



# Factors influencing quality of life in caregivers of adolescents with developmental disabilities

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## ABSTRACT

**Objectives:** Caring for adolescents with developmental disabilities (DD) is stressful and challenging, and mothers usually provide care for these children in Korea. This study aimed to identify factors influencing quality of life (QoL) in mothers of adolescents with DD.

**Methods:** A predictive design was used. Data were collected from a web-based survey administered to a convenience sample of 154 mothers of adolescents with DD from October to November 2020. Data were analyzed using the t-test, analysis of variance, Pearson correlation coefficients, and multiple regression.

**Results:** Perceived health, depression, and family strength were significantly correlated with QoL. Multiple regression showed that family strength, perceived health, depression, and monthly household income influenced the participants' QoL, and these factors accounted for 69.2% of variance in QoL. Family strength was the factor most strongly affecting QoL ( $\beta = 0.39$ ).

**Conclusion:** The study results indicate that health professionals and policy-makers need to pay attention to the overall QoL and physical and psychological health of mothers of adolescents with DD. Since our findings raise the importance of family strength in the QoL of this population, programs to improve family strength need to be implemented and strengthened. Interventions to improve perceived health and decrease depression should be applied, and knowledge on adolescent characteristics and changes should be delivered to caregivers when providing education and consultations. The findings will be helpful for developing educational and counseling programs for this population.

Received: June 28, 2021

Revised: April 17, 2022

Accepted: July 27, 2022

**Keywords:** Adolescent; Caregivers; Developmental disabilities; Quality of life

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## Introduction

The Korean Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities defines “persons with developmental disabilities” as persons with intellectual disabilities (ID), persons with autism spectrum disorder, and persons that are otherwise severely impaired in social and daily functioning due to arrested or delayed processes of

normal development. The Act explicitly stipulates that respecting persons with developmental disabilities (DD) and ensuring their welfare is a responsibility that extends beyond the state, local governments, and public programs to all citizens [1]. However, if recent events involving persons with DD are any indication, both the Korean government and the general public appear to have largely failed in this legally-mandated responsibility. Last year, a child with DD and his mother, despairing of their circumstances, took their own lives [2]. More recently, a woman in her 50s, caring for a daughter with DD, also made the fatal decision to take her own life [3]. These tragic testaments to the struggles of families with children with DD highlight the urgent need for increased public support for this population.

Children with DD are most often cared for by family members, and families with children with DD have been reported to have lower levels of adaptability and cohesion than families with typically developing (TD) children [4]. In households with adolescents with ID, caring for these children and the financial burden this places on the family have a particularly strong negative impact on various aspects of family life, including family function, atmosphere, and sibling relationships [5,6]. Boehm et al. [7] reported that the families of children with ID and/or autism spectrum disorder in the transitional period are in great need of support. According to Eo and Yoo [8] family strength, which means positive aspects of family characteristics such as bonding between family members, problem-solving strategies, and conversation skills, helps family members lead healthy lives. Therefore, family strength and the quality of life (QoL) of caregivers of adolescents with DD deserve attention, but research on this topic is scarce.

Caring for children with DD also has an impact on caregivers' health. Burke and Fujiura [9] noted that the health conditions of caregivers of persons with ID or DD were significantly poorer than those of noncaregivers. Another previous study [10] also found that parents of children with DD experience sleep deprivation and other stressors that have negative consequences on their health. Perceived health, which is an individual perception of one's own health, affects one's QoL and has been recognized as an important indicator in the assessment of health needs [11], as self-rated health has been reported to be consistent with one's objective health status [12].

Parents of children with DD experience high levels of caregiver stress [13] and struggle with mental health problems such as depression and anxiety [9,10,13–15], and they are further reported to face a higher caregiving burden and have a lower QoL [16]. According to Boo et al. [17], depression has a negative effect on QoL of mothers caring

for adult children with DD, mediating the negative effect of care burden on the QoL of this population. Furthermore, Patton et al. [13] found that high levels of caregiving stress among caregivers of adolescents with ID increase with the age of the caregiver, thereby suggesting the need for special attention to physical and mental health in caregivers, especially in caregivers of adolescents with DD.

