

Parenting Style Impacts on Quality of Life in Children with Cerebral Palsy

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Objective To assess the impact of parenting style and disease severity on quality of life (QOL) in children with cerebral palsy (CP).

Study design Thirty-nine children with CP, their siblings, and their parents participated in the study. Probands and siblings, ages 6 to 18 years, completed questionnaires on parenting style (accepting, rejecting, controlling, and autonomy allowing) using the Children's Report of Parental Behavior Inventory. Parents completed generic (Child Health Questionnaire [CHQ]) and disease-specific (Pediatric Outcomes Data Collecting Instrument [PODCI]) QOL questionnaires for both children. A physician determined disease severity with the Gross Motor Function Classification System.

Results In children with CP, parenting style positively correlated with the CHQ scores: physical summary and psychosocial summary ($r = 0.40$, $P = .01$) and family activities scale ($r = 0.34$, $P = .03$). Autonomy allowing parenting style impacted on psychosocial aspects of QOL, as reflected by CHQ scores, more than the degree of disability. In other domains of QOL, the effect of parenting style was greater than IQ, anxiety, and socioeconomic status.

Conclusions Parenting style is a significant factor in QOL in CP and the only known factor to impact on the psychosocial domains of the CHQ, exceeding the effect of disease severity. Because QOL is an important treatment goal in children with CP, early family interventions, particularly those focusing on parenting style, should be considered. (*J Pediatr* 2007;151:56-60)

Traditionally, treatment of children with chronic diseases focused on physical aspects of the disease, and treatment efficacy was measured primarily by means of physical improvement. In the past decade, quality of life (QOL), defined as well-being across various broad domains, has become an important treatment goal in chronic diseases, including cerebral palsy (CP).¹⁻⁵ CP is a non-progressive disorder of movement and posture caused by a defect or injury to the immature brain, and its impact is further exacerbated by disabilities other than the motor impairments, such as epilepsy, learning disabilities, and behavioral and emotional problems.^{6,7} Whereas treatment modalities for CP have been documented in a multitude of studies, there are few data on their subjective impact on children with CP and their families.^{3,8-11}

Earlier studies revealed that children with only mild CP have lower QOL scores than the healthy population.¹²⁻¹⁷ Although QOL scores in the physical domains correlated well with the level of motor disability, this was not the case for scores in the psychosocial scales. This finding points to the importance of factors affecting QOL other than level of motor disability.

Parenting style is one of the most important family variables in the child's psychosocial development.^{18,19} Parenting behaviors are complex, but can be represented in a 2-dimensional model for clinical and research work.²⁰⁻²² One dimension is parental control and restriction versus autonomy allowance: parental control is extensive regulation of the child's behaviors and actions, autocratic parental decision-making, overprotection, and instructions to the child about how he or she should think or feel.^{20,23} Parental autonomy allowance is characterized by ways parents enable their child to act freely and be independent.¹⁹ The second dimension is parental rejection and hostility versus acceptance and support: parental criticism is characterized by coldness, indifference, and lack of pleasure from being with the child, whereas parental acceptance is a warm and welcoming attitude, active listening, and emotional involvement in the child's life.

The goal of this study was to assess the impact of parenting style on the QOL of children with CP and their siblings.

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CHQ	Child Health Questionnaire	PODCI	Pediatric Outcomes Data Collecting
CP	Cerebral palsy		Instrument
GMFCS	Gross Motor Function Classification System	QOL	Quality of life

METHODS

Participants

Families of children with CP ($n = 47$) who fulfilled these criteria were identified: 1) an unequivocal diagnosis of CP made by a pediatric neurologist; 2) IQ score ≥ 75 ; 3) age 6 to 18 years; 4) a school-age sibling with normal intelligence; 5) parents with a working knowledge of Hebrew. The 8 families who declined participation had similar demographic features to the 39 who participated. The mean age of probands was 12.0 ± 3.1 years (58% boys), and the mean age of siblings was 13.2 ± 2.9 (46% boys). Eighteen siblings (42%) were older than the probands, 15 (34%) were younger, and 7 (24%) were the same age (twins). Full scale IQ of probands was 94 ± 17 , and it was 109 ± 12 for siblings. Socioeconomic status was high for 31% of the families, middle for 33% of the families, and low for 36% of the families.

