*Fizyoterapi Rehabilitasyon. 2010; 21(1):3-10*

# A comparison of quality of life in children with cerebral palsy and neuromuscular diseases

Ayşe KARADUMAN, Öznur YILMAZ, Emine H TÜZÜN, Mintaze KEREM GÜNEL, Bahar ARAS, Akmer MUTLU, Tülay TARSUSLU, Özgen ARAS

[Karaduman A, Yılmaz Ö, Tüzün EH, Kerem Günel M, Aras B, Mutlu A, Tarsuslu T, Aras Ö. A comparison of quality of life in children with cerebral palsy and neuromuscular diseases. Fizyoter Rehabil. 2010;21(1):3-10. *Serebral palsi ve nöromusküler hastalığı olan çocuklarda yaşam kalitesinin karşılaştırılması.*]

Research Article

**A Karaduman, M Kerem Günel**
Hacettepe University,
Faculty of Health Sciences,
Department of Physical Therapy and Rehabilitation, Ankara, Türkiye
PT, PhD, Prof

**Ö Yılmaz**
Hacettepe University,
Faculty of Health Sciences,
Department of Physical Therapy and Rehabilitation, Ankara, Türkiye
PT, PhD, Assoc Prof

**EH Tüzün**
Başkent University,
Faculty of Health Sciences,
Department of Physical Therapy and Rehabilitation, Ankara, Türkiye
PT, PhD, Assoc Prof

**B Aras, Ö Aras**
Dumlupınar University, School of Health Sciences, Department of Physical Therapy and Rehabilitation, Kütahya, Türkiye,
PT, PhD, Assist Prof

**Address correspondence to:**
Prof. Dr. Ayşe Karaduman
Hacettepe University,
Faculty of Health Sciences
Department of Physical Therapy and Rehabilitation, 06100 Samanpazarı, Ankara, Türkiye
E-mail: aykaradu@hacettepe.edu.tr

**Purpose:** This study aimed to compare health-related quality of life (HRQoL) between children with cerebral palsy (CP) and neuromuscular diseases (NMD). **Material and methods:** A total of 61 children with CP and 50 children with NMD, ages ranged from 5-18 years participated in this study. Patients' and parents' characteristics were recorded. The HRQoL was assessed using the Child Health Questionnaire Parent Form 50 (CHQ-PF50). The children's functional level was assessed using Barthel Index. **Results:** There were statistically significant differences between the groups in the scores of the general health perceptions, parental impact-emotional and parental impact-time subscales of the CHQ-PF50 ($p<0.05$). Children with CP and with NMD showed different patterns of HRQoL in terms of some subscales of the CHQ-PF50 ($p<0.05$). General health perception and parental impact-emotional and parental impact-time scores of children with NMD were worse than those with CP. **Conclusion:** In the pediatric group, quality of life of the children and their families affected differently in children with CP and NMD. Specific characteristics of both diseases should be taken into consideration while planning treatment programs and during follow-ups.

**Key words:** Neuromuscular diseases, Cerebral palsy, Quality of life, Disability evaluation, Child.

## Serebral palsi ve nöromusküler hastalığı olan çocuklarda yaşam kalitesinin karşılaştırılması

**Amaç:** Bu çalışma, nöromusküler hastalığı (NMH) olan çocuklar ile serebral palsili (SP) çocukların sağlıkla ilişkili yaşam kalitelerini (HRQoL) karşılaştırmak amacıyla planlandı. **Gereç ve yöntem:** Yaşları 5-18 yaş arasında değişen, 61 serebral palsili çocuk ve 50 NMH'li olan çocuk çalışmaya alındı. Olguların özellikleri kaydedildi. Yaşam kalitesi Çocuk Sağlık Anketi Aile Formu 50 (CHQ-PF50) kullanılarak değerlendirildi. Çocukların fonksiyonel seviyeleri Barthel İndeksi ile değerlendirildi. **Sonuçlar:** Gruplar arasında, CHQ-PF50'nin alt skalaları olan genel sağlık algılaması, ailesel etki-emosyonel ve ailesel etki-zaman skorlarında anlamlı fark bulundu ($p<0.05$). NMH'li çocuklar ile SP'li çocukların HRQoL'leri, CHQ-PF50'nin bazı alt skalalarında fark gösterdi ($p<0.05$). NMH'li olan çocukların genel sağlık algılaması, ailesel etki-emosyonel ve ailesel etki-zaman skorları SP'li çocuklarla karşılaştırıldığında daha kötüydü. **Tartışma:** Pediatrik grupta SP ve NMH'li çocukların ve ailelerin yaşam kaliteleri farklı şekillerde etkilenir. Kronik süreçte her iki grubun hastalığa ait özellikleri tedavi programlarının planlanması ve takipte dikkatle ele alınmalıdır.