Several previous studies in children with DD have reported that mothers tend to be the primary caregivers [4,6,16,18,19], and mothers of adolescents with or without DD are often women of middle age undergoing various physical and mental changes due to aging and menopause [19]. These findings underscore the fact that mothers of adolescents with DD tend to face greater caregiving challenges than middle-aged women in general or mothers of nonadolescents with DD. Therefore, examining factors influencing QoL in mothers of adolescents with DD and determining the needs of this group from the perspective of health science may offer new and potentially important insights into the field.

QoL is defined as an overall assessment of well-being that is composed of 3 elements: an objective description of life conditions, a subjective feeling of well-being (including physical, material, social, emotional well-being, and the extent of personal development and activity), and a set of personal values that are applied as weights of the previous 2 elements [20]. Furthermore, physical, material, social, and emotional well-being, as well as the extent of personal development and activity, include a variety of sub-concepts; for example, physical well-being includes health, fitness, and mobility, and social well-being includes family life, acceptance and support. Therefore, this predictive study aimed to identify factors influencing QoL in mothers of adolescents with DD through a comprehensive examination of key components of QoL, including physical, mental, and social health. The specific objectives of this study were (1) to assess QoL, perceived health, depression, and family strength; (2) to examine correlations between QoL, perceived health, depression, and family strength; (3) and to determine predictive factors influencing the QoL of mothers caring for adolescents with DD.

## Materials and Methods

### Participants

Participants were recruited with the help of 2 organizations in South Korea: the Korea Association of Persons with Developmental Disabilities and the Mothers with Children with Developmental Disabilities Association, through the convenience sampling process. Because no nationwide list of mothers of children with DD in adolescence existed,

the author contacted the above 2 organizations, which have contact lists of members who are mothers caring for children with DD. These organizations have their headquarters in 2 separate metropolitan cities, respectively, and have branches nationwide. The inclusion criteria were mothers who were caring for adolescents with DD (with adolescent criteria including attendance at middle or high school or age between 13 and 20 years) and who were able to understand the survey questions without assistance. A call for participation was transmitted to the heads of the 2 associations, along with the online survey questionnaire so that the project could be publicly announced to the members of the respective organizations. Those who wished to participate in the study were invited to access the survey website at their convenience and to complete the survey. On the first page of the online survey, information about the purpose of the study, inclusion and exclusion criteria, the number of total questions and the general process of the survey, and confidentiality and voluntary participation was given. Prior to the start of the survey, participants checked a box to confirm their voluntary consent to participate in this study. In total, 154 participants were included in the final sample.

### Instruments

Sixteen items elicited information on the general characteristics of the participants, including the mother's age, marital status, and job, and the child's sex, age, disability type and rating, birth order, school level and type, health issues, and medication. Based on previous research, items on household income, caregiving hours, and discussions about child rearing [16,17,21] were included.

### Quality of life

QoL was measured using the Korean version of the World Health Organization Quality of Life Instrument, Brief Scale developed by Min et al. [22]. The 26-item instrument consists of general QoL items and domains of physical, psychological, social, and environmental health. All items were measured on a 5-point scale, with higher scores indicating higher QoL. The internal reliability of the Korean version of this tool at the time of development was shown by a Cronbach's  $\alpha$  value of 0.90, and Cronbach's  $\alpha$  was 0.95 in this study.

### Perceived health

Perceived health was measured with a visual analogue scale, which is widely used to assess pain or measure the severity of a patient's symptoms in clinical settings [23]. In this study, the scale was adapted to suit the online survey

environment. Participants were asked to rate their perceived health on a scale of 0 to 10, with 0 representing "very poor" and 10 "excellent." Higher scores indicate a better perceived health status.

