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Determinants of Health-related Quality of Life Among Mothers of Children With Cerebral Palsy

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ABSTRACT

Purpose: Caring for a child with cerebral palsy (CP) can impact both the physical and mental health of parents. However, determinants associated with health-related quality of life (HRQOL) in these parents have yet to be adequately examined. The study aims were to identify the determinants affecting HRQOL among mothers of children with CP.

Design and Methods: Participants in this cross-sectional study (N = 180) were mothers of children with CP recruited from clinical and school-based settings in Korea. Variables examined were characteristics of child (demographic factors and disability parameter), mother (demographic factors, number of chronic conditions, health-promoting behaviors (HPB), and parenting stress), and environmental factors (use of personal assistant care, leisure time and social support). Multivariate regression analysis was performed to examine the child, mother, and environmental factors associated with HRQOL.

Results: The HRQOL results revealed that the physical HRQOL was higher than mental HRQOL in the sample. Longer length of disability of children and lower number of chronic conditions of mothers were significant factors of higher physical HRQOL. Lower parenting stress, more leisure time, engagement in HPB, and greater social support were significantly associated with higher mental HRQOL.

Conclusions: The levels of HRQOL of mothers of children with CP were very low and our findings suggest modifiable factors. Decreasing parenting stress, engaging in HPB, and providing social support should be considered when developing psychosocial intervention for this population.

Practice Implications: Study results may inform programs aimed at health promotion, stress reduction, and QOL improvement among parents of children with disabilities.

Introduction

Cerebral palsy (CP) is defined as a "group of permanent disorders of the development of movement and posture" resulting from non-progressive disturbances that occur in the developing fetal or infant brain. The motor disorders of CP are often accompanied by conditions such as disturbance of sensation, perception, cognition, and communication; epilepsy; and secondary musculoskeletal problems (Rosenbaum et al., 2007). As the most common physical disability in childhood (Luscombe & Courtney, 2008), CP has incidence rates ranging from 1.5 to >4 per 1000 live births (Arneson et al., 2009; Bhasin, Brocksen, Avchen, & Braun, 2006; Maenner et al., 2016; Paneth, Hong, & Korzeniewski, 2006; Van Naarden Braun et al., 2015). In Korea, the current estimated prevalence of CP among children is 3.2 per 1000 (Park et al., 2011). Among the age-specific brain injuries of Koreans, CP shows the highest incidence between the ages of 0 and 9, accounting for 57.8% of the brain injuries in this age group (Jeong, Jeong, & Bang, 2013). Technological advances in medicine and improved healthcare have greatly increased the lifespan of many children with CP over the past two decades (Eker & Tüzün, 2004). Children with chronic limitations and possible long-term dependence, such as those with CP, require substantial support (Fujiura, 2014; Raina et al., 2004). The mother frequently assumes the primary burden of taking care of such a child, but often with little or no social support (Bella, Garcia, & Spadari-Bratfisch, 2011). Moreover, in Korean families, mothers alone usually take responsibility for caring for children with a disability (Oh & Lee, 2009) and are likely to be the family members most affected by the situation (Cho & Hong, 2013). Providing the intensive care needed by children with long-term functional limitations may impact the health and quality of life of parents (Davis et al., 2010).

However, little is known about the impact of caregiving on health-related quality of life (HRQOL) among mothers of children with CP. HRQOL consists of multiple dimensions of health status and well-being (Ware Jr. & Sherbourne, 1992); it encompasses both physical and mental health and refers to the impacts of health, illness, and its

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treatment on quality of life (Ferrans, Zerwic, Wilbur, & Larson, 2005). Because it represents specific health aspects of well-being, HRQOL has been used to assess how the individual's well-being may be influenced by a disease, disability, or disorder (Bullinger, 2003). With respect to caregivers of children with CP, researchers have found that a gender difference in HRQOL exists, with female caregivers having lower HRQOL than male caregivers (Byrne, Hurley, Daly, & Cunningham, 2010).

The caregiving literature generally shows that providing care for a child with CP has potentially adverse effects on HRQOL. In fact, compared to primary caregivers for typically developing children, parents of children with CP have often been found to have lower HRQOL scores (Bella et al., 2011; Khanna et al., 2011; Ones, Yilmaz, Cetinkaya, & Caglar, 2005; Tuna, Unalan, Tuna, & Kokino, 2004). Caregiver health problems have negative implications for children, families, and the community, resulting in lower productivity and higher healthcare costs for the caregivers in addition to negative impacts on the quality of caregiving and increased services and costs for the children (Brehaut et al., 2004; Khanna et al., 2011). As such, measuring HRQOL among mothers of children with CP is important in that it could have direct implications for their health status.

