

ORIGINAL ARTICLE

Mediating effects of family functioning on the relationship between care burden and family quality of life of caregivers of children with intellectual disabilities in Mongolia

Jinhee Kim¹  | Hyunlye Kim¹  | Seojin Park²  | Jaeyong Yoo¹  | Delgersuren Gelegjamts^{1,3} 

¹Department of Nursing, College of Medicine, Chosun University, Gwangju, South Korea

²Department of Nursing, Donggang University, Gwangju, South Korea

³Department of Nursing, College of Medicine, Mongolian National University, Ulaanbaatar, Mongolia

Correspondence

Hyunlye Kim, Department of Nursing, College of Medicine, Chosun University, 309 Pilmun-daero, Dong-gu, Gwangju, 61452, South Korea.
Email: hlkim5207@chosun.ac.kr

Funding information

This research was supported by Leading University Project for International Cooperation through the National Research Foundation of Korea (NRF) funded by the Ministry of Education (MOE) (NO. NRF-2016H1A7A2A02913910).

Background: Intellectual disabilities are characterized by constant and complex needs for care that place a heavy burden on the families of affected individuals and affect their overall quality of life. We evaluated the mediating effects of family functioning on the relationship between care burden and the family quality of life of caregivers of children with intellectual disabilities in Mongolia.

Methods: Data were collected from a sample of 150 caregivers of children with intellectual disabilities from October 2017 to November 2017. Multiple linear regression analyses were performed to examine the mediating effects of family functioning.

Results: Family functioning had a partial mediating effect ($\beta = .702, p < .001$) on the relationship between care burden and family quality of life.

Conclusion: Family functioning should be considered when developing a social support intervention to improve family quality of life among caregivers of children with intellectual disabilities.

KEYWORDS

care burden, family caregiver, family functioning, intellectual disability, quality of life

1 | INTRODUCTION

There are approximately 1 billion people with disabilities worldwide, and 80% of people with disabilities live in developing countries (World Health Organization, 2011). A survey by the United Nations Economic and Social Commission for Asia and the Pacific showed that the prevalence of disability in Mongolia is 3.9% (108,071 persons); physical disability comprises 29% of this disability, and mental/intellectual disability comprises 19% (United Nations Economic and Social Commission for Asia and the Pacific, 2015). Mongolia is a developing country in Central Asia that has experienced positive economic growth since its political shift to democracy in the early 1990s. This transition led to further development of the

social welfare system as well as wider coverage of social insurance. However, given poor financial resources, inefficient service delivery systems and scarce professional manpower, Mongolia continues to lack effective social welfare programmes to meet the needs of people with disabilities and their families (Choi & Davaasuren, 2016). In addition, contextual barriers (e.g. long distances and lack of transportation, low population density and harsh climate conditions related to the geographic features of Mongolia) interfere with the ability of community-based services to reach families with disabled children (Como & Batdulam, 2012).

The birth and parenting of children with disabilities have negative psychological, sociocultural and economic impacts on family members (Summers et al., 2005; Yoon & Kim, 2015). In particular,

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2020 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd

the burden of care for disabled children is higher due to lower living standards and poor social support systems in developing countries (Mobarak et al., 2000; Thuy & Berry, 2013). Care burden is also related to the type of disability. In families with children who have intellectual disabilities, which are characterized by severe limitations of mental functioning and adaptive behaviour, the caregiver burden is higher because of difficulties with communication and independent self-care (Malhotra et al., 2012; Schalock et al., 2007). Caring for children with intellectual disabilities places considerable demands on parents in terms of time and effort, resulting in a greater care burden for the entire family (Tadema & Vlaskamp, 2010). Disadvantageous life events and genetic vulnerability can increase the risks of mental health problems among people with intellectual disabilities. These individuals often need psychological therapy and require long-term care by their families throughout childhood and early adulthood (Vereenoghe & Langdon, 2013). A study regarding differences in care needs throughout the life cycles of families with children who have disabilities revealed that the care burden is highest among parents with young children (Kim et al., 2015).

Studies of families in stressful situations use a strengths-based view that emphasizes health, adaptation and quality of life (QoL); these factors explain why some families have better life experiences (Ylvén et al., 2006). With the growing emphasis on family-centred care in the field of intellectual disabilities, interest in family QoL has also increased (Hu et al., 2012). Note that families with intellectually disabled children have reported greater caregiver burden, more problematic family functioning, lower marital satisfaction and a lower sense of coherence (Al-Krenawi et al., 2011). These negative impacts associated with disabilities result in tension and conflict between couples, lack of closeness between parents and other children, and eventual negative effects on QoL in the disabled child's family (Hu et al., 2012; Hwang et al., 2010; Malhotra et al., 2012; Seo et al., 2016).

However, these negative experiences do not extend to all parents of children with disabilities. In some families, children with disabilities may be the source of positive changes, such as stronger cohesion within the family, improved intimacy among family members and reconsideration of family members' surroundings and their lives (Kim, 2001). Therefore, it is necessary to investigate the factors associated with positive adjustments among family members when caring for children with disabilities.

