# The Relationship Between Gross Motor Function and Quality of Life Among Children with Cerebral Palsy

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## *ABSTRACT*

***Purpose:*** *The aim of this study was to determine the relationship between gross motor function and quality of life among children with Cerebral Palsy (CP).*

***Method:*** *This observational analytical study with cross-sectional design, was conducted at Yayasan Pembinaan Anak Cacat (YPAC) Bandung, Sekolah Luar Biasa (SLB) Cileunyi, and Paediatric Neurology Clinic of Dr. Hasan Sadikin Hospital Bandung, Indonesia, from March 2011 to September 2012. Gross motor function was assessed using Gross Motor Function Scale (GMFCS). Cerebral Palsy-Quality of Life (CP-QOL) questionnaire for parent-proxy version was used to assess quality of life of children with CP. Statistical analysis was done using Spearman rank test to determine the relationship between variables.*

***Results:*** *Participants were 31 children with CP, between 4 -12 years of age. The most common type of CP was spastic quadriplegia (17 of the 31 children). Around 17 children had mild disability (GMFCS level I and II), 3 children had moderate disability (GMFCS level III), and 16 children had severe disability (GMFCS level IV and V). Majority of the parents had senior high school level education. Most of the fathers were self-employed while most of the mothers were housewives. Gross motor function was not significantly correlated to quality of life in general in children with CP (rs=-0.153, p=0.205). Although gross motor function was significantly correlated to pain and the impact of disability (rs=-0.313, p=0.043), other aspects of quality of life (social well-being and acceptance, feeling about functioning, participation and physical health, emotional well-being and self-confidence, access to services, and family health) were not significantly correlated (p>0,05) to it.*

***Conclusions:*** *Gross motor function in children with CP was correlated to pain and the impact of disability domain of quality of life.*

***Key words:*** *cerebral palsy, CP-QOL, GMFCS, gross motor function, quality of life.*

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# INTRODUCTION

Cerebral palsy (CP) is a descriptive, non-specific term pertaining to motor function disorder that is evident in early infancy and is characterised by changes in muscle tone (typically spasticity or rigidity), muscle weakness, involuntary movements, ataxia, or a combination of these abnormalities. This condition is a result of brain dysfunction and is not episodic or progressive (Swaiman and Wu, 2006). Children with CP often exhibit other neurologic impairments including intellectual disability, epilepsy, speech and language disorder, hearing and vision impairment, behaviour disorder, and secondary musculoskeletal problems (Sankar and Mundkur, 2005; Swaiman and Wu, 2006; Rosenbaum et al, 2007).

Quality of life in children with CP is a complex construct that is influenced by many factors. Chronic disorders of movement and posture in children with CP will cause a decrease in functioning and inability to perform activities of daily living (Engel et al, 2005; Parkinson et al, 2009; Sauve, 2010). Various accompanying comorbid disorders and pain may negatively impact on their quality of life (Houlihan et al, 2004; Tuzun et al, 2004; Parkinson et al, 2009). Children with CP may also experience a wide range of social and emotional problems, such as rejection by friends, depression, frustration, anxiety, and anger. In addition, treatment and care of children with CP can be burdensome to parents in terms of cost, time and stress, leading to the risk of unstable family conditions and low ability to cope with problems. Therefore, the quality of life of children with CP is one of the important assessments in evaluating the effectiveness of treatment of CP (Viehweger et al, 2008).

The aim of this study was to determine the relationship between gross motor function and quality of life among children with CP in Indonesia.

# METHOD

This was an observational analytical study with cross-sectional design, conducted at Yayasan Pembinaan Anak Cacat (YPAC) Bandung, Sekolah Luar Biasa (SLB) Cileunyi, and Paediatric Neurology Clinic of Dr. Hasan Sadikin Hospital Bandung, from March 2011 to September 2012. Data were collected by consecutive sampling and determined by correlation analysis formula. The study sample consisted of 31 children with CP who met the inclusion criteria, or their primary caregivers.

The inclusion criteria were:

1) Children with CP, between 4 -12 years of age
2) Children already diagnosed with CP by a doctor.