To our knowledge, eight studies to date have investigated factors associated with quality of life or HRQOL in caregivers of children with CP (Byrne et al., 2010; Carona, Crespo, & Canavarro, 2013; Eker & Tüzün, 2004; Lee, Eo, & Kim, 2005; Ones et al., 2005; Raina et al., 2005; Skok, Harvey, & Reddihough, 2006; Tseng et al., 2016). Most of the studies have one or more of three key limitations: (1) they were not guided by a theory or framework, (2) they were based mainly on bivariate analyses without controlling for covariates, and thus (3) they did not simultaneously and comprehensively consider the determinants impacting caregivers' health (Tseng et al., 2016). Thus, additional research is needed to comprehensively examine the determinants of HRQOL in this population while simultaneously controlling for confounding effects.

As caregivers are strongly influenced by their children's health, functioning, and social environment (World Health Organization [WHO], 2007), it is important that caregiver health be considered in the comprehensive context of the family system. The International Classification of Functioning, Disability and Health (ICF) and the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) offer the advantages of addressing the impacts of both the child's and caregiver's characteristics on caregiver health and quality of life as well as accounting for contextual factors shared by child and caregiver (Tseng et al., 2016). Both are universal and multidimensional frameworks for health, human functioning, and disability developed by the WHO. ICF is used for adults, and ICF-CY is used for children and youth. ICF-CY includes all the contents of ICF plus additional content, but the components of the two frameworks are the same. Specifically, ICF and ICF-CY form a comprehensive classification system for how health-related conditions affect people's lives. The purpose of this system is to provide a scientific basis for understanding and studying health and health-related states, outcomes, and determinants (WHO, 2007).

As shown in Fig. 1, ICF contains components of health and health-related states to allow description of a person's functioning and disability within a dynamic interaction between health condition and contextual factors. ICF is made up of two parts. Based on the ICF definition provided by WHO (World Health Organization, 2001) the first part, functioning and disability, includes (1) body function and structure and (2) activity and participation. Body function is defined as "the physiological functions of body systems (including psychological functions)," and body structure is defined "anatomical parts of the body." Activity and participation is defined as "the execution of a task or action by an individual and involvement in a life situation." The second part of ICF, contextual factors, involves environmental factors and personal factors. Environmental factors is defined as "the physical, social and attitudinal environment in which people live and conduct their lives." Personal factors are also a component of contextual factors but is not classified in ICF because of the large social and cultural variance associated with such factors. Health condition interacts with activity but is also not classified in ICF. Notably, ICF encompasses all biopsychological aspects of the human health and health-related components of quality of life (QOL). ICF not only offers a well-integrated and standardized approach to healthcare but also serves as a framework for building a comprehensive picture of factors that may influence people's QOL (Chen, Tseng, Shieh, Lu, & Huang, 2014).

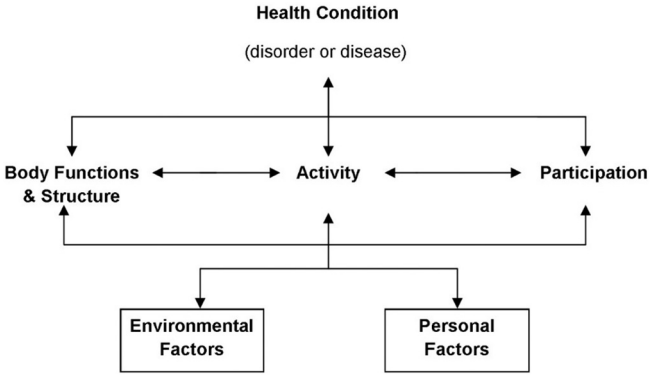

Fig. 1. The ICF/ICF-CY model including six dimensions of functioning and disability (WHO, 2007; p.18).

As noted above, to overcome the limitations of previous studies and to understand HRQOL more comprehensively, a holistic approach is called for (Tseng et al., 2016). More comprehensive analysis involving each ICF domain is necessary to encompass the factors associated with HRQOL among mothers with children having CP. That is, for both children and mothers, the ICF/ICF-CY domains of body function and structure, activity, participation, and contextual factors should be considered. Therefore, the purpose of this study was to investigate the HRQOL of mothers of children with CP in Korea and to comprehensively identify factors associated with HRQOL among these mothers. The potential factors were categorized into three groups: child characteristics, mother characteristics, and environmental factors.

Methods

Design

The specific aims of this study were met employing a descriptive, cross-sectional design involving use of self-administered questionnaires.

Sample

A convenience sample of 180 Korean mothers having children with CP was recruited from one university-affiliated hospital (53 mothers, 29.4%), four pediatric rehabilitation centers (88 mothers, 48.9%), and two special education schools (39 mothers, 21.7%) in Seoul, Gyeonggi, and Incheon Provinces in Korea.