### Depression

Depression was measured using the Korean Depression and Anxiety Scales developed by Choi et al. [24]. This 12-item instrument using a 5-point Likert scale, with 0 representing "not at all true" and 4 "very true," assigns scores from 0 to 48. Higher scores indicate greater severity of depression. The cut-off point of this instrument is 14. The internal reliability of the tool was shown by Cronbach's  $\alpha$  values of 0.95 at the time of development and 0.93 in this study.

### Family strength

Family strength was measured using the Korea Family Strength Scale developed by Eo and Yoo [8]. This 34-item tool consists of 4 sub-domains, including family engagement, communication, value system, and adaptability. Each item is measured using a 5-point Likert scale in which answers range from "not at all true" (1 point) to "very true" (5 points), with total scores of 34 to 170, and higher scores indicate higher family strength. In the work of Eo and Yoo [8], the internal reliability of all items was shown by a Cronbach's  $\alpha$  value of 0.94, and according to research by Hong and Han [25], the overall internal reliability of the tool was demonstrated by a Cronbach's  $\alpha$  value of 0.98. In this study, Cronbach's  $\alpha$  was 0.98.

### Data Collection

Data were collected from October to November 2020. G\*Power 3.1.9.7 [26] was used to estimate a suitable sample size with power ( $1-\beta$ ) set at 0.90, a 2-tailed significance level ( $\alpha$ ) of 0.05, and a medium regression effect size of 0.15. Three independent variables were used for this calculation, along with 3 general characteristics, which in previous studies [21] have been shown to be factors influencing the QoL. The calculation resulted in a sample of 123, and considering a 10% dropout rate, the required sample size was 135. Out of 220 questionnaires answered, 64 containing multiple answers or those completed by mothers outside of the target group were discarded. Of the remaining 156, 154 were retained for further analysis after discarding 2 that showed abnormal values. As this more than satisfied the size calculated using the G\*Power program, the sample size used in this study was adequate.

### Data Analysis

The data were analyzed using IBM SPSS ver. 25.0 (IBM

Corp., Armonk, NY, USA). The general characteristics of participants, perceived health, depression, family strength, and QoL were presented as frequencies and percentages and as means and standard deviations. The t-test, F-test, and Scheffé test were performed to test for differences in perceived health, depression, family strength, and QoL according to participants' general characteristics. Meanwhile, Pearson correlation coefficients were used to measure correlations between perceived health, depression, family strength, and QoL, and stepwise multiple linear regression was used to determine factors influencing QoL.

### Ethical Considerations

This study was conducted after receiving permission from the Institutional Review Board of Kyungpook National University (IRB No: 2020-0094).

## Results

### General Characteristics of Participants

More than half of the participants were over 47 years old, most participants had a spouse or a live-in partner (89.6%), and 53.2% were currently employed. The average monthly household income was 4.39 million Korean won, with 61.7% having an income of less than the average. Slightly more than half (51.9%) of participants spent more than 12 hours per day caregiving, and the majority (88.3%) discussed the concerns of caregiving with others. Among 154 children, 70.8% were boys, and 56.5% were age 16 or higher; 50% had ID, 40.3% had autism, and 9.7% had both ID and autism; 51.9% had grade 1 disabilities, 38.3% had grade 2, and 9.7% had grade 3; 54.5% were firstborn; 54.5% were enrolled in an elementary or middle school and 45.5% were in high school or higher-level institutions; 43.5% attended special classes in regular school, while the remaining attended special schools or other types of alternative schools; 25.3% needed full support in activities of daily living (ADL), 33.1% needed a lot of help, and the rest required little support; and finally, 34.4% had health issues, while 48.1% were on medication for health issues (Table 1).