**Anahtar kelimeler:** Nöromusküler hastalıklar, Serebral palsi, Yaşam kalitesi, Özürün değerlendirilmesi, Çocuk.

Both cerebral palsy (CP) and neuromuscular diseases (NMD) are among the most common causes of disability in the children. Although results vary from one study to another, the prevalence of CP is approximately 2-3 of every 1000 live-born children in the Western world.[1-4] The childhood prevalence of NMD has been estimated to be 24.9-42.0 x $10^{-5}$.[5-7] In comparison to developed countries, the prevalence of CP is nearly twice higher in Turkey.[8] However, currently there is no study to demonstrate the prevalence of NMD in Turkey. According to the results of a survey conducted by Tunca et al. on the families of 260 children with NMD, it was determined that 67.76% of the families did not have adequate knowledge about the disease, and the most important problem restricting social life and education of families and children was physical inadequacy (55.37%) and accompanied problems and economic incapability.[9]

The common characteristic of CP and NMD is that they result in disabilities of various degrees, which develop in childhood and affect the quality of life. The most important difference between these two disease groups is that CP leads to chronic functional disability, while NMD leads to progressive disability.[10,11] As the disease progresses, the patients with NMD become more and more dependent in activities of daily living.[12]

The World Health Organization (WHO) defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.[13] In particular it is a person's self reported, subjective account of their quality of life across a number of dimensions. This is sometimes called health-related quality of life (HRQoL) with health referring to the WHO definition as a state of complete physical, mental and social well-being.[14] HRQoL also distinguishes quality of life from concepts which include factors external to the person such as poverty, living in a police state, and wider environmental factors such as pollution.[15] HRQoL is also distinct from concepts such as functional disability or handicap which were sometimes called quality of life. Measurement of quality of life in children has lagged behind that of adults because of concern about the reliability of children's self reports, and the different values they place on particular health states as compared to adults. Early work developed measures for specific diseases such as cancer and asthma for the purpose of contributing to the evaluation of medical interventions, but there is now a need for generic measures which allow comparisons not only across children with different disease states but also across children with and without impairments.[13]

The functional independence levels and the quality of life of children with disabilities and the life quality of parents have gained increased importance in recent years. In general, HRQoL measures aim to provide a more complete picture of the individual that is complementary to specific functional assessments, which is the traditional focus of clinicians.[16]

Relatively new generic measures of health and well-being, such as the Child Health Questionnaire (CHQ),[16] highlight subjective perspectives that concentrate on aspects of health important to all children: physical, emotional social and family dimensions.[17]

Progression and the problems in CP and NMD differ when compared with each other. Thus, families may experience different problems and need of care. The aim of this study was evaluate the HRQoL on children with CP compared with those with NMD.

## MATERIALS AND METHODS

### Participants

Inclusion criteria for the study were being diagnosed as CP or NMD by a pediatric neurologist and referred to our unit and volunteered to be participate in the study. Exclusion criteria were not having a definite diagnosis of children and unwillingness to participate in the study. A comparison study was conducted on 111 pediatric patients; 61 (54.95%) children with CP and 50 (45.04%) children with NMD.

Of the 50 children with NMD, 29 (58%) had Duchenne Muscular Dystrophy, 13 had (26%) Congenital Muscular Dystrophy, 1 (2%) had Limb

Girdle Muscular Dystrophy, 1 (2%) had Spinal Muscular Atrophy, 5 (10%) had Neuropathy, and 1 (2%) had Myopathy. Of the subjects with CP 52 (85.2%) were spastic, 5 (8.2%) were dyskinetic, 2 (3.3%) were ataxic and 2 (3.3%) were hypotonic. According to extremity distribution, 27 (44.3%) subjects were classified as quadriparetic, 24 (39.3%) subjects as diparetic, and 10 (16.4%) subjects as hemiparetic.

In addition to children, their mothers were also included in the study. In this study, all of the interviewed caregivers were the mothers of the children. Each mother was informed about the study, and they gave their consent to participate.