The exclusion criteria were:

1) Children with other chronic diseases that are not associated with cerebral palsy comorbid factors, such as tuberculosis, diabetes mellitus, congenital heart disease, asthma bronchiale, renal failure, haemophilia, thalassemia, and malignancy.

Written informed consent was obtained from parents of all participants.

Ethics approval was obtained from the Health Research Ethics Committee of the Faculty of Medicine, Padjadjaran University/ Dr. Hasan Sadikin Hospital.

Identities of all participants were recorded. Their gross motor functions were assessed using Gross Motor Function Scale (GMFCS), which varies from Level I (e.g. walking independently) through to Level V (e.g. unable to sit alone), and their quality of life was measured by the Cerebral Palsy-Quality of Life (CP-QOL) questionnaire. This is a new questionnaire designed specifically to measure the quality of life among children with cerebral palsy. While the parents-proxy version of this questionnaire is psychometrically sound, early results of the child self-report version suggest that it has good psychometric properties. For parents-proxy version, the 2-week test-retest reliability ranged from r= 0.76 to 0.89, and internal consistency ranged from 0.74 to 0.92. The questionnaire was also moderately correlated to the CHQ and KIDSCREEN, supporting the validity of the CP-QOL child and parents-proxy version. This questionnaire had also been validated in the Indonesian language. For parents-proxy version, the 2-week test-retest reliability has Cronbach Alpha coefficient reliability 0.83 and 0.94, with internal consistency rs=1.0, indicating very good validity and reliability. This questionnaire assesses 7 aspects of quality of life including social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being and self-confidence, access to services, pain and feeling about disability, and family health. Children who were able to fill out the questionnaires by themselves were given the CP-QOL child-version questionnaire; for those who were unable to do so, the CP-QOL parents-proxy version questionnaires were given to the child's primary caregiver. Almost all of the items in the questionnaire begin with the stem: 'How do you think your child feels about... ?' and have a 9-point rating scale, where 1=very unhappy, 3=unhappy, 5=neither happy nor unhappy, 7=happy, and 9=very happy. A few items where this stem or rating scale is not appropriate, such as pain, have the following stem and rating scale: 'How does your child feel about the amount of pain….?', where 1=not upset at all, and so on up to 9=very upset. The items are then transferred to a scale with a possible range of 0 -100. The algebraic mean of item values is computed for each domain. The CP-QOL child version is designed to provide several domain scores and items are, therefore, aggregated and averaged. Data were analysed using SPPS 17 programme at 95% confidence level with p value ≤0.05. Statistical analysis was done using Spearman rank test to determine the relationship between variables.

## RESULTS

As demonstrated in Table 1, 31 children with CP, between 4 -12 years of age, met the inclusion criteria. The most common type of CP was spastic quadriplegia (17/31 children). Around 17 children had mild disability (GMFCS level I and II), 3 children had moderate disability (GMFCS level III), and 16 children had severe disability (GMFCS level IV and V). Majority of the parents had senior high school level education. Most of the fathers were self-employed, while the mothers were housewives.

**Table 1: Demographic Characteristics**

| Demographics | Frequency |
|---|---|
| **Age (year)** | |
| Mean (SD) | 9.26 (2.54) |
| Median | 10 |
| Range | 4–12 |
| **Sex** | |
| Female | 15 |
| Male | 16 |
| **CP Type** | |
| Spastic diplegia | 14 |
| Spastic quadriplegia | 17 |
| **GMFCS Level** | |
| I | 5 |
| II | 7 |

| | |
|---|---|
| III | 3 |
| IV | 11 |
| V | 5 |
| **Child's Education** | |
| Schooled | 14 |
| Not schooled | 17 |
| **Mother's Education** | |
| Primary School | 4 |
| Junior High School | 8 |
| Senior High School | 14 |
| University | 5 |
| **Mother's Occupation** | |
| Labour | 3 |
| Trade | 1 |
| Teacher | 1 |
| Civil servants | 1 |
| Unemployed | 25 |
| **Father's Education** | |
| Primary School | 3 |
| Junior High School | 6 |
| Senior High School | 15 |
| University | 7 |
| **Father's Occupation** | |
| Labour | 6 |
| Trade | 4 |
| Teacher | 1 |
| Civil servants | 5 |
| Entrepreneur | 14 |
| Unemployed | 2 |

*SD: Standar of Deviation*

The score results of CP-QOL parents-proxy version questionnaire, based on GMFCS level in children with CP, are presented in Table 2. The lowest average values were seen in emotional well-being, pain and impact of disability, and family health aspects of quality of life.