Procedures

Study approvals were obtained from the Institutional Review Boards of one university (University of Illinois at Chicago) and one Korean university-affiliated hospital (Yonsei Medical Center) as well as from each of four Korean pediatric rehabilitation centers and two Korean special education schools. When mothers expressed interest in study participation, we confirmed that they met the inclusion criteria: that is, that they had children with CP aged 6 months to 12 years who lived with them, served as primary caregivers for their children, were able to read and understand Korean, and were willing to provide informed consent. Mothers who did not identify themselves as primary caregivers

were excluded from the study. Data collection was conducted in both clinical and school-based settings. In the two Korean special education schools, teachers usually put notes into children's bags when they have a message to caregivers (most children at the schools have intellectual or speech disabilities). The survey package which includes an information sheet, consent form and survey were delivered with notes and returned through the children's bag when mothers agreed to participate in the study. Teachers at the special education schools collected completed survey and it was delivered to the researcher. Of 242 mothers who met the inclusion criteria, 62 declined to participate due to lack of time, lack of interest in completing the survey, and other reasons. Ultimately, we recruited 180 Korean mothers who met the inclusion criteria and provided informed consent; thus, the response rate was 74.4%.

Measures

A survey was employed to measure (1) child characteristics, (2) maternal characteristics, and (3) environmental factors in addition to HRQOL as a dependent variable. All the survey instruments that were employed in the study were available in Korean.

Child Characteristics

Child characteristics measured were chosen based on the ICF-CY domains of health condition and body function and structure in addition to personal factors. For health condition, disability severity level was measured. For the disability severity level, Korea's legal disability standard for people with brain lesions was used. In Korea, rehabilitation doctors diagnose the legal disability grade of brain lesions and the level of independence of most children diagnosed with CP so they can receive government financial and social support. Grades range from 1 to 6, with 1 indicating the highest level of disability severity. For body function and structure, we identified the total number of accompanying disabilities. For accompanying disabilities, we used the survey results to determine whether or not the child had the five most common conditions: hearing problems, vision problems, speech disorders, seizures/epilepsy, and intellectual impairment. Finally, for personal factors, we identified child age, gender, and term of disability (<1 year, 1 to <3 years, 3 to 5 years, and >5 years).

Maternal Characteristics

Maternal characteristics included health condition, body function and structure, activity and participation, and personal factors. For health condition, each mother's physical health status was measured according to the number of chronic conditions she reported. The following list of 13 chronic conditions was based on a previous study that reported frequent chronic conditions of caregivers of children with CP: allergies, asthma, arthritis, back problems, cancer, diabetes, high blood pressure, heart disease, migraine/headache, sinusitis, stomach disease, sleeping problems, and other (Brehaut et al., 2004).

For body function and structure, parenting stress was measured. Parenting stress can be defined as the magnitude of stress in the parent-child system (Abidin, 1990), and we measured this factor using Stress Level of Mothers with Children with CP (SMCP) (Lee & Lee, 1997). This instrument has 44 items in six subdomains (perceived stress due to child's current status, child's treatment, child's future, perception of the child's problems, perceived family problems due to the child, and social attitudes toward the child). Two of these items were excluded because of high rates of non-applicability among participants. Mothers respond to items on a 5-point Likert scale; higher scores indicate higher stress. In Lee & Lee's, 1997 study, the SMCP's internal consistency was 0.94, and its test-retest reliability was 0.97; in our study, the Cronbach's alpha for the SMCP was 0.93.

Activity and participation were measured using Health Promoting Lifestyle Profile-II (HPLP-II). This questionnaire has 52 items that evaluate the frequency with which individuals perform activities to increase their health potential and wellness level (Acton & Malathum, 2000). The instrument contains six subscales used to measure major dimensions of a healthy lifestyle: health responsibility, physical activity, nutrition, interpersonal relations, spiritual growth, and stress management. The instrument uses a 4-point response scale; higher scores indicate that respondents achieve a healthy lifestyle more frequently. The HPLP-II's content validity and reliability have been reported for Koreans; a Cronbach's alpha value of 0.84 was reported for the total instrument score (Lee, Chang, Yoo, & Yi, 2005). In our study, the Cronbach's alpha was 0.96. Finally, personal factors measured consisted of the mothers' age, marital status (married or other), education level (less than high school, graduation of high school, graduation of college, and graduation of graduate school), religion (yes or no), monthly household income (the Korean equivalent of <1000 U.S. dollars; 1000 to <3000 dollars; 3000 to 5000 dollars; and over 5000 dollars), and employment status (yes or no).

Environmental Factors

Environmental factors measured included number of children, time constraints, personal assistant care, and social support. Time constraints were measured as mothers' caregiving time and personal leisure time in average hours per day. Personal assistant care, which is funded by the Korean government, was measured as whether or not mothers were using this service. Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) developed by Zimet et al. in 1988. This instrument measures perceived level of support from family, friends, and significant others (Zimet, Powell, Farley, Werkman, & Berkoff, 1990). The MSPSS has 12 items rated on a 5-point scale. In a study of Korean parents of children and young adults with disabilities, the Cronbach's alpha value for the total social support score was 0.88 (Im & Oh, 2014). In our study, the Cronbach's alpha was 0.95.