The study was conducted in the Pediatric Rehabilitation Units of the Faculty of Health Sciences, Department of Physical Therapy and Rehabilitation at Hacettepe and Baskent Universities. Ethical approval was obtained from the Hacettepe University Ethics Committee.

**Primary Outcome Measure:**

***Health Related Quality of Life***

We used Child Health Questionnaire Parent Form 50 (CHQ-PF50) to assess the HRQoL of children. It is a generic quality of life instrument that has been designed for children aged 5 to 18 years of age. The parent version of CHQ-PF50 was cross culturally adapted and validated into the Turkish language.[17] CHQ-PF50 contains 50 items, and measures the following concepts: physical functioning, role/social-physical limitations, general health perception, bodily pain/discomfort, role/ social, emotional/behavioral limitations, self-esteem, mental health, behavior, emotional impact on parents, impact on the parent's personal time, limitations in family activities, and family cohesion. It also includes a single item, change in health, which compare the current health with a person's health one year ago. Two additional single items are contained within the multi-item scales and can be used to represent an independent concept of global behavior and global general health. The scores for each health concept ranged from 0 to 100, with a higher score indicating better functioning and wellbeing. Questionnaires were administered by interview technique.[16] Mothers are instructed to take the 4-week period preceding their entry into the study into consideration.

**Other assessments**

Clinical data, demographic characteristics and ambulation levels of the patients were recorded. Ambulation levels of the children were classified into three categories; able to walk independently, able to walk with help, and unable to walk. The ages of the mothers, their education level, marital and employment status were recorded. Education level was classified as illiterate, primary school, secondary school, high school or university graduate. Their marital status was recorded as married, divorced or widowed. Their employment status was also recorded as employed or unemployed.

The Turkish version of the modified Barthel Index was used to measure the functional status of subjects.[18] This index includes 10 categories. Subjects were rated as unable, dependent, or independent in the following areas: feeding, bathing, grooming, dressing, bowel continence, bladder continence, toilet use, transfer, mobility on level surfaces, and ability to negotiate stairs. Total scores ranged from zero to 100, with highest scores representing the greatest level of functional independence.

**Statistical analysis:**

All statistical tests were performed using SPSS software for Windows, version 13.0 (SPSS Inc., Chicago, USA). The Skewness and kurtosis were used to determine whether data were normally distributed. Since none of the variables meet criteria for a normal distribution, non-parametric tests were used to compare quantitative variables between the two groups. Variances were evaluated using Levene's test and shown to be homogeneous before the ANCOVA test was performed. Because the modified Barthel Index score and ambulation status of children were different at the study entry, these variables were treated as co-variants in the ANCOVA test. In all cases two-tailed tests were used. A $p<0.05$ was used to define statistically significant difference.

## RESULTS

The age range of the children in both groups was 5 to 18 years. The mean age of the children with CP and NMD were 8.5±3.1 years and 9.1±5.7

years, respectively. The mean age of the mothers of children with CP and NMD were 33.3±7.0 years and 36.6±5.7 years, respectively (Table 1). There were no significant differences in age and gender distribution between the groups ($p>0.05$). Socio-demographic characteristics of the mothers in both groups were similar with respect to education level, marital and employment status ($p>0.05$).

Ambulation level of the children was significantly different between the two groups ($p<0.05$) (Table 1). Sixty eight percent of the children with NMD were independent while walking. While 37.7% of the children with CP could walk independently, and 62.3% needed assistance in walking or were wheelchair bound. Children with NMD had significantly higher Barthel Index scores than those of the children with CP (48.6±29.2 versus 72.6±23.4, respectively) ($p<0.05$).

Table 2 summarizes the scores on the CHQ-PF50 subscale scores. After controlling for covariates (total score of the modified Barthel Index and the ambulation status of the children), the ANCOVA results revealed statistically significant differences between the groups in general health perceptions, and the parental impact-emotional and the parental impact-time subscale scores of the CHQ-PF50 ($p<0.05$).

## DISCUSSION

Assessing the functional ability of disabled children is an important criterion in determining rehabilitation goals and deciding on therapeutic approaches. While there are many measurement tools to evaluate the functional status and disability of adult patients, and even many measurement tools particular to diseases, there are a limited number of measures for children.[19, 20] Functional status refers to the degree which an individual is able to perform socially allocated roles free of physical and mental limitations; it focuses on the performance of specific tasks such as activities of daily living.[21,22] One of the most important factors affecting the level of disability and rehabilitation in children is growth. The level of functional dependency increases with growth. Accompanying progressive diseases, secondary complications, environmental and social problems aggravate the condition, all negatively affect the QoL both children and their family. In the published literature, QoL measures can be disease specific or generic. There are a limited number of studies in NMD, although a great number of studies have been performed on QoL in other progressive conditions such as malignancy.