Raising children with disabilities requires a reassessment of family functioning to determine how families manage such situations (Taanila et al., 2002). Family functioning involves communication, cohesion, flexibility, role performance and coping processes within families. These aspects are often measured using the Family Adaptability and Cohesion Scales (Summers et al., 2005). Well-functioning families of children with disabilities are able to maintain the functioning of the family member with the disability through problem solving, a sense of coherence, positive coping and positive adaptation, these factors contribute to a better life through adversity (Ylvén et al., 2006). In families with children who have intellectual disabilities, family functioning helps reduce externalizing behaviours, develop self-esteem and maintain psychological stability

(Sikora et al., 2013; Xue et al., 2014). Therefore, we hypothesized that family functioning could aid in overcoming the burden of care and help to maintain QoL in families with children who have intellectual disabilities.

This study focused on the care burden, family functioning and family QoL (FQoL) for caregivers of children with intellectual disabilities in Mongolia. Previous studies have reported that family-strengthening factors have a mediating effect on the impact of the parenting burden of children with disabilities, thus improving the FQoL (Seo et al., 2016; Yoon & Kim, 2015). Our Korea-Mongolia joint research team sought to identify whether family functioning has mediating effects on the relationships between care burden and FQoL, neither of which have been investigated in Mongolia. Identifying causal structures may provide a basis when applying interventions to improve QoL in families of children with intellectual disabilities. In addition, it will help to emphasize the need for social support among Mongolian families with children who have intellectual disabilities.

2 | METHODS

2.1 | Study design

This cross-sectional survey identified the mediating effects of family functioning on the relationship between care burden and FQoL among caregivers of children with intellectual disabilities in Mongolia.

2.2 | Participants and sampling

Participants in this study were 150 primary caregivers of children with intellectual disabilities. The children were students in the largest elementary school for the disabled in Ulaanbaatar, Mongolia. The participants were adults who understood the purpose and content of the study, were able to communicate and fill out questionnaires, and voluntarily agreed to participate in the study. The number of participants in this study was determined based on a power analysis with G*Power 3.1.9.2. In total, 138 participants were needed for multivariate regression analyses with an effect size of 0.15, a significance level of 0.05, a power of 0.95, and five predictors. We included 150 participants in the study, anticipating a possible 10% dropout rate. Data for all participants were used in the analyses, as no participant provided unsatisfactory responses.

2.3 | Data collection and procedure

The data collection period for this study was from 30 September 2017, to 31 October 2017. Data collection was performed during individual home visits. First, we visited a school for the disabled in Ulaanbaatar City, Mongolia, as well as the B district office that governs the school. After we explained the purpose and content of the

study, we received approval to perform the data collection. A family communication letter was also sent to each family, and the primary caregiver who agreed to participate was selected as the research subject. For the survey, a total of nine people participated in this study, including three professors from the Department of Nursing, Social Welfare and Public Health Sciences at Mongolian University, social workers and researchers working at national research institutes related to the disabled, and assistants in the nursing department. These nine people were trained in a 1-day workshop 1 week before data collection. They formed groups of 2–3 people, including a member who was a self-driving driver and contacted each family participating in this study before visiting them directly. Participants were asked if they required help to fill out the questionnaire comfortably and honestly without interruption and received help when requested. All participants filled out the questionnaire after receiving sufficient explanation of the research content and survey method from the research assistants.

2.4 | Ethical considerations

This study protocol was approved by the institutional review board of C University, with which we are affiliated (approval no.: 2-1041055-AB-N-01-2017-0046). Research assistants trained for this study provided potential participants with explanations of the purpose and content of the study, instructions regarding the questionnaire and statements of participants' ethical rights. If potential participants agreed to participate in the study, they were asked to sign a written consent form and complete the questionnaire. In addition, research assistants explained that the data collected would be used for research purposes only and could be withdrawn at any time upon request by the participants. The time required to complete the questionnaire was approximately 20 min. The collected questionnaire data were encoded and entered into the computer.

2.5 | Measures

The selected Korean version of the questionnaire was translated into Mongolian and back-translated by two bilinguals: one Mongolian who has lived in Korea for many years and has a PhD in Social Welfare, and one Korean who has lived in Mongolia for many years and is a professor of Korean Studies at the University of Mongolia. They determined whether there was a difference in the meaning of the translation–reverse translation results and, in case of a conflict, reached an agreement through discussion. The Mongolian version of the questionnaire was further corrected and supplemented by review opinions from a total of five expert groups consisting of three professors from the Department of Nursing, one professor of Social Welfare, and one professor of Public Health Sciences at Mongolian University. Finally, the Mongolian questionnaire was completed after it had been revised according to the results of a pilot study of a total of 10 people, including three teachers at a disabled children's school,

two professors of social welfare and public health and five parents of children with intellectual disabilities who lived in Mongolia.

2.5.1 | General characteristics

The following general characteristics of the participants were recorded: sex, age, relationship with the children who had intellectual disabilities, education level, monthly family income, presence of alternative caregivers, presence of other children with disabilities, educational experience related to disability, perceived health status and care delivery time. The following general characteristics of children with intellectual disabilities were recorded: sex, age, presence of multiple disabilities and degree of disability.

