Study on the quality of life of children with cerebral palsy

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Abstract. [Purpose] This study aims to analyze the factors that affect the quality of life of children with cerebral palsy. [Subjects and Methods] The study subjects were 138 children, aged 7–12, who suffer from cerebral palsy. Factors affecting subjects’ quality of life were evaluated using the ICF-CY; quality of life was evaluated using the KIDSCREEN 52 – Health-Related Quality of Life questionnaire. Multiple regression analysis was conducted. [Results] The factors related to physical functions that affect subjects’ quality of life were mental function, sensory function and pain, genitourinary and reproductive function, as well as neuromusculoskeletal and movement-related functions. Factors related to activities and participation were learning and applying knowledge, self-care, interpersonal interactions and relationships, major life areas, and community, social and civic life. Lastly, factors related to the environment were products and technology, natural environment and human made changes to environment, and attitude. [Conclusion] In order to improve the quality of life of children with cerebral palsy, the compound effects of several factors should be comprehensively considered without being limited to a specific variable from physical function. And children should be provided with ample opportunities to participate in diverse activities and their physical functions, as well as the environmental factors, should improve.

Key words: Quality of life, Cerebral palsy, ICF-CY

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INTRODUCTION

The characteristics of cerebral palsy include delayed sensory and mental developments, incomplete development of the concept of movement and social skills due to restrictions in physical activities and lack of physical experience¹. Depending on the severity, the clinical prognosis ranges from being able to walk and run, similar to children without disabilities, to being unable to carry out basic functions needed for survival, such as breathing and swallowing². In addition, based on their physical abilities, their range of participation in daily activities is very wide³. Although they receive partial benefits, educationally and socially, school-aged children with cerebral palsy have difficulties participating in activities. Children with disabilities should be given quality of life similar to what normal children receive, and should perform their allocated social duties⁴, ⁵. Studies have reported that different environments, including home, local community, and school affect the individual activities of children with cerebral palsy⁶.

The World Health Organization (WHO) has developed the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), based on the need for a classification in order to measure health, education, and social activities of children and youth⁷. A different version of the ICF-CY checklist was developed using shortened categories of each disease to identify disabilities related to health, and to explain disabilities and health conditions of children and youth.
The aim of this study is to analyze the factors (physical functions, environmental factors, and activities and participation) that affect the quality of life of children with cerebral palsy using the ICF-CY. Diverse factors that should be considered to increase the quality of life in real-life activities will be confirmed without being restrained to the conventional method, which only takes into account the functional aspects of children with cerebral palsy.

SUBJECTS AND METHODS

The subjects of this study were 138 children, between the ages 7–12, who were diagnosed with cerebral palsy living in the Jeollanam-do. Children who could understand instructions from their guardian and the researchers were selected. All subjects signed the consent form approved by the Sehan University Institutional Review Board. All surveys were filled out with the children’s information, without identifying names by the 10 physical therapist who received education about the ICF-CY. Out of the initial 160 surveys, 22 surveys were deemed unsuitable and were excluded. A total of 138 surveys were collected and used for data analysis.

The ICF-CY checklist, for 7–12 years of age, was used to survey the subjects’ physical functions, environmental factors, as well as activities and participation. Physical function was divided into 8 categories; environmental factors were divided into 5 categories, and the evaluation can be done on the obstacles and promoting factors; and activities and participation was divided into 9 categories. Activities and participation can be separated into performance evaluation and ability evaluation. The performance evaluation, which evaluates each subject’s individual abilities in real life situations, was used in this study. This study evaluated the obstacles that can interfere with the subjects’ individual performances.

The KIDSCREEN 52-HRQOL, which is used to evaluate the subject’s quality of life, was developed by Ravens-Sieberer et al. The survey is used on school-aged children and youth, with or without chronic diseases, between the ages of 8 to 18, and is answered by the parents. The survey is composed of 10 categories with a total of 52 questions.

