental period, causing activity limitation, frequently accompanied by sensory, cognitive, behavioral disorders and, sometimes epilepsy.

Recent studies indicate a prevalence of CP from 1.5 to more than 4 per 1000 children [9], with an increase in the last decades [10]. According to World Health

Statistic, the high quality of prenatal care, skilled birth care and postnatal care of the mother and newborns, decreased the worldwide rate of death in the first month of life by over 40% in the last 17 years [11]. But, on the other hand, the improved rate of survival of preterm and low-birth-weight infants – both being consider risk factors for CP [9, 12] – raise concerns about the increased frequency of occurrence of neurodevelopmental sequelae, especially on CP.

Cerebral palsy was mentioned for the first time in 1843 by an English orthopedic surgeon named William Little in a series of lectures entitled "Human body deformities" and, as a result, CP was known for many years like "Little's Disease". In the early stages of the disease or at an earlier age it may not be obvious the neurodevelopmental delay due to the immaturity of the nervous system. Motor deficits in CP include weakness, fatigue, incoordination, spasticity, clonus, rigidity, and spasms. Spasticity is an increased muscle tone who can lead to muscle stiffness, functional impairment, and atrophy, followed by muscle fibrosis, contractures, and subsequent musculoskeletal deformities. McGillivray (2016) mentions that, in over 86% of the over 17 million patients diagnosed with CP worldwide, the predominant motor type of CP was spasticity [13]. It was reported a 30% higher incidence of CP in males than in females [14]. According to the topographic distribution of motor involvement: CP can be classified as monoplegia, diplegia, hemiplegia, triplegia, quadriplegia, and double hemiplegia [15]. Among the associated complications may be encountered: cognitive impairment, eating disorders, bladder and bowel dysfunctions sleep disturbances, visual and orthopedic abnormalities. It is well known that "not all children with CP are cognitively impaired, the commonest type (spastic diplegic CP) is characterized by normal cognition" [16].

Quality of life, defined as "the extent to which persons enjoy a good life by achieving a balance in their relations with themselves and with others through creating and sustaining adequate conditions and own potentials over the life course" [17], provides important information about the way in which the adolescent and his parent/caregiver perceive the activity limitations and the participation restrictions due to the impairments in body functions and structures.

A literature review from 1980 to 2007 performed by Viehweger to identify existing HRQoL scales in CP patients shown that is necessary to develop new scales and to improve the available ones, because the properties of existing scales "do not allow for its full and satisfying use" [18].

Livingstone et al. described well-being as having two components: an objective ("functional status" and "health status") and a subjective one ("QoL and HRQoL") [19].

Arnaud (2008) and Gilson (2014) point out that "grater severity of impairment was not always associated with poorer quality of life" [20–21], QoL being related rather to the way in which the individual feels that is accepted by the environment in which he carries out his activity (family, school, society). Studies indicated that "disabled children experience most of

life as do non-disabled children”, thus is needed to support social and educational policies that... ensure their right as citizens, rather than as disabled children, to participate fully in society” [3].

Pain is considered an important factor that depreciated the QoL due to its physical and psychological effects. Another element with negative impact on quality of life was parents’ stress [22], generated by perception of children’s illness (physical, socio-emotional and cognitive problems, financial strain etc.), they reporting lower results in all assessed domains. Mpundu-Kaambwa (2018) also highlighted the negative impact of children’s chronic disease on QoL reported by parents/caregivers [23].

Berrin has shown in 2007 that, next to pain, fatigue also have a negative impact on one of the QoL domains: school functioning [24]. Teachers should consider these aspects and adapt curricular components to adolescents’ potential so that adolescents with special needs can benefit from a quality education that will facilitate their integration into the labor market. In 2006 Varni – the PedsQL developer – demonstrated that fatigue is inversely correlated with school functioning [25].

In addition to above mentioned comorbidities, sleep disturbances are frequently encountered in CP. They affect both the psycho-emotional status of the child and the compliance with the therapeutic-rehabilitative interventions, leading to a “decreased overall HRQoL” [26].

According to Majnemer, psychosocial well-being it doesn’t appear to be correlated with motor and other activity limitation, these influencing only physical well-being [27].