2.5.2 | Care burden

The Caregiver Burden Inventory, developed by Novak and Guest (1989), was translated into Mongolian to measure the burden of care in families with children who have intellectual disabilities. The tool consists of five subconcepts: time dependence, developmental burden, physical burden, social burden and emotional burden. This tool uses a 5-point Likert scale for each of 24 questions; responses to each question range from "not at all" (1) to "almost always" (5). The total score ranges from 24 to 120, with higher scores indicating a higher burden of care. Scoring between 24 and 39, 40 and 71, and 72 and 120 was considered to indicate a mild, moderate and severe level of burden, respectively (Senmar et al., 2019). Internal reliability (Cronbach's alpha) ranged from 0.73 to 0.86 for each subconcept at the time of development and was 0.91 for all questions in this study.

2.5.3 | Family functioning

Olson's Family Adaptability and Cohesion Evaluation Scales III (Olson, 1986) was translated into Mongolian to measure family functioning. This tool consists of adaptability (10 items) and cohesion (10 items). This tool uses a 5-point Likert scale; responses to each item range from "not at all descriptive" (1) to "very descriptive" (5). The total score ranges from 20 to 100, with higher scores indicating higher family functioning. Internal reliability (Cronbach's alpha) was 0.92 at the time of development and 0.91 for all items in this study.

2.5.4 | Family quality of life

To measure FQoL, we translated the Beach Center Family Quality of Life Scale (Summers et al., 2005), developed for families with children who have intellectual and developmental disabilities, into Mongolian. The tool consists of five subconcepts: family interaction, parenting, emotional well-being, physical/material well-being and disability-related supports. This tool uses a 5-point Likert scale for

each of the 25 questions; responses to each question range from “not at all descriptive” (1) to “very descriptive” (5). The total score ranges from 25 to 125, with higher scores indicating higher FQoL. Internal reliability (Cronbach's alpha) was 0.90 at the time of development and 0.92 for all questions in this study.

2.6 | Data analyses

We analysed data using SPSS Statistics for Windows, version 23.0. General and disability-related characteristics, as well as the degrees of major variables, were identified through descriptive statistics (frequency, percentage, mean and standard deviation). Independent *t* tests and one-way analyses of variance were conducted to identify differences in care burden, family functioning and FQoL with respect to the characteristics of caregivers and children with intellectual disabilities. Scheffe's test was performed for post hoc analyses. Correlations between care burden, family functioning and FQoL were analysed with Pearson correlation analyses. To examine the mediating effects of family functioning on the relationship between care burden and FQoL, we performed multiple regression analyses using a three-step verification procedure described by Baron and Kenny (1986). The Sobel test was used to determine the statistical significance of the mediating effects.

3 | RESULTS

3.1 | General and disability-related characteristics

Analyses of the general characteristics of primary caregivers for children with intellectual disabilities showed that 85.3% ($n = 128$) were women. Of the caregivers, 74.7% ($n = 112$) were mothers, 12.0% ($n = 18$) were grandparents, and 8.7% ($n = 13$) were fathers. The average age of the caregivers was 41.01 ± 10.48 years and most participants were 30–39 years old (43.3%). In terms of education, 50.7% ($n = 76$) of the caregivers had graduated from college or higher. Most participants (57.3%, $n = 86$) had 250,000 to 740,000 MNT (\$100.54–\$297.59) in monthly family income. Most reported that there were alternative caregivers (62.0%) and no other disabled children (84.7%). Most participants (83.3%) had no educational experience related to caring for children with disabilities. Caregivers perceived their health as moderate (42.7%, $n = 64$), healthy (36.7%, $n = 55$) or unhealthy (20.7%, $n = 31$). The average daily care time for children with intellectual disabilities was 12.32 ± 5.48 hr (Table 1).

Of the children with intellectual disabilities, 59.3% ($n = 89$) were boys and 40.7% ($n = 61$) were girls. The mean age of these children was 7.15 ± 2.50 years and most children were 6–10 years old (68.7%, $n = 103$). A total of 81.3% ($n = 122$) had other disabilities in addition to intellectual disabilities. The degree of disability was rated moderate (60.0%, $n = 90$), severe (21.3%, $n = 32$), mild (12.7%, $n = 19$) or extremely severe (6.0%, $n = 9$; Table 1).

3.2 | Care burden, family functioning and family quality of life

The average care burden score was 2.72 ± 0.68 out of 5. The mean total score was 65.38 ± 16.38 (range 32–114), indicating a moderate level of burden. A mild, moderate and severe level of burden was determined in 5.3%, 56.7% and 38.0% of the participants, respectively. The burden of care differed with respect to monthly family income ($F = 4.489$, $p = .005$), the presence of alternative caregivers ($t = 1.184$, $p = .007$), the perceived health status of the caregiver ($F = 14.774$, $p < .001$) and the degree of disability of the children with intellectual disabilities ($F = 3.431$, $p = .019$). Specifically, the burden of care was highest when the monthly family income was low, when the perceived health status of the caregiver was unhealthy, when the degree of disability of the children with intellectual disabilities was severe, and when there was no alternative caregiver (Table 1).

The average family functioning score was 3.81 ± 0.66 out of 5. Family functioning differed with respect to education level ($F = 6.125$, $p = .003$), monthly family income ($F = 7.771$, $p < .001$), the presence of other children with disabilities ($t = 1.706$, $p = .016$) and the perceived health status of the caregiver ($F = 6.036$, $p = .003$). Specifically, family functioning was highest when the education level and monthly family income were high, when there were no other children with disabilities and when perceived health was healthy (Table 1).

