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Mediating Effects of Parental Family Adaptation on the Quality of Life of Children With Down Syndrome: A Study of Father–Mother Dyads

Seung Hyeon Yang¹  | Chang Gi Park² | Eun Kyoung Choi³ 

¹College of Nursing, Research Institute of AI and Nursing Science, Gachon University, Incheon, Republic of Korea | ²College of Nursing, University of Illinois Chicago, Chicago, Illinois, USA | ³College of Nursing and Mo-Im Kim Nursing Research Institute, Yonsei University, Seoul, Republic of Korea

Correspondence: Eun Kyoung Choi (ekchoi@yuhs.ac)

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ABSTRACT

Aim: To investigate the impact of parenting stress in both fathers and mothers on the quality of life (QoL) of children with down syndrome (DS) and the mediating effect of family adaptation.

Design: This cross-sectional study was conducted between April 2023 and August 2023.

Methods: A total of 106 father–mother dyads of children with DS aged 2–12 years in South Korea were included. The parents independently completed questionnaires assessing parenting stress, family adaptation, and their children's QoL. The Actor–Partner Interdependence Mediation Model was used for the dyadic analysis.

Results: The direct effect of parenting stress on children's QoL was not significant; however, the indirect effect of family adaptation was significant. Fathers' parenting stress indirectly influenced their children's QoL through their own and their mothers' family adaptations. Conversely, mothers' parenting stress indirectly influenced their children's QoL through their own family adaptation, although the mediating effect of fathers was not statistically significant.

Conclusions: Higher family adaptation in both fathers and mothers was associated with an improved QoL in children with DS. The pathways through which parents influenced their children's QoL differed but were interdependent. Therefore, dyadic interventions aimed at improving family adaptation in both fathers and mothers may help improve the QoL of children with DS.

Impact: This is the first study to examine parental influence on children's QoL based on dyadic interactions among fathers, mothers, and children with DS. This study highlights the importance of assessing and promoting fathers' and mothers' levels of family adaptation to improve the QoL of children with DS. Nurses should consider effective dyadic interventions for families that include both parents to maximise improvements in the QoL of children with DS.

Patient or Public Contribution: No patient or public contributions.

Reporting Method: This study adhered to the STROBE guidelines for cross-sectional studies.

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1 | Introduction

Down syndrome (DS) is the most prevalent chromosomal condition, with approximately 95% of cases resulting from a complete or partial extra copy of chromosome 21 and a global prevalence of 1 in 800 (Bull 2020). Individuals with DS often experience cognitive impairment and various physical health issues, including congenital heart disease, hearing deficits, vision problems, thyroid dysfunction, and sleep disorders. Advances in medical technology have significantly increased the life expectancy of individuals with DS, from an average of 30 years in the 1970s to 60 years in 2002 (Bull 2020). Consequently, most individuals with DS now reach adulthood, underscoring the crucial role of care and parenting within the family from an early age.

2 | Background

Children are born and raised within a family unit; therefore, family interactions are important. Parents, in particular, have a significant influence on the growth, development, and adaptation of children with chronic conditions. Therefore, researchers studying these children should carefully consider the role of parents in their research (Ramos et al. 2018). In general, parents of children with DS face several challenges compared to parents of children without disabilities. They often report elevated parenting stress levels as they manage health complications associated with DS, as well as a lack of an adequate social support system, which can contribute to family conflicts and maladaptation (Choi and Van Riper 2017). Moreover, heightened parenting stress negatively impacts not only the quality of life (QoL) of the entire families of children with chronic conditions but also that of the children themselves (Droogmans et al. 2021).

Furthermore, the QoL of children with chronic conditions is influenced by their family's ability to successfully adapt to and manage chronic conditions (Christian 2019). This indicates that families of children with chronic conditions, including DS, must acquire knowledge about the condition and self-management skills, monitor and manage the associated symptoms, and adapt to a new lifestyle. In other words, family adaptation should be considered a predictor of QoL in children with DS.

Family adaptation can be evaluated using family management styles (Hickey et al. 2018). 'Family management' refers to the role of the family in actively coping with conditions and various healthcare situations (Knafl et al. 2021). In this context, the family responds to the child's condition as a unified entity. 'Management' describes the active behaviour of family responses, whereas 'style' is utilised to delineate a consistent pattern of responses. In other words, a family management style can be conceptualised as a consistent pattern of responses to a condition in which the family responds proactively as a unified entity.

This approach has been applied to families with children with various chronic conditions, including DS, asthma, diabetes, paediatric cancer, and epilepsy (Knafl et al. 2021). Prior research has shown a correlation between the family management style of parents and

several key outcomes, including parental depression, parenting stress, family functioning, and children's health outcomes and QoL (Im et al. 2019; Zhang et al. 2013). Specifically, family management style has been identified as a mediator between parenting stress and children's QoL. As parenting stress increases, parents struggle to manage their children's conditions, leading to a decline in children's QoL (Im et al. 2019). However, previous studies have limitations; they often exclusively included mothers or a limited number of fathers, failing to adequately describe family dynamics involving both parents.

In the family unit, fathers play an indispensable role along with mothers, balancing various functions. Fathers serve as protectors, providers, and educators, influencing all aspects of their children's development (Amodia-Bidakowska et al. 2020). Furthermore, paternal adaptation characteristics differ from those of maternal adaptation. In stressful circumstances, fathers tend to rely on family-level resources, such as family resilience and problem-focused coping strategies, whereas mothers more often seek support from friends and use emotion-focused coping (Fisher et al. 2023). Given these distinctive paternal attributes and the interdependent nature of families, examining the interactions between fathers and mothers is essential for understanding the dynamics of their relationships.

