# Effect of Social Support on Parenting Stress of Korean Mothers of Children with Cerebral Palsy

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Abstract. [Purpose] This study investigated the effect of perceived social support on the parenting stress of mothers who have children with cerebral palsy (CP). [Methods] This study was conducted using surveys, literature review, and interviews. Survey data were collected from 181 mothers of children (under 18 years of age) with CP. [Results] Level of disability, mother's health status and social support were significant predictors of the parenting stress of mothers. [Conclusion] We have to comprehend and share the psychological and physical affliction of mothers having much difficulty nurturing children with CP. Also, the government should take social responsibility for the upbringing of their children, developing back-up programs for mothers and making them comprehensively available to support the psychological and physical health of mothers of children with CP.

**Key words:** Cerebral palsy, Parenting stress, Social support

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### INTRODUCTION

Cerebral palsy (CP) refers to a group of disorders in the development of movement and posture, which causes limitations of activity that are attributed to non-progressive disturbances occurring in the developing fetal or infant brain<sup>1)</sup>. Early diagnosis and intervention is especially critical with CP, since the brain damage resulting from CP itself may be non-progressive, but it can lead to various subsequent conditions. According to the 2008 statistics compiled by the Division of Policy for Persons with Disabilities of the Ministry of Health and Welfare2), among the age-specific brain injuries of Koreans, CP has the highest incidence between the ages 0–9, at 57.8%. As noted, CP is the largest category of infant brain injuries.

If the parents of children with a disability fail to cope with stress induced by the unusual challenges experienced by the family and don't develop the skills necessary for parenting, it may result in a serious family crisis. Among the family members, mothers who are primarily responsible, show the highest rate of parenting stress, which results in depression and family troubles<sup>3)</sup>. This is due to the mother generally assuming more responsibility for the child<sup>4)</sup>, and undertaking most of the additional care necessary for a child with disability<sup>5)</sup>.

The parenting stress of mothers of children with CP can be interpreted as a composite and negative response to the physical, social, economical and psychological experience of families nurturing children with CP6). Moreover, stress experienced by the mothers of children with CP may

be identified as physiological response stress, the level of physiological stress associated with physical fatigue, neuralgia, and convulsion, and emotional response stress, the level of response to the discomfort associated with nervousness, anxiety, distress, grief and interaction with others<sup>7</sup>). Therefore, adequate assistance and opportunities must be provided to help mothers cope with such stress and to accomplish excellent role performance.

Currently in Korea, the provision and standards of various supports aiding the parenting of children with CP are inconsistent, and the standards of service support or the policies pertaining to problematic situations are extremely insufficient<sup>8)</sup>.

Furthermore, there is a deficit of social welfare service policies, as well as pertinent research. In other words, until now, there has been little research into the stress of mothers parenting children with  $CP^{9-12}$ , yet there has been little research into the correlation between social support and the parenting stress of mothers, and the proposed solutions are insubstantial. Accordingly, this present study examined the extent and necessity of practical assistance for the reduction of the parenting stress of mothers in order to propose a basis for the establishment of effective welfare planning.

## SUBJECTS AND METHODS

This study surveyed 181 mothers of children under the age of 12, diagnosed with CP, who were undergoing rehabilitation therapy at university or rehabilitation hospitals located in Seoul and Gyeonggi-Do province. The scope of social support was restricted to close friends, friends, family and medical facilities, which mothers of children with CP embraced as social support mediums. All research subjects

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agreed to participation in the study, and data were collected via survey. The response rate of the mothers of children with CP was 100%. The present study was supported by Dongguk University and approved by Dongguk University Institutional Review Boards, and written consent was provided by all the subjects.

The "Stress Level of Mothers with Children with CP Measurement Tool" (SMCP) was developed by Lee, Jiwon<sup>13</sup>, who conducted an in-depth interview of 20 mothers of children with CP to evaluate their stress levels. In this study it was used as the measurement tool for measuring the stress levels of the mothers of children with CP. It has 44 questions, each of which are answered on a 5 point scale on which "strongly agree" is scored as 5 points and "strongly disagree" is scored as 1 point, with a higher score signifying greater parenting stress.

The test-retest of the SMCP shows a correlation of Pearson r=0.97, and a reliability of Cronbach  $\alpha$ =0.94.

A measuring tool for social support was developed for informal and formal support. First, in order to measure informal support, the CPSS (Carolina Parents Support Scale), developed by Bristol<sup>14)</sup>, was modified and supplemented via consultation with an associated specialist in order to correspond to Korean reality, resulting in a tool consisting of 8 questions. Each question was scored on a scale of 4 points, with "very supportive" yielding 4 points and "very unsupportive" yielding 1 point, a higher score implying greater acquisition of informal support. The reliability of the modified survey was Cronbach α=0.767. Then, in order to measure the formal support, CPSS was modified and supplemented again to correspond to Korean reality, resulting in a survey consisting of 9 questions. Each question was scored on a scale of 4 points, with "very supportive" yielding 4 points and "very unsupportive" yielding 1 point, a higher score implying greater acquisition of formal support. The reliability of the modified survey was Cronbach  $\alpha$ =0.838.