The average FQoL score was 3.77 ± 0.64 out of 5. FQoL differed with respect to education level ($F = 5.980$, $p = .003$), monthly family income ($F = 12.147$, $p < .001$), the presence of other children with disabilities ($t = 3.414$, $p = .003$) and the perceived health status of the caregiver ($F = 9.062$, $p < .001$). Specifically, FQoL was highest when the education level and monthly family income were high, when there were no other children with disabilities and when perceived health was healthy (Table 1).

Correlations between key variables are presented in Table 2. Family functioning was negatively correlated with care burden ($r = -.336$, $p < .001$). FQoL was negatively correlated with care burden ($r = -.255$, $p = .002$) and positively correlated with family functioning ($r = .838$, $p < .001$).

3.3 | Mediating effects of family functioning

To verify the mediating effects of family functioning on the relationship between care burden and FQoL, we performed multiple regression analyses using the three-phase procedure described by Baron and Kenny (1986). In the first stage, care burden had a significant effect on family functioning ($\beta = -.255$, $p = .002$). In the second stage, when we controlled for general characteristics related to FQoL (education level, monthly family income and perceived health status of the caregiver), care burden had a significant effect on FQoL ($\beta = -.214$, $p = .008$). In the third stage, family functioning ($\beta = .702$, $p < .001$) and care burden ($\beta = -.104$, $p = .033$) had significant effects on FQoL. In addition, the effect of care burden on FQoL was

reduced in the third stage compared to the first stage, which indicates that family functioning has a partial mediating effect on the relationship between care burden and FQoL. The Sobel test showed that the mediating effect of family functioning was statistically significant ($Z = -3.15, p = .002$; Table 3). Figure 1 shows the interrelations among care burden, family functioning and FQoL in families with children who have intellectual disabilities, as determined by this method.

4 | DISCUSSION

Rehabilitation and social support to address the rights and needs of disabled people and their families are an emerging priority in Mongolia (Khan et al., 2018). In the present study, we investigated the interrelations among care burden, family functioning and FQoL in families with children who have intellectual disabilities in Mongolia. We found that the primary caregivers of children with intellectual

TABLE 1 Care burden, family functioning and family quality of life according to general and disability-related characteristics

Variables	Categories	N (%)	Care burden		Family functioning		Family quality of life	
			M ± SD	F or t (p)	M ± SD	F or t (p)	M ± SD	F or t (p)
Primary caregiver	Total		2.72 ± 0.68		3.81 ± 0.66		3.77 ± 0.64	
	Gender							
	Male	22 (14.7)	2.68 ± 0.60	1.484 (.648)	3.90 ± 0.47	4.467 (.368)	3.95 ± 0.56	0.952 (.140)
	Female	128 (85.3)	2.75 ± 0.69		3.80 ± 0.68		3.74 ± 0.65	
	Age (years)							
	<30	14 (9.3)	2.44 ± 0.57	1.333 (.260)	3.63 ± 0.74	1.103 (.358)	3.72 ± 0.71	0.824 (.512)
	30–39	65 (43.3)	2.75 ± 0.63		3.78 ± 0.66		3.71 ± 0.61	
	40–49	44 (29.3)	2.89 ± 0.68		3.79 ± 0.68		3.74 ± 0.71	
	50–59	14 (9.3)	2.65 ± 0.87		4.08 ± 0.52		3.98 ± 0.51	
	≥60	13 (8.7)	2.65 ± 0.72		3.97 ± 0.58		3.95 ± 0.57	
	Relationship with children [†]							
	Father	13 (8.7)	2.59 ± 0.62	1.920 (.129)	3.93 ± 0.42	0.412 (.744)	3.98 ± 0.50	1.281 (.283)
	Mother	112 (74.7)	2.80 ± 0.66		3.78 ± 0.69		3.71 ± 0.66	
	Sibling	6 (4.0)	2.17 ± 0.41		3.73 ± 0.84		3.94 ± 0.78	
	Grandparents	18 (12.0)	2.77 ± 0.77		3.92 ± 0.54		3.91 ± 0.51	
	Educational level [§]							
	≤Middle school	27 (18.0)	2.91 ± 0.67	2.909 (.058)	3.47 ± 0.70	6.125 (.003) a < c	3.52 ± 0.63	5.980 (.003) a, b < c
	High school ^b	47 (31.3)	2.85 ± 0.68		3.76 ± 0.74		3.64 ± 0.77	
	≥College ^c	76 (50.7)	2.61 ± 0.67		3.96 ± 0.54		3.93 ± 0.50	
	Monthly family income (10,000MNT) [§]							
	<25 ^a	2,516.7	2.92 ± 0.75	4.489 (.005) a, b > d	3.34 ± 0.80	7.771 (<.001) a < b, c, d	3.22 ± 0.84	12.147 (<.001) a < b, c, d
	25–74 ^b	86 (57.3)	2.81 ± 0.66		3.82 ± 0.61		3.77 ± 0.51	
	75–124 ^c	29 (19.3)	2.60 ± 0.58		4.01 ± 0.49		4.04 ± 0.50	
	≥125 ^d	10 (6.7)	2.11 ± 0.52		4.28 ± 0.45		4.26 ± 0.53	
	Alternative caregiver							
	Yes	93 (62.0)	2.63 ± 0.62	1.884 (.007)	3.86 ± 0.59	2.150 (.238)	3.84 ± 0.62	0.226 (.057)
	No	57 (38.0)	2.93 ± 0.73		3.73 ± 0.75		3.64 ± 0.70	
	Other children with disabilities							
	Yes	23 (15.3)	2.82 ± 0.57	1.205 (.564)	3.50 ± 0.76	1.706 (.016)	3.40 ± 0.77	3.414 (.003)
	No	127 (84.7)	2.73 ± 0.70		3.86 ± 0.62		3.83 ± 0.59	
	Experience of disability education							
	Yes	25 (16.7)	2.57 ± 0.53	1.586 (.173)	3.76 ± 0.54	2.615 (.719)	3.70 ± 0.59	0.175 (.618)
	No	125 (83.3)	2.78 ± 0.70		3.82 ± 0.68		3.78 ± 0.65	
	Perceived health status [§]							
	Healthy ^a	55 (36.7)	2.52 ± 0.62	14.774 (<.001) a, b < c	4.00 ± 0.61	6.036 (.003) a > c	4.00 ± 0.60	9.062 (<.001) a > b, c
	Moderate ^b	64 (42.7)	2.67 ± 0.67		3.78 ± 0.54		3.73 ± 0.53	
	Unhealthy ^c	31 (20.7)	3.27 ± 0.52		3.51 ± 0.84		3.43 ± 0.74	
	Daily caring time (hours)							
	≤5	9 (6.0)	2.75 ± 0.68	1.408 (.234)	3.68 ± 0.72	2.058 (.089)	3.70 ± 0.44	1.712 (.150)
	6–10	57 (38.0)	2.58 ± 0.53		3.74 ± 0.64		3.68 ± 0.57	
	11–15	47 (31.3)	2.84 ± 0.65		3.70 ± 0.67		3.70 ± 0.69	
	16–20	23 (15.3)	2.89 ± 0.92		4.08 ± 0.57		4.05 ± 0.71	
	≥21	14 (9.3)	2.79 ± 0.81		4.06 ± 0.67		3.90 ± 0.64	