### Differences in Perceived Health, Depression, Family Strength, and QoL According to General Characteristics

Participants with a monthly household income of less than 4.39 million Korean won ( $t = -5.16, p < 0.001$ ) and with firstborn children ( $t = -2.27, p = 0.025$ ) reported statistically lower scores in QoL, while those who discuss caregiving concerns with others showed significantly higher QoL scores than those who did not ( $t = 3.01, p = 0.003$ ). Perceived

**Table 1.** Differences in perceived health, depression, family strength, and quality of life by general characteristics (n = 154)

Variable	Category	n (%)	Mean ± SD (range)		Perceived health		Depression		Family strength		Quality of life	
			Mean ± SD	SD	Mean ± SD	t or F(p)	Mean ± SD	t or F(p)	Mean ± SD	t or F(p)	Mean ± SD	t or F(p)
Mother's age (y)	<47	69 (44.8)	47.18 ± 4.07	5.61 ± 2.11	0.92 (0.360)	1.04 ± 0.86	0.81 (0.419)	2.91 ± 0.82	1.18 (0.238)	2.98 ± 0.68	1.39 (0.167)	
	≥47	85 (55.2)	(37-60)	5.28 ± 2.26		0.93 ± 0.77		2.75 ± 0.85		2.83 ± 0.62		
Spouse	Yes	138 (89.6)		5.47 ± 2.17	0.70 (0.482)	0.96 ± 0.80	-0.85 (0.397)	2.86 ± 0.85	1.70 (0.092)	2.92 ± 0.64	1.08 (0.283)	
	No	16 (10.4)		5.06 ± 2.46		1.14 ± 0.91		2.49 ± 0.69		2.73 ± 0.74		
Job	Yes	82 (53.2)		5.57 ± 2.06	-0.873 (0.384)	0.85 ± 0.73	2.12 (0.036)	2.82 ± 0.83	0.002 (0.998)	2.95 ± 0.64	-1.06 (0.293)	
	No	72 (46.8)		5.26 ± 2.34		1.13 ± 0.88		2.82 ± 0.86		2.84 ± 0.66		
Household income, x10 <sup>4</sup> KRW (mo)	<439	95 (61.7)	439.29 ± 296.68	5.25 ± 2.21	-1.27 (0.207)	1.07 ± 0.85	1.78 (0.077)	2.57 ± 0.75	-5.11 (<0.001)	2.70 ± 0.58	-5.16 (<0.001)	
	≥439	59 (38.3)	(80-3,000)	5.71 ± 2.15		0.83 ± 0.72		3.23 ± 0.83		3.21 ± 0.64		
Caregiving hours (d)	<12	74 (48.1)		5.82 ± 1.95	2.18 (0.031)	0.75 ± 0.75	-3.48 (0.001)	2.81 ± 0.85	-0.16 (0.873)	2.99 ± 0.65	1.76 (0.081)	
	≥12	80 (51.9)		5.06 ± 2.35		1.19 ± 0.81		2.83 ± 0.83		2.81 ± 0.64		
Discussion with others	Yes	136 (88.3)		5.43 ± 2.17	0.08 (0.935)	0.93 ± 0.80	-2.11 (0.037)	2.88 ± 0.85	3.88 (0.001)	2.95 ± 0.65	3.01 (0.003)	
	No	18 (11.7)		5.39 ± 2.43		1.35 ± 0.80		2.34 ± 0.51		2.47 ± 0.50		

(Continued to the next page)

