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Family responses and influencing factors in raising children with developmental disabilities: A cross-sectional study in South Korea

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Family responses, which encompass how families respond to raise children with developmental disabilities (DDs) and manage their child's condition, have a profound impact on both the child and the family as a whole. Demographic and contextual factors contribute to shaping family responses and overall experiences. Gaining a comprehensive understanding of family responses to raising children with DDs and the influencing factors is essential. This study examined how families responded to caring for their children with DDs and determined the factors associated with the family responses. A cross-sectional online survey was conducted with 200 parents of children with DDs in South Korea between September 2020 and October 2021. Families reported unfavorable perceptions across multiple aspects of family management and experienced difficulties in day-to-day caregiving. Various factors, including the child's age, gender, and diagnosis, as well as parental age, gender, and education, were associated with different aspects of family responses. Higher levels of social support, from relatives, friends, and others in general, were linked to more positive family responses. This study highlights the challenges faced by these families and underscores the critical role of social support in promoting positive family responses. Moreover, this study emphasizes the importance of providing tailored interventions that take into account demographic and contextual factors to address the specific needs of families of children with DDs.

Keywords Children with developmental disabilities, Family demographic, Social support, Family perception

Developmental disabilities (DDs) refer to conditions arising from impairments in physical and behavioral functioning, learning, or language abilities that begin during the developmental period and cause limitations in day-to-day functioning throughout one's lifetime[1]. Examples of such conditions include autism spectrum disorder (ASD), Down syndrome (DS), attention-deficit/hyperactivity disorder, cerebral palsy, and various learning disabilities[2]. Globally, the number of children with DDs continues to rise[3]. Zablotsky et al.[4] found a significant increase in the prevalence of DDs in the United States during 2009–2011 and 2015–2017, from 16.2% to 17.8%, respectively. Rah et al.[5] reported that the prevalence of DDs in South Korea (hereinafter Korea) increased more than fourfold between 2003 and 2017.

How a family responds to caring for a child with a DD is essential, not only for the child but also for the family as a unit[6]. Knafl et al.[7] stated that the responses of families raising children with chronic conditions reflect their perceptions of the child, the abilities and efforts required to manage the condition, and the perceived impact of the condition on both the child's and the family's future. These family responses shape the functioning of individual family members and the family unit. Minnes et al.[8] found that families with a positive perception of their ability to manage day-to-day situations related to children with DDs found more benefits in raising their child and experienced lower distress levels. Hsiao[6] reported that families who perceived more stress regarding rearing children with ASD had lower family quality of life (QoL) levels. Given the connections between families' responses to raising a child with DD and family life, enhancing positive family perceptions and exploring factors that influence perceptions are critical. Moreover, the growing significance of a family-centered approach, which emphasizes involving families in the delivery of the services for their children with DDs[9], further underscores the importance of understanding these perceptions and contributing factors.

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Studies have highlighted that various demographic and contextual factors could influence a family's responses to having children with DDs. The most frequently considered demographic factors include the type of DDs and the level of severity, which could influence levels of family stress or family adaptation[3,9–11]. Some studies have shown a child's age to be a contributing factor to family experiences. For example, Zeng et al.[12] reported that maternal stress levels were significantly higher during the early childhood period (ages 1–3) compared to later developmental stages (ages 5–19) among mothers of children with DDs.

Research indicates that the parent's sex is regarded as an influential factor for family responses related to rearing a child with DD, with mothers of children with DDs exhibiting more parenting stress and lower levels of family QoL than fathers[13]. Also, the possible relationships between financial status, parental stress, and family functioning among families of children with DDs have been supported by prior studies[3,6,9].

Further, the positive effects of supportive environments for families of children with DDs have been consistently stressed as contextual factors[14]. Meleady et al.[9] reported that higher levels of informal support (e.g., support from significant others) and formal support (e.g., support from the autism communities and service providers) were associated with better life satisfaction among Irish families of children with ASD. Similarly, Lei and Kantor[14] found a positive relationship between social support and family adaptability and cohesion in Chinese families of children with ASD.

However, a critical gap remains in the existing literature regarding a comprehensive understanding of how diverse family demographics and social, economic, and cultural contexts shape the experiences of families raising children with DDs[15]. Therefore, this study aimed to examine how families of children with DDs respond to rearing their children and to explore the associations between various demographic and contextual factors and family responses among Korean families.

Specifically, we hypothesized the following: (1) family demographic factors including parent and child age and gender, parental education level, religion, income, and the child's diagnosis would be associated with variations in family responses; and (2) higher levels of contextual factors, particularly perceived social support and support from relatives and friends, would be associated with more favorable family responses.