(Continues)

TABLE 1 (Continued)

Variables	Categories	N (%)	Care burden		Family functioning		Family quality of life		
			M ± SD	F or t (p)	M ± SD	F or t (p)	M ± SD	F or t (p)	
Child with intellectual disabilities	Sex	Male	89 (59.3)	2.66 ± 0.65	1.827 (.070)	3.79 ± 0.65	0.3534 (.724)	3.74 ± 0.64	0.582 (.561)
		Female	61 (40.7)	2.86 ± 0.70		3.83 ± 0.67		3.80 ± 0.64	
	Age (years)	≤5	35 (23.3)	2.75 ± 0.68	0.122 (.885)	3.94 ± 0.70	2.161 (.119)	3.79 ± 0.66	2.374 (.097)
		6–10	103 (68.7)	2.73 ± 0.69		3.80 ± 0.60		3.80 ± 0.58	
		≥11	12 (8.0)	2.83 ± 0.64		3.49 ± 0.91		3.39 ± 0.95	
	Multiple disabilities [‡]	Yes	122 (81.3)	2.72 ± 0.70	0.665 (.458)	3.85 ± 0.65	0.089 (.063)	3.80 ± 0.65	0.698 (.144)
		No	26 (17.3)	2.83 ± 0.63		3.59 ± 0.68		3.60 ± 0.57	
	Degree of disability [§]	Mild ^a	19 (12.7)	2.30 ± 0.74	3.431 (.019)	3.93 ± 0.63	0.386 (.763)	3.90 ± 0.61	0.512 (.675)
		Moderate ^b	90 (60.0)	2.80 ± 0.72	(a < b,c)	3.77 ± 0.68		3.72 ± 0.68	
		Severe ^c	32 (21.3)	2.87 ± 0.42		3.82 ± 0.54		3.81 ± 0.50	
Extremely severe ^d		9 (6.0)	2.67 ± 0.56		3.89 ± 0.87		3.72 ± 0.64		

[†]N is 149.

[‡]N is 148.

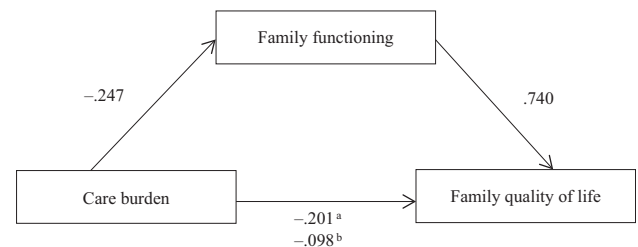
[§]Scheffe's post hoc test.

disabilities were mainly their mothers (74.7%). This is similar to findings in many other countries, including Korea. Since the establishment of a diplomatic relationship between Mongolia and Korea in March 1990, Mongolia has experienced an increasing number of cultural similarities due to increasing exchanges between the two countries. In Mongolia, as in Korea, mothers have primary responsibility

for parenting (Nansaldorj, 2016). There is increasing evidence regarding the impact of caring for children with intellectual disabilities on the well-being of mothers. In a cross-cultural study, mothers caring for child with intellectual disabilities experienced poor mental health and increased child-related stress (McConkey et al., 2008). Changing perspectives in studies of families of children with intellectual disabilities emphasize family strengths and adaptation, predominantly

TABLE 2 Correlations between care burden, family functioning and family quality of life

Variables			(N = 150)	
	CB	FF	CB	FQoL
Care burden (CB)	1			
Family functioning (FF)	-.336 (<.001)	1		
Family quality of life (FQoL)	-.255 (.002)	0.838 (<0.001)	1	



^a is direct effect, ^b is mediating effect.