Data regarding additional variables influencing parenting stress for mothers, such as the sex of children (1=Male, 2=Female), age (1=Less than 24 month, 2=Between 24–72 months, 3=More than 72 months), term of disability (1= Less than 1 year, 2= Between 1–3 years, 3=Between 3–5 years, 4= More than 5 years), severity of disability (1= Mild, 2= Average severity, 3= Very severe), age of mothers (1= Less than 30 years of age, 2= More than 30 years of age), level of education (1=High school graduate or lower, 2=University graduate or higher), family income (1= Less than 1,000,000 KRW, 2=Between 1,000,000–3,000,000 KRW, 3=Between 3,000,000–5,000,000 KRW, 4=More than 5,000,000 KRW) were collected.

Furthermore, a tool (1 question) developed by Ware, Davis, and Donald<sup>15)</sup>, scored on a scale of 4 points, with "very healthy" yielding 4 points and "very unhealthy" yielding 1 point, a higher score implying better health conditions, was utilized to examine the health conditions for mothers of children with CP.

The characteristics of the subjects are presented as frequencies and percentages. Analysis of variance (ANOVA) was conducted in order to examine the relevance between the parenting stress of mothers and the characteristics of

the children. Hierarchial multiple regression analysis was employed to uncover variations (p<0.05) significant in the univariate analysis with respect to factors influencing the parenting stress of mothers while solution enter was utilized to identify predictable factors. The characteristics of children were entered in the first step and the characteristics of the mothers in the next. In the final step the total scores of social support were entered into the prediction model independently as formal and informal supports. Statistical analysis was performed utilizing SPSS ver. 17.0.

### RESULTS

As shown in Table 1, the correlation between factors associated with the parenting stress of mothers and the parenting stress itself, resulted in positive correlations with severity of disability, while the correlations pertaining to education levels and health conditions of mothers and family income were negative.

The results of hierarchial multiple regression analyses are presented in Tables 2. As a result of analyzing factors influencing the parenting stress of mothers of children with CP, as well as modifying the efficacy of other variables in the final step, the overall model, the severity of disability of children, health condition of mothers and social support were identified as significant predictors of parenting stress. Among others, independent examination of social support, as formal and informal support, subsequently identified informal support as a significant predictor of parenting stress.

## DISCUSSION

The present research surveyed 181 mothers of children diagnosed with CP who are currently undergoing rehabilitation treatment at university hospitals or special rehabilitation hospitals, in order to examine the factors influencing the parenting stress of mothers of children with CP with reference to social support provided to the mother.

The general characteristics of the children with CP, such as sex and age were not significantly different, though parenting stress was positively associated with the severity of the disorder of the children with CP, revealing that parenting stress increases with increased severity of the disorder (r=0.302, p<0.01). This outcome is in agreement with the results of preceding studies<sup>3, 8-10, 16)</sup> reporting that parenting stress of the parent increases with the severity of a child's disability. Our results are analogous to those of Lena E. Svedberg<sup>17)</sup>, who concluded that parents nurturing CP children who cannot walk perceive more stress than those with CP children who can walk. Moreover, there are many circumstances of CP, in which mental retardation accompanies physiological disability, exacerbating the stress of parents<sup>18)</sup>.

Parenting stress was not dependent on age or general characteristics of mothers. On the other hand, parenting stress demonstrated negative correlations with the mother's level of education, level of income and health conditions, indicating that parenting stress increases with lower level of education (r=-0.168, p<0.05), lower level of income (r=-0.281, p<0.01) and poorer health condition (r=-0.227,

Table 1. Correlation of parenting stress of mothers

	Parenting Stress	Term of Disability	Severity of Disorder	Education Level of Mother	Family Income	Health of Mother	Social Support
Parenting Stress	1	0.090	0.302**	-0.168*	-0.281**	-0.227**	-0.260**