According to WHO, dependency in activity, restriction in social participation, and quality of life should be handled as multi-dimensional concepts affecting each other. Studies concerning measurements of the pediatric functional outcomes and life quality have been receiving more attention recently.[25]

In our study, we assessed quality of life of disabled children with progressive and chronic diseases. The modified Barthel index was used to determine the disability levels of the children, and CHQ-PF50 which is a generic measure was utilized in the assessment of life quality. We preferred the modified Barthel Index, because it does not require special certification to use.

Of the 111 children in the two different disease groups, 23 children (37.7%) in the CP group and 34 children (68%) in the NMD group maintained independent ambulation. Although the ambulation levels differed between the groups, the scores of both the two groups in the physical functioning, emotional / behavioral limitations, and role/ social-physical limitations subscales of the CHQ-PF50 were similar. That results indicated that though the number of patients who maintain independent ambulation in the NMD group was higher, the children in both two groups are restricted from social participation on a similar level. We thought that child's level of independence in ambulation was not a primary factor affecting quality of life.

A study conducted by Wake et al. using CHQ-PF50 showed that physical health level of children decreases as the level of disability increases. They also found that the severity of disease does not affect psychosocial health level of children and families emotional impact scores.[26]

In our study, general health perception, emotional impact on parents, impact on the

parent's personal time scores in the CHQ-PF50 differed between the two groups. The general health perception score indicated that the mothers of the children with NMD believed that their children were in bad health, and the health state of their children could become worse. In addition, the emotional impact on parents score indicated that the families of the children with NMD have a higher level of apprehension about physical and/or psychosocial health of their children as compared to those of the CP group.

We observed that the families of the children with CP were less apprehensive about their children's health compared to the NMD group. The time spared by the family to attend to their own needs was less restricted in the CP group. This may be due to the longer acceptance process of the families of children with CP when compared to the NMD group. In a study conducted on the mothers of children with Duchenne Muscular Dystrophy to investigate parental stress, it was found that stress increased more with social interaction and behavioral problems than the physical reasons result from the disease.[27] In the same study, it was indicated that maternal stress showed similarity in the mothers of children with CP and Duchenne Muscular Dystrophy. However, both groups suffered more stress compared to

**Table 1. Socio-demographic and clinical characteristics of participants.**

| | Cerebral Palsy (N=61) | Neuromuscular Diseases (N=50) | p |
|---|---|---|---|
| **Children** | | | |
| Age (years) (mean (SD)) | 8.5 (3.1%) | 9.1 (5.7%) | 0.244 * |
| Gender (n (%)) | | | |
| Male | 28 (45.9%) | 14 (28.0%) | |
| Female | 33 (54.1%) | 36 (72.0%) | 0.053 † |
| Ambulation levels (n (%)) | | | |
| Independent | 23 (37.7%) | 34 (68.0%) | |
| With assistance | 17 (27.9%) | 6 (12.0%) | |
| No walking | 21 (34.4%) | 10 (20.0%) | **0.006 †** |
| **Mothers** | | | |
| Age (years) (mean (SD)) | 33.3 (7.0%) | 36.6 (5.7%) | **0.001 *** |
| Education (n (%)) | | | |
| Illiterate | 2 (3.3%) | 0 (0) | |
| Primary school | 33 (54.1%) | 24 (48.0%) | |
| Secondary school | 11 (18.0%) | 7 (14.0%) | |
| High school | 11 (18.0%) | 11 (22.0%) | |
| University | 4 (6.6%) | 8 (16.0%) | 0.703 †† |
| Marital Status (n (%)) | | | |
| Married | 58 (95.1%) | 50 (100.0%) | |
| Divorced / Widowed | 3 (4.9%) | 0 (0) | 0.251 ** |
| Employment status (n (%)) | | | |
| Employed | 14 (23.0%) | 9 (18.0%) | |
| Unemployed | 47 (77.0%) | 41 (82.0%) | 0.522 † |

* Mann-Whitney U test. † ChiSquare test. †† Kolmogorov-Smirnov Test. ** Fisher's Exact Test.