Methods

Design and participants

To identify family responses to childcare and the associated variables among families of children with DDs, a cross-sectional study was conducted online in Korea from September 2020 to October 2021. This study included parents of children with a range of DDs to identify overarching patterns and influencing factors that may be common across conditions. Eligible participants were parents of children with DDs whose children were under 21 years old and lived with the family, and the parents could access the internet. The United Nations Convention on the Rights of the Child[16] defines children as individuals under the age of 18. However, given that developmental delays often persist into late adolescence and early adulthood, this study included participants up to 21 years of age. Although DDs typically have an onset in childhood, caregiving demands frequently extend into early adulthood due to continued dependency and support needs[17]. Including this broader age range allowed for a more comprehensive understanding of family experiences across critical developmental stages.

Measures

The use of all measurement instruments was formally approved and confirmed by the original authors.

Family demographics

A survey was conducted on family demographic information, including age and gender of parents and children, types of DDs, parents' educational level, religion, family income, and marital status.

Contextual factors

We used the Korean versions of the Relative and Friend Support Index (RFSI) and the Social Support Index (SSI) from the Family Index of Regenerativity and Adaptation—General (FIRA-G), as developed by Choi[18], to assess the levels of perceived support among families. The RFSI uses a five-point Likert scale and comprises eight items. Higher scores indicate higher levels of support from friends and relatives in managing stressful situations. The Cronbach's alpha of the RFSI was 0.82 at the time of its original development[19] and 0.80 in the present study. The SSI comprises 17 items rated on a five-point Likert scale that measure the social support a family receives. The Cronbach's alpha of the SSI was 0.82 at the time of its original development[19] and 0.81 in the present study.

Family responses

We used the Korean version of the Family Management Measure (FaMM) to examine family responses to raising children with DDs[20]. The FaMM is based on the Family Management Style Framework to identify the family responses to managing a child with chronic conditions[7]. The instrument assesses (1) the family's perception of their child (child's daily life, five items); (2) the family's ability to handle the child's condition (condition management ability, 12 items); (3) mutual understanding between partners in addressing the child's condition (parental mutuality, eight items); (4) the degree that rearing the child adds complexity to family life (family life difficulty, 14 items); (5) the impact of the condition on their child's and family's future (view of condition impact, 10 items); and (6) the efforts needed to manage the child's condition (condition management effort, four items). For the child's daily life, condition management ability, and parental mutuality scales, higher scores represent the family's perception of greater ease in caring for the child with DD. For family life difficulty, perception of condition impact, and condition management effort scales, higher scores indicate that the family experiences greater difficulties and more effort in rearing the child with DDs. Originally, the Cronbach's alpha coefficients for the FaMM ranged from 0.72 to 0.91[7]. The internal consistency reliability of the FaMM scales in this study ranged from 0.74 to 0.86, except for the perception of condition impact (0.44) and condition management effort (0.50) scales; these two scales were therefore excluded from the regression analyses.

Data analysis

SAS software (version 9.4; SAS Institute, Cary, NC, USA) was used to analyze the collected data. Regression analyses were used to examine how family characteristics and contextual variables affected family responses. First, bivariate regression analyses were performed on each family's demographic/contextual variables and the FaMM scales to assess the significance and slope estimates. Among the family demographic variables, parents' level was categorized as "baccalaureate and graduate" and "high school and less than high school" to form a dichotomous variable. Family income was categorized as "more than 5,500,000" and "less than 5,500,000," using the value of the average monthly income (KRW) per household in Korea[21], to form a dichotomous variable. To account for diagnostic variability, child diagnosis was included as a dichotomous variable (ASD vs. non-ASD) in the regression analyses, based on evidence that families of children with ASD tend to experience greater challenges than those of children with other DDs[22].

For each FaMM scale, a composite regression model was created with family demographic and contextual variables that were meaningful in bivariate relationships. Finally, a parsimonious model was generated using the backward elimination approach. The backward method is used to build a parsimonious and interpretable regression model by starting with all predictors and systematically removing non-significant variables to reduce overfitting, address multicollinearity, and improve predictive accuracy, especially in exploratory research contexts[23].

Multicollinearity was assessed using tolerance values, with all values exceeding the 0.10 threshold suggested by Polit[24], indicating no concerns. In addition, extreme outliers were identified (studentized residuals [SRs] outside of ± 3), constant variance was checked with a model specification test[24], and the Shapiro–Wilk (S–W) test was conducted with SRs to evaluate the model assumption of the final regression models. The final models satisfied the assumption of normality.