<sup>\*</sup> p<0.05, \*\* p<0.01

Table 2. The factors associated with parenting stress of mothers

	Variables				
	va	Mean (SD)			
	Sex	Male	146.56 (33.85)		
- Child	Sex	Female	139.49 (30.13)		
		Less than 24 months	143.23 (32.81)		
	Age	Between 24–72 months	139.91 (34.20)		
		More than 72 months	144.96 (30.89)		
		Less than 1 year	145.00 (31.49)		
	T*	Between 1–3 years	139.39 (36.12)		
	Term of disability *	Between 3–5 years	127.20 (32.17)		
		More than 5 years	148.33 (29.74)		
		Mild	125.57 (33.05)		
	Severity of disability **	Average severity	143.97 (31.57)		
		Very severe	152.12 (28.01)		
Mother ==	A ~~	Less than 30 years of age	131.43 (26.42)		
	Age	More than 30 years of age	142.77 (32.05)		
	Level of education*	High school graduate or lower	149.67 (32.52)		
	Level of education	University graduate or higher	138.74 (31.29)		
		Less than 1,000,000 KRW	165.63 (18.21)		
	Family in some **	Between 1,000,000-3,000,000 KRW	148.99 (31.67)		
	Family income **	Between 3,000,000-5,000,000 KRW	138.78 (28.95)		
		More than 5,000,000 KRW	127.96 (38.20)		
		very unhealthy	142.71 (42.57)		
	Health conditions **	unhealthy	155.41 (33.58)		
	rieaun conditions	healthy	145.46 (30.83)		
		very healthy	129.78 (28.21)		

<sup>\*</sup> p<0.05, \*\* p<0.01

p<0.01). Haley<sup>19)</sup> also reported lower stress levels in mothers possessing higher level of education, and Kim Soo-hyeon<sup>12)</sup> revealed that the financial status of mothers of children diagnosed with CP influenced parenting stress in a negative correlation, concluding that the lower stress level may be due to a better ability to resolve economical difficulties experienced as a result of parenting children with disabilities.

Our results are in agreement with Lee Ji-won<sup>13)</sup>, who described the influence of the health condition of mothers on parenting, and Lena E. Svedberg<sup>17)</sup>, who identified a relationship between parents health condition and the stress they experienced in parenting children with CP, verifying that caring for children with CP has a physically negative effect.

From this, it can be understood that, as the severity of the disability of a child with CP increases, the assistance required by the mother will increase, resulting in increased dependency and subsequent physiological stress as well as psychological burden. Inclusion of economic difficulty or problematic health condition of the mother would exacerbate the experienced burden. Therefore, intervention for parenting stress should be considered an exceptionally important issue.

The present study examined social support independently as informal support and formal support. According to research by Hong Ji-yeon<sup>20)</sup>, social support provided to the mothers of children with CP is aimed at allowing efficient coping and adaptation to stress, and proficient adjustment of social support would make successful adaptation possible. Moreover, research by Cohen and Wills<sup>21)</sup> suggests that social support is a significant coping resource, reducing stress and improving personal adaptation levels by reducing

pessimistic emotions while promoting optimistic emotions.

The present study demonstrated there is a negative correlation (r=-0.260, p<0.01) between social support and the parenting stress of mothers. This result was comparable to those of several previous studies<sup>3, 8, 16, 22, 23)</sup> that reported a negative correlation between social support and parenting stress, and that increased social support yielded decreased parenting stress. Furthermore, in hierarchial multiple regression analysis, social support was independently examined as formal support and informal support, but of parenting stress only informal support was identified as a significant predictor ( $\beta$ = -1.117, p<0.01).

In other words, informal support has a perceptible influence on the parenting stress of mothers of children with disabilities, rather than formal support, indicating that emotional intervention is relatively indispensable for mothers of children with disabilities. In his research, Jeon Jae-il<sup>24</sup>) acknowledged the significance of formal support based on an analysis of the most influential support, in affecting the quality of life of mothers of children with disabilities. Kim Sung-su<sup>25)</sup> revealed that an increased level of social support positively influenced childhood negligence while increased economic stress contributed to increased childhood negligence of children with developmental disorders, as well as the level of depression of mothers. Results of the in-depth survey of the present study disclosed a firm demand for lessening the physical and financial burden of caring for disabled children, indicating the significance of formal support for mothers, and the necessity of organizing a relevant welfare support system.

In summary, the present study revealed that the characteristics of children with CP and mothers, as well as social support intercorrelated, and that social support reduces the burden and stress of parenting experienced by mothers. Therefore, we must understand and ameliorate the adversity, physiological and psychological afflictions experienced through parenting of children with CP. In addition, the responsibility of parenting for children with disabilities must be administered at a national level and various support programs must be comprehensively provided for mothers to maintain their psychological and physical health.

The limitations of the present study were as follows.

First, there are difficulties in the generalization of the results of the present study. Information concerning children with CP who are enrolled in special-education schools or those who live at home, was not been incorporated. Therefore, it may be impractical to apply the results to all mothers of children with CP, and an expanded sampling region and a large number of subjects will be essential in future studies.

Second, research into social support for not only the mother of children with CP, but for the members of the family should be conducted. In particular, the brothers and sisters of children with disabilities should be carefully studied and research on understanding the difficulties and negligence felt by siblings is required.

Third, during the conduct for the present study, we perceived that there had been inadequate research into the leisure activities of mothers of children with disabilities. Various studies of leisure activities, which may improve the quality of life for mothers, must be conducted.

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