THE EFFECTS OF A FAMILY SUPPORT PROGRAM INCLUDING RESPITE CARE ON PARENTING STRESS AND FAMILY QUALITY OF LIFE PERCEIVED BY PRIMARY CAREGIVERS OF CHILDEREN WITH DISABILITIES IN KOREA

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In this study, a family support program was carried out for primary caregivers of children with disabilities. The program included respite care, recreation programs, counseling, and social support coordination based on individual needs of each family. In order to verify the intervention effects, parenting stress and family quality of life were measured before and after the intervention. Twenty-one primary caregivers who have children with disabilities attending a special school located in Buchon, Korea participated in the study. The experimental group A (sevencaregivers) was provided with respite care services only whereas the experimental group B (seven caregivers) was provided with a multifaceted family support program including recreational programs, counseling, and social support coordination in addition to respite care services. No support was provided to the control group (seven caregivers). The results showed a significant difference in the change of family quality of life between the experimental group B and the control group. However, there was no significant difference among three groups in parenting stress. Discussion about the results and implications for future research is presented.

Children depend upon their family members, who are their first teachers and lifelong friends. This is more true to children with disabilities. However, it is very challenging for families to take care of children with disabilities, especially when the families do not have enough support and resources. Many families experience fatigue, depression, and helplessness caused by parenting stress. Therefore, empowering families with all possible resources and services will ultimately help them cope with various challenges they confront as they care for their children with disabilities. In this article, we report on the effects of a family support program on parenting stress and family quality of life.

Families of children with disabilities face ongoing challenges and crises beyond their control. It has been shown in the literature that birth and caring of children with disabilities cause extreme parenting stress to family members, hinders conversations among the family members, relatives, and neighbors, and jeopardize the family or couple relationships. Primary caregivers, especially, are faced with day-to-day burden and difficulties to a greater extent than other family members. This is primarily because full responsibility of caring a child is being imposed on one person who spends most of the time with the child. Accordingly, the parenting stress that mothers, who are often the primary caregivers among family members, feel is more serious than that of other family members (Kim, 1995; Seo, 1991).

As an ecological perspective evolved, research communities are paying more attention to various environments surrounding the children and the interaction between the environments and children. Following this tendency, support for environments that have close relationships with children with disabilities is also becoming more important. In Korea, the *Special Education Act for Individuals with Disabilities* enacted in 2007 proclaimed, in Article 28 on Related Services, that superintendents should provide family support such as family counseling for the students with disabilities and their families. Before this act, family support was regarded as a synonym of parent education, but the act expanded the concept of family support to a wide range of services not only for building family capacity regarding child development and education but also for enhancing family quality of life.

Respite care is one of various ways to support families. It is a short-term childcare service to provide parents or primary caregivers of children with disabilities with a temporary rest. In some countries, respite care is one of the family support programs that parents preferred the most (Abelson, 1999). It is reported that respite care reduces primary caregivers‘ stress and has positive effects on the family (Aldgate, 1998; Apolloni & Triest, 1983; Botuck & Winsberg, 1991; Joyce, Singer & Isralowitz, 1983; Openden, Symon, Koegel, & Koegel, 2006; Wikler, Hanusa, & Stoycheff, 1986). In addition, Ireland, United Kingdom and some other countries already have respite care services specified in the laws and ensure the right to respite care for families of children with disabilities (MacDonald, Fitzsimons, & Walsh, 2006). In USA, a nationwide respite care service center (i.e., ARCH National Respite Network) is run for families of children with disabilities or with chronic illness.