FIGURE 1 Model of the mediating effects of family functioning on the relationship between care burden and family quality of life

TABLE 3 Mediating Effects of Family Functioning (FF) on the Relationship Between Care Burden (CB) and Family Quality of Life (FQoL)

Steps	B	β	t (p)	R ²	Adjusted R ²	F (p)
1. CB → FF	-.247	-.255	3.214 (.002)	.065	.059	10.327 (.002)
2. CB → FQoL	-.201	-.214	2.675 (.008)	.249	.223	7.154 (.008)
3. CB, FF → FQoL				.734	.722	139.932 (<.001)
FF → FQoL	.740	.702	16.120 (<.001)			
CB → FQoL	-0.098	-.104	2.148 (.033)			

Sobel test: Z = -3.15, p = .002

related to mothers and their ability to manage child-related stresses (Knight, 2013). Therefore, these findings should be considered by experts in the fields of health care and social support. Future in-depth explorations of caring experiences, perceived care burden and FQoL should include grandmothers and fathers.

In this study, the care burden of primary caregivers was slightly higher than the median value (2.72 ± 0.68). The overall average was 65.38, which was higher than the caregiver's burden of 57.4 reported for the case of older patients undergoing haemodialysis (average age 72.4 in patients) in a study using the same tool conducted in Iran (Senmar et al., 2019). In addition, the proportion of participants who experienced a severe burden was higher (38.0%) than the 25.0% reported by Senmar et al. These high burden scores demonstrate the need for interest in the burden of caregivers of children with intellectual disabilities. The results also showed that the burden of care differed with respect to family income, the presence of alternative caregivers, the perceived health status of the caregiver and the degree of disability in children with intellectual disabilities. Kim et al. (2015) explored the burden of care in families of disabled children through life. They found that the physical and economic burden was higher when children with disabilities were young. In addition, the degree of disability of the affected children, care time, caregiver health status, household income and spousal conflict influenced the parental care burden. Because social and economic support systems have a significant impact on parental care burden in developing countries (Mobarak et al., 2000), there is a need for an institutional social care system that includes family support at the national level.

The family functioning of primary caregivers was higher than the median value, out of 5 (3.81 ± 0.66). Moreover, family functioning differed with respect to education level, family income, the perceived health status of the caregiver and the presence of other children with disabilities. In a sample of Mexican families of children with intellectual disabilities, family functioning was a major contributing factor to positive family adaptation (Noriega et al., 2011). Healthcare professionals must assess a variety of factors associated with family functioning to determine which factors enhance family adaptation. In the present study, family functioning was negatively correlated with care burden. This finding indicates that family functioning can reduce the care burden of caregivers for children with disabilities. Caicedo (2014) surveyed parents of children with special care needs in the United States, and the results of that study revealed that caregivers have many unmet physical and mental health problems, compromised family functioning and a massive care burden. To reduce the burden of care, which can threaten the caregiver's health, community health interventions can focus on strengthening family functioning. Based on the findings of a literature review, Ylvén et al. (2006) suggested that individualization, the encouragement of flexibility in coping strategies and harmonization of strategies between partners are important factors for eliciting positive family functioning. There is a need to develop effective interventions for families of children with disabilities that consider these factors.

The FQoL of primary caregivers was higher than the median value, out of 5 (3.77 ± 0.64). The FQoL differed with respect to

education level, family income, the perceived health status of the caregiver and the presence of other children with disabilities. Because these factors related to QoL are difficult to resolve at the individual level, there is a need for assistance by the national social welfare system. Correlation analyses showed that the FQoL of participants was negatively correlated with care burden and positively correlated with family functioning. Thus, reducing the care burden and strengthening family functioning would aid in improving QoL. QoL plays a role in protecting and strengthening human rights in the field of intellectual disabilities (Verdugo et al., 2012). Therefore, QoL should be considered an important issue for social welfare professionals. To improve the QoL of families with children who have intellectual disabilities, it may be helpful to assess care burden and family functioning as this would enable the development of more appropriate interventions.

Finally, we found that family functioning had a partial mediating effect on the relationship between care burden and FQoL. Family resiliency mediates the relationship between care burden and QoL in Korean families with disabled children (Seo et al., 2016; Yoon & Kim, 2015). These findings indicate that the positive and healthy aspects of the family contribute to overcoming family hardship and maintaining QoL despite the potentially high burden in families with children who have intellectual disabilities. Therefore, strengthening family functioning will aid in improving the QoL of children with intellectual disabilities. However, low- and middle-income countries are limited in their ability to provide effective family support interventions because of a lack of funding and well-trained therapists; therefore, distinct and detailed strategies are needed to resolve these challenges in developing countries (Einfeld et al., 2012). In Mongolia, a community-based rehabilitation programme intended to improve the lives of people with disabilities at the community level was first proposed by the World Health Organization in the 1970s, this programme is ongoing. Community health workers must be trained and prepared for the transition from treatment to rehabilitation as this will ensure that community-based rehabilitation programmes achieve their intended purpose and are implemented effectively (Como & Batdulam, 2012; Jansen-van Vuuren & Aldersey, 2018). In addition to the development of psychosocial interventions that consider the factors identified in this study, training that involves rehabilitation may be an effective method of introducing well-designed social support programmes that have been proven in developed countries (Einfeld et al., 2012). Furthermore, effective programmes require long-term maintenance, as they continue to experience unique and complex care needs related to parenting in families with children who have intellectual disabilities (Caicedo, 2014).