## Table 2 : The Score of CP-QOL Parents-proxy version Questionnaire based on GMFCS Level in CP Children

| GMFCS Level | | $Y_1$ | $Y_2$ | $Y_3$ | $Y_4$ | $Y_5$ | $Y_6$ | $Y_7$ | Total |
|---|---|---|---|---|---|---|---|---|---|
| I | Mean | 827.5 | 702.5 | 657.5 | 357.5 | 792.5 | 405 | 197.5 | 3.490 |
| | (SD) | (243.4) | (278.2) | (308.9) | (172.7) | (160.2) | (224.6) | (87.7) | (1.192.5) |
| | Median | 875 | 850 | 782.5 | 450 | 787.5 | 525 | 175 | 4.487.5 |
| | Range | 475– | 375– | 175– | 75– | 550– | 550– | 75– | 2.050– |
| | | 1.150 | 1.000 | 1.000 | 500 | 937.5 | 937.5 | 300 | 4.962 |
| II | Mean | 919.6 | 771.4 | 780.4 | 469.6 | 857.1 | 448.2 | 300 | 4.546.4 |
| | (SD) | (149.8) | (54.3) | (137.5) | (58.1) | (73.5) | (109.5) | (76.7) | (402.2) |
| | Median | 925 | 750 | 825 | 500 | 850 | 450 | 312.5 | 4.662.5 |
| | Range | 712.5– | 725– | 537.5– | 362.5– | 750– | 312.5– | 137.5– | 3.962.5– |
| | | 1.175.5 | 875 | 937.5 | 525 | 962.5 | 600 | 375 | 5.137.5 |
| III | Mean | 916.7 | 916.7 | 854.2 | 462.5 | 858.3 | 454.8 | 291.7 | 4.754.8 |
| | (SD) | (28.7) | (115.5) | (26.0) | (12.5) | (237.6) | (123.3) | (81.3) | (538.9) |
| | Median | 900 | 850 | 862.5 | 462.5 | 850 | 525 | 287.5 | 4.614.5 |
| | Range | 900– | 850– | 825– | 450– | 625– | 312.5– | 212.5– | 4.300– |
| | | 950 | 1.050 | 875 | 475 | 1.100 | 527 | 375 | 5.350 |
| IV | Mean | 892.4 | 698.9 | 721.6 | 385.2 | 721.6 | 370.5 | 244.3 | 4.034.1 |
| | (SD) | (141.6) | (190.2) | (160.3) | (105.4) | (331.5) | (192.9) | (100.8 | (857.3) |
| | Median | 925 | 775 | 762.5 | 437.5 | 712.5 | 337.5 | 3) | 4.337.5 |
| | Range | 625– | 350– | 412.5– | 225– | 125– | 62.5– | 300 | 3.250– |
| | | 1.075 | 875 | 900 | 500 | 1.112.5 | 700 | 0–350 | 4.600 |
| V | Mean | 935 | 717.5 | 722.5 | 435 | 867.5 | 267.5 | 272.5 | 4.217.5 |
| | (SD) | (28.5) | (170.8) | (279.7) | (56.9) | (105.5) | (81.8) | (68.7) | (549.9) |
| | Median | 925 | 800 | 837.5 | 450 | 900 | 300 | 300 | 4.425 |
| | Range | 900– | 450– | 237.5– | 337.5– | 687.5– | 150– | 150– | 3.250– |
| | | 975 | 875 | 925 | 475 | 962.5 | 362.5 | 312.5 | 4.600 |
| Total | Mean | 897.2 | 739.9 | 737.5 | 415.3 | 800.4 | 385.1 | 258.5 | 4.233.9 |
| | (SD) | (142.9) | (178.9) | (196.3) | (103.3) | (224.7) | (165.2) | (88.9) | (778.3) |
| | Median | 925 | 800 | 775 | 450 | 850 | 350 | 300 | 4.425 |
| | Range | 475– | 350– | 175– | 75– | 125– | 62.5– | 0–375 | 2.050– |
| | | 1.175 | 1.050 | 1.000 | 525 | 1.112.5 | 700 | | 5.350 |
| | P value*) | 0.274 | 0.943 | 0.698 | 0.536 | 0.236 | 0.231 | 0.037 | 0.629 |