In Korea, the importance of respite care for children with disabilities has recently been recognized and, as a result, some pilot programs have been launched. For example, the Ministry of Health and Welfare launched *Children with Disabilities Care Service* in 2007 to provide a respite care for low-income families of children with severe disabilities under 18. Also, some local branches of the Korea Parents Association began to provide respite care programs and the number of such branches is continuously increasing. However, the number of families that have used these programs is still very limited due to insufficient funding, rigid eligibility criteria such as severity of disability and income level, and the absence of systematic management and supervision. Fortunately, the Congress passed *Children with Disabilities Welfare Support Act* in 2011 that provided the legal basis for the respite care services. Article 24 of this law says that it is a responsibility of government and local authorities to provide care and respite services for families of children with disabilities in order to reduce parenting stress and to help general social activities of primary caregivers. These changes definitely reflect the change in social awareness on the importance of family well-being in development and welfare of children with disabilities. In spite of these social changes, however, there are a very limited number of studies that investigate best practices in providing respite care and their effects on family. Especially in this study, an effort was made to differentiate the effect of respite care services from other components of a family support program by comparing a group provided with respite care services only to a group provided with other services in addition to respite care. We believed that the attempt like this would provide valuable insights to the field regarding the scope and intensity of family support. The research questions are as follows: Is there a significant difference among three groups (experimental group A that was provided with respite care only, experimental group B that was provided with respite care and other family support, and the control group without any support) (1) in parenting stress?, (2) in family quality of life?

Methods

Participants

The participants of the study were 21 primary caregivers of elementary students with disabilities attending a special school located in Buchen, Korea. The school provides a specialized educational setting for students who have intellectual or physical disabilities. Participating families were recruited through school newsletters which explained the purpose of the study and the services participants would receive. A total of 43 families applied for participation. Among them, 21 families that had never experienced similar programs before and those with family income below 150% of poverty level were finally selected for the study. Twenty-one participants were divided into 3 groups: 2 experimental groups (A, B) and 1 control group. Each family of Group A (seven caregivers) was provided with a 4-hour session of respite care twice a week. Group B (sevencaregivers) was provided with respite care as well as other family support programs including recreation programs, counseling, and social support coordination based on each family‘s individual needs. The third group (seven caregivers) was a waitlist control group (see Table 1). Random assignment was not feasible because participation in Group B required some level of time commitment from caregivers. Therefore, Group B was organized first, on a voluntary basis, and then the other two groups (Group A and the control) were organized. Although random assignment was not achieved, every effort was made to make three groups matched on important variables such as children‘s age, gender, disability level, and the age and education level of primary caregivers. The characteristics of the participants are presented in Table 2.

Time and Settings

The program was implemented for approximately six months. Training for respite care providers was conducted in the conference room, classrooms, and therapy rooms located in the school. Respite care was provided in each family's house. The activities offered as a part of the family support program for Group B were done in the community such as movie theaters, culture centers, parks, and department stores. Counseling sessions and social support coordination were provided either in homes or school.

Table 1. Organization of the study participants

Group	Experimental Group A	Experimental Group B	Control Group
Organization	7 families (Respite care only)	7 families (Respite care and additional support)	7 families (waitlist control group)

Table 2. Characteristics of the participants

Group	No.	Caregiver		Child‘s gender	Child‘s age	Disability[a] (Tier[b])	Income Level[c]	Remark
		Age/education level	Relation					
Experimental A	1	37/High school	Mother	Male	9	ID(1)	I	Single-mom
	2	41/High school	Mother	Female	10	CD(2)	II	
	3	36/High school	Mother	Male	10	ID(1)	I	5 children
	4	35/Elementary school	Mother	Male	10	ID(1)	I	3 children have disabilities
	5	38/High school	Mother	Male	11	ID(1)	I	
	6	48/High school	Mother	Male	11	ID(1)	I	
	7	41/Elementary school	Mother	Female	12	ID(2)	I	
Experimental B	1	33/High school	Mother	Female	9	ID(2)	I	Single-mom
	2	36/Elementary school	Mother	Male	9	ID(2)	I	5 children
	3	39/Middle school	Mother	Male	10	ID(2), CD(2)	I	older sister also has disabilities
	4	55/Middle school	Grand-mother	Female	11	ID(3)	III	Single-dad, unstable income
	5	39/High school	Mother	Male	11	ID(2)	II	
	6	40/High school	Mother	Male	11	ID(1)	I	Single-mom
	7	33/High school	Aunt	Male	12	ID(2)	I	
Control	1	44/College	Mother	Female	9	ID(1)	II	
	2	38/High school	Mother	Male	9	ID(1)	II	
	3	41/College	Mother	Female	9	BL(1)	III	7 family members
	4	38/High school	Mother	Female	9	ID(1)	II	older brother also has disabilities
	5	33/High school	Mother	Male	10	ID(2)	I	3 children
	6	41/High school	Mother	Female	11	ID(1)	II	
	7	38/High school	Mother	Female	12	ID(1)	III	under pressure of heavy debts

[a] ID: Intellectual Disability, CD: Communication Disorder, BL: Brain Lesion Disability

[b] Tier is determined when the child goes through diagnosis to register as a person with disabilities under Individuals with Disabilities Welfare Act. Tier 1 is the most severe condition.