While studies examining the relationship between children with chronic conditions and their caregivers are increasing (Mendes et al. 2017), studies specifically focusing on the relationship between children with DS and their caregivers remain scarce. To the best of our knowledge, no previous studies have simultaneously examined fathers, mothers, and their children with chronic conditions, such as DS, within a dyadic analytical framework. Previous studies examining dyadic relationships between parents and children with chronic conditions have predominantly focused on mothers as they frequently assume the role of primary caregivers (Mendes et al. 2017). Therefore, mothers have been the primary focus of family studies, whereas fathers have often been excluded and regarded merely as supportive of mothers (Amodia-Bidakowska et al. 2020). However, given the distinctive role of fathers and their significance in child rearing, their inclusion in research is essential. Thus, it is crucial to examine how parental interactions, involving both fathers and mothers, influence the quality of life of children with DS, using a dyadic analytical framework.

3 | The Study

3.1 | Aims

This study aimed to comprehensively investigate the effect of the interaction between parenting stress and family adaptation in both fathers and mothers as caregivers on the QoL of children with DS.

3.2 | Specific Objectives

1. To determine parenting stress levels and family adaptation experienced by fathers and mothers of children with DS, as well as the children's QoL.

2. To verify the mediating effect of family adaptation on the relationship between parenting stress in fathers and mothers of children with DS and children's QoL.
3. To explore the actor and partner effects of parenting stress and family adaptation among fathers and mothers of children with DS to understand how these factors affect children's QoL.

4 | Methods

4.1 | Study Design

This cross-sectional study was conducted between April 2023 and August 2023. This study was conducted in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology Reporting Guidelines, as detailed in the Appendix S1.

4.2 | Participants

Participants were recruited from three sources: (1) the DS Welfare Center, (2) an online community of parents of children with DS, and (3) the Korean Parents' Network for People with Disabilities. Although not all families of children with DS in Korea are active in these three organisations, the lack of a registration system made this approach the most effective way to reach the largest number of families and ensure equitable participation opportunities.

The following criteria were used to determine the eligibility of study participants. The study encompassed biological or social fathers and mothers of children with DS aged two to twelve years. Eligible participants had to live with their children with DS, understand the questionnaire, and respond independently. Individuals who did not speak Korean were excluded. To examine the influence of fathers and mothers on the QoL of children with DS, adolescents aged > 12 years were excluded because parental influence on children has been shown to decrease with age (Lam et al. 2014). Additionally, parents who did not live with their children with DS were excluded, as their interaction patterns might be different and thus not align with the purpose of the study.

4.3 | Data Collection

The directors of the welfare centres, online community administrators, and representatives of the parents' association were duly informed of the purpose and procedures of the study, as well as the potential benefits to the participants. Following approval, a recruitment announcement was disseminated via a website or online community. Parents of children with DS who expressed an interest in participating were able to provide contact details to the researchers via a quick response code. Subsequently, the researchers contacted the fathers and mothers separately via telephone to ascertain their eligibility in accordance with the established criteria. The eligible participants received written information regarding the study. The online survey link, along with the consent form, was sent two days later to allow parents sufficient time to consider participation. Fathers and mothers

could independently consent to or decline participation. To ensure the confidentiality of the data and prevent one parent's response from influencing that of the other, separate links to the online survey were provided to each parent. Furthermore, the participants were unable to ascertain whether the other parent had responded. In addition, a distinctive response code was generated and sent to each parent's mobile device, enabling precise matching between fathers and mothers. Upon completion of the survey by both parents, a US\$ 15 gift card was sent to their mobile devices.

4.4 | Sample Size

The sample size for the study was determined based on the guidelines proposed by Du and Wang (2016) for dyadic data analysis using multilevel modelling. Accordingly, the minimum number of participants required for this study was 100 pairs. To account for a potential 10% dropout rate, a minimum of 112 pairs was recruited.

4.5 | Measures

4.5.1 | QoL Of Children With DS

The QoL of children with DS was assessed using the Korean version of the Paediatric Quality of Life Inventory 4.0 Generic Core Scale (PedsQL 4.0) (Kook and Varni 2008). The PedsQL 4.0 is a questionnaire designed to assess difficulties perceived by the child or parent across four domains: physical, emotional, social, and school functioning. The questionnaire was designed for children and adolescents aged 2–18 years (Kook and Varni 2008). Considering the cognitive impairments frequently observed in children with DS (Bull 2020), this study employed parent-proxy reports to assess the child's QoL, with the child's QoL variables calculated as the mean of the fathers' and mothers' scores.

The questionnaire for children aged 2–4 years comprised eight items related to physical health and 13 items related to psychosocial health (five items each for emotional and social functioning and three items for school functioning), totaling 21 items. For children aged 5–12 years, the school functioning domain included five items, resulting in a total of 23 items. Each item was rated on a five-point Likert scale, with responses ranging from 0 (no problem) to 4 (the problem was almost always present). Each item was reverse-coded and linearly transformed to a 0–100 scale following the PedsQL 4.0 scoring protocol, such that 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. Higher scores indicate better quality of life. In this study, the mean physical and psychosocial health scores reported by fathers and mothers were used to define the QoL of children with DS. The internal consistency of the Korean version was 0.75–0.88 (Kook and Varni 2008), with values in this study ranging from 0.74 to 0.88.

4.5.2 | Parenting Stress

Parenting stress in fathers and mothers of children with DS was assessed using the Korean version of the Parenting Stress Index, 4th

Edition Short Form (PSI-4-SF) (Chung et al. 2019). The PSI-4-SF, a condensed version of the 120-item PSI-4, consist of 36 items. It is a self-report questionnaire designed to measure parenting stress among parents of children aged 1–12 years (Chung et al. 2019). The scale comprises three subscales: ‘Parental Distress’ (12 items), measuring the difficulties experienced by parents in their role; ‘Parent–Child Dysfunctional Interaction’ (12 items), assessing the interaction between parent and child; and ‘Difficult Child’ (12 items), evaluating the challenging behavioural characteristics of the child that make parenting difficult. Each item is rated on a five-point Likert scale, ranging from 1 (not at all) to 5 (very much so), with total scores ranging from 36 to 180. Higher scores indicate greater levels of parenting stress. The internal consistency of the Korean version was reported to range from 0.83 to 0.93 (Chung et al. 2019), and in the present study, it fell within a similar range, between 0.81 and 0.91.