**Table 2. Descriptive statistics and ANCOVA results* on subscales of Child Health Questionnaire Parent Form-50 (CHQ-PF50).**

| | Cerebral Palsy | Neuromuscular diseases | | |
|---|---|---|---|---|
| | X±SD | X±SD | F | p |
| Physical Functioning | 42.63±39.06 | 44.44±40.66 | 1.484 | 0.226 |
| Role/Social-Emotional | 58.09±40.35 | 75.52±33.87 | 1.728 | 0.192 |
| Role/Social-Physical | 55.17±41.77 | 68.30±36.37 | 0.370 | 0.544 |
| Bodily Pain/Discomfort | 65.08±27.96 | 68.69±29.10 | 0.026 | 0.873 |
| Behavior | 62.02±21.3 | 56.95±27.80 | 1.124 | 0.291 |
| Mental Health | 60.82±21.08 | 53.95±24.20 | 3.078 | 0.082 |
| Self Esteem | 62.00±22.78 | 66.48±18.91 | 0.000 | 0.989 |
| General Health | 36.28±17.55 | 30.60±19.68 | 5.684 | 0.019* |
| Parental Impact-Emotional | 41.47±34.13 | 29.30±27.01 | 7.042 | 0.009* |
| Parental Impact-Time | 47.73±36.67 | 45.70±28.55 | 4.049 | 0.047* |
| Family Activities | 56.20±27.99 | 56.69±29.20 | 1.416 | 0.237 |
| Family Cohesion | 61.96±22.88 | 66.39±23.76 | 0.094 | 0.760 |

*p<0.05. The total score of modified Barthel Index and ambulation status of children were used as co-variants.

controls. Stress and behavioral changes may be due to the functional status of the child. It was suggested to conduct similar studies on different disease groups on maternal stress and family function.[27]

Mothers with depression and anxiety problems rate some problems and HRQoL of their children with exaggeration.[28] This was one of the limitations in our study. Therefore, we suggest that mood state of the mothers should also be assessed in future studies.

Mothers of children with severe disability were not able to work outside the house due to care needs of their children.[29] Similarly, of the mothers who participated in our study, 77% in the CP group and 82% in the NMD group were not working, and did not consider working due to care needs of their children.

In the literature, it is indicated that the questions in the CHQ do not reflect the child's state according to the level of disability, and this poses a limitation in studies conducted by using the CHQ. Schneider et al. reported that activities in some questions particularly in parameters related to physical function of the CHQ necessitated participation, and they were not physically and mentally appropriate for the children's state because of requiring higher skills. Families did not answer these questions and data relating to these questions were reflected as data in the scoring.[25] Similarly, in our study, since children in the NMD group had proximal muscle weakness or were wheelchair bound. They were not able to perform activities such as playing football and running. Therefore, they received the lowest score in this section. In our study, the application of direct interviews by face to face contact prevented data loss.

In conclusion, children with CP and with NMD showed different patterns of HRQoL. General health perception, emotional impact on parents and impacts on the parent's personal time of children with NMD were worse than those of CP. Not only children but also their mothers must be taken into account when managing the children with NMD. These specific problem areas associated with NMD, if improved, may yield the greatest benefits for children and their families. Such knowledge may also inform policy and decision makers to generate protocols to optimize outcomes.