Health-related Quality of Life

HRQOL was measured using the Korean version of Short Form-12 version 2 (SF-12 v2). SF-12 v2 addresses eight domains of health: physical functioning (PF), role limitations due to physical health (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role limitations (RE), and mental health (MH) (Ware Jr., Kosinski, & Keller, 1996). The self-report scores for subjective physical health status are the PF, RP, BP, and GH scores, and those for subjective mental health status are the VT, SF, RE, and MH scores. Psychometric properties of the Korean SF-12 v2 were evaluated for the Korean general population (Kim et al., 2014); the Cronbach's alpha values were 0.83 for physical HRQOL and 0.79 for mental HRQOL. In our study, the Cronbach's alpha values were 0.77 for physical HRQOL and 0.84 for mental HRQOL.

Data Analysis

We performed all statistical analyses using SPSS Statistics version 18 (SPSS Inc., 2009). Descriptive statistics (means, standard deviations [SD], and frequencies) were employed to describe child and maternal characteristics and environmental factors. A Cronbach's alpha value was estimated for each scale. Multivariate linear regression was applied to identify significant factors associated with HRQOL. A two-sided $p \leq .05$ was considered to be statistically significant. For sample size, we followed Cohen's guideline for describing effect size (Cohen, 2009). Using a power calculation program, we calculated the required sample size for the study as 153 to achieve a power of 0.80, an effect size of 0.15, and a significance level of 0.05 with 19 factors for multivariate linear regression (Faul, Erdfelder, Lang, & Buchner, 2007). Therefore, the total sample size of 180 met applicable requirements.

Results

Sample Characteristics

Table 1 shows characteristics of the children with CP. The children's mean age was 6.38 years (SD = 3.19 years) (range 10 months-12 years). About 69% of the children had one or more accompanying disabilities. Speech disability was the most frequent (53.9%), followed by intellectual disability (32.8%). Most children (61.1%) had been diagnosed with first-degree disability, which is the most severe of the six disability levels. About half of the children (52.8%) had been diagnosed with CP 5 or more years previously.

Tables 2 and 3 show maternal characteristics and environmental factors. The participants' mean age was 39.7 years (SD = 4.7), and ages ranged from 27 to 56 years. Most participants were married (94.4%) and highly educated (68.3% had a college degree or above), and about 39% of participants had a monthly income less than approximately 3000 U.S. dollars. Among the participants, the mean number of chronic conditions was 2.13 (SD = 1.91), and 80.6% had more than one chronic condition. Back pain was the most frequent condition (47.2%), followed by migraine/headache (40%) and sleep problems (26.1%). Regarding environmental factors, 67.8% of participants had more than one child, and 43.3% were receiving respite support. The mean score for social support was 3.28 (SD = 0.86). Participants reported an average of 1.63 h (SD = 1.5) per day for personal leisure time was and 14.8 h (SD = 6.3) per day for caregiving. The mean mental HRQOL score was lower (M = 40.73, SD = 10.6) than the mean score for physical HRQOL (M = 44.52, SD = 8.0).

Multiple Regression Analyses

Results of multiple regression using physical HRQOL and mental HRQOL as the dependent variables and 19 factors are presented in Table 4. The two overall models with all 19 factors were statistically significant and explained 37% of the variance for prediction of physical HRQOL and 55% of the variance for prediction of mental HRQOL. In the physical HRQOL model, mothers with fewer chronic conditions ($t = -5.33$, $p < .001$) and mothers of children with longer terms of disability ($t = 2.02$, $p < .05$) showed higher physical HRQOL. Factors associated with mental HRQOL differed from those for physical HRQOL. Specifically, higher mental HRQOL was associated with lower parenting stress ($t = -4.75$, $p < .001$), more leisure time ($t = 2.37$. $p < .05$), engagement in health-promoting behaviors ($t = 2.05$, $p < .05$), and greater social support ($t = 3.98$, $p < .001$).

Table 1
Children characteristics (N = 180).

	N (%)	Mean (SD)
Age (years)		6.38 (SD: 3.19)
Gender (one datum missing)		
Male	98 (54.4%)	
Female	81 (45.0%)	
Accompanying disabilities[a]		
Hearing	10 (5.6%)	
Vision	27 (15.0%)	
Speech	97 (53.9%)	
Epilepsy/seizure	55 (30.6%)	
Intellectual	59 (32.8%)	
Number of accompanying disabilities		
1	50 (27.8%)	
2	33 (18.3%)	
3	32 (17.8%)	
None	56 (31.1%)	
Korean legal standard for categorizing disability severity		
1st	110 (61.1%)	
2nd	14 (7.8%)	
3rd	19 (10.6%)	
4th	8 (4.4%)	
5th	8 (4.4%)	
6th	5 (2.8%)	
Not diagnosed	13 (7.2%)	
Not known	3 (1.7%)	
Term of disability		
<1 year	17 (9.4%)	
1 year to <3 years	42 (23.3%)	
3 years to <5 years	26 (14.4%)	
≥5 years	95 (52.8%)	

[a] All applicable conditions identified.