To justify the number of predictors, post hoc power analyses were conducted using G*Power 3.1. Based on the observed R^2 values for each regression model, effect sizes (f^2) ranged from 0.21 to 0.68. With an alpha level of 0.05 and a sample size of 200, all models demonstrated statistical power greater than 0.99, indicating that the sample size was more than adequate for detecting the observed effects.

Procedure

The data collection procedure adhered to the ethical guidelines established by the Declaration of Helsinki. This study was approved by the Institutional Review Board of Korea University [KUIRB-2020-0322-01].

A convenience sampling method was employed to recruit participants. To enhance the representativeness of the sample, the authors contacted a representative of the National Center for Disabled Children and Developmental Disabilities and the leaders of over 30 support groups for children with DDs in Korea, and obtained approval to post research flyers on their websites. The flyer included an online survey link (SurveyMonkey) and provided information on the study's purpose, eligibility criteria, and ethical considerations. Parents of children with DDs who were interested in this study had access to the online survey. Informed consent was obtained from all subjects. We verified the child's initials, date of birth, and IP address to prevent duplicate responses. The online survey platform was configured to require responses to all items before allowing participants to proceed to the next section; consequently, the dataset contained no missing data. After completing the survey, participants received a mobile coupon gift (10,000 KRW).

Results

Family demographic and contextual variables

A total of 200 Korean parents (92.0% mothers) of children with DDs participated in this study. All parents were married, and most had a bachelor's degree (80.5%). Approximately 40% of the families had an annual income of over 5,500,000 KRW. The mean age of children with DDs was 11.17 years (standard deviation [SD] = 4.23), and there were more boys (67.0%) than girls. The most frequently reported diagnosis was ASD (49.4%), followed by intellectual disability (29.8%) (Table 1).

The mean RFSI score was lower than the reported norms (M = 22.36; norm = 25 for preschoolers and 24 for adolescents; McCubbin & Thompson, 1987) (Table 2). The mean SSI score was higher than the norms (M = 54.50; norm = 45.3 for preschoolers and 47.9 for adolescents[25]).

Family responses to rearing a child with DD

The mean scores of the FaMM scales were 11.68 (SD = 4.01) for the child's daily life, 37.49 (SD = 7.04) for condition management ability, 13.81 (SD = 3.06) for condition management effort, 48.54 (SD = 9.41) for family life difficulty, 32.04 (SD = 4.57) for perception of condition impact, and 24.90 (SD = 5.95) for parental mutuality (Table 3).

Relationships among family demographic, contextual, and response variables

We generated final models after conducting bivariate and composite regression analyses between each variable of families' demographic (parent/child age and gender, parent's education, religion, income, child diagnosis), contextual (relative and friend support, social support), and family response variables (child's daily life, condition management ability, parental mutuality, family life difficulty) (Table 4).

For child's daily life, relative and friend support was a significant positive predictor (β = 0.344, $p < 0.001$), while parent's age was negatively associated (β = –0.197, $p < 0.05$). In the model for condition management ability, child age negatively predicted outcomes (β = –0.162, $p < 0.001$), while social support exerted a strong

Characteristics	N (%)
Parent's age	29–60 years (*M* = 42.1 years, *SD* = 4.8)
Parent's gender	
Female	184 (92.0)
Male	16 (8.0)
Parent's education	
Less than high school	1 (0.5)
High school	24 (12.0)
Baccalaureate	161 (80.5)
Graduate	14 (7.0)
Identifying with a religion	
Yes	86 (43.0)
No	114 (57.0)
Family income (won)	
Less than 1,000,000	2 (1.0)
1,000,000–2,500,000	11 (5.5)
2,500,000–4,000,000	50 (25.0)
4,000,000–5,500,000	58 (29.0)
5,500,000–7,000,000	48 (24.0)
7,000,000–8,500,000	26 (13.0)
More than 8,500,000	5 (2.5)
Child's age	4–21 (*M* = 11.17 years, *SD* = 4.23)
Child's gender	
Male	134 (67.0)
Female	66 (33.0)
Diagnosis*	
Autism spectrum disorder	116 (49.4)
Intellectual disability	70 (29.8)
Attention-deficit/hyperactivity disorder	24 (1.3)
Genetic disorder	11 (4.7)
Cerebral palsy	8 (3.4)
Hearing disorder	3 (1.3)
Other	3 (1.3)

Table 1. Descriptive statistics for family demographics (N = 200). *N = 235, including multiple diagnoses.

Contextual influences	M (SD)	Range
Relative and friend support	22.36 (6.24)	8–38
Social support	54.50 (8.56)	29–84

Table 2. Descriptive statistics for contextual influences: relative and friend support and social support (N = 200).