[c] I: Poverty level (beneficiary of the National Basic Livelihood Security Act), II: Below 120% of the poverty level, III: Between 120-150% of the poverty level

Outcome Measures

Parenting Stress Index-Short Form (PSI/SF). To measure the extent of changes in parenting stress of the caregivers, Parenting Stress Index Short Form developed by Abidin (1990) was used. This study used the index translated by Lee (1995). Applicability and validity were verified by 7 special education teachers with more than 6 years of teaching experience and 3 special education professionals who had master's degree in special education. This index consists of 38 questions in 3 domains, using 5-point Likert scale from *Not at all* (1 point) to *Very Likely* (5 point). The range of possible total score is from 36 to 180. The higher the total score is, the higher the parenting stress is. The reliability coefficient is .91, which is quite high.

Family Quality of Life Scale. To measure family quality of life, Beach Center Family Quality of Life Scale developed in 2003 and validated in 2006 was used. The items of this scale were developed based on literature review and qualitative research with primary caregivers of children with disabilities and professionals who worked with them (Poston et al., 2003). The scale was revised through a couple of validating process and has revealed good psychometric properties (Hoffman et al., 2006; Park et al., 2003). This 25-item scale consists of 5 domains, including family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support, and uses a 5-point Likert scale. The higher the score is, the higher the family quality of life is. The Cronbach's alpha reported in Hoffman et al. (2006) was .88. The same professionals who reviewed the other two outcome measures also examined this scale to see if there would be any need for re-translation stemming from cultural and societal differences between U.S. and Korea.

Independent Variable

Respite care was provided to both Group A and Group B while other family support components (recreation programs, counseling, and social support coordination) were provided only to Group B. Below is the description of each element.

Respite care. The effect of respite care program can vary according to the service providers‘ qualities and program operation. The ARCH (Access to Respite Care and Help) support center (1990) suggested the elements for a successful respite care program: services provider training, proper minimum period (about 6 months), listening to the family‘s opinions, providing various programs, focusing on the family and flexible operation. These elements were the basis of the operation guideline of respite care provided in this study. Trained caregivers provided respite care for the families of the Group A and Group B twice a week for 6 months (4 hours each time). Even though respite care was provided on a regular basis, schedule adjustment was allowed based on family needs. Respite care providers were required to attend monthly meetings to discuss concerns and problems occurred during their service time. Also, various training sessions including music and art lessons were offered to the providers to improve their capacity for caring children.

Recreation program. Peterson and Stumbo (2000) suggested that the qualities of recreation is determined by one's ability to explore and search for the information regarding recreation as well as one's awareness and utilization of recreational resources. Based on these suggestions, efforts were made in this study to help the families improve their ability to design their own recreational life, through offering various information on recreational resources available in the community, and have them choose the recreation activities themselves so that the families can plan and enjoy their leisure even after the study. This recreational program was provided once a month and each family was allowed to choose the types and contents of recreational activities based on their needs and preferences.

Counseling. A counseling program was conducted in order to actively solve the problems families face while keeping a close bond with them. Counseling primarily consisted of 1) identifying current issues and needs in the family and providing psychological empathy, 2) providing information and assistance to build up social support network for the families and 3) providing informational and emotional support to help primary caregivers with parenting children with disabilities. The counseling was given once a month for about one hour. The specific content of counseling was different depending on each family's situation, but there were also some common contents across families.

Social support coordination. Most family support literature emphasizes utilization of resources available in the community. In this study, information on various resources in the community was offered to participating families and, based on the information, families determined the services and supports they needed. By providing a list of community resources and having families choose what they wanted, we expected families to utilize available resources even after the study was completed. For some families, existing resources available in the community were not enough to meet their needs. In this case, the first author contacted several social service organizations and private agencies in the community and asked them to consider additional supports. A list of social service organizations and private agencies that had possible resources for families of children with disabilities was also provided to the families of Group B.