Each proband was examined at home by a pediatric neurologist (A.A.) who reviewed the medical chart and assessed motor disability. The parents and the children completed the tools outlined below independently. In accordance with the instructions of each tool, clarifications to queries were, or were not, provided by the psychologist or the pediatric neurologist. For those children who were not competent readers, the questions were read aloud, and a brief explanation or example was provided, when necessary.

Measures

The Gross Motor Function Classification System (GMFCS) measures severity of CP and rates outcome of motor function in a scale ranging from I to V and was completed by the physician (A.A.). CP was graded as mild when the child could walk independently (I/II), moderate when the child was ambulant with assistive devices (III), and severe when the child was wheelchair dependent (IV/V).^{15,24} Table I provides information on CP subtype, severity of motor deficit and comorbid conditions.

Parental Questionnaires

The Child Health Questionnaire parent form-50 (CHQ-PF-50; validated Hebrew version) is a generic questionnaire that evaluates aspects of QOL, with 50 questions. A score of 0 represents the worst health state, and a score of 100 represents the best health state. The CHQ has 2 summary scores: physical and psychosocial.^{25,26}

The Pediatric Outcomes Data Collection Instrument (PODCI) is a 55-question disease-specific questionnaire that assesses parent-perceived functional health status of physical function, pain/comfort, expectations from treatment, and happiness with physical condition (100 reflects best health status).^{27,28} The version used was translated into Hebrew specifically for this study.

Demographic Questionnaire

Relevant medical information, comorbid conditions, and socioeconomic status were provided by the parents.²⁹

Table I. Characteristics of probands ($n = 39$) by motor severity of cerebral palsy (Gross Motor Function Classification System level)

Parameter	Mild ($n = 12$)	Moderate ($n = 13$)	Severe ($n = 14$)
Type of CP n (%)			
Hemiplegia ($n = 8$)	6 (15.5)	2 (5.0)	0
Diplegia ($n = 12$)	6 (15.5)	5 (13.0)	1 (2.5)
Quadriplegia ($n = 19$)	0	6 (15.5)	13 (33.0)
Comorbid conditions n (%)			
ADHD and/or LD ($n = 20$)	8 (20.5)	4 (10.0)	8 (20.5)
Epilepsy ($n = 7$)	1 (2.5)	2 (5.0)	4 (10.0)
Speech and language disorders ($n = 8$)	3 (7.5)	1 (2.5)	4 (10.0)
Etiology of CP n (%)			
Prematurity ($n = 27$)	7 (18.0)	11 (28.0)	9 (23.0)
Complicated labor at term ($n = 5$)		2 (5.0)	3 (7.5)

Mild, GMFCS levels 1-2; *Moderate*, level 3; *Severe*, levels 4-5; *ADHD*, attention deficit hyperactivity disorder; *LD*, learning disabilities.

Questionnaires Completed by the Children

The Children's Report of Parental Behavior Inventory (CRPBI), validated Hebrew version, is a 40-item questionnaire evaluating 4 domains of the mother's parenting style as experienced by the child: accepting, rejecting, controlling, and autonomy allowing.^{20,30}

The Revised Children's Manifest Anxiety Scale (RCMAS), validated Hebrew version,^{31,32} is a 37-item questionnaire that evaluates the child's level of anxiety according to self-report.

The Wechsler Intelligence Scale for Children-Revised (WISC-R), Hebrew version was also used.³³

Statistical Analysis

Demographic, descriptive, and comparative statistics were computed with the SPSS statistical package software (version 11). Internal consistency was estimated by computing Cronbach's α coefficient for each scale. Because we used multidimensional instruments, Cronbach's α was computed for each subscale. The concurrent validity of the different instruments was assessed by examining the association between different scales that measure the same health domain. The t test for dependent samples was used to compare the CHQ scores between the child with CP and the sibling.

Multivariate regression analysis was used to compare the CHQ and PODCI scores of the children with CP according to the severity of the disability.