Family response	Description	M (SD)	Range
Child's daily life	Parents' views of their child and the child's everyday life	11.68 (4.01)	5–23
Condition management ability	Families' capability to manage the child's condition	37.49 (7.04)	16–57
Condition management effort	Families' efforts required to manage the child's condition	13.81 (3.06)	5–20
Family life difficulty	The extent to which raising a child with a chronic condition makes family life more difficult	48.54 (9.41)	19–69
View of condition impact	Parents' views of the severity of the condition and its significance to their child's and family's future	32.04 (4.57)	16–43
Parental mutuality	Parents' support, shared views, and satisfaction with how partners work together to deal with their child's condition	24.90 (5.95)	9–40

Table 3. Descriptive statistics for family responses (N = 200).

Family response	Model	*F*	R^2	Adjusted R^2	*B*
Child's daily life	Parent age	21.63	0.180	0.172	−0.197*
	Relative and friend support				0.344***
Condition management ability	Child age	67.10	0.405	0.399	−0.162***
	Social support				0.620***
Parent mutuality	Social support	81.42	0.291	0.288	0.540***
Family life difficulty	Parent gender (ref: male)	13.27	0.292	0.270	0.126*
	Parent education (ref: lower)				0.158*
	Child gender (ref: male)				−0.181*
	Child diagnosis (ref: non-ASD)				0.130*
	Relative and friend support				−0.255***
	Social support				−0.238**

Table 4. Final regression models for family response (N = 200). ASD, Autism Spectrum Disorder, ref, reference group. * $p < .05$. ** $p = .001$. *** $p < .001$

positive influence (β = 0.620, $p < 0.001$). Parent mutuality was significantly predicted solely by social support (β = 0.540, $p < 0.001$). In the final regression model predicting family life difficulty, six variables emerged as significant predictors. Compared to male caregivers, female caregivers reported significantly greater family life difficulty (β = 0.126, $p < 0.05$). Parents with higher education levels experienced greater difficulty than those with lower education (β = 0.158, $p < 0.05$), and families of male children reported more difficulty than those of female children (β = −0.181, $p < 0.05$). Furthermore, families of children diagnosed with ASD reported higher family life difficulty compared to those with non-ASD diagnoses (β = 0.130, $p < 0.05$). Both relative and friend support (β = −0.255, $p = 0.001$) and social support (β = −0.238, $p < 0.01$) were significant factors, associated with reduced perceived family life difficulty.

Accordingly, the research hypotheses were supported, as family demographic factors were associated with differences in family responses, and higher levels of social support and support from relatives and friends were linked to more favorable responses.

Discussion

This study sheds light on family responses to rearing children with DDs and delineates their relationships with family demographics and contextual variables among Korean families of children with DDs. Overall, families reported unfavorable perceptions across all domains of the FaMM, with mean scores more negative than those previously reported among Korean families of children with chronic or atopic conditions[20,26], as well as Korean families participating in a multi-country comparative study on children with DS[27]. As these studies were conducted prior to the COVID-19 pandemic, the more unfavorable family responses observed in the current sample may, in part, reflect the heightened stress and disruptions experienced during the pandemic period in which this study was conducted.

However, consistent evidence suggests that such difficulties among Korean families predate the pandemic, potentially due to systemic limitations in disability-related support. Korea's public expenditure on welfare for individuals with disabilities accounts for 0.8% of Korea's gross domestic product, while the average is 2.0% among the 38 other OECD member countries[28]. Additionally, the policy discrepancy between central and local governments, along with the limited scope of support policies that focus primarily on the child with DD rather than addressing the needs of both the child and the family, has been identified as a significant barrier to effective service delivery in Korea[29]. Strengthening policies to address these challenges will enhance the sustainability and effectiveness of service support for children with DDs and their families.

A key finding of this study is the role of child characteristics—particularly diagnosis, sex, and age—in shaping family experiences. The families of male or older children with ASD showed lower levels of management abilities and higher levels of life difficulties. Studies have consistently shown that families of children with ASD experience higher levels of stress than those of children with other DDs[22], a vulnerability that may have been further exacerbated by pandemic-related lockdowns.

Few studies have examined the relationships between the sex of children with DDs and family responses[3], and their results are inconclusive. While some found no association between a child's sex and parental stress[30], others reported significant links[10], indicating the need for further research into how gender dynamics shape family responses.