This study has some limitations. First, the participants were recruited from among families with children at one school for the disabled in one region of Mongolia and it may be challenging to generalize the results of this study to other populations. We suggest that qualitative or longitudinal studies be performed to explore the experiences and attributes of families with children who have intellectual disabilities, as these aspects change as the

affected children grow. Studies similar to ours but with additional participants and the inclusion of other regions are needed to identify more precisely the mediators that affect QoL. In addition, the original language of the measurement tools used in this study was English or Korean. For our study, it was translated-back-translated, reviewed and revised several times, but there may still have been limitations caused by differences in the Mongolian environment. Research aimed at developing the tools needed to assess the same aspects but in a Mongolian context should be actively conducted. Nonetheless, the results of this study are meaningful in that they support the need for a family strengths-centred approach and integrated perspective that considers the multidimensional issues involved in caring for children with intellectual disabilities in Mongolia.

5 | CONCLUSION

This study was conducted to investigate the relationships between the family care burden, family functioning and quality of life in the families of children with intellectual disabilities. The results show that family functioning mediates the relationship between care burden and quality of life in families with disabled children. Thus, family functioning should be considered when developing a social support intervention programme aimed at improving the family quality of life among caregivers of children with intellectual disabilities.

CONFLICT OF INTEREST

The authors have no current or potential conflicts of interest to declare.

ETHICAL CONSIDERATIONS

This study was approved by the institutional review board of C University, with which we are affiliated (approval no.: 2-1041055-AB-N-01-2017-0046).

ORCID

Jinhee Kim  <https://orcid.org/0000-0002-8037-9174>
 Hyunlye Kim  <https://orcid.org/0000-0001-6279-6559>
 Seojin Park  <https://orcid.org/0000-0001-9262-9161>
 Jaeyong Yoo  <https://orcid.org/0000-0002-1212-5121>
 Delgersuren Gelegjamts  <https://orcid.org/0000-0001-5074-150X>

REFERENCES

- Al-Krenawi, A., Graham, J. R., & Al Gharaibeh, F. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society, 26*(2), 139–150. <https://doi.org/10.1080/09687599.2011.543861>
- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173–1182.
- Caicedo, C. (2014). Families with special needs children: Family health, functioning, and care burden. *Journal of the American Psychiatric Nurses Association, 20*(6), 398–407. <https://doi.org/10.1177/1078390314561326>
- Choi, C. S., & Davaasuren, L. (2016). Social welfare situation and challenge in Mongolia: Compared with Korea's social welfare. *Korean NPO Review, 15*(1), 3–22.
- Como, E., & Batdulam, T. (2012). The role of community health workers in the Mongolian CBR programme. *Disability, CBR & Inclusive Development, 23*(1), 14–33. <https://doi.org/10.5463/DCID.v23i1.96>
- Einfeld, S. L., Stancliffe, R. J., Gray, K. M., Sofronoff, K., Rice, L., Emerson, E., & Yasamy, M. T. (2012). Interventions provided by parents for children with intellectual disabilities in low and middle income countries. *Journal of Applied Research in Intellectual Disabilities, 25*(2), 135–142. <https://doi.org/10.1111/j.1468-3148.2011.00678>
- Hu, X., Wang, M., & Fei, X. (2012). Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(1), 30–44. <https://doi.org/10.1111/j.1365-2788.2011.01391.x>
- Hwang, K. R., Ko, I. Y., & Yong, H. C. (2010). Effects of mother's personal character acceptance toward disability, and stress of parenting a disabled child on the life quality of family with a disabled child. *Korean Journal of Physical and Multiple Disabilities, 53*(2), 1–22. <https://doi.org/10.20971/kcpmd.2010.53.2.1>
- Jansen-van Vuuren, J. M., & Aldersey, H. M. (2018). Training needs of community-based rehabilitation workers for the effective implementation of CBR Programmes. *Disability, CBR & Inclusive Development, 29*(3), 5–31. <https://doi.org/10.5463/DCID.v29i3.742>
- Khan, F., Amatya, B., Avirmed, B., Kyoung Yi, Y., Shirmen, B., Tsegmid, N., ... Galea, M. P. (2018). World health organization global disability action plan: The Mongolian perspective. *Journal of Rehabilitation Medicine, 50*(4), 358–366. <https://doi.org/10.2340/16501977-2207>
- Kim, M. O. (2001). A study on the effects of family resilience of adaptation of family of children with disabilities. *Korean Journal of Family Social Work, 8*(8), 9–40.
- Kim, Y. R., Kim, G. E., & Kim, S. Y. (2015). A study on factors influencing the care burden of parents having children with developmental disabilities: The focus on the children's life cycle. *The Women's Studies, 88*(1), 117–164.
- Knight, K. (2013). The changing face of the 'good mother': Trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society, 28*(5), 660–673. <https://doi.org/10.1080/09687599.2012.732540>
- Malhotra, S., Khan, W., & Bhatia, M. S. (2012). Quality of life of parents having children with developmental disabilities. *Delhi Psychiatry Journal, 15*(1), 173–174.
- McConkey, R., Truesdale-Kennedy, M., Chang, M. Y., Jarrah, S., & Shukri, R. (2008). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies, 45*(1), 65–74. <https://doi.org/10.1016/j.ijnurstu.2006.08.007>
- Mobarak, R., Khan, N. Z., Munir, S., Zaman, S. S., & McConachie, H. (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology, 25*(6), 427–433. <https://doi.org/10.1093/jpepsy/25.6.427>
- Nansaldorj, S. (2016). *Basic research on the view on childbearing of Mongolian parents*. Master's thesis, Sookmyung Women's University.
- Noriega, J. Á. V., Mendoza, P. B., & Abril, M. F. H. (2011). A multifactor view from the Mexican family with a child with intellectual disability. *Interdisciplinary Journal of Family Studies, 16*(2), 39–53.
- Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist, 29*(6), 798–803. <https://doi.org/10.1093/geront/29.6.798>