RESULTS

QOL in Children with CP and Their Siblings

As expected, the parental report on health of children with CP was poorer for every subscale of the CHQ (Table II). The physical summary score and the psychosocial summary score were more than 2 SD lower than that of their healthy siblings

Table II. Child Health Questionnaire scores of probands with cerebral palsy, siblings, and normative sample

Scale	CP probands (n = 39)	Siblings (n = 39)	t value*	P value	Normative sample (n = 64)
Physical Functioning	41.3 ± 32.1	94.8 ± 16.6	7.77	.000	97.2 ± 12.2
Role/Social Limitations-Physical	56.4 ± 39.7	96.7 ± 11.3	6.23	.000	98.7 ± 7.5
Role/Social Limitations-Emotional Behavioral	71.8 ± 31.6	95.9 ± 12.9	4.66	.000	99.3 ± 3.4
Bodily Pain/Discomfort	74.1 ± 24.4	88.3 ± 13.8	3.69	.001	92.7 ± 14.3
Behavior	71.4 ± 16.3	81.8 ± 10.1	3.16	.003	83.8 ± 14.6
Mental Health	64.6 ± 14.3	77.0 ± 10.6	4.39	.000	80.1 ± 9.2
Self-Esteem	68.5 ± 17.2	87.5 ± 11.5	5.94	.000	90.9 ± 11.2
General Health	59.4 ± 16.9	73.0 ± 14.8	3.92	.000	77.8 ± 13.3
Parent Impact-Emotional	58.1 ± 27.3	82.4 ± 20.0	4.47	.000	87.2 ± 14.9
Parent Impact-Time	76.1 ± 27.0	93.7 ± 16.9	3.34	.002	95.3 ± 10.2
Family Activities	72.8 ± 22.2	89.2 ± 15.8	3.78	.001	91.9 ± 12.4
Family Cohesion	64.1 ± 26.8	65.7 ± 29.1	0.00	1.000	84.2 ± 17.3
Physical Summary Score	35.7 ± 17.6	50.9 ± 10.9	9.15	.000	54.6 ± 3.3
Psychosocial Summary Score	43.9 ± 14.5	51.2 ± 7.9	6.26	.000	54.6 ± 6.2

*t test was used to compare probands to siblings.

Table III. Child Health Questionnaire scores as a function of the motor severity of cerebral palsy according to Gross Motor Function Classification System

Scale scores ± SD/severity of CP	Mild (n = 13)	Moderate (n = 12)	Severe (n = 14)	F	P value
Physical Functioning	73.1 ± 22.3	41.2 ± 22.9	11.9 ± 12.7	32.8	.000
Role/Social Limitations-Physical	74.4 ± 35.8	61.1 ± 37.2	35.7 ± 38.0	3.8	.031
Role/Social Limitations-Emotional Behavioral	73.5 ± 31.3	80.6 ± 28.9	62.7 ± 33.9	1.1	.356
Bodily Pain/Discomfort	74.1 ± 24.4	78.3 ± 19.9	68.6 ± 33.2	0.6	.568
Behavior	76.2 ± 16.1	81.3 ± 10.1	69.0 ± 17.4	3.9	.028
Mental Health	64.6 ± 13.9	69.6 ± 13.4	60.4 ± 14.9	1.4	.264
Self-Esteem	73.4 ± 20.5	72.6 ± 13.5	60.4 ± 14.6	2.6	.086
General Health	61.5 ± 17.4	60.1 ± 19.7	56.8 ± 14.5	0.3	.770
Parent Impact-Emotional	63.5 ± 20.0	71.5 ± 29.8	41.7 ± 23.8	5.1	.011
Parent Impact-Time	76.9 ± 27.8	92.6 ± 11.9	92.6 ± 11.9	5.4	.009
Family Activities	79.2 ± 19.6	84.7 ± 14.3	56.5 ± 21.3	8.4	.001
Family Cohesion	67.3 ± 25.8	66.7 ± 26.8	58.9 ± 28.8	0.4	.676
Physical Summary Score	42.5 ± 15.3	36.9 ± 10.0	28.6 ± 13.7	15.2	.000
Psychosocial Summary Score	43.9 ± 16.4	47.4 ± 12.1	40.9 ± 12.7	2.8	.076