Procedures

***Respite care provider training*.** With the help from a local YMCA and an entrusted home management center that had a list of volunteers and job-seekers, 12 respite care providers were recruited. Eleven of them had nursery teacher certificates, and one was an undergraduate student majoring in special education. The descriptions of the providers are presented in Table 3.

Table 3. Descriptions of the respite care providers

Name	Age	Education level	Certificate	Related work experiences	Families served
Jung	40	High school	Nursery teacher	part-time babysitting, 4 months	A1
An	38	High school	Nursery teacher	special school dormitory life coach, 2 years	A2/B1
Cho	47	High school	Nursery teacher	nursery, 3 months	A3
Yi	40	High school	Nursery teacher	para teacher in special education, 1 year	A4/A5
Jeon	42	High school	Nursery teacher	part-time baby setting, 4 months	A6
Jang	47	High school	Nursery teacher	part-time baby setting, 8 months	A7
Kang	50	High school	Nursery teacher	no	B2
Kim	44	High school	Nursery teacher	no	B3
Chung	32	University	Nursery teacher	Sunday school teacher, 2 years	B4
Lee	22	High school	no	undergraduate student in special education	B5
Ahn	40	High school	Nursery teacher	afterschool program para teacher, 6 months	B6
Han	45	High school	Nursery teacher	full-time babysitting, 2 years	B7

Eight sessions of respite care provider training were conducted for 4 weeks, each session lasting approximately two hours. The contents of the training were adapted from the training manual for respite care providers proposed by Sturtevant & Elliott (1994). Table 4 shows an overview of the training contents. Various instructional strategies including lectures, activities, discussions, observations, and field training were used to deliver the contents effectively. The providers were paid about seven dollars per hour for their service. The school district to which the special school belonged provided financial support for this payment.

Table 4. Overview of the respite care provider training

Session	Topic	Training contents
1	Understanding of disability	- definitions, types, causes and characteristics of disability - environmental influences on disability
2	Problem behavior	- types and causes of various problem behavior (using videos) - how to deal with problem behavior
3	Crisis management	- guidelines for crisis situation, first-aid
4	Teaching self-help skills	- how to teach eating, toileting, dressing and grooming
5	Music and art	- introduction of various music, dance and art activities that can be used when caring children with disabilities
6	Meet the child	- visiting the classroom of the child whom the provider will take care of, observing the child, having lunch with the child at school
7	Meet the child's teacher	- meeting the teacher of the child to learn child's characteristics and to take advice about best ways to work with the child
8	Home visit	- visiting the child's house, observing the child at home, getting to know the families

Pre-test. A pretest on parenting stress and family quality of life was conducted at the school three days before the program started. Participating twenty-one primary caregivers were asked to visit school to complete two scales. For three caregivers who could not visit school on that day, researcher visited their home to get their responses.

Program implementation. Respite care was provided to Group A and B twice a week. Trained respite care providers were assigned to one or two families. In this assignment, time availability of the respite care providers was the most important factor in matching (i.e., a respite care provider who is available during the time blocks that a primary caregiver wants to get respite was assigned to the family). In each visit, while the respite care provider was working for 4 hours with the child with disabilities, the child's primary caregiver was given free time. When primary caregivers wanted to adjust respite hours and if it was agreed upon by respite care providers, schedule change was allowed as long as a total of 32 hours of respite care per month was delivered to the family. At the end of the first week of respite care, individual meetings with each primary caregiver were held to find out any concerns or issues regarding respite care.

Respite care providers were required to attend monthly meetings. At the meeting, the providers shared information and teaching tips for working effectively with children with disabilities and discussed concerns and challenges they faced during respite care provision. After several respite care visits, the providers requested additional training to learn various activities that they could use in working with children with disabilities, so a workshop on balloon activities and art therapy was provided.

In addition to this respite care provision, Group B was provided with other family supports composed of (1) recreation programs, (2) counseling, and (3) social support coordination. Recreation programs were conducted once a month. Recreational activities were determined based on families' preferences and needs identified from family needs survey. Participating caregivers had a chance to meet other caregivers of children with disabilities during recreation activities and as time went by, they exchanged information and emotional support with one another. The caregivers were also encouraged to bring other family members for the recreation activities. Table 5 shows the description of the recreation programs.