Table 1. Continued

Variable	Category	n (%)	Perceived health		Depression		Family strength		Quality of life	
			Mean±SD	t or F(p)	Mean±SD	t or F(p)	Mean±SD	t or F(p)	Mean±SD	t or F(p)
Child's sex	Boy	109 (70.8)	5.43±2.27	0.02 (0.982)	0.94±0.81	-0.93 (0.353)	2.84±0.83	0.57 (0.568)	2.91±0.65	0.26 (0.794)
	Girl	45 (29.2)	5.42±2.02		1.07±0.81		2.76±0.87		2.88±0.65	
Child's age (y)	< 16	67 (43.5)	5.10±2.01	-1.62 (0.108)	1.04±0.88	0.84 (0.403)	2.84±0.79	0.31 (0.761)	2.86±0.63	-0.59 (0.554)
	≥ 16	87 (56.5)	5.68±2.31		0.93±0.76		2.80±0.88		2.92±0.67	
Disability type	Intellectual	77 (50.0)	5.30±2.02	0.32 (0.730)	0.95±0.84	2.01 (0.138)	2.77±0.76	0.44 (0.647)	2.91±0.60	0.04 (0.961)
	Autistic	62 (40.3)	5.60±2.39		0.92±0.72		2.83±0.88		2.90±0.70	
	Both	15 (9.7)	5.40±2.32		1.37±0.98		2.99±1.04		2.85±0.75	
Disability rating	1	80 (51.9)	5.30±2.39	0.39 (0.677)	1.05±0.86	1.00 (0.370)	2.87±0.92	0.67 (0.512)	2.91±0.67	0.45 (0.640)
	2	59 (38.3)	5.63±1.96		0.86±0.73		2.80±0.74		2.92±0.63	
	3	15 (9.7)	5.33±2.02		1.07±0.90		2.60±0.74		2.75±0.62	
Birth order	1	84 (54.5)	5.18±2.21	-1.56 (0.122)	1.14±0.89	2.79 (0.006)	2.72±0.84	-1.63 (0.104)	2.79±0.69	-2.27 (0.025)
	≥ 2	70 (45.5)	5.73±2.15		0.79±0.66		2.94±0.82		3.03±0.58	
School level	≤ Middle school	84 (54.5)	5.12±2.13	-1.94 (0.055)	1.09±0.89	1.87 (0.064)	2.79±0.80	-0.43 (0.667)	2.84±0.64	-1.14 (0.255)
	≥ High school	70 (45.5)	5.80±2.22		0.85±0.69		2.85±0.88		2.96±0.66	
School type	Special class in regular school	67 (43.5)	5.64±2.19	1.06 (0.291)	0.90±0.72	-1.06 (0.292)	2.90±0.73	1.07 (0.288)	2.94±0.61	0.72 (0.472)
Level of activities of daily living	Special school & others	87 (56.5)	5.26±2.19		1.04±0.88		2.76±0.91		2.86±0.68	
	Need full support	39 (25.3)	4.41±1.97	0.16 (0.001)	1.26±0.84	3.67 (0.028)	2.73±0.88	0.32 (0.727)	2.74±0.64	1.79 (0.170)
	Need a lot of support	51 (33.1)	5.45±2.52	a<c <sup>b</sup>	0.96±0.84	a<c <sup>a</sup>	2.83±0.88		2.90±0.66	
	Need little support	64 (41.6)	6.03±1.81		0.82±0.73		2.86±0.79		2.99±0.64	
Health issues	Yes	53 (34.4)	5.00±2.32	-1.77 (0.079)	1.19±0.89	2.23 (0.028)	2.80±0.91	-0.21 (0.831)	2.80±0.66	-1.29 (0.198)
	No	101 (65.6)	5.65±2.10		0.87±0.75		2.83±0.80		2.95±0.64	
Medication	Yes	74 (48.1)	4.96±2.26	-2.60 (0.010)	1.17±0.87	2.93 (0.004)	2.76±0.88	-0.86 (0.393)	2.84±0.64	-1.04 (0.300)
	No	80 (51.9)	5.86±2.05		0.80±0.71		2.88±0.80		2.95±0.66	

SD, standard deviation; KRW, Korean won.  
<sup>a</sup>)Scheffé test.