4.5.3 | Family Adaptation

Family adaptation among fathers and mothers of children with DS was evaluated using the Korean version of the Family Management Measure (FaMM) (Kim and Im 2013). The FaMM is a self-report questionnaire developed based on the Family Management Style Framework to comprehensively measure the family management styles of families with children with chronic conditions. The questionnaire consists of 53 items distributed across six dimensions: (1) Child’s Daily Life, (2) Condition Management Ability, (3) Parental Mutuality, (4) Condition Management Effort, (5) Family Life Difficulty, and (6) View of Condition Impact (Kim and Im 2013).

The six dimensions of the FaMM are classified into two categories: the positive aspects of family management (PFM) and the challenging aspects of family management (CFM). This classification is based on the level of difficulty in managing a child’s condition (Hickey et al. 2018; Zhang et al. 2013). PFM includes three dimensions: Child’s Daily Life, Condition Management Ability, and Parental Mutuality, where higher scores indicate more effective management of the child’s condition and greater family adaptation. In contrast, CFM includes three dimensions: Family Life Difficulty, Condition Management Effort, and View of Condition Impact, where a higher total score indicates that family life is oriented towards the management of a child’s condition, with greater difficulties and lower family adaptation (Hickey et al. 2018; Zhang et al. 2013).

In this study, the distinction between these two aspects of family management, namely, the level of family adaptation, was defined as the difference between the total scores of the PFM and CFM, ranging from –115 to 97. A higher score indicated superior family adaptation. The internal consistency of this study was 0.89 and 0.91 for the PFM and CFM, respectively, indicating a high degree of reliability.

4.5.4 | General Characteristics and Control Variables

This study surveyed the demographic characteristics of fathers and mothers of children with DS, including age, education level, marital status, cohabitation, religion, occupation, family

economic level, couple satisfaction, primary caregiver, and co-parenting level. Couple satisfaction and the level of co-parenting were used as covariates in the analysis.

In this study, overall couple satisfaction was controlled to focus on parental mutuality in the FaMM, which refers to couple satisfaction with aspects of managing children with DS, as perceived by fathers and mothers. The level of couple satisfaction was evaluated using the Korean version of the Couple Satisfaction Index 4-item Short Form (CSI 4) (Kim et al. 2022). The CSI 4 is a self-report questionnaire designed to assess levels of couple satisfaction. The scale comprises four items selected from the original 32-item Couple Satisfaction Index (Kim et al. 2022). The first item employs a seven-point Likert scale, whereas the remaining three items use a six-point scale, with a total score range of 0–21. Higher scores indicate greater couple satisfaction, whereas scores below the cut-off point of 13.25 indicate dissatisfaction in the marital relationship. The internal consistency of the Korean version was 0.93 (Kim et al. 2022), and in the present study, it was 0.94.

To mitigate potential bias related to parental roles, fathers’ and mothers’ levels of co-parenting were employed as control variables. The co-parenting level was assessed using the Korean version of the co-parenting scale, ‘My Time Spent as a Parent: Child Care Activities’. This scale was originally developed by the National Institute of Child Health and Human Development under the National Institutes of Health in the United States and was later adapted by the research team of the Panel Study on Korean Children. The co-parenting scale comprises 16 everyday childcare activities and uses a five-point Likert scale. The mean score of the 16 items was calculated, with scores below 3 indicating that fathers are more involved in co-parenting activities and scores higher than 3 indicating that mothers are more involved. The internal consistency of the Korean version in previous research was 0.91 (Ok 2017), and in the current study, it was 0.88.

The demographic characteristics of children with DS included sex, age, type of childcare or school, and sibling relationships. Additionally, this study investigated the clinical characteristics of the condition, including age at diagnosis, history of health problems, and types of treatments received.

4.6 | Statistical Analysis

Data were analysed using the statistical software package SPSS (version 26; IBM, Seoul, South Korea). Descriptive statistics were used to delineate the general and disease characteristics of the participants and their children. Paired *t*-tests and Pearson’s chi-squared tests were used to determine whether significant differences existed between the variables for fathers and mothers. Pearson’s correlation analyses were conducted to identify potential correlations between the variables reported by the fathers and mothers and their children’s QoL. To investigate the mediating effect of family adaptation and interdependence on the relationship between parenting stress in fathers and mothers of children with DS and the children’s QoL, an Actor–Partner Interdependence Mediation Model analysis was conducted using the MEDYAD macro (Coutts et al. 2019) in SPSS.

The MEDYAD macro employs a bootstrapping test to verify the effectiveness of the mediation path using 10,000 samples (Coutts et al. 2019). This approach was developed based on ordinary least squares regression, which independently estimates each predictor. In contrast, structural equation models estimate all predictors simultaneously using the maximum likelihood estimation. As a result, the parameter estimates in one regression do not influence those in the other regressions. The MEDYAD macro generates 95% bootstrap confidence intervals (CI) and has been validated even when the collected data deviate from a normal distribution (Coutts et al. 2019; Preacher and Hayes 2008). The effect of the mediator was considered significant if zero was not included in the CI. This study employed the MEDYAD macro to investigate the dyadic, direct, and indirect effects among the variables. The variables were controlled to determine their potential influence on the family adaptation of fathers and mothers and the QoL of children with DS. The variables included parents' ages, education levels, level of co-parenting, couple satisfaction, children's age and sex, and logarithmically transformed average annual household income.