and a historical Israeli control group.²⁶ Scores in all the physical scales of the CHQ were markedly lower for children with severe CP compared with those for children with moderate and mild CP (Table III). Responses to the PODCI questionnaire, which taps the ability to function in activities of daily life, were similar (Table IV; available at www.jpeds.com). Parents gave higher scores on the psychosocial and parent impact-time scales of the CHQ for their children who had moderate CP than for their children with mild CP (psychosocial summary score 47.4 ± 12.1 and 43.9 ± 16.4, respectively; parent impact-time score 92.6 ± 11.9 and 76.9 ± 27.8, respectively). For siblings, there was no correlation between parents' CHQ scores and the level of disability of their sibling with CP.

Effect of Parenting Style on Health Status

The parenting style questionnaire has 4 variables: parental acceptance, parental rejection, parental control, and

parental autonomy allowance. We were able to collapse the 4 groups into 2 categories, "acceptance/rejection" and "autonomy/control," because these pairs were negatively correlated in our study ($r = -0.69$ for acceptance and rejection, and $r = -0.29$ for parent control and autonomy allowance).²¹

We found a positive correlation between the autonomy allowing parenting style and the CHQ physical summary ($r = 0.400$, $P = .012$), psychosocial summary ($r = 0.403$, $P = .012$), and family activities scale scores ($r = 0.341$, $P = .030$). The accepting parenting style also positively correlated with the psychosocial summary score ($r = 0.363$, $P = .022$; Table V). We also documented a positive correlation between the autonomy allowing parenting style and the PODCI "Happiness with Physical Condition" domain ($r = 0.550$, $P = .003$).

For the siblings, there was no correlation between the autonomy allowing parenting style for any of the CHQ scale scores. The accepting parenting style correlated positively only with parent impact-emotional scale ($r = 0.433$, $P =$

Table V. Correlations between the Child Health Questionnaire scores and parenting style, anxiety level, age, IQ, and socioeconomic status in children with cerebral palsy*

	Physical summary score	Psychosocial summary score	Family cohesion	Family activities	Parent impact—emotional	Parent impact—time
Parenting style—Acceptance/Rejection	0.18 (.167)	0.36 (.022)†	0.04 (.414)	0.06 (.382)	0.13 (.235)	0.28 (.067)
Parenting style—Autonomy/Control	0.40 (.012)†	0.40 (.012)†	0.28 (.061)	0.34 (.030)†	0.20 (.142)	0.04 (.418)
Anxiety level (RCMAS)	0.14 (.215)	0.24 (.091)	0.14 (.228)	0.32 (.038)†	0.20 (.140)	0.47 (.003)†
Age	0.30 (.070)	0.09 (.340)	0.28 (.094)	0.10 (.316)	0.10 (.321)	0.46 (.012)†
IQ	0.18 (.194)	0.05 (.399)	0.06 (.395)	0.07 (.372)	0.12 (.290)	0.12 (.291)
Socioeconomic status	0.13 (.268)	0.19 (.185)	0.29 (.087)	0.25 (.118)	0.10 (.318)	0.09 (.341)

RCMAS, Revised Children’s Manifest Anxiety Scale.

*After controlling for severity of the motor disability, 1-tailed significance: $r(P)$.

† $P < .05$.

.008) and family cohesion scale ($r = 0.592, P = .000$), but not with any physical or psychosocial scale scores.

Parenting style influenced QOL as reflected by CHQ scores in children with CP after controlling for the level of disability and its influence was greater than these factors: age, IQ, anxiety level, and socioeconomic status (Table V). The parenting style did not correlate with the socioeconomic status or education of the parents.