All collected data were analyzed using Windows SPSS 18.0 (SPSS Inc., Chicago, IL, USA). Multiple regression analysis was conducted to analyze the factors that affect the quality of life. The statistical significance level was set to α=0.05.

RESULTS

The quality of life affecting factors from the physical function category of the ICF-CY were analyzed. The coefficient of determination ($R^2$) of the independent variables related to the quality of life, a dependent variable, was determined to be 57.2%. The F-value was 25.44, which means that it was statistically significant (p=0.00). Evaluation of the contributions of independent variables on dependent variables, and statistical significance showed that mental function (p=0.00), sensory function and pain (p=0.02), genitourinary and reproductive functions (p=0.01), and neuromusculoskeletal and movement-related functions (p=0.00) were independent variables that significantly affected the quality of life (Table 1).

The quality of life affecting factors from the activities and participation category of the ICF-CY were analyzed. The coefficient of determination ($R^2$) of the independent variables related to the quality of life, a dependent variable, was determined to be 60.2%. The F-value was 25.51, which means that it was statistically significant (p=0.00). Evaluation of the contributions of independent variables on dependent variables, and statistical significance showed that learning and applying knowledge (p=0.00), self-care (p=0.00), interpersonal interactions and relationships (p=0.00), major life areas (p=0.00), and community, social, and civic life (p=0.00) were independent variables that significantly affected the quality of life (Table 2).

The quality of life affecting factors from the environmental factors category of the ICF-CY were analyzed. The coefficient of determination ($R^2$) of the independent variables related to the quality of life, a dependent variable, was determined to be 57.3%. The F-value was 40.18, which means that it was statistically significant (p=0.00). Evaluation of the contributions of independent variables on dependent variables and statistical significance showed that products and technology (p=0.03), natural environment and human made changes to environment (p=0.00), and attitude (p=0.03) were independent variables that significantly affected the quality of life (Table 3).

DISCUSSION

Using the ICF-CY, physical function, activities and participation, and environmental factors were analyzed to determine which factors affect the quality of life of children with cerebral palsy. The results provide the factors that should be considered in order to improve the quality of life in real-life activities of children with cerebral palsy.

Based on previous studies on the effects of the physical functions on the quality of life of children with cerebral palsy, Cho et al. reported that a significant difference was observed in the qualities of life between the school-aged children with cerebral palsy who can ambulate, and normal children who can ambulate. A study by Lee and Ko reported a significant correlation between the quality of life and the ability to go to the bathroom in children with cerebral palsy. A study by Cho et al. reported that quality of life was observed to be significantly higher in children with cerebral palsy who have intelligence and gross motor function, and have no pain. Engel et al. reported that health is a factor that affects happiness subjectively. Therefore, pain and physical limitations interfere with daily activities and consequently lower the quality of life. These results are similar to the results from this study, which reported that physical functions (sensory function and pain, genitourinary...
and reproductive functions, neuromusculoskeletal and movement-related functions, and mental functions) significantly affect the quality of life of children with cerebral palsy. In order to improve the quality of life of children with cerebral palsy, the compound effects of several factors should be comprehensively considered without being limited to a specific variable from physical function.

Based on previous studies on the effects of the variables from the activities and participation category on the quality of life of children with cerebral palsy, Lee and Ko\(^{10}\) reported a significant correlation between the quality of life of children with cerebral palsy and self-help, movement, and social cognition. A study by Yoo et al.\(^{13}\) showed that the types of leisure activities that affect the quality of life of children with cerebral palsy were informal activities (drawing, reading, etc.) and frequent social activities. These results were obtained while restricting each subject’s individual characteristics (gender, age, type of cerebral palsy, Gross Motor Function Classification System and Manual Ability Classification System). Therefore, the results directly show the correlation between activities and participation, and quality of life of children with cerebral palsy.