4.7 | Ethical Consideration

The study protocol was reviewed and approved by the Institutional Review Board of Yonsei University Health System on April 14, 2023 (4-2023-0214). The consent form for participation in the study included comprehensive information regarding the research purpose, methodology, anonymity of the participants, confidentiality, and the right to withdraw from the study at any time. Participants were also informed that they could withdraw from the survey at any point during their participation.

5 | Results

5.1 | Characteristics of the Sample

A total of 132 father–mother pairs were enrolled in the study, with 106 pairs included in the final analysis (Figure 1). Of the 26 excluded pairs, 12 were because of duplicate applications; four did not reside with their father, mother, or child; four did not meet the child's age criteria; three could not be contacted; two had one parent decline participation; and one withdrew their consent.

The mean age of the fathers was 43.23 ± 5.09 years, while that of the mothers was 41.70 ± 4.78 years (Table 1). Significant differences were found in parental age ($p < 0.001$), education level ($p = 0.029$), and employment status ($p < 0.001$); whereas marital status and religious affiliation did not differ significantly. The mean annual family income was $\$52,794 \pm 21,231$, placing these families in the middle-income range given the national median for four-person households in South Korea in 2023 ($\$54,008$).

The mean age of children with DS was 5.83 ± 2.79 years, with 60.4% being male (Table 2). In most cases (83.0%), the mother was the primary caregiver. Additionally, 55.7% of the children had one

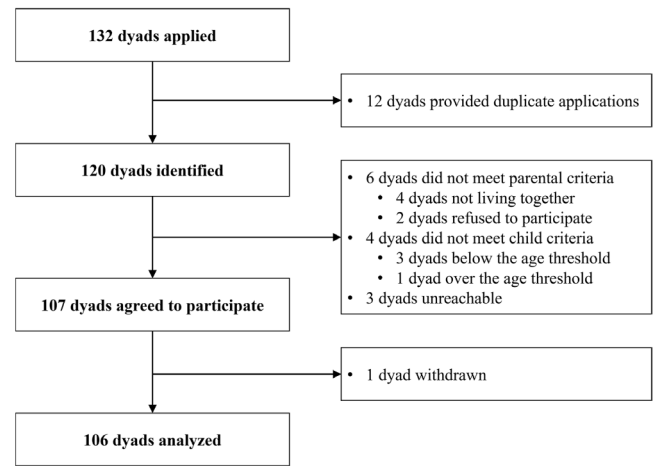


FIGURE 1 | Flow diagram of participant recruitment.

sibling. The mean age at diagnosis was 1.18 ± 2.43 months, with a median of 1 month and an interquartile range of 1–1 months, indicating that most children were diagnosed very early, with 90.6% diagnosed within the first month. The relatively large standard deviation was due to a few children diagnosed much later, including one at 8 months and one at 24 months. The most common health problem was congenital heart disease (73.6%), whereas the primary ongoing therapy was speech and language therapy (88.7%).

5.2 | Children's QoL, Parenting Stress, Family Adaptation, Co-Parenting, and Couple Satisfaction

No statistically significant differences were observed between fathers' and mothers' perceived levels of overall, physical, or psychosocial QoL in their children with DS (Table 3). Furthermore, no significant differences were observed in the independent variables of parenting stress between fathers and mothers. The mediating variable, family adaptation level, showed no difference between fathers and mothers, nor did PFM or CFM. However, discrepancies were observed between parents in the control variables of couple satisfaction and co-parenting. Fathers exhibited a higher level of couple satisfaction than did mothers, whose scores fell below the established cut-off of 13.25 (Kim et al. 2022). Statistically significant differences were observed in co-parenting levels between fathers and mothers. Both generally indicated greater maternal involvement in childcare activities, but the extent of this perception differed significantly.

5.3 | Relationship Between Variables

The relationship between parenting stress, family adaptation, and the QoL of children with DS, either as perceived by parents or measured using the parents' mean values, was investigated. The variables demonstrated correlations ranging from weak to strong. Excluding the expected high correlations between family adaptation and its components (PFM and CFM), as well as between the children's QoL and the proxy reports by fathers and mothers, all correlation coefficients were below 0.80; indicating

TABLE 1 | Demographic characteristics of the parents of children with DS ($N = 212$).

Variable	Category	Father (N=106)	Mother (N=106)	p ^a
		Mean ± SD (range) or n (%)		
Age (years)		43.23 ± 5.09 (31–55)	41.70 ± 4.78 (29–54)	<0.001
Annual family income (\$)		52,794.42 ± 21,231.70 (5000–112,500)		
Marital status	First	100 (94.3)	101 (95.3)	0.757
	Second	6 (5.7)	5 (4.7)	
Education level ^b	≤ High school	24 (22.6)	10 (9.4)	0.029
	College or university	59 (55.7)	72 (67.9)	
	≥ Graduate school	23 (21.7)	24 (22.6)	
Employment	Employed	104 (98.1)	56 (52.8)	<0.001
	Unemployed	2 (1.9)	50 (47.2)	
Religion	Yes	68 (64.2)	73 (68.9)	0.467
	No	38 (35.8)	33 (31.1)	

Abbreviation: SD, standard deviation.

^a p -value calculated using the paired t -test or Pearson's chi-squared test.^bPercentages may not total exactly 100% due to rounding.

no multicollinearity among predictors used in the mediation model (Table 4).