DISCUSSION

We found that parenting style was a most important factor affecting the psychosocial aspects of QOL of children with CP. The impact of parenting style on psychosocial aspects of QOL was far greater than other factors assessed in this study, including severity of illness, IQ, socioeconomic status, and anxiety level. Autonomy allowing and accepting parenting styles, in contrast to controlling and rejecting parenting styles, were reflected in improved mental health, higher self-esteem, better behavior, and less social and emotional limitations as reported by the parents. Parenting style is the first specific factor shown to implicate psychosocial aspects of QOL in children with CP.^{12,13} Parenting style also had a significant influence on the physical scales and impact-on-family scales, as did severity of illness.

All siblings had normal QOL regardless of the presence of a sibling with CP or disease severity. The effect of parenting style was specific to the children with CP. Perhaps healthy children can cope with various parenting styles, whereas a handicapped child, who is at risk for lower QOL, is particularly likely to benefit from an autonomy allowing and accepting parenting style.

The accepting parenting style influenced only the psychosocial domains of the CHQ, while the autonomy allowing parenting style also affected physical and family activities scale scores. The results point to the importance of autonomy allowance in these children despite their physical disability. The effect of parenting style during childhood on QOL of children with CP might be even more significant later in their lives. Recent studies suggest that both the physical and psychosocial well being of children with CP can deteriorate with

the transition from youth to adulthood.³⁴⁻³⁶ The autonomy allowing parenting style during childhood may prepare children with CP for more independent lives as adults.

Level of disability is a proven determinant of QOL.^{12-14,16,17} We found that children with CP, regardless of their level of disability, had lower QOL scores than their siblings and healthy control subjects. Furthermore, the physical scale scores were significantly lower in children with severe disability than children with mild or moderate disability. However, the degree of disability did not affect the psychosocial scores in a similar manner.^{12-14,16,17} The scores on the psychosocial scales were lower for children with mild CP than for children with moderate CP. A possible explanation is that children with mild CP measure themselves and are compared by their parents to the healthy population, although children with moderate CP exclude themselves from the “healthy group.”

Studies on QOL are highly subjective in nature and as such have inherent limitations. Although we used common and conventional tools, we were fully aware of their limitations being parent-based rather than child-based. We therefore used multiple questionnaires, generic and disease-specific, and found that they exhibit high internal consistency and correlate well with each other.

The consensus that improving QOL is an important treatment goal in children with CP mandates measures and treatment that enhance this goal. This study demonstrates that parenting style is not only a significant factor in QOL in children with CP, but is the only known factor to impact on psychosocial aspects of QOL, emphasizing the overwhelming importance of parenting style on the well being of these children. This offers a therapeutic option for enhancing QOL for those with this debilitating, life-long disease. Parent-child interaction approaches such as the “filial therapy training” or the “stepping stones triple P program” are examples of effective interventions for enhancing parenting style while impacting children’s behavior and emotional stability.³⁷⁻³⁹ We suggest, therefore, that family-directed interventions be instituted early in the course of the treatment program of the child with CP, particularly those focusing on parenting style.

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Table IV. Pediatric Outcomes Data Collecting Instrument scores as a function of the motor severity according to the Gross Motor Function Classification System

PODCI subscales	Mild (n = 13)	Moderate (n = 12)	Severe (n = 14)	F*	P value*
Upper Extremity and Physical Function	77.6 ± 20.2	67.7 ± 15.6	32.1 ± 23.9	18.00	.000
Transfers and Basic Mobility	92.5 ± 7.3	60.3 ± 12.9	27.9 ± 10.0	33.02	.000
Sports and Physical Functioning	70.9 ± 17.9	30.4 ± 12.5	20.2 ± 24.6	26.38	.000
Pain/Comfort	88.6 ± 13.5	86.9 ± 15.7	75.0 ± 16.2	1.04	.366
Expectations from Treatment	75.2 ± 17.0	91.2 ± 18.9	79.9 ± 19.3	2.67	.087
Happiness with Physical Condition	72.5 ± 23.4	66.7 ± 11.3	52.6 ± 14.9	2.66	.088
General Function and Symptoms†	82.4 ± 10.9	61.3 ± 0.7	38.8 ± 1.0	24.34	.000

*F; P: The comparison, using the general linear model, was between probands with mild and moderate disability and those with severe disability.

†This summary score is computed as a composite of the first 4 domains (the 3 physical function domains and the pain and comfort domains).