Examining physical activity in adults with CP, Waltersson discovered that adults who used to perform physical activity as adolescents had a double probability to do it as adults, too [28]. QoL had been positively influenced by physical activity performance but, aging and reducing frequency of participation had a negative effect on all QoL domains [29].

A cross-sectional cohort study which examined the HRQoL in children and adolescents with CP reported the higher rate of HRQoL in children, followed by adolescents and, in the end, parents. An explanation could be the way in which children feels the limitations and restrictions, which have different significance as the child becomes adolescent, while the parents/caregivers tend to compare their children with healthy children [30].

In 2018 Ozkan compared children’s QoL and mothers’ burden in different types of CP and established that the lowest children’s QoL score was reached in quadriplegia, followed by hemiplegia and diplegia, and demonstrated the existence of a significant negative correlation between mothers’ burden and child’s QoL [31]. There have been found “positive correlations”... between parent physical health and the physical function of their children with CP... and between parent mental health and the emotional function... psychosocial function... and total health-related quality of life of their children” [32].

Our goal was to assess QoL of adolescents with CP – without major cognition impairment – and to find out if there is any discrepancy between adolescents’ self-report and parents’ proxy-report and any correlation between the assessed dimensions (activities of daily living, school activities, movement and balance, pain and hurt, fatigue, eating, speech and communication).

MATERIAL AND METHODS

In the study, 162 patients diagnosed with CP and their parents/caregivers were assessed during hospitalization at the National Teaching Centre for Neuropsychomotor Rehabilitation in Children “Dr. Nicolae Robanescu” (NTCNRC), during 2018 using Pediatric Quality of Life Inventory PedsQL™3.0 Cerebral Palsy Module (PedsQL CP), to determine health-related quality of life (HRQoL) dimensions specific to CP.

The study has been approved by the Ethics Committee of NTCNRC under no. 9586/15.12.2017. Written informed consent from parents/caregivers and adolescent assent were obtained prior to their participation to the study.

The selection of cases for setting up the patients’ study group had as criteria for inclusion/exclusion the patients’ age and their level of cooperation.

The group has the following characteristics:

- age ranging from 11 to 18 years;
- asymmetric distribution: 35% girls, 65% boys;
- all of them, even those with development disability, had an acceptable level of cooperation during the assessments and were users of medical textiles.

The criterion for inclusion/exclusion the adolescents’ parents/caregivers in the study was only their level of cooperation.

PedsQL CP is a health-related quality-of-life instrument developed by Varniet et al. [25], which emphasizes the adolescent’s perception. It has 2 components: adolescent self-report and parent proxy-report (to assess parents’ perceptions of their child’s HRQoL), which consist of 35 items divided into seven subscales:

- Daily Activities (9 items),
- School Activities (4 items),
- Movement and Balance (5 items),
- Pain and Hurt (4 items),
- Fatigue (4 items),
- Eating Activities (5 items), and
- Speech and Communication (4 items)

to find out how much of a problem each item has been for adolescent during the past one month.

For adolescents who did not have the capacity for self-administration, but did have the capacity for self-report, the PedsQL CP was interviewer-administered. Otherwise, the instrument was self-administered for both parents/caregivers and adolescents, excepting the ones who needed help in reading the items, which could choose between self-administration and interviewer-administration.

Knowing that “children and family members influence one another in transaction through development”

[33], parents and adolescents were questioned separately so as not to influence each other's opinion and perception.

For both adolescents and parents/caregivers, responses are given on a 5-point Likert scale with: 0 (*never a problem*), 1 (*almost never a problem*), 2 (*sometimes a problem*), 3 (*often a problem*), and 4 (*almost always a problem*). Each scale is then linearly transformed and reverse-scored to a 0–100 scale (0=100, 1=75, 2=50, 3=25, 4=0), so that higher scores indicate lower problems and a better HRQoL. The statistical processing of primary data was performed with the Statistical Package for the Social Sciences IBM SPSS Statistics for Windows, Version24.

RESULTS

During the study, 162 adolescents with CP and their parents completed PedsQL CP. Almost two-thirds of the sample of adolescents was male. The CP types encountered in study group were hemiplegia (39%), diplegia (31%), quadriplegia (22%), triplegia (4%) and the mixed form (4%) as shown in figure 1.