5.4 | Daydic and Direct Effects

After controlling for the fathers' and mothers' ages, education levels, couple satisfaction, co-parenting level, children's age and sex, and the log-transformed average annual household income in the analysis, five out of twelve paths were found to be statistically significant (Figure 2; Table 5). The results indicated that fathers' parenting stress significantly influenced fathers' family adaptation (effect = -0.966 , $p < 0.001$) and showed a marginal association with mothers' family adaptation (effect = -0.196 , $p = 0.069$). However, mothers' parenting stress significantly affected only their own family adaptation (effect = -0.786 , $p < 0.001$). Fathers' family adaptation had a statistically significant impact on children's physical QoL (effect = 0.292 , $p = 0.028$), whereas mothers' family adaptation significantly influenced both children's physical (effect = 0.251 , $p = 0.039$) and psychosocial QoL (effect = 0.205 , $p = 0.007$). Nevertheless, neither paternal nor maternal parenting stress had a direct effect on children's physical or psychosocial QoL.

5.5 | Indirect Effects

Of the eight indirect effects, five were significant (Table 6). Fathers' parenting stress showed a significant indirect effect on children's physical QoL through fathers' family adaptation (effect = -0.282 , 95% CI [-0.528 , -0.034]); while the indirect path through mothers' family adaptation was not statistically significant (effect = -0.049 , 95% CI [-0.122 , 0.002]). In addition, fathers' parenting stress had a significant indirect effect on children's psychosocial QoL through

mothers' family adaptation (effect = -0.040 , 95% CI [-0.093 , -0.001]). Mothers' parenting stress had a significant impact on their children's physical (effect = -0.197 , 95% CI [-0.368 , -0.036]) and psychosocial QoL (effect = -0.161 , 95% CI [-0.272 , -0.057]), mediated through mothers' family adaptation.

6 | Discussion

The objective of this study was to examine the relationship between parenting stress and family adaptation in parents of children with DS and its subsequent impact on the children's QoL. To our knowledge, this is the first study to simultaneously examine fathers, mothers, and their children with chronic conditions, including DS, employing a dyadic analytical framework to investigate how parental interactions are associated with children's QoL. The findings indicate that parenting stress in fathers and mothers of children with DS is interrelated, with parental family adaptation functioning as a mediating factor that affects children's QoL.

This study demonstrated that the impact of parenting stress on children's QoL was fully mediated by family adaptation, emphasising the importance of a family-level approach to interventions. However, it is incorrect to assume that interventions should be provided only to one parent. Frank et al. (2015), using the Positive Parenting Program (Triple P) with both fathers and mothers of children aged 3–8 years with behavioural problems, found that the intervention was more effective and lasted longer when both parents participated compared with when only one did. In a study conducted by Zeiler et al. (2023), an 8-week parent education intervention was provided to 91 pairs of parents of children with anorexia, resulting in reduced distress, depression, anxiety, and burden, as well as improved caregiving skills. Specifically, fathers' involvement suppressed mothers'

TABLE 2 | Demographic and clinical characteristics of children with DS ($N=106$).

Variable	Category	Mean $\pm$ SD (range) or n (%)
Age (years)		5.83 $\pm$ 2.79 (2–12)
	2–4 years	39 (36.8)
	5–7 years	39 (36.8)
	8–12 years	28 (26.4)
Sex	Male	64 (60.4)
	Female	42 (39.6)
School type	Daycare	41 (38.7)
	Kindergarten	7 (6.6)
	SEN school	11 (10.4)
	Mainstream with SEN unit	41 (38.7)
	Mainstream	1 (0.9)
	Home raising	2 (1.9)
	Others	3 (2.8)
Primary caregiver ^a	Mother	88 (83.0)
	Father	8 (7.5)
	Father and mother	5 (4.7)
	Grandparent	4 (3.8)
	Activity assistant	1 (0.9)
Siblings	Alone	26 (24.5)
	One	59 (55.7)
	Two or above	21 (19.8)
Age at diagnosis (months)		1.18 $\pm$ 2.43 (0–24)
Health problems	Congenital heart disease	78 (73.6)
	Vision problems	47 (44.3)
	Thyroid function problems	39 (36.8)
	Dental problems	37 (34.9)
	Hearing problems	36 (34.0)
	Musculoskeletal problems	21 (19.8)
	Sleeping problems	16 (15.1)
	Digestive problems	15 (14.2)
	Urologic problems	11 (10.4)
	Neurogenic problems	9 (8.5)
	Dermatologic problems	7 (6.6)
	Others	24 (22.6)

(Continues)

TABLE 2 | (Continued)

Variable	Category	Mean $\pm$ SD (range) or n (%)
Therapy ^b	Speech and language therapy	94 (88.7)
	Sensory integration therapy	39 (36.8)
	Occupational therapy	38 (35.8)
	Physical therapy	34 (32.1)
	Cognitive therapy	26 (24.5)
	Others	52 (49.1)

Abbreviations: SD, standard deviation; SEN, special educational needs.

^aMultiple response.^bPercentages may not total exactly 100% due to rounding.

negative coping behaviours, such as overprotection or emotional over-involvement. In other words, fathers and mothers interact with each other and have different effects depending on their respective roles. Future research should focus on developing and providing interventions based on father–mother interactions to improve the QoL of children with DS.

The findings indicated that fathers' parenting stress influenced children's psychosocial QoL through the mediation of mothers' family adaptation. However, this study did not provide evidence that mothers' parenting stress affects the children's QoL through the mediation of fathers' family adaptation. In other words, a partner effect was observed in which fathers influenced mothers, but the opposite was not evident. These findings are consistent with those of previous dyadic studies of fathers and mothers of typically developing children and children with autism spectrum disorder (Kang et al. 2017; Wang et al. 2020). The results suggest that the interaction between fathers and mothers is significant in determining the influence that fathers exert on mothers, but not vice versa. This indicates the need to consider discrepancies in parenting responsibilities between couples. In three studies, including the present one, a higher percentage of fathers than mothers were economically active. This suggests that, regardless of whether children have chronic conditions, fathers typically assume the role of economic provider within the family, spending less direct time on childcare than mothers and assuming a supportive role. Therefore, the role of mothers in childcare and caregiving is emphasised, and research on children consistently highlights the impact of fathers on mothers, who serve as the primary caregivers. These dynamics suggest that while fathers may be less involved in direct caregiving, they still play a crucial role in the family system, particularly in influencing mothers' experiences and coping strategies. Understanding these father–mother interactions can help develop more effective family-centred interventions and support systems for families raising children with chronic conditions or disabilities.