health showed statistically significant differences according to the caregiving hours ( $t=2.18, p=0.031$ ), level of child's ADL ( $F=0.16, p=0.001$ ), and whether the child was on medication ( $t=-2.60, p=0.010$ ). A *post-hoc* analysis showed significantly higher perceived health in participants with children who needed little support than in participants with children who needed full support in ADL. Depression was higher among participants whose caregiving hours were more than 12 per day ( $t=-3.48, p=0.001$ ), with firstborn children ( $t=2.79, p=0.006$ ), with children who needed full support in ADL ( $F=3.67, p=0.028$ ), with children who had health issues ( $t=2.23, p=0.028$ ), and with children on medication ( $t=-2.60, p=0.010$ ); Participant with jobs ( $t=2.12, p=0.036$ ), and who had discussions with others ( $t=-2.11, p=0.037$ ) showed significantly lower depression than the other groups. A *post-hoc* analysis showed that depression in participants with children who needed full support in ADL was significantly higher than in participants with children who needed little support. Family strength was significantly higher in participants with a household income of 4.39 million Korean won or more than in their counterparts ( $t=-5.11, p<0.001$ ), and was significantly higher among those who discussed caregiving concerns than among those who did not ( $t=3.88, p=0.001$ ) (Table 1).

### Perceived Health, Depression, Family Strength, and QoL of Participants

Table 2 presents the mean scores of variables. Perceived health had a mean score of  $5.43 \pm 2.19$  out of 10 points, and depression had a mean score of  $11.73 \pm 9.74$  out of 48, with 31% scoring above the cut-off point of 14. The mean score

for family strength was  $2.82 \pm 0.84$  out of 5, and among the 4 sub-domains, family engagement showed the highest score ( $2.99 \pm 0.93$ ) and the family value system showed the lowest score ( $2.67 \pm 0.93$ ). QoL had a mean score of  $2.90 \pm 0.65$  out of 5, and among the sub-domains, the highest score was for physical health at  $3.05 \pm 0.75$  and the lowest was for environmental health at  $2.78 \pm 0.74$  (Table 2).

### Correlations between Perceived Health, Depression, Family Strength, and QoL

QoL showed positive correlations with perceived health ( $r=0.60, p<0.001$ ) and family strength ( $r=0.64, p<0.001$ ), but negative correlations with depression ( $r=0.61, p<0.001$ ). Perceived health was positively correlated with family strength ( $r=0.29, p<0.001$ ) and negatively correlated with depression ( $r=-0.53, p<0.001$ ). Depression was negatively correlated with family strength ( $r=-0.31, p<0.001$ ) (Table 3).

### Factors Influencing QoL

Stepwise multiple regression analysis was performed with birth order, monthly household income, and discussion of caregiving concerns with others (as general characteristics that were statistically significantly correlated with participants' QoL) as dummy variables and with perceived health, depression, and family strength as independent variables. The values of the coefficients of correlation were less than 0.8 for all variables, with the level of tolerance above 0.1 and the value of the variation inflation factor below 10, suggesting there was no multicollinearity. Two outliers with a standardized residual greater than 3 in absolute value were deleted and the regression was re-performed. The residuals

**Table 2.** Perceived health, depression, family strength, and quality of life ( $n=154$ )

Variable	Category	n (%)	Mean $\pm$ SD	Range of scale
Perceived health			$5.43 \pm 2.19$	0–10
Depression	< 14	106 (68.8)	$11.73 \pm 9.74$	0–48
	$\geq 14$	48 (31.2)		
Family strength	Engagement		$2.99 \pm 0.93$	1–5
	Communication		$2.73 \pm 0.78$	1–5
	Value system		$2.67 \pm 0.93$	1–5
	Adaptability		$2.85 \pm 0.78$	1–5
	Total		$2.82 \pm 0.84$	1–5
Quality of life	Overall quality of life and general health		$2.81 \pm 0.86$	1–5
	Physical health		$3.05 \pm 0.75$	1–5
	Psychological health		$2.88 \pm 0.69$	1–5
	Social health		$2.94 \pm 0.76$	1–5
	Environmental health		$2.78 \pm 0.74$	1–5
	Total		$2.90 \pm 0.65$	1–5

SD, standard deviation.