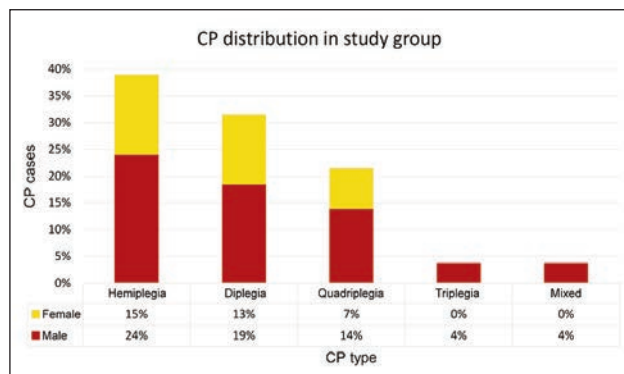


Fig. 1. Participants' characteristics

Both parents and adolescents reported how much of a problem each item from all 7 domains (ADL, school activity, movement and balance, pain and hurt, fatigue, eating activities, speech and communication) has been for adolescent during the past one month. The descriptive analysis for PedsQL CP is presented below in table 1 (adolescents' self-report parents' proxy-report).

There is a statistically significant difference between the answers of parents and children on the PEDsQL questionnaire for all the groups of variables, with the exception of School, where the responses were found to be not statistically different. Motor and cognitive impairments haven't been perceived by adolescents as a limitation regarding the school activities. An explanation of the discrepancies between adolescents' and parents' report regarding school activities, with parents reporting a lower QoL, could be the bullying phenomenon that disabled children are often subjected to, as mentioned in the literature, too [34]. In ADL domain adolescents have an average value of 585.5 (table 1), while parents have an average value of 486.57. Table 2 states that this difference is statistically significant. These mean that adolescents and parents have different perception on adolescents' activities of daily living.

As we can see from the tables 3–5, none of the variables are significantly different for males and females. Quality of life statistics, although slightly different for the two groups (e.g.: ADL value for males is over 40 points higher than females), are not different enough to infer any kind of general, population valid effect.

Of all types of CP, the adolescents with quadriplegia have the lowest QoL in all assessed domain, except for the fatigue. The ANOVA test shows that our groups are significantly different in their perceptions

Table 1

SCALE DESCRIPTIVE ANALYSIS FOR PEDSQL 4.0 GENERIC CORE SCALES PARENT PROXY-REPORT AND CHILD SELF-REPORT					
Items		Group statistics			
		N	Mean	Std. Deviation	Std. Error Mean
ADL	Parents	162	486.5741	258.80667	20.33377
	Children	162	587.5000	256.41233	20.14566
School	Parents	162	225.4630	127.55075	10.02133
	Children	162	252.7778	131.69936	10.34728
Balance	Parents	162	297.2222	126.46655	9.93615
	Children	162	402.7778	111.69919	8.77592
Pain	Parents	162	318.9815	100.88142	7.92599
	Children	162	375.0000	42.62359	3.34883
Fatigue	Parents	162	273.6111	127.08662	9.98487
	Children	162	316.6667	88.85923	6.98144
Eating	Parents	162	367.5926	103.46815	8.12923
	Children	162	418.9815	93.82344	7.37147
Total	Parents	162	0.6589	0.18364	0.01443
	Children	162	0.7790	0.14491	0.01139