However, these phenomena may vary depending on the identity of the primary caregiver. A study conducted by Shin et al. (2010) examined family adaptation level among adolescents from

TABLE 3 | Distributions of children's quality of life, parental stress, family adaptation, and control variables.

		Overall (N= 212)	Father (N= 106)	Mother (N= 106)	
Variables	Range	Mean ± SD (Range)	Mean ± SD (Range)	Mean ± SD (Range)	p ^a
Dependent variable					
Child's quality of life	0–100	61.28 ± 16.52 (15.48–98.61)	61.19 ± 16.15 (17.86–98.61)	60.37 ± 16.92 (15.48–92.86)	0.204
Physical health	0–100	58.73 ± 21.54 (3.13–100)	59.85 ± 21.73 (3.13–100)	57.61 ± 21.40 (9.38–100)	0.191
Psychosocial health	0–100	62.80 ± 15.52 (17.5–100)	63.60 ± 15.04 (25–100)	61.99 ± 16.01 (17.5–96.15)	0.285
Independent variable					
Parenting stress	36–180	84.03 ± 17.20 (40–133)	82.59 ± 18.08 (40–128)	85.47 ± 16.23 (52–133)	0.166
Mediating variable					
Family management style					
PFM	25–125	87.01 ± 12.44 (52–121)	87.56 ± 11.98 (56–121)	86.46 ± 12.92 (52–119)	0.415
CFM	28–140	78.91 ± 15.32 (35–119)	78.87 ± 15.54 (35–119)	78.94 ± 15.18 (50–118)	0.960
Family adaptation level (PFM-CFM)	–115–97	8.10 ± 25.94 (–63–86)	8.69 ± 25.89 (–63–86)	7.52 ± 26.11 (–57–59)	0.654
Control variables					
Couple satisfaction	0–21	13.49 ± 4.84 (0–21)	13.96 ± 4.78 (0–21)	13.02 ± 4.89 (0–21)	0.046
Co-parenting	1–5	3.68 ± 0.49 (2.44–4.94)	3.60 ± 0.42 (2.69–4.54)	3.76 ± 0.54 (2.44–4.94)	<0.001

Abbreviations: CFM, challenging aspects of family management; PFM, positive aspects of family management; SD, standard deviation.

^a*p*-value calculated using the paired *t*-test.

divorced families, using the primary caregiver as the unit of analysis. The findings showed no significant difference in children's adaptation levels between the groups in which the father or mother was the primary caregiver. This suggests that parental influence on children's family adaptation should not be distinguished based on sex alone but rather on the individual who assumes the role of the primary caregiver. As mothers were the primary caregivers in this study, their role in family adaptation had a significant impact on the children's QoL. However, in recent years, the number of fathers serving as primary caregivers has been increasing, with mothers assuming economic roles (Kim et al. 2023). Therefore, future research should focus on role-based rather than sex-based approaches.

The QoL score of children with DS in this study was 61.28 points, lower than that of children with DS in other countries (Fucà et al. 2022; Xanthopoulos et al. 2017). This discrepancy was particularly evident in physical QoL, which requires cautious interpretation considering the children's age and the survey's specific attributes. The age range in this study was 2–12 years, with 39.8%

of children aged 2–4 years, which likely influenced the overall QoL score. The survey for this age group included activities such as walking and running, which children with DS develop more slowly than do those without disabilities. Children with DS typically achieve walking and running milestones later than children without disabilities, with average estimates around 26 months for walking and 50 months for running, although individual variability exists (Winders et al. 2019). Therefore, while PedsQL 4.0, a tool applicable to a diverse population, has the advantage of being used regardless of conditions, it may not fully consider the delayed motor development characteristic of DS, thus resulting in lower physical QoL scores. Future studies should consider using tools designed to reflect the specific characteristics of children with DS when comparing their QoL.

The level of family adaptation among parents of children with DS was evaluated by calculating the difference between PFM and CFM scores. Although no significant difference was observed between fathers and mothers in total scores, their level of family adaptation was lower than that reported in other

TABLE 4 | Pearson correlations among variables for fathers, mothers and children with DS ($N = 212$).

Variable	Father						Mother						Child ^a	
	1	2	3	4	5	6	7	8	9	10	11	12	13	13
Father														
1: Physical QoL	—													
2: Psychosocial QoL	0.704***	—												
3: PS	-0.224*	-0.420***	—											
4: PFM	0.309**	0.506***	-0.698***	—										
5: CFM	-0.318**	-0.478***	0.759***	-0.766***	—									
6: Family adaptation	0.334***	0.521***	-0.779***	0.923***	-0.955***	—								
Mother														
7: Physical QoL	0.670***	0.498***	-0.079	0.160	-0.227*	0.211*	—							
8: Psychosocial QoL	0.487***	0.510***	-0.178	0.186	-0.194*	0.203*	0.776***	—						
9: PS	-0.259**	0.257**	-0.275**	-0.218*	-0.120	-0.270**	0.274**	0.317**	—					
10: PFM	0.389***	-0.378***	0.407***	0.227*	0.190	0.229*	0.337***	0.381***	-0.631***	—				
11: CFM	-0.364***	0.488***	-0.461***	-0.272**	-0.200*	-0.297**	-0.394***	-0.427***	0.656***	-0.726***	—			
12: Family adaptation	0.404***	-0.471***	0.470***	0.271**	0.210*	0.286**	0.396***	0.437***	-0.693***	0.917***	-0.940***	—		
Child^a														
13: Physical QoL	0.915***	0.658***	-0.167	0.258**	-0.299**	0.299**	0.612***	0.690***	-0.214*	0.288**	-0.324**	0.331**	—	
14: Psychosocial QoL	0.681***	0.860***	-0.340***	0.393***	-0.381***	0.411***	0.738***	0.878***	-0.338***	0.354***	-0.419***	0.418***	0.776***	

Abbreviations: CFM, challenging aspects of family management; CS, couple satisfaction; PFM, positive aspects of family management; PS, parenting stress; QoL, quality of life.