Studies on children's age and family experiences also have yielded mixed findings. Alhuzimi[10] and Zeng et al.[12] reported higher levels of stress in parents of younger children with DDs compared to parents of older ones. Others, however, exhibited the opposite result, indicating that parental stress increased as children with DDs aged[22,31], a finding that aligns with the results of the current study. As children with DDs age, their families often experience increased challenges and uncertainties regarding the transition from childhood to adulthood, including issues related to healthcare services, leaving school, employment, or living independently[31]. During this process, families may need to adjust their expectations, which can increase stress[22]. When developing interventions for families of children with DDs, service providers should consider that certain child characteristics may heighten the family's vulnerability.

Regarding parental factors, the findings suggest that older parents, those with higher educational attainment, and mothers experience greater difficulties in caring for their children. As older children with DDs face complex transitions, their similarly aging parents may experience heightened caregiving burdens, a dynamic that professionals should carefully consider in service planning. Additionally, the wide age range among parents in our sample may reflect generational differences in attitudes, coping styles, and expectations regarding caregiving and DDs. Future research could categorize parents into generational cohorts to examine whether and how generational factors shape family responses, thereby enhancing our understanding of family experiences across diverse age groups.

The association between parental education and family difficulty remains inconclusive, as prior studies report mixed findings. While some have linked higher parental education levels to better family QoL and functioning among families of children with DDs—potentially due to increased resources and healthier behaviors[6,32]—others found that higher education is associated with greater mental health challenges among caregivers of children with ASD[33]. Educated parents often hold higher expectations for their children with DDs[34], which could lead to a higher risk of perceiving their child and family functioning unfavorably when their expectations are not met. Further research is needed to clarify these relationships and inform tailored family support interventions.

Consistent with prior studies, the current findings indicate that mothers perceive more family difficulties than fathers, reflecting well-documented disparities in caregiving burden and stress among families of children with DDs[6,13]. This may be attributed to traditional gender roles, particularly in Asian cultures, where mothers predominantly take on primary caregiving responsibilities[35]. The cumulative emotional and practical demands placed on mothers may contribute to their more negative perceptions of family functioning. These findings underscore the need for family interventions that promote equitable caregiving roles and spousal collaboration.

Furthermore, this study confirmed that higher perceived support from relatives and friends was associated with more positive family appraisals of raising a child with DD, with the child's condition viewed as less disruptive to family life. Informal support plays a critical role in buffering parenting stress and enhancing adaptive functioning, as it provides emotional relief and practical assistance[36]. In collectivist societies like Korea, where stigma and reluctance to seek formal help are prevalent[14,37], informal networks may be especially vital in shaping family experiences and resilience.

While informal support from relatives and friends is culturally significant in Korea, this study also underscores the importance of perceived formal support. Families reporting higher levels of social support were more likely to view their child's condition as manageable and expressed greater satisfaction with spousal involvement in care. Prior studies similarly highlight the positive impact of social support on family cohesion, adaptability, and maternal perceptions[14,38]. Nonetheless, many families continue to report insufficient or fragmented support that fails to address holistic family needs[10,29]. Future research should prioritize the design and evaluation of culturally responsive interventions that integrate both formal and informal support systems to promote family experiences.

Notwithstanding these important findings, this study has limitations. First, the use of self-reported measures may have introduced social desirability bias and recall bias. In particular, child diagnoses were reported by parents based on their recollection of clinical assessments, which could result in misclassification or inaccuracies. Although parental report is a widely accepted method in large-scale research on DDs, the absence of verification through medical records or clinical assessments limits the precision of diagnostic categorization. Second, data collection through online surveys limited participation to individuals with internet access, potentially excluding less connected populations. Third, the sample was heavily skewed toward mothers, which may limit the generalizability of the results to fathers or other family members. Given that mothers are often the primary caregivers in many cultural contexts, including Korea, their perspectives may have disproportionately influenced reported family responses. Future research should aim to incorporate diverse caregiver perspectives, confirm diagnoses through clinical documentation where feasible, and employ longitudinal or mixed-methods designs to enrich understanding of family adaptation processes.

Conclusion

This study examined the responses of Korean families raising children with DDs and explored their associations with family demographics and contextual factors. These families displayed unfavorable perceptions of their experiences in raising children with DDs. It is crucial to ensure the availability of ample resources and welfare provisions to address the unique needs of the families. Further, healthcare, education, and social support providers should consider the potential impact of various family characteristics on the experiences of raising children with DDs and develop tailored interventions for these families.

Data availability

The data underpinning the conclusions of this study are available upon request from the corresponding author

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Author contributions

Anna Lee: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Roles/Writing—original draft; and Writing—review & editing. Won-Oak Oh: Conceptualization; Validation; Roles/Writing—original draft; and Writing—review & editing. Eun Ju Park: Validation; Roles/Writing—original draft; and Writing—review & editing.

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Declarations

Competing interests

The authors declare that they have no competing interests.

Additional information

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