SCALE DESCRIPTIVE ANALYSIS FOR PEDSQL 4.0 GENERIC CORE SCALES PARENT PROXY-REPORT AND CHILD SELF-REPORT										
Items		Independent Samples Test								
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper	
ADL	Equal variances assumed	0.347	0.556	-3.526	322	0.000	-100.92593	28.62359	-157.23879	-44.61307
	Equal variances not assumed			-3.526	321.972	0.000	-100.92593	28.62359	-157.23880	-44.61305
School	Equal variances assumed	1.640	0.201	-1.896	322	0.059	-27.31481	14.40463	-55.65388	1.02425
	Equal variances not assumed			-1.896	321.671	0.059	-27.31481	14.40463	-55.65399	1.02436
Balance	Equal variances assumed	3.351	0.068	-7.962	322	0.000	-105.55556	13.25684	-131.63651	-79.47460
	Equal variances not assumed			-7.962	317.160	0.000	-105.55556	13.25684	-131.63802	-79.47310
Pain	Equal variances assumed	123.685	0.000	-6.510	322	0.000	-56.01852	8.60442	-72.94649	-39.09054
	Equal variances not assumed			-6.510	216.707	0.000	-56.01852	8.60442	-72.97758	-39.05946
Fatigue	Equal variances assumed	32.885	0.000	-3.534	322	0.000	-43.05556	12.18352	-67.02490	-19.08621
	Equal variances not assumed			-3.534	288.054	0.000	-43.05556	12.18352	-67.03556	-19.07555
Eating	Equal variances assumed	1.246	0.265	-4.683	322	0.000	-51.38889	10.97373	-72.97816	-29.79962
	Equal variances not assumed			-4.683	318.965	0.000	-51.38889	10.97373	-72.97893	-29.79885
Total	Equal variances assumed	9.919	0.002	-6.535	322	0.000	-0.12011	0.01838	-0.15626	-0.08395
	Equal variances not assumed			-6.535	305.483	0.000	-0.12011	0.01838	-0.15627	-0.08394

Table 3

SCALE DESCRIPTIVE ANALYSIS FOR PEDSQL 4.0 GENERIC CORE SCALES PATIENT GENDER					
Group Statistics					
Items	Gender	N	Mean	Std. Deviation	Std. Error Mean
ADL	female	60	560.0000	251.02333	32.40697
	male	102	603.6765	259.38801	25.68324
School	female	60	253.7500	133.94479	17.29220
	male	102	252.2059	131.02334	12.97324
Balance	female	60	417.5000	94.02713	12.13885
	male	102	394.1176	120.49693	11.93097
Pain	female	60	381.2500	43.57562	5.62559
	male	102	371.3235	41.83257	4.14204
Fatigue	female	60	315.0000	74.10483	9.56689
	male	102	317.6471	96.83022	9.58762
Eating	female	60	422.5000	84.71037	10.93606
	male	102	416.9118	99.13998	9.81632
Total	female	60	0.7804	0.13861	0.01789
	male	102	0.7782	0.14916	0.01477

Table 4

SCALE DESCRIPTIVE ANALYSIS FOR PEDSQL 4.0 GENERIC CORE SCALES PATIENT GENDER										
Items		Independent Samples Test								
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
1	2	3	4	5	6	7	8	9	10	11
ADL	Equal variances assumed	1.013	0.316	-1.047	160	0.297	-43.67647	41.70520	-126.04014	38.68720
	Equal variances not assumed			-1.056	127.100	0.293	-43.67647	41.35022	-125.50047	38.14753
School	Equal variances assumed	0.000	0.999	0.072	160	0.943	1.54412	21.49371	-40.90384	43.99208
	Equal variances not assumed			.071	121.604	0.943	1.54412	21.61771	-41.25169	44.33992
Balance	Equal variances assumed	6.268	0.013	1.289	160	0.199	23.38235	18.13596	-12.43437	59.19908
	Equal variances not assumed			1.374	147.593	0.172	23.38235	17.02057	-10.25315	57.01785
Pain	Equal variances assumed	0.908	0.342	1.436	160	0.153	9.92647	6.91200	-3.72404	23.57698
	Equal variances not assumed			1.421	119.751	0.158	9.92647	6.98597	-3.90555	23.75849

Table 4 (continuation)

1	2	3	4	5	6	7	8	9	10	11
Fatigue	Equal variances assumed	2.332	0.129	-0.183	160	0.855	-2.64706	14.50080	-31.28472	25.99060
	Equal variances not assumed			-0.195	149.144	0.845	-2.64706	13.54429	-29.41055	24.11643
Eating	Equal variances assumed	1.135	0.288	0.365	160	0.716	5.58824	15.30613	-24.63986	35.81633
	Equal variances not assumed			0.380	139.481	0.704	5.58824	14.69550	-23.46649	34.64296
Total	Equal variances assumed	1.414	0.236	0.093	160	0.926	0.00221	0.02365	-0.04450	0.04891
	Equal variances not assumed			0.095	131.198	0.924	0.00221	0.02320	-0.04369	0.04811