**Table 3.** Correlations among perceived health, depression, family strength, and quality of life ( $n = 154$ )

Variable	Perceived health	Depression	Family strength	Quality of life
Perceived health	1			
Depression	-0.527 (<0.001)**	1		
Family strength	0.285 (<0.001)**	-0.306 (<0.001)**	1	
Quality of life	0.600 (<0.001)**	-0.609 (<0.001)**	0.641 (<0.001)**	1

Data are presented as  $r$  ( $p$ ).

\*\* $p < 0.01$ .

were then tested for normality and homoscedasticity. The regression model was statistically significant ( $F = 54.98$ ,  $p < 0.001$ ), with the adjusted coefficient of determination (adjusted  $R^2$ ) standing at 69.2. Among factors influencing the participants' QoL, family strength ( $\beta = 0.39$ ) was the most important factor, followed by perceived health, depression, and monthly household income, in descending order (Table 4).

## Discussion

The current study aimed to identify factors influencing the QoL of mothers of adolescents with DD. The QoL score of participants in this study was  $2.90 \pm 0.65$  on a 5-point scale, which is somewhat low compared to previous studies, as described below. The mean parental QoL score of a previous study using the same tool as the current study, but without differentiating the ages of children with DD, was  $3.11 \pm 0.62$ , and the corresponding score for mothers was  $3.02 \pm 0.61$  [21]. In Wakimizu et al. [16], the mean QoL score in parents of children with DD aged 2 to 16 years was  $3.22 \pm 0.53$ , with 84.5% of participants being mothers. For further comparison, the mean QoL of Korean women with endometrial cancer was  $3.12 \pm 0.55$  [27], and the QoL in grandparents caring for grandchildren was 66.53 out of 100 [28]—higher than the corresponding score in this study, which, if converted to a score of 100, would be 56.36. To summarize, the level of QoL in mothers caring for adolescents with DD was shown to be lower than that of parental caregivers of children with DD of all age groups, as well as in comparison to middle-aged female patients and elderly women caring for grandchildren. These findings point to the need for increased attention for mothers caring for adolescents with DD and greater efforts to develop intervention programs to help raise their QoL.

In the current study, family strength was found to be the factor most strongly influencing QoL in the participants. A number of studies about parenting children with DD [4–6,21,29,30] support the findings of the current study—that is, the family as a unit of caring for children with DD

is important for QoL in mothers. In the current research, the family engagement score, which measures closeness or familial bonds, was the highest among the sub-domains of family strength, while the score for the family value system, which refers to the shared rules and values of decision-making and respect among family members, was the lowest. Previous research [6] reported that parental sharing of responsibility tends to be lower among parents of children with ID than among parents of TD children, and mothers of children with autism displayed lower levels of family adaptability and cohesion than mothers of TD children [4]. A stressful situation such as disability may alter the dynamics of family function, and negative family coping is common in such situations [31]. Since the participants of the current study were primary caregivers of children with DD in adolescence, which is a transitional phase with many changes acting as potential stressors, measures to improve family strength, especially coping and decision-making skills, need to be implemented. Previous research [32] has reported that relationships with family and friends and spirituality were contributing factors to family QoL of parents of children or adults with ID, which could be considered in planning support programs for this population.

This study found that perceived health also influenced the participants' QoL; however, compared with previous studies [19,28], participants' perceptions of their own health seemed poor. The results of this study do not necessarily indicate that the participants had urgent health care needs, but the subjective rating of one's own health reflects one's objective health status [12]. Considering that the participants were women of middle age (average age, 47.18 years), they seemed to be facing a double burden of major changes—that is, they were undergoing their own changes due to aging and menopause [19], and at the same time, they needed to cope with changes of their children with DD in the transitional period. Therefore, health professionals should pay careful attention to the health needs of this population. Furthermore, it has been reported that poor levels of perceived health in mothers of children with disabilities

**Table 4.** Factors influencing quality of life in caregivers caring for adolescents with developmental disabilities ( $n = 154$ )