Table 2
Maternal characteristics (N = 180).

	N (%)	Mean (SD)
Age (years)		39.7 (4.70)
Marital status		
Married	170 (94.4%)	
Other (partnered/divorced/widowed)	10 (5.6%)	
Religion		
Yes	123 (57.2%)	
No	77 (42.8%)	
Education		
Less than high school	5 (2.8%)	
Graduate of high school	52 (28.9%)	
Graduate of college	112 (62.2%)	
Graduate of graduate school	11 (6.1%)	
Occupation		
Yes	31 (17.2%)	
No, or on leave from occupation	149 (82.8%)	
Income		
<1000 dollars	11 (6.1%)	
1000 to <3000 dollars	59 (32.8%)	
3000 to 5000 dollars	72 (40.0%)	
>5000 dollars	38 (21.1%)	
Number of chronic conditions[a]		2.13 (1.91)
0	35 (19.4%)	
1	48 (26.7%)	
2	38 (21.1%)	
>3	59 (32.8%)	
3 frequently reported chronic conditions[a]		
Back pain	85 (47.2%)	
Migraine/headache	72 (40.0%)	
Sleep disorders	47 (26.1%)	
Parenting stress		3.44 (0.62)
Health-promoting behaviors		1.96 (0.45)

[a] All applicable conditions identified.

Discussion

This study investigated the level of HRQOL among mothers of children with CP and evaluated the impacts of child, maternal, and environmental factors on HRQOL of mothers using the ICF framework. Results showed that the level of HRQOL of the mothers in the sample was very low: the mean physical HRQOL was 44.5 (SD = 8.0), and the mean mental HRQOL was 40.7 (SD = 10.6). For comparison, in the general population aged 30 to 39 years in Korea, the mean physical HRQOL

Table 3
Environmental factors and HRQOL (N = 180).

	N (%)	Mean (SD)
Number of children		1.92 (0.82)
1	58 (32.2%)	
2	86 (47.8%)	
3	30 (16.7%)	
>3	6 (3.3%)	
Use of personal assistant care		
Yes	78 (43.3%)	
No	102 (56.7%)	
Social support		3.28 (0.86)
Personal leisure time per day (hour)		1.63 (1.5)
Caregiving time per day (hour)		14.8 (6.3)
Physical HRQOL		44.5 (8.0)
Mental HRQOL		40.7 (10.6)

Table 4
Multiple regression for variables predicting HRQOL (N = 180).

	Physical HRQOL			Mental HRQOL		
	B	SE	*t*	B	SE	*t*
Children characteristics						
Age of child	−0.25	0.30	−0.83	−0.02	0.33	−0.06
Gender of child	−0.88	1.16	−0.75	−1.34	1.26	−1.06
Severity of disability	0.12	0.47	0.27	−0.02	0.51	−0.04
Term of disability	1.79	0.89	2.02*	−1.11	0.96	−1.15
Number of accompanied disorders	0.12	0.53	0.23	0.36	0.58	0.62
Maternal characteristics						
Age of mothers	−0.07	0.16	−0.45	−0.004	0.17	−0.03
Income	0.30	0.76	0.39	0.55	0.82	0.67
Education level	1.23	1.01	1.21	−0.97	1.10	−0.88
Marital status	−1.98	2.71	−0.73	2.95	2.94	1.00
Employment	1.15	1.42	0.81	0.34	1.54	0.22
Religion	0.58	1.21	0.48	−2.10	1.31	−1.60
Number of chronic conditions	−1.82	0.34	−5.33***	−0.11	0.37	−0.29
Parenting stress	−2.10	1.21	−1.74	−6.24	1.31	−4.75***
Health-promoting behaviors	1.28	1.63	0.79	3.62	1.77	2.05*
Environmental factors						
Number of children	−0.94	0.76	−1.20	0.97	0.82	1.18
Use of personal assistant care	−1.96	1.32	−1.48	2.08	1.44	1.45
Caregiving time	−0.60	1.22	−0.49	0.51	1.33	0.39
Leisure time	0.64	1.20	0.53	3.07	1.30	2.37*
Social support	−0.09	0.89	−0.11	3.84	0.96	3.98***
	$R^2 = 0.37$, F = 4.30, p < .001			$R^2 = 0.55$, F = 9.14, p < .001		

* p < .05.
*** p < .001.

and mental HRQOL were 54.3 and 53.5, respectively (Kim et al., 2014). A three-point or more difference in mean summary scores is considered clinically significant (Ware et al., 2008). Given the known adverse impact of caregiving responsibilities on health outcomes of mothers of children with CP, it was not surprising that mothers in our study had HRQOL lower than the Korean norm. The low HRQOL scores observed in mothers of children with CP indicate that the mothers constitute an at-risk population.