Table 5

DSCALE DESCRIPTIVE ANALYSIS FOR PEDSQL 4.0 GENERIC CORE SCALES CEREBRAL PALSY TYPE									
Items		Descriptives							
		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
1	2	3	4	5	6	7	8	9	10
ADL	diplegia	45	616.6667	252.93729	37.70566	540.6759	692.6574	175.00	900.00
	hemiplegia	69	675.0000	229.36934	27.61282	619.8995	730.1005	100.00	900.00
	quadriplegia	36	395.8333	255.61550	42.60258	309.3455	482.3212	75.00	825.00
	triplegia	6	550.0000	0.00000	0.00000	550.0000	550.0000	550.00	550.00
	mixed	6	550.0000	0.00000	0.00000	550.0000	550.0000	550.00	550.00
	total	162	587.5000	256.41233	20.14566	547.7162	627.2838	75.00	900.00
School	diplegia	45	293.3333	125.38577	18.69141	255.6633	331.0034	50.00	400.00
	hemiplegia	69	266.3043	116.61794	14.03915	238.2897	294.3190	100.00	400.00
	quadriplegia	36	156.2500	141.97271	23.66212	108.2133	204.2867	0.00	400.00
	triplegia	6	325.0000	27.38613	11.18034	296.2600	353.7400	300.00	350.00
	mixed	6	300.0000	0.00000	0.00000	300.0000	300.0000	300.00	300.00
	total	162	252.7778	131.69936	10.34728	232.3439	273.2117	0.00	400.00
Balance	diplegia	45	411.6667	90.39057	13.47463	384.5103	438.8230	225.00	500.00
	hemiplegia	69	433.6957	98.40886	11.84703	410.0553	457.3360	175.00	500.00
	quadriplegia	36	308.3333	123.05632	20.50939	266.6971	349.9696	100.00	450.00
	triplegia	6	450.0000	0.00000	0.00000	450.0000	450.0000	450.00	450.00
	mixed	6	500.0000	0.00000	0.00000	500.0000	500.0000	500.00	500.00
	total	162	402.7778	111.69919	8.77592	385.4470	420.1085	100.00	500.00
Pain	diplegia	45	385.0000	33.02891	4.92366	375.0770	394.9230	275.00	400.00
	hemiplegia	69	370.6522	44.34087	5.33801	360.0003	381.3040	250.00	400.00
	quadriplegia	36	362.5000	51.23475	8.53913	345.1647	379.8353	250.00	400.00
	triplegia	6	400.0000	0.00000	0.00000	400.0000	400.0000	400.00	400.00
	mixed	6	400.0000	0.00000	0.00000	400.0000	400.0000	400.00	400.00
	total	162	375.0000	42.62359	3.34883	368.3867	381.6133	250.00	400.00

Table 5 (continuation)

1	2	3	4	5	6	7	8	9	10
Fatigue	diplegia	45	358.3333	63.06562	9.40127	339.3863	377.2803	225.00	400.00
	hemiplegia	69	293.4783	104.81533	12.61828	268.2989	318.6577	50.00	400.00
	quadriplegia	36	314.5833	78.46177	13.07696	288.0357	341.1310	175.00	400.00
	triplegia	6	300.0000	54.77226	22.36068	242.5200	357.4800	250.00	350.00
	mixed	6	300.0000	0.00000	0.00000	300.0000	300.0000	300.00	300.00
	total	162	316.6667	88.85923	6.98144	302.8797	330.4537	50.00	400.00
Eating	diplegia	45	435.0000	90.35913	13.46994	407.8531	462.1469	200.00	500.00
	hemiplegia	69	429.3478	74.87201	9.01353	411.3616	447.3340	200.00	500.00
	quadriplegia	36	366.6667	119.07381	19.84563	326.3779	406.9554	75.00	500.00
	triplegia	6	412.5000	68.46532	27.95085	340.6501	484.3499	350.00	475.00
	mixed	6	500.0000	0.00000	0.00000	500.0000	500.0000	500.00	500.00
	total	162	418.9815	93.82344	7.37147	404.4243	433.5387	75.00	500.00
Total	diplegia	45	0.8286	0.12683	0.01891	0.7905	0.8667	0.57	0.96
	hemiplegia	69	0.8056	0.12047	0.01450	0.7766	0.8345	0.56	0.99
	quadriplegia	36	0.6548	0.16536	0.02756	0.5988	0.7107	0.44	0.96
	triplegia	6	0.8107	0.01174	0.00479	0.7984	0.8230	0.80	0.82
	mixed	6	0.8143	0.00000	0.00000	0.8143	0.8143	0.81	0.81
	total	162	0.7790	0.14491	0.01139	0.7565	0.8015	0.44	0.99