*Note: Y1: Social well-being and acceptance aspect. Y2: Feeling about functioning aspect. Y3: Participation and physical health aspect. Y4: Emotional well-being and self-confidence aspect. Y5: Access to service aspect. Y6: Pain and impact of disability aspect. Y7: Family health aspect. *) Kruskal-Wallis Test.*

The relationship between gross motor function and quality of life that was conducted by Spearman rank correlation test with 95% confidence level indicates that the gross motor function was significantly associated only with pain and the impact of disability aspect of quality of life (Table 3).

**Table 3: The relationship of Gross Motor Function to aspects of Quality of Life among Children with CP based on CP-QOL Parents-proxy version Questionnaire.**

| Aspects of Quality of Life | rs | P value |
|---|---|---|
| Social well-being and acceptance | 0.238 | 0.099 |
| Feeling about functioning | -0.081 | 0.332 |
| Participation and physical health | 0.017 | 0.463 |
| Emotional well-being and self-confidence | -0.126 | 0.249 |
| Access to service | 0.032 | 0.431 |
| Pain and impact of disability | -0.313 | 0.043 |
| Family health | 0.073 | 0.348 |
| Total score of quality of life | -0.153 | 0.205 |

*Note: rs: correlation coefficient (Spearman rank)*

# DISCUSSION

This is the first study that analyses the relationship between gross motor function and quality of life among children with CP in Indonesia. As the researchers were unable to find children with CP who could fill out the study questionnaires by themselves, the assessment of quality of life was done using the CP-QOL parents-proxy version questionnaire.

Based on the Spearman rank correlation test, the results of this study indicate that there was no significant relationship between gross motor function and total score of quality of life among children with CP (rs=-0.153, p=0.205). There are several possible reasons for the weak relationship between gross motor function and quality of life in general, including the limited sample size and sampling, as well as many other factors that influence responses to the given questions. First, since the questionnaires in this study were filled by parents of children with CP, the answers about the children's feelings are the perceptions of the parents. It is possible that these are not the children's actual feelings about their disabilities since the children did not answer directly.

Secondly, children with disability have adapted to their condition from the beginning and they do not know about any other health condition (Vitale et al, 2001). Quality of life depends on the balance between body, mind, soul and spirit within, as well as from establishing and maintaining harmonious relationship between the child with disabilities and the external environment in a social context. Children with disabilities will have a good quality of life when they understand and accept their condition and are in a good social environment. The condition in which a person has disability yet has a good quality of life is called "the disability paradox" (Albrecht and Devlieger, 1999).

The results of this study revealed that only pain and the impact of disability aspect of quality of life had significant relationship to gross motor function (p=0.043). This is consistent with the study of Shelly et al (2008) which revealed a significant relationship between gross motor function and pain, and the impact of disability aspects of quality of life. This is also consistent with the study of Houlihan et al (2004) which revealed that the incidence of pain was correlated to motoric dysfunction level and nasogastric tube insertion. The more severe the disability level of CP children, the more pain they experience.

Pain is likely to have a negative impact on the quality of life of children with CP. Those who experience pain will be absent from school more often, and will reduce their participation in family and social activities. In addition, pain in children with CP will also have an impact on their parents, who will experience anxiety and stress. Therefore, it is important to evaluate pain in children with CP in order to improve the quality of life for the whole family. Doctors should be able to help reduce the pain, either with physical, drug, or psychological therapy (Houlihan et al, 2004; Parkinson et al, 2009).