Table 5. Description of the recreation programs

Session	Description
1	Families getting to know each other, watching movie, having dinner together
2	Karaoke, having dinner together
3	Mountain climbing (caregivers chose when and where to climb)
4	Mountain climbing with other family members, having dinner together
5	Watching a performance (caregivers chose what to watch from a list of movies, plays, and other performances provided by the researcher in the previous session, each caregiver was provided with 2 tickets of the performance that she chose)
6	Wrapping up the program (caregivers shared opinions regarding the recreation program) Introducing recreation resources (e.g., brochures, websites) available in the community

Counseling was another component of the family supports provided to the primary caregivers in Group B. A total of 6 counseling sessions were conducted with each family and at least two sessions were conducted at the family's home. Table 6 shows the main contents of counseling. In each session, families' concerns, issues, and questions related with the topic of the session were discussed. In addition, the primary caregivers gave feedback and suggestions for current program during counseling and an effort was made to improve the program based on their input.

For social support coordination, a variety of community agencies were contacted by phone calls or through site visits before the program started in order to see what kind of resources and services those agencies could offer for families of children with disabilities. Since all participating families had low income, they were able to use the services and resources at no cost. Some agencies even offered scholarships for children or financial aid (e.g., rice) for families. Based on the needs identified from the family needs survey and conversations conducted at the first counseling session, a list of resources and services available in the community were made available to each family. The first author assisted the primary caregivers when they contacted the agencies to get help or when they applied for services at the beginning of this study, but gradually the caregivers were able to utilize the resources and services of their choice with minimal help. Table 7 shows examples of social supports connected to each family of Group B and the community agencies that provided the supports.

Post-test. One week after the program ended, post-tests were conducted. The procedures were the same as the pretest.

Data Analysis

Kruskal-Wallis tests were used to see if there were any differences among groups in parenting stress and family quality of life. Nonparametric statistics was used because sample size was small and the assumption of equal variances was not met. A Mann-Whitney test was used to follow up when a significant difference among three groups was found

Table 6. Main contents of counseling

Session	Topic	Description
1	Family needs	- conducting Family needs survey (Dunst, Trivette, & Deal, 1988) to assess family needs and to prioritize them - building trust through sufficient conversation
2	Parenting	- exchanging opinions about parenting - talking about the primary caregiver‘s parenting stress, the family members‘ attitude toward parenting and other issues. - planning for free time
3	Stress management	- active listening to family stories about parenting stress - introducing families to the stress management programs available in the community
4	Monitoring & additional needs	- soliciting families' opinions about the program provided so far and seeking suggestions and advice - identifying additional family needs that were not found in the 1st week
5	Other family members	- discussing problems and issues that each family member has - providing information about the programs that might help the individual family members and connecting them to the program
6	Wrap up & referral	- evaluating the family support program - connecting the primary caregivers who want ongoing counseling to the counseling agencies available in the community

Results

Parenting Stress

The means and standard deviations of parenting stress measured by the Parenting Stress Index are shown in Table 8. A Kruskal-Wallis test was conducted to compare the changes in scores of Group A, Group B, and the control group. Descriptive statistics showed that parenting stress of the primary caregivers from both experimental groups was reduced after the intervention while it increased for the control group, but this difference was not statistically significant (Table 9).

Family Quality of Life

The means and standard deviations of family quality of life measured by the Beach Center Family Quality of Life Scale are shown in Table 10. The family quality of life score of Group B increased the most among the three groups. A Kruskal-Wallis test was conducted to compare the changes in scores of the three groups (Table 11). From the analysis, a significant difference among three groups was found.

In order to follow up the result of Kruskal-Wallis test, a Mann-Whitney test was conducted. As shown in Table 12, there was a significant difference between the experimental group B and the control group, but there was no significant difference in other pairs. Therefore, it can be concluded that the respite care services combined with other family supports had positive effects on family quality of life while respite care alone did not make any difference.