We found that HRQOL was determined by a number of variables within the child characteristics, maternal characteristics, and environmental factors categories. This finding is consistent with a previous study which found that determinants of QOL of caregivers of children with CP were influenced by factors associated with all three categories, which demonstrates the multidimensional influences on HRQOL of caregivers of children with CP (Tseng et al., 2016). However, the determinants within the child characteristics, maternal characteristics, and environmental factors categories varied between physical HRQOL and mental HRQOL. For physical HRQOL, one child characteristic, term of disability, and one maternal characteristic, number of chronic conditions, were significant determinants. None of the environmental factors were significant determinants of physical HRQOL. On the other hand, for mental HRQOL, child characteristics were not significant determinants, but two maternal characteristics, parenting stress and health-promoting behaviors, as well as two environmental factors, social support and leisure time, were significant determinants.

Regarding the significant determinants of physical HRQOL in this study, the only significant child characteristic was term of disability. That is, a longer term of disability predicted a higher physical HRQOL among mothers of children with CP. To our knowledge, no previous research has investigated use of children's term of disability to predict HRQOL of mothers of children with CP, and thus it is difficult to compare our finding with previous study results. One plausible explanation for our finding is that as the term of disability is prolonged, mothers adjust to their caregiving activities and their physical health QOL improves. A previous study suggested that parents were typically overwhelmed in the initial stages of their adjustment to their children's diagnosis with CP (Piggot, Hocking, & Paterson, 2003). Another potential explanation is that up to the point of adolescence, the aging that accompanies a longer term of disability may make children less dependent on their mothers for physical assistance, again resulting in the mothers' improved physical health QOL. One previous study suggested that the parental impact of having a child with CP may change depending on the child's age (Lin, 2000).

The severity of disability of children is one important factors associated with HRQOL in caregivers of children with CP. In this study, however, severity of disability was not found to be a significant HRQOL determinant for mothers of children with CP. To date, the findings on severity of disability have been inconsistent across studies. For example, a clinical assessment tool measuring the functional mobility of children with disabilities, the Gross Motor Function Classification System (GMFCS), has been used to assess severity of disability for children with CP (Skok et al., 2006). While some studies reported that a better GMFCS grade predicted higher HRQOL (Dehghan, Dalvand, Feizi, Samadi, & Hosseini, 2014; Eker & Tüzün, 2004), other studies using the GMFCS (Ones et al., 2005; Tuna et al., 2004) or an independence level based on GMFCS grade (Byrne et al., 2010) did not predict HRQOL of caregivers of children with CP. However, these findings should be cautiously interpreted because except for Dehghan et al. (2016), previous researchers employed small sample sizes and comparative designs and did not include covariates. Further research employing larger sample sizes with covariates is needed to more conclusively evaluate the impact of severity of disability of children with CP on mothers' HRQOL.

As expected, the mother's number of chronic conditions was a significant determinant of physical HRQOL in the study. The prevalence of chronic conditions was high, with 80.6% of mothers reporting one or more. Among the chronic conditions listed, back pain was the most prevalent (47.2%), followed by migraine/headache (40%). These findings are consistent with those of Brehaut et al. (2004), who reported that 35.5% of Canadian caregivers of children with CP had back problems and 24.2% had migraines/headaches. In particular, because many children with CP need physical assistance with their daily activities such as mobility, dressing, and bathing (Raina et al., 2005), their caregivers have a high risk of musculoskeletal disorders. In fact, one study showed that caregivers of children with CP had a higher prevalence of musculoskeletal disorders than caregivers of healthy children (Kaya et al., 2010). Another study reported that the prevalence of lower back pain (80.3%) was significantly higher for female caregivers of children with physical disabilities than the prevalence (40.5%) when children did not require physical assistance with transfers (Tong et al., 2003). However, there is a scarcity of research on caregiving-related chronic conditions such as musculoskeletal disorders among caregivers of children with physical disabilities, including CP. As such, a scientific foundation, such as population-based studies addressing the prevalence of caregiving-related chronic conditions and caregiving characteristics, is needed to inform policies and interventions for such caregivers.

Regarding mental HRQOL determinants for mothers of children with CP, parenting stress was a significant determinant. In general, the findings for the parenting stress-HRQOL relationship in parents of children with disabilities are varied, and different measures have been used to obtain them. Previous studies indicated that parenting stress was inversely associated with quality of life (Cho & Hong, 2013), physical health (Johnson, Frenn, Feetham, & Simpson, 2011), mental health (Tseng et al., 2016), and both physical and mental health (Huang, Chang, Chi, & Lai, 2014). In addition, high parenting stress has been associated with low parenting satisfaction (Wanamaker & Glenwick, 1998) and decreased well-being (Raina et al., 2005; Skok et al., 2006). Furthermore, the ways that parents deal with their stress may adversely affect their parenting ability, which in turn can lead to difficulties in the child such as behavior problems, which may lead to more parenting stress (Ketelaar, Volman, Gorter, & Vermeer, 2008).