Values are Pearson correlation coefficients (r). * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

^aThe child's quality of life value represents the mean of the fathers' and mothers' proxy-reported values.

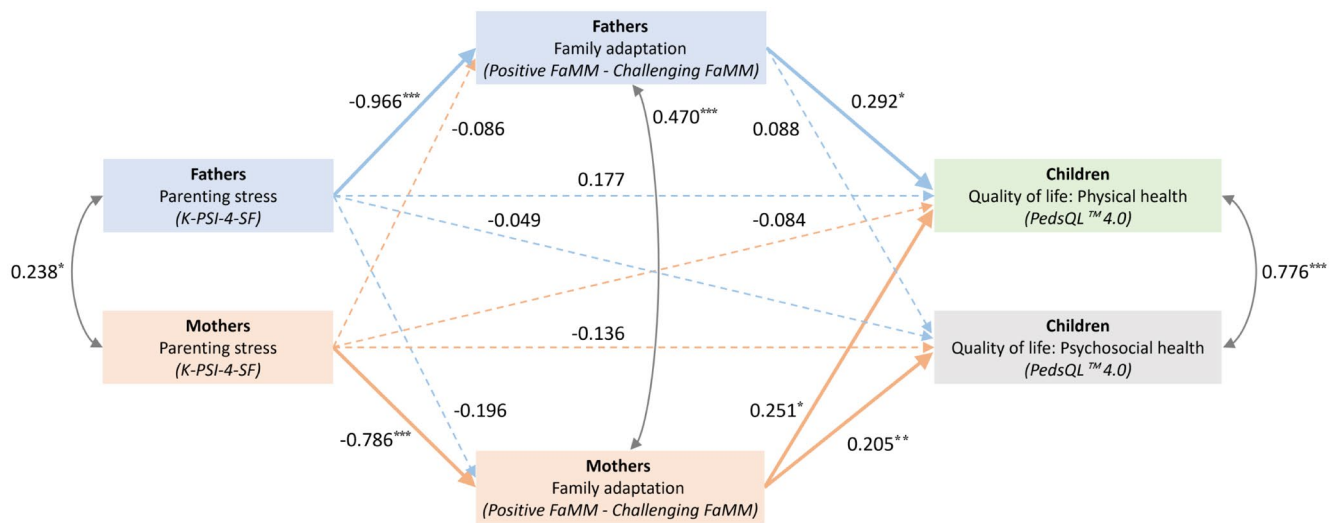


FIGURE 2 | Dyadic effects of parenting stress, family adaptation, and quality of life. Control variables included fathers' age, education level, co-parenting, and couple satisfaction; mothers' age, education level, co-parenting, and couple satisfaction; the child's age and sex; and annual family income. The child's quality of life value represents the mean of the fathers' and mothers' proxy-reported values. Blue lines indicate the effects of fathers' variables, whereas the orange lines represent the effects of mothers' variables. Dashed lines represent insignificant effects, whereas bold lines indicate significant effects. The numbers above the lines correspond to direct effects. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

TABLE 5 | Dyadic effects of parenting stress, family adaptation, and quality of life.

Paths			Effect	SE	<i>t</i>	<i>p</i>
Father PS	→	Father FA	−0.966	0.098	−9.902	<0.001
Father PS	→	Mother FA	−0.196	0.107	−1.840	0.069
Mother PS	→	Father FA	−0.086	0.112	−0.768	0.445
Mother PS	→	Mother FA	−0.786	0.123	−6.398	<0.001
Father FA	→	Child Physical QoL	0.292	0.131	2.233	0.028
Father FA	→	Child Psychosocial QoL	0.088	0.082	1.081	0.283
Mother FA	→	Child Physical QoL	0.251	0.120	2.096	0.039
Mother FA	→	Child Psychosocial QoL	0.205	0.075	2.751	0.007
Father PS	→	Child Physical QoL (direct effect)	0.177	0.163	1.085	0.281
Father PS	→	Child Psychosocial QoL (direct effect)	−0.049	0.101	−0.482	0.631
Mother PS	→	Child Physical QoL (direct effect)	−0.084	0.157	−0.537	0.592
Mother PS	→	Child Psychosocial QoL (direct effect)	−0.136	0.098	−1.392	0.167

Note: Values are unstandardized regression coefficients (*b*). Control variables included fathers' age, education level, co-parenting, and couple satisfaction; mothers' age, education level, co-parenting, and couple satisfaction; the child's age and sex; and annual family income. The child's quality of life value represents the mean of the fathers' and mothers' proxy-reported values.

Abbreviations: FA, family adaptation; PS, parenting stress; QoL, quality of life; SE, standard error.

countries. A review by Van Riper et al. (2021) on family management styles among parents of children with DS across 11 countries revealed that the FaMM scores were in the lower range, comparable to existing Korean scores. These findings indicate that parents of children with DS in Korea face greater challenges in family management and adaptation compared with those in other countries.

The social perceptions of people with disabilities in Korea and related Confucian values provide a context for understanding

these challenges. Although DS is a genetic condition, it often manifests as a social disability due to societal attitudes and structural barriers. Individuals with disabilities frequently experience social exclusion in Korea (Park 2017), and families of children with disabilities have reported a higher prevalence (69.1%) of discrimination during child rearing (Choi and Yoo 2015). This discrimination was primarily observed during the process of admission to childcare facilities and educational institutions (37.9%) and during academic tenure (35.3%). Therefore, it can be posited that children with disabilities face heightened

TABLE 6 | Indirect effects of parenting stress and family adaptation on predicting quality of life.