## REFERENCES


1. Pharoah PO, Cooke T, Rosenbloom I, et al. Trends in birth prevalence of cerebral palsy. Arch Dis Child. 1987; 62: 379-384.
2. Boyle CA, Yeargin-Allsopp M, Doernberg NS, et al. Prevalence of selected developmental disabilities in children 3-10 years of age: the Metropolitan Atlanta Developmental Disabilities Surveillance Program 199l. MMWR CDC Surveill Summ. 1996;45:1-14.
3. Dubowitz W. The Muscular Dystrophies. In: Muscle Disorders in Childhood. Second Edition. WB Saunders Company. London; 1994:34-134.
4. Drougia A, Giapros V, Krallis N, et al. Incidence and risk factors for cerebral palsy in infants with perinatal problems: a 15-year review. Early Hum. Dev. 2007; 83: 541-547.
5. Tangsrud SE, Halvorsen S. Child neuromuscular disease in southern Norway. Prevalence, age and distribution of diagnosis with special reference to non-Duchenne muscular dystrophy. Clin Genet. 1988;34:145-152.
6. Ahlström G, Gunnarsson LG, Leissner P, et al. Epidemiology of neuromuscular diseases, including the postpolio sequelae, in a Swedish county. Neuroepidemiology. 1993;12:262-269.
7. Merlini L, Stagni SB, Marri E, et al. Epidemiology of neuromuscular disorders in the under-20 population in Bologna Province, Italy. Neuromuscul Disord. 1992;2:197-200.
8. Serdaroğlu A, Cansu A, Ozkan S, et al. Prevalence of cerebral palsy in Turkish children between the ages of 2 and 16 years. Dev Med Child Neurol. 2006;48:413-416.
9. Tunca O, Karaduman A, Aras O. Nöromusküler hastalıklarda fizyoterapi rehabilitasyonun aile ve çocuk üzerindeki etkileri. Fizyoter Rehabil. 1996;8:7-12.
10. Livingston MH, Rosenbaum PL, Russell DJ, et al. Quality of life among adolescents with cerebral palsy: what does the, literature tell us? Dev Med Child Neurol. 2007;49:225-231.
11. Piccininni M, Falsini C, Pizzi A. Quality of life in hereditary neuromuscular diseases. Acta Neurol Scand. 2004;109:113-119.
12. Uchikawa K, Liu M, Hanayama K, et al. Fuctional status and muscle strength in people with Duchenne muscular dystrophy living in the community. J Rehabil Med. 2004;36:124-129.
13. Colver A. SPARCLE group. Study protocol: SPARCLE- a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. BMC Public Health. 2006;6:105.
14. WHOQOL Assesment Group. Development and general psychometric properties. Soc Sci Med. 1998;46:1569-1855.
15. World Health Organization. Preamble to the Constitution of the World Health Organization. International Health Conference. New York, 19-22 June, 1946. (Official Records of the World Health Organization,no2,p100) http://www.who.int/about/definition/en/print.html, 2003.
16. Landgraft JM, Abetz L, Ware JE. In The CHQ User's Manual. Boston: The Health Institute, New England Medical Center; 1996.
17. Ozdogan H, Ruperto N, Kasapçopur O, et al. The Turkish version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ). Clin Exp Rheumatol. 2001; 19(4 Suppl 23):158-162.
18. Küçükdeveci AA, Yavuzer G, Tennant BA, et al. Adaptation of the modified Barthel index for use in physical medicine and rehabilitation in Turkey. Scand J Rehabil Med. 2000;32:87-92.
19. Raina P, O'Donnell, Rosenbaum P, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics. 2005;115:e626-636.
20. Nereo NE, Fee RJ, Hinton VJ. Parental stress in mothers of boys with duchenne muscular dystrophy. J Pediatr Psychol. 2003;28:473-484.
21. Natterlund B, Ahlstrom G. Activities of daily living and quality of life in persons with muscular dystrophy. J Rehabil Med. 2001;33:206-211.
22. Hinton VJ, Fee RJ, Goldstein EM, et al. Verbal and memory skills in males with Duchenne muscular dystrophy. Dev Med Child Neurol. 2007;49:123-128.
23. Dickinson H, Parkinson K, McManus V, et al. Assessment of data quality in a multi-centre cross-sectional study of participation and quality of life of children with cerebral palsy. BMC Public Health. 2006;6: 273.
24. Rosenbaum PL, Livingston MH, Palisano RJ, et al. Quality of life and health-related quality of life of adolescents with cerebral palsy. Dev Med Child Neurol. 2007;49:516-521.
25. Schneider JW, Gurucharri LM, Gutierrez AL, et al. Health related quality of life and functional outcome measures for children with cerebral palsy. Dev Med Child Neurol. 2001;43:601-608.
26. Wake M, Salmon L, Reddihough D. Health status of Australian children with mild to severe cerebral palsy: cross-sectional survey using the Child Health Questionnaire. Dev Med Child Neurol. 2003;45:194-199.
27. Bakker JP, De Groot IJ, Beelen A, et al. Predictive factors of cessation of ambulation in patients with Duchenne Muscular Dystrophy. Am J Phys Med

Rehabil. 2002;8l:906-912.
28. Wiley R, Renk K. Psychological correlates of quality of life in children with cerebral palsy. J Dev Phys Disabil. 2007;19:427-447.
29. Curran AL, Sharples PM, White C, et al. Time costs of caring for children with severe disabilities compared with caring for children without disabilities. Dev Med Child Neurol. 2001;43:529-533.