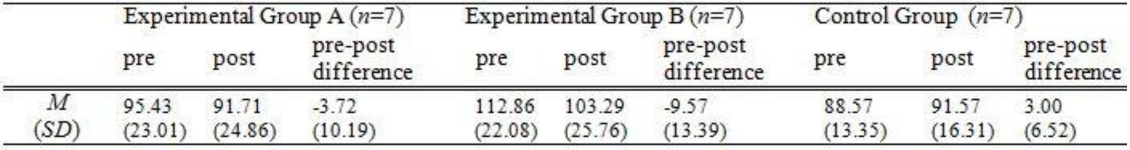
Discussion

The findings of the present study showed that respite care services combined with a multifaceted family support program including recreation programs, counseling, and social support coordination had a positive effect on family quality of life whereas respite care services only did not make any statistically significant difference. Several factors of the intervention seemed to contribute to this result. First, the primary caregivers of Group B, provided with respite care and other family supports, experienced a variety of activities and support from the program in addition to free time generated from respite care services. This must have led to the increase of the family quality of life. Family quality of life encompasses multiple domains such as family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. The program including recreation, counseling, and social support coordination as well as respite care seems to have affected these various domains.

Table 7. Social supports for each family and supporting agencies

Family	Examples of social supports	Supporting agencies
B1	- speech therapy for the child (once a week) - stress management program for mom (once a week)	A welfare center
	- individual physical activity training for the child (twice a week)	S fitness center
	- scholarship for the child (approx. $100 per each semester) - financial aid (10kg rice per each winter for 4 years)	Local Lions club
B2	- speech therapy for the child (once a week)	C community welfare center
	- sibling program (once a week)	D welfare center
	- dental treatment for the child	Local Public Health Center
	- transportation (twice a month)	B transportation services
	- scholarship for the child (approx. $100 per each semester) - financial aid (10Kg rice & 3Kg Kimchi per each winter for 2 years)	Local Lions club
B3	- mentoring for the child from a college student (once a week)	E University
	- dental treatment for the child	Local Public Health Center
	- yoga class for mom's stress management (once a week)	E welfare center
	- weekend museum tour (2nd and 4th Saturday for a month)	H museum
	- scholarship for the child (approx. $100 per each semester) - financial aid (10Kg rice & 3Kg Kimchi per each winter for 2 years)	Local Lions club
B4	- obesity treatment for the child (twice a month)	S fitness center
	- summer camp program (for 3 days)	Fairchild
	- career training for grandmother (once a month)	A welfare center
	- individual physical activity training for the child (twice a week)	S fitness center
B5	- mentoring for the child from a college student (once a week)	E University
	- individual physical activity training for the child (twice a week)	S fitness center
	- ophthalmologic treatment	Local Public Health Center
	- couple counseling program for parents (once a week)	P city family support center
B6	- therapy program for the child (twice a week)	E Welfare Center
	- investigation and treatment for child abuse and neglect	P city child abuse prevention center
	- re-diagnosis of child's disability conditions	P disability welfare center
	- parent education on stress management and alcohol syndrome (once a week)	S welfare center
	- transportation (twice a month)	Red-cross volunteer center
B7	- weekend program for the child (2nd and 4th Saturday for a month)	Fairchild, ecology museum
	- summer camp program (for 3 days)	Fairchild
	- school-commuting training for the child (once a week)	volunteers of H Inc.
	- dental treatment for the child	Local Public Health Center
	- transportation (twice a month)	G volunteer center

Table 8. Means (*M*) and standard deviations (*SD*) for Parenting Stress Index



	Experimental Group A (*n*=7)			Experimental Group B (*n*=7)			Control Group (*n*=7)		
	pre	post	pre-post difference	pre	post	pre-post difference	pre	post	pre-post difference
M	95.43	91.71	-3.72	112.86	103.29	-9.57	88.57	91.57	3.00
(*SD*)	(23.01)	(24.86)	(10.19)	(22.08)	(25.76)	(13.39)	(13.35)	(16.31)	(6.52)

Table 9. Kruskal-Wallis test analysis for Parenting Stress Index (*N* = 21)

Chi-squared	Freedom	Significance rate
5.058	2	.080

**p*<.05

Table 12. Means (*M*) and standard deviations (*SD*) for Family Quality of Life Scale