Despite the known beneficial influence of health-promoting behaviors on HRQOL, no previous studies have examined health-promoting behaviors as a determinant of HRQOL among mothers of children with CP. In this study, health-promoting behaviors were found to be a significant determinant of mental HRQOL. Researchers have consistently found that engaging in health-promoting activities is linked to increased general physical and mental well-being (Pender, Murdaugh, Parsons, et al., 2006; Savoy & Penckofer, 2014; Uphold, Holmes, Reid, Findley, & Parada, 2007). Indeed, health-promoting behaviors were shown to be positively correlated with HRQOL among female caregivers of older family members (Lo, 2009). Even though many researchers have found that engaging in health-promoting activities is an essential self-care activity to increase general health status and quality of life (Acton & Malathum, 2000), the demands of parenting children with disabilities may prevent mothers from engaging in such activities. This may be the case because mothers spend so much time providing care for children with disabilities that they have little time or energy to engage in health-promoting behaviors (Kuster, Badr, Chang, Wuerker, & Benjamin, 2004).

Providing care to children with disabilities may hinder mothers from engaging in health-promoting behaviors. For example, mothers of children with CP are prone to sleep problems. As many children with CP have sleep disorders due to associated conditions such as seizures, motor impairment, or pain, their caregivers are also likely to experience sleep disturbance as a result of providing night-time care (Adiga, Gupta, Khanna, Taly, & Thennarasu, 2014). By way of contrast, in one study, mothers of children with disabilities who slept uninterrupted were found to participate in health-promoting activities more frequently and experience higher mental quality of life than peers with more interrupted sleep (Bourke-Taylor, Pallant, Law, & Howie, 2013). Also, caregiving may reduce the energy level of caregivers of children with CP, as higher fatigue levels have been observed in this population compared to caregivers of typically developing children. Fatigue also has been correlated with greater depression and lower quality of life among caregivers of children with CP (Garip et al., 2017). Given these findings, mothers of children with CP may have little time, energy, or motivation to pursue health-promoting behaviors.

Among the environmental factors considered, our results also highlight the influence of social support and personal leisure time on mental HRQOL. First, we found that social support was a significant determinant of mental HRQOL. Social support has been established as a major determinant of caregiving adjustment for children with chronic physical conditions (Carona et al., 2013; Wallander & Varni, 1989), as social support can provide a buffer against stressful life events and is related to well-being, especially for persons under stress (Skok et al., 2006). Furthermore, previous studies have consistently suggested that social support is associated with several outcome variables among caregivers of children with disabilities, including maternal stress (Shin, 2002), maternal well-being (Raina et al., 2005; Skok et al., 2006), QOL (Cho & Hong, 2013), and HRQOL (Khanna et al., 2011; Marchal, Maurice-Stam, Hatzmann, van Trotsenburg, & Grootenhuis, 2013). In addition to social support, mothers with more personal leisure time showed higher mental HRQOL in this study. This result is consistent with a previous finding that having enough personal time significantly predicted HRQOL among parents of children with disabilities (Marchal et al., 2013). It is notable that mothers in our sample averaged only 1.63 h per day of leisure time but averaged 14.8 h per day of caregiving time; these findings indicate that they had insufficient time for self-care activities or rest, which may have resulted in decreased mental HRQOL. A previous study also suggested that time pressure was a significant predictor of maternal depression symptoms among mothers of children with CP (Sawyer et al., 2011).

These findings are important for several reasons. First, they demonstrate the importance of including comprehensive determinants based on the ICF framework in research, as children's and mothers' characteristics and environmental factors could be identified and their interactions controlled for. For example, mothers lacking social support would have difficulty finding time to be involved in health-promoting behaviors, and thus such mothers are more likely to compromise their health and quality of life. Also, when children in disadvantaged families lacking access to resources have an acute illness or chronic condition, this additional layer of complexity negatively impacts the caregivers' quality of life (Christian, 2017). In Korea, mothers are more likely to rely on family members for informal support in caring for their children with disabilities or when they face problems than on external sources of formal support (Shin, 2002). For this reason, professional support and formal services should be made readily available to mothers and other caregivers of children with CP. Davis et al. (2010) found that parents of children with CP in the U.S. experienced insufficient support from formal services and felt that they had to be extremely proactive and work very hard to find the services they needed (Davis et al., 2010). These difficulties may be even greater for mothers of children with CP in Korea, where strong social stigma toward people with disabilities can motivate families to rely on informal sources of social support (Shin, 2002). In fact, Shin (2002) found that Korean mothers had less informal and professional support than American mothers and that Korean mothers experienced more stress (Shin, 2002).