of the PedsQL 4.0 Generic Core Scales, differences that we can analyze from the table 6 results. Thus, for Pain scores, mixed and triplegia results are significantly higher (the mean score is 400) than quadriplegia patients (mean score is 362).

The reliability and internal consistency analysis followed that the items corresponding to each construct have a Cronbach's Alpha value over 0.7 and a composite reliability over 0.7. The Cattell Scree plot and the Total Variance Table resulted from the exploratory

Table 6

SCALE DESCRIPTIVE ANALYSIS FOR PEDSQL 4.0 GENERIC CORE SCALES CEREBRAL PALSY TYPE						
Items	ANOVA					
	Sum of Squares	df	Mean Square	F	Sig.	
ADL	Between Groups	1905937.500	4	476484.375	8.619	0.000
	Within Groups	8679375.000	157	55282.643		
	Total	10585312.500	161			
School	Between Groups	466748.641	4	116687.160	7.877	0.000
	Within Groups	2325751.359	157	14813.703		
	Total	2792500.000	161			
Balance	Between Groups	460717.391	4	115179.348	11.681	0.000
	Within Groups	1548032.609	157	9860.080		
	Total	2008750.000	161			
Pain	Between Groups	18929.348	4	4732.337	2.716	0.032
	Within Groups	273570.652	157	1742.488		
	Total	292500.000	161			
Fatigue	Between Groups	118716.033	4	29679.008	4.043	0.004
	Within Groups	1152533.967	157	7340.981		
	Total	1271250.000	161			
Eating	Between Groups	157123.792	4	39280.948	4.894	0.001
	Within Groups	1260133.152	157	8026.326		
	Total	1417256.944	161			
Total	Between Groups	0.729	4	0.182	10.781	0.000
	Within Groups	2.652	157	0.017		
	Total	3.381	161			

factor analysis done with SPSS Statistics using an oblique Promax rotation shows that all seven latent variables or constructs have eigenvalues greater than one, and the largest covariance explained by one factor is 28.845%, thus common method bias not being a concern [34]. Only 14 of the all 35 variables measured have a significant effect on the result. One item of the speech and communication domain – how difficult is for other people to understand the patient when he speaks (Var 35) – has the greatest influence on QoL. It is followed by ability to button his/her own shirt (Var 02), ability to use scissors (Var 11) and the ability to cut his/her food (Var 31). For school activities there was no statistically significant difference, so parents and children have similar perceptions regarding this domain (table 7).

Table 7

RELIABILITY ANALYSIS		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
0.714	0.850	7

CONCLUSIONS

The research emphasized the existence of discrepancies between adolescents' and parents' reports regarding the QoL of adolescents with CP, with adolescents reporting a higher QoL than did their parents, as it is also reported in the literature [35]. One explanation for these differences may be that parents relate to the performance of healthy children and the restrictions and limitations – mainly the motor ones –

their children are encountered, are perceived to have a negative impact on the ability of children to integrate into family, school and social life. The psychological and social burden of the parents increases the child's psychological discomfort, which can lead to a lower compliance with rehabilitation treatment.

Both parents and children should be advised and encouraged, so that the latter learn new skills that will make possible the appearance of a degree of comfort reflected in physical and financial independence and social inclusion too.

Future work should explore factors that led to these different perceptions of QoL.

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AUTHORS CONTRIBUTION

All the authors have contributed equally to the realization of this work and have approved of its publication.

RECOGNITION

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