Variable	B	SE	$\beta$	t	p	VIF
(Constant)	1.680	0.181		8.628	<0.001	
Perceived health	0.096	0.016	0.323	5.869	<0.001	1.441
Depression	-0.228	0.045	-0.285	-5.048	<0.001	1.676
Family strength	0.303	0.041	0.391	7.435	<0.001	1.393
Household income (mo)	0.193	0.067	0.145	2.869	0.005	1.212
$R^2 = 0.832$ , adjusted $R^2 = 0.692$ , $F = 54.978$ , $p < 0.001$						

B, unstandardized estimates; SE, standardized error;  $\beta$ , standardized estimate; VIF, variation inflation factor.

can negatively affect their ability to meet their children's needs [10]. Marquis et al. [18] stated that the health of caregivers of children with DD is influenced by a range of mutually interacting factors, including social factors, personal characteristics of caregivers and/or children, and family factors as opposed to only a few specific factors. The implication of this is that more medical and nursing efforts are needed to help improve the health of mothers caring for adolescents with DD.

Depression was another factor influencing QoL in the participants of the current study, and 31% of participants had scores above the cut-off point of 14. This finding is mostly consistent with the work of Scherer et al. [15], which reported that 31% of parents of children with ID or DD had scores above the cut-off value for depression. For mothers caring for adult children with DD, depression was found to have a direct negative effect on QoL, and it was found to be an indirect mediating factor of care burden on the QoL [17]. The work of Manor-Binyamini [33] found that regardless of the disability status of children, emotional and psychological support are essential for all parents of adolescents insofar as this phase of children's development presents particular parenting challenges. Moreover, a previous study [34] pointed out the critical importance of providing psychological support to parents of children and adolescents with DD, and concrete evidence for the benefits of emotional support has also been reported [14]. Therefore, emotional and psychological interventions and strong support systems must be designed and conducted for the population of the current study.

Consistent with the belief that financial stability is an essential component in QoL [20], this study finds monthly household income to be a meaningful influence on the QoL in participants. This result is in line with previous studies reporting that teenage children with ID have been shown to place a high financial burden on families [5], and income was the most important social factor influencing caregiving decisions in families with children with DD [18]. The results of this study and previous findings indicate that the economic conditions of a family exert significant influence

on various aspects of well-being in caregivers of children with DD; therefore, financial support should be delivered to needy households with children with DD as part of social efforts to help improve QoL in caregivers.

The generalizability of the study results is limited because the respondents may not have been representative of all mothers caring for adolescents with DD in Korea. It also has a limited ability to show changes in QoL across children's developmental stages. Moreover, insofar as the survey was focused on mothers, this study does not provide insights into the QoL of other family caregivers. Future research should expand the scope of study to examine infants and adults with DD in addition to adolescents, as well as to consider family caregivers other than mothers, in order to gain an understanding of differences in QoL in different types of caregivers and of changes occurring in QoL across time.

## Conclusion

This predictive study investigated factors influencing QoL in mothers of adolescents with DD. The results of this study indicate that family strength had the strongest influence on QoL in participants of this study, followed by perceived health, depression, and monthly household income. This suggests the need to explore ways to improve family strength among families with adolescents with DD in order to enhance the QoL of caregivers. The result of this study may provide reference data for designing and developing intervention programs aimed at enhancing QoL in this population.

## Notes

### Ethics Approval

This study was conducted after receiving permission from the Institutional Review Board of Kyungpook National University (IRB No: 2020-0094).

### Conflicts of Interest

The author has no conflicts of interest to declare.

### Funding

This research was supported by the National Research Foundation of Korea (No: 2018R1C1B5083776).



**Availability of Data**

The datasets are not publicly available but are available from the corresponding author upon reasonable request.

**Additional Contributions**

The author would like to thank all the participants, especially Ms. Park & Ms. Kwak, members of the Mothers with Children with Developmental Disabilities Association for the cooperation in data collection, and express sincere gratitude to JC who has guided this study from the beginning to the end.

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