The study findings have practical implications for health professionals, researchers, and policymakers. First, healthcare providers should recognize their collective professional responsibility to monitor the well-being of caregivers of children with disabilities. In particular, health professionals working with children with disabilities in healthcare, community, and home settings are ideally situated to assess the health status of caregivers. As these personnel become familiar with individual children and caregivers during multiple interactions over time, they can provide education and advice about the importance of health maintenance, assess healthcare needs, and provide support such as recommending preventive healthcare services or providing referrals if necessary. In addition, as noted earlier, psychosocial issues such as parenting stress have been consistently identified among caregivers of children with CP. However, a 2017 integrative review revealed that healthcare providers still primarily focused on patient disease and treatment rather than on family-centered care. Based on this finding, providers need to develop more comprehensive perspectives toward psychological and social determinants of health for families of children with chronic conditions or serious illness (Tallon, Kendall, Priddis, Newall, & Young, 2017).

Moreover, researchers should give greater attention to developing interventions to promote health and quality of life for caregivers of children with disabilities. While a growing body of research has shown the adverse effects of caregiving on health outcomes among caregivers of children with disabilities, intervention research for these caregivers, particularly on their physical health outcomes, has been very limited. Additional, rigorous interventions that reflect caregivers' life context, such as home-based programs that accommodate their lack of time, should be developed and evaluated.

Finally, the study findings have important implications for provision of services for children with disabilities such as CP and their families. As noted earlier, it is typically difficult for caregiving mothers to reserve time for themselves, and formal services such as respite care can help to relieve their caregiving burden. For example, previous studies found that respite care services providing temporary relief from caregiving responsibilities reduced maternal stress and depression (Chan & Sigafoos, 2001; Herman & Marcenko, 1997). In addition, from the public health perspective, the health of caregivers of children deserves more attention. Parents of children with disabilities are typically subjected to longer periods of caregiving responsibility than caregivers of older family members because the children typically live longer (Talley & Crews, 2007). Moreover, it is important to recognize that the health risks faced by caregivers of children with disabilities may be underestimated because they are relatively young and are able to employ strategies that effectively mask the progression to the negative health effects of middle age and beyond (Jackson, Knight, & Rafferty, 2010). Public policies that support interventions to prevent and reduce

health problems for these caregivers would improve their HRQOL, realize savings in health care costs, and enhance the quality of the caregiving role.

Limitations

This study has several limitations that should be acknowledged. First, this study did not include a control comparison. Future studies should include caregivers of typically developing children to allow comparisons of HRQOL between groups and confirm HRQOL determinants. Second, use of a cross-sectional design did not allow us to establish causal relationships between the determinants identified and HRQOL. Longitudinal research examining changes in physical and mental quality of life is needed to assess differences in mothers' caregiving adjustments over time. In addition, cultural differences between Korean and Western societies could limit the generalizability of our findings. Korean society has been highly influenced by Confucianism, under which the strong sense of collective identity may result in greater social stigma for families having children with disabilities than is typically found in Western societies (Choi, Park, & O'Brien, 2017). Moreover, Korean mothers of children with disabilities are expected to devote themselves to caring for the children with limited formal support. Thus, mothers of children with disabilities in Korea may be more likely to experience parenting stress and low mental quality of life than their Western counterparts. Finally, our participants were recruited from clinical settings and special education schools. This fact may have impacted the characteristics of the children involved in this study, which could lead to recruitment of more severe degree of disability of the children with CP.

Conclusions

In spite of its limitations stated above, this study also has strengths related to generalizability and methodological matters. In previous studies of caregivers of children with CP, data have mainly been collected in clinical settings, but this study combined data obtained in both clinical and community-based settings to more fully represent the study population. Also, our study's response rate was about 74.4%, which is relatively high; moreover, because one of our data collection sites was the hospital serving the largest number of children with CP in Korea, our participants came from all regions of the country. In addition, this study simultaneously took into account factors from the entire scope of the ICF framework while controlling for confounders. This approach allowed us to comprehensively examine potential and identified determinants of child characteristics, maternal characteristics, and environmental factors associated with HRQOL.

Our study identified the level of HRQOL and significant HRQOL determinants among mothers of children with CP. Our findings add to the body of literature indicating that the low HRQOL of mothers of children with CP is an important public health concern that must be taken seriously. The results of this study indicate that the HRQOL of these mothers was determined by multidimensional variables, including child characteristics, maternal characteristics, and environmental factors. As such, this study's findings comprehensively identify the multidimensional influences on HRQOL of mothers of children with CP.

Author Statement

All authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, all authors certify that this material or similar material has not been submitted.

Conflict of Interest

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A statement on ethical approval

Study approvals were obtained from the Institutional Review Boards of one university (University of Illinois at Chicago, approval number: 20151218-93866) and one Korean university-affiliated hospital (Yonsei Medical Center, approval number: 4-2016-0083) as well as from each of four Korean pediatric rehabilitation centers and two Korean special education schools.

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