Path					Effect	Boot SE	Boot LLCI	Boot ULCI
Father PS	→	Father FA	→	Child Physical QoL	−0.282	0.125	−0.528	−0.034
Father PS	→	Mother FA	→	Child Physical QoL	−0.049	0.101	−0.122	0.002
Father PS	→	Father FA	→	Child Psychosocial QoL	−0.085	0.073	−0.236	0.051
Father PS	→	Mother FA	→	Child Psychosocial QoL	−0.040	0.024	−0.093	−0.001
Mother PS	→	Father FA	→	Child Physical QoL	−0.025	0.048	−0.155	0.032
Mother PS	→	Mother FA	→	Child Physical QoL	−0.197	0.084	−0.368	−0.036
Mother PS	→	Father FA	→	Child Psychosocial QoL	−0.008	0.018	−0.059	0.012
Mother PS	→	Mother FA	→	Child Psychosocial QoL	−0.161	0.054	−0.272	−0.057

Note: Values are unstandardized indirect effects (*b*) with 95% bootstrap confidence intervals. Control variables included fathers' age, education level, co-parenting, and couple satisfaction; mothers' age, education level, co-parenting, and couple satisfaction; the child's age and sex; and annual family income. The child's quality of life value represents the mean of the fathers' and mothers' proxy-reported values.

Bold indicates the key results for interpretation.

Abbreviations: FA, family adaptation; LLCI, lower limit of 95% confidence interval; PS, parenting stress; QoL, quality of life; SE, standard error; ULCI, upper limit of 95% confidence interval.

discrimination as they mature and their social networks expand beyond the familial domain. Parents raising children with disabilities in such environments have lower levels of adaptation than do those in other countries.

This suggests that, from the perspective of the social determinants of health, an individual's health is determined by social conditions such as the place of birth, upbringing, and residence (World Health Organization 2010). It can be argued that Korean society exerts a more deleterious influence on the health of individuals with disabilities than do other societies. Compared with societies that promote greater inclusion and reduced social exclusion for individuals with disabilities (Babik and Gardner 2021), parents in Korea may face more significant challenges in adapting to the lives of their children with disabilities. Improving societal perceptions of disability is a complex undertaking that requires governmental intervention. According to the World Health Organization (2010), the conceptual framework for social determinants of health, government welfare and redistribution policies significantly affect individual health. Therefore, the active discourse and implementation of government policies are vital for improving societal attitudes that negatively affect the health of individuals with disabilities.

6.1 | Strengths and Limitations of the Work

This pioneering study employs a dyadic model to examine the interactions between fathers, mothers, and their children with DS, providing insights into family dynamics and the impact of father–mother interactions on children's QoL. By including both fathers and mothers in the analysis, this study highlights the importance of fathers as caregivers and addresses a gap in previous research, which has primarily focused on mothers.

This study has several limitations. First, child-level measurements were based on parent-proxy reports, as many children with DS have cognitive impairments that limit their ability to express themselves. When self-reports were possible, they

typically reflected higher-functioning children who may not represent the broader DS population. Additionally, the wide age range (2–12 years) made it challenging to obtain consistent input from teachers or other caregivers. To partially address these limitations, we used the mean of fathers' and mothers' assessments to capture a broader parental perspective. Future studies could consider qualitative or multi-informant approaches, particularly for older children with DS. The analyses were also not stratified by developmental stage or comorbidity profiles, though these factors may differently affect parenting stress, family adaptation, and children's QoL. Additionally, most primary caregivers were mothers, which may have influenced the mediation pathways observed. This study focused on father–mother dyads, representing only one family structure, and should not be interpreted as implying two-parent heterosexual families are the preferred or sole context for effective parenting. Future studies should incorporate stratified analyses, examine families where fathers are primary caregivers, and include diverse family configurations. Findings from studies involving other chronic conditions should also be interpreted with caution, given differences in condition trajectories and family experiences.

6.2 | Implications for Policy and Practice

Nurses and nursing researchers should develop and implement early family-centred dyadic intervention programmes that include both fathers and mothers. Unlike other chronic conditions, DS can be diagnosed immediately after birth, providing an opportunity for early family adaptation interventions. The interactions between fathers and mothers identified in this study provide a basis for developing tailored intervention programmes to improve family adaptation and QoL of children with DS. Strengthening support systems for fathers and implementing policies that encourage paternal involvement in caregiving are crucial. Government policies should focus on reducing social exclusion and discrimination against individuals with disabilities, as these factors significantly impact family adaptation and children's QoL.

7 | Conclusions

This study investigated the impact of the interactions between fathers and mothers of children with DS on their children's QoL. Specifically, it clarified the mediating effect of family adaptation on parenting stress and QoL in children with DS. To our knowledge, this is the first study to jointly examine fathers, mothers, and their children with chronic conditions, including DS, through a dyadic framework to explore associations with children's QoL. The interactions between fathers and mothers identified in this study can serve as a foundation for developing dyadic intervention programmes aimed at improving the QoL of children with chronic conditions.

Author Contributions

S. H. Yang, C. G. Park and E. K. Choi: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; S. H. Yang, C. G. Park and E. K. Choi: Involved in drafting the manuscript or revising it critically for important intellectual content; S. H. Yang, C. G. Park and E. K. Choi: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; S. H. Yang, C. G. Park and E. K. Choi: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Ethics Statement

The study protocol was reviewed and approved by the institutional review board of the Yonsei University Health System on April 14, 2023 (4-2023-0214).

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Research data are not shared.

Peer Review

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.70153>.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Appendix S1:** STROBE statement—checklist of items that should be included in reports of cross sectional studies.