### Table 1. The quality of life affecting factors from the physical function

| Variables                                                                 | Standard regression coefficient |
|--------------------------------------------------------------------------|--------------------------------|
| b1  Mental functions                                                     | −0.60**                        |
| b2  Sensory functions and pain                                           | −0.16*                         |
| b3  Voice and speech functions                                           | −0.09                          |
| b4  Functions of the cardiovascular, haematological, immunological and respiratory systems | −0.05                          |
| b5  Functions of the digestive, metabolic and endocrine systems          | 0.10                           |
| b6  Genitourinary and reproductive functions                             | 0.17*                          |
| b7  Neuromusculoskeletal and movement related functions                  | −0.25**                        |
| b8  Functions of the skin and related structures                         | 0.08                           |

Adjusted R\(^2\)=0.572, F=25.44 (**p<0.001).
*p<0.05, **p<0.001

### Table 2. The quality of life affecting factors from the activities and participation

| Variables                                      | Standard regression coefficient |
|-----------------------------------------------|--------------------------------|
| d1 Learning and applying knowledge            | −0.28**                        |
| d2 General tasks and demands                  | −0.06                          |
| d3 Communication                              | 0.16                           |
| d4 Mobility                                   | −0.10                          |
| d5 Self care                                  | 0.35***                        |
| d6 Domestic life                              | −0.16                          |
| d7 Interpersonal interactions and relationships| −0.26**                        |
| d8 Major life areas                           | −0.33***                       |
| d9 Community, social and civic life           | −0.36**                        |

Adjusted R\(^2\)=0.602, F=25.512 (**p<0.001).
**p<0.01, ***p<0.001

### Table 3. The quality of life affecting factors from the environmental factors

| Variables                                         | Standard regression coefficient |
|---------------------------------------------------|--------------------------------|
| e1 Products and technology                        | −0.14*                         |
| e2 Natural environment and human made changes to environment | −0.70**                        |
| e3 Support and relationships                      | −0.29                          |
| e4 Attitudes                                      | 0.42*                          |
| e5 Services, systems and policies                 | 0.04                           |

Adjusted R\(^2\)=0.573, F=40.175 (**p<0.001).
*p<0.05, **p<0.001
Study by Shikako-Thomas et al.\(^4\) also reported that friends and membership to a community of similar aged children are basic factors that promote higher quality of life. Therefore, in order to improve the quality of life of children with cerebral palsy, opportunities to diversify real life activities should be provided instead of solely improving physical functions.

The Korean Institute for Health and Social Affairs\(^5\) reported that 31.2% of disabled children stated that they received discrimination during admission or transfer to elementary schools. In addition, 50.3% of disabled children responded that they have been socially discriminated by similar aged students. Of disabled children who responded positively to needing assistive equipment stated that the reason they did not previously purchase any assistive equipment was because the cost was too high (51.6%), there were no suitable equipment (12.9%), and because they did not know where to purchase the equipment (6.8%). The responses to the question that asked whether their current home had convenient structures were “slightly uncomfortable” (20.9%) and “very uncomfortable” (3.4%). Therefore, in the case of people with cerebral disability, common house structures could be an obstacle that restricts daily activities. The responses to the question that asked people with cerebral disability whether they need help for daily activities were “partial help needed” (30.6%), “a lot of help needed” (20.5%), and “help from others needed most of the time” (22.4%). A total of 47.8% of the respondents answered that they own a vehicle. The use of the vehicles was predominantly for commuting and outings (50.0%), and 80.0% of the car owners had a guardian who operated the vehicle for them. Similar to the results of this study, the results above indicate that attitude, products and technology, natural environment, and artificial changes in the environment are very important variables that significantly affect the quality of life. In order to improve the quality of life of children with cerebral palsy, help from others, along with diverse environmental support for daily life, is necessary.

This study confirmed the factors (physical functions, environmental factors, and activities and participation) that affect the quality of life of children with cerebral palsy. Although this study did not take into account the subjects’ individual characteristics, such as gender and cerebral palsy type, the results could provide variables that should be considered in establishing interventions to improve the quality of life of children with cerebral palsy. In addition, this study can be used as the basis or reference for guidelines for appropriate allocation of assistance by understanding children with cerebral palsy.

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