In this study, participation and physical health aspect of quality of life did not show a significant relationship with gross motor function level. This is contradictory, because children with CP who experience pain are bound to have a negative influence on family activities and social participation (Houlihan et al, 2004; Parkinson et al, 2009; Sauve, 2010). The results of this study are also contrary to the research conducted by McManus et al (2008) which examined the quality of life and participation in daily activities of CP pre-teens in Ireland and showed that the higher the levels of disability, the lower the participation in daily activities . This study also contradicts the study by Shelly et al (2008) in Australia which showed that the aspect of physical health and participation had a significant relationship with motor function level in children with CP.

The current study has revealed no significant relationship between gross motor function and the feeling about functioning aspect of quality of life. This is not in accordance with previous studies that maintain a significant relationship between the two (Shelly et al, 2008). Factors influencing this condition are the level of parental education and the local culture, and it is possible that the children's cognitive levels contribute too. Given that all the children in the study had cognitive impairment, they seemed unconcerned about the ability to use their limbs, communicate with others, perform daily activities, as well as about their chances in life and their ability to keep up with their peers.

Several studies have shown that the gross motor function was not related to the psychosocial domain of quality of life (Vargus-Adams J, 2005; Livingstone et al, 2007; Arnaud et al, 2008; Shelly et al, 2008; Liu et al, 2009). This is in accordance with the findings in this study, wherein the GMFCS levels revealed no significant relationship with psychosocial domains of quality of life, which were assessed from the perspectives of social well-being and acceptance as well as emotional well-being and self-confidence. This can be due to other factors that influence the psychosocial domain of quality of life, such as parenting style. Autonomic/ permissive and accepting type of parents will ensure the child is accepted and is treated well. In addition, environmental factors such as family and friends who accept and support the child's condition, may make the child feel more comfortable and foster a feeling of belonging and stable emotions.

This study showed no significant relationship between gross motor function level and family health aspect of quality of life. Most parents gave a low score on the family health aspect of quality of life questions (average of 258.5) in all GMFCS levels. The family health domain in the CP-QOL questionnaire asks how the parents feel about their physical health, work situation, family financial situation, and how happy they are. Most parents' answers were 'unhappy' and 'very unhappy'. This is possible, considering that most of them were of low socioeconomic status and their level of education was senior high school. Thus, in this study most parents were not satisfied with their family health.

This study also showed no significant relationship between gross motor function and the access to services aspect of quality of life. This was assessed by asking questions about how parents feel regarding access to health care, paediatricians, and the availability of special equipment at home, at school, or in the neighbourhood. Most parents gave a good score for this aspect of quality of life (800.4 ±224.7); in other words, most of them were quite satisfied with the facilities they already had. This is quite strange, considering the lack of facilities and infrastructure for children with CP in the community, as well as the fact that most of the families do not have wheelchairs, walkers or other mobility aids. One explanation could be the existence of government health insurance for poor families, owing to which they were financially compensated for the expenses incurred for their children's therapy. In addition, local cultural factors tend to make parents feel satisfied and grateful for what they have, despite the minimal facilities and infrastructure available for children with CP.

Children with the same level of disability may adapt to the situation at different levels. The important thing is how families treat and accept their children with disability. The child who is well-accepted by the family will adapt more easily, as compared to a child whose family is less accepting (Magill-Evans et al, 2001;Houlihan et al, 2004;Glenn et al, 2008). A study conducted by Majnemer et al (2007) showed that high levels of parental stress and low parental coping ability will have a negative effect on the child's quality of life. Parents of children with CP run the risk of experiencing stress, unstable family conditions, and low ability to cope with problems. Levels of parental stress will affect the children's behaviour and psychosocial adjustment (Albrecht and Devlieger, 1999; Majnemer et al, 2007; Glenn et al, 2008). Therefore, there is a need to conduct more research into the quality of life of children with CP by examining the stress levels of the parents.

## CONCLUSION

Gross motor function was correlated to pain and the impact of disability domain of quality of life in children with CP in Indonesia.

### Limitations

This study did not analyse the influence of type and number of accompanying comorbid disorders, the use of medications and frequency of physiotherapy, as well as the stress levels of the parent/primary caregiver, which can affect the quality of life for children with CP. Further research is also required, using questionnaires that can be completed by children with CP themselves, in order to get more accurate information about their feelings.

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