- Olson, D. H. (1986). Circumplex model VII: Validation studies and FACES III. *Family Process*, 25(3), 337–351. <https://doi.org/10.1111/j.1545-5300.1986.00337.x>
- Schallock, R. L., Luckasson, R. A., & Shogren, K. A. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45(2), 116–124. [https://doi.org/10.1352/1934-9556\(2007\)45\[116:TROMR U\]2.0.CO;2](https://doi.org/10.1352/1934-9556(2007)45[116:TROMR U]2.0.CO;2)
- Senmar, M., Rafiei, H., Yousefi, F., Razaghpour, A., & Bokharaei, M. (2019). Caregiver burden among family caregivers of older patients receiving hemodialysis and its relevant factors. *Journal of Nephro pharmacology*, 8(1), e12. <https://doi.org/10.15171/npj.2019.12>
- Seo, B. J., Yoon, S. O., & Kim, W. H. (2016). Mediating effect of family resilience on the impact of parenting burden of parents with children with intellectual disability on the quality of life. *Journal of Intellectual Disabilities*, 18(2), 101–115.
- Sikora, D., Moran, E., Orlich, F., Hall, T. A., Kovacs, E. A., Delahaye, J., ... Kuhlthau, K. (2013). The relationship between family functioning and behavior problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(2), 307–315. <https://doi.org/10.1016/j.rasd.2012.09.006>
- Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research*, 49(10), 777–783. <https://doi.org/10.1111/j.1365-2788.2005.00751.x>
- Taanila, A., Syrjälä, L., Kokkonen, J., & Järvelin, M. R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28(1), 73–86. <https://doi.org/10.1046/j.1365-2214.2002.00244.x>
- Tadema, A. C., & Vlaskamp, C. (2010). The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities*, 38(1), 41–48. <https://doi.org/10.1111/j.1468-3156.2009.00561.x>
- Thuy, N. T. M., & Berry, H. L. (2013). Social capital and mental health among mothers in Vietnam who have children with disabilities. *Global Health Action*, 6(1), 18886. <https://doi.org/10.3402/gha.v6i0.18886>
- United Nations Economic and Social Commission for Asia and the Pacific. (2015). *Disability at a glance 2015: Strengthening employment prospects for persons with disabilities in Asia and the Pacific*. Bangkok: Author.
- Verdugo, M. A., Navas, P., Gómez, L. E., & Schallock, R. L. (2012). The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 56(11), 1036–1045. <https://doi.org/10.1111/j.1365-2788.2012.01585.x>
- Vereenooghe, L., & Langdon, P. E. (2013). Psychological therapies for people with intellectual disabilities: A systematic review and meta-analysis. *Research in Developmental Disabilities*, 34(11), 4085–4102. <https://doi.org/10.1016/j.ridd.2013.08.030>
- World Health Organization. (2011). *World report on disability 2011*. Geneva: Author.
- Xue, J., Ooh, J., & Magiati, I. (2014). Family functioning in Asian families raising children with autism spectrum disorders: The role of capabilities and positive meanings. *Journal of Intellectual Disability Research*, 58(5), 406–420. <https://doi.org/10.1111/jir.12034>
- Ylvén, R., Björck-Åkesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 253–270. <https://doi.org/10.1111/j.1741-1130.2006.00089.x>
- Yoon, S. O., & Kim, W. H. (2015). The effect of parenting burden on quality of life of parents of children with disabilities: Focusing on mediating effect of family resilience. *The Korean Journal of Early Childhood Special Education*, 15(2), 133–149.

How to cite this article: Kim J, Kim H, Park S, Yoo J, Gelegjamts D. Mediating effects of family functioning on the relationship between care burden and family quality of life of caregivers of children with intellectual disabilities in Mongolia. *J. Appl. Res. Intellect. Disabil.* 2021;34:507–515. <https://doi.org/10.1111/jar.12814>