	Experimental Group A (*n*=7)			Experimental Group B (*n*=7)			Control Group (*n*=7)		
	pre	post	pre-post difference	pre	post	pre-post difference	pre	post	pre-post difference
M	64.86	75.00	10.14	63.00	78.14	15.14	84.71	82.43	-2.28
(*SD*)	(21.30)	(26.05)	(9.22)	(25.29)	(26.63)	(13.71)	(11.64)	13.09)	(7.85)

Table 13. Kruskal-Wallis test analysis for Family Quality of Life Scale (*N* = 21)

Chi-squared	Freedom	Significance rate
6.203	2	.045*

**p*<.05

Table 14. Mann-Whitney test analysis for Family Quality of Life in three groups

Group	Differences between pre-test and post-test		*U*
	Average rank	Rank sum	
A (*n*=7)	6.50	45.50	0.39
B (*n* =7)	8.50	59.50	
A (*n* =7)	9.64	67.50	0.05
C (*n* =7)	5.35	37.50	
B (*n* =7)	9.92	69.50	0.03*
C (*n* =7)	5.07	35.50	

**p*<.05

Second, the primary caregivers of Group B were able to obtain specific supports that the family really needed because the program was tailored to the needs of the individual family. Especially, counseling and social support coordination was provided to help each family solve their unique problems and this resulted in the primary caregivers acquiring confidence in managing their family life despite their child‘s disability.

Third, connecting the families of Group B to social support network must have brought changes in family quality of life. With the support obtained from the network, primary caregivers became able to solve immediate problems and learned how to seek assistance from the network. The primary caregivers were very much satisfied with this. They also experienced the feeling that they were cared by community and society. All of these are related with emotional well-being and physical/material well-being. In addition, many of the supports that the families received from social support coordination were for their children with disabilities as shown in Table 7 (e.g., speech therapy, physical activity training). Those disability-specific supports provided to their children without any additional cost, reduced families‘ financial burden and helped the primary caregivers regain positive outlook for their child‘s future, which also seemed to explain the increase of family quality of life in this group. This result is related to earlier studies indicating that connecting families to social support helps the parents, especially the mother, (Deiner & Whitehead, 1988; Powell & Hecimovic, 1981; Warren & Cohen, 1985) and that it enhances the family quality of life (Grant & McGrath, 1990; Turnbull, 1988).

Lastly, even though the primary caregivers were the participants of this study, the contents of the supports were for the entire family. In recreation programs, the primary caregivers were allowed to consider other family members in choosing recreation activities and were encouraged to bring other family members to the activities. In counseling, issues and needs of the whole family were dealt with in conversations with primary caregivers. In social support coordination, the social supports linked to each family were not only for children with disabilities but also for their non-disabled siblings and the whole family. These components must have contributed to the changes in their family quality of life. This result supports the findings of previous studies showing that creating opportunities for families to spend time together facilitates active family interaction, which is one of the primary factors of family quality of life (Cho & Kim, 2005) and that family quality of life can be improved by services not only for the person with disabilities but also for the other family members (Park et al., 2003).

On the other hand, parenting stress was not affected by the family support program implemented in this study. Earlier studies showed that respite care and social support led to parents‘ stress reduction (Apolloni & Triest, 1983; Botuck & Winsberg, 1991; Joyce et al., 1983; Shin & Jung, 1998; Wikler et al., 1986) and that family support program and social support increased parents‘ parenting efficacy (Kim, 2006; Kim & Park, 2010; McDonald, Gregorie, Poertner, & Early, 1997). Results of this study were not consistent with existing literature. A couple of reasons can be inferred. First, there have been many changes and crises in participating families, such as childbirths, divorces, child abuse and neglect, and diseases, while this study has been underway. Such being the case, some primary caregivers had to deal with many family issues rather than devoting time and energy for parenting their children with disabilities. These factors could have increased parenting stress, which offset the gains coming from the family support program.

In addition, the children with disabilities in this study had quite severe disabilities and thus, caring the children was a very tough job for both primary caregivers and respite care providers. Many respite care providers expressed concern regarding their capacity to care for the children in spite of 8 sessions of training and monthly meetings. Therefore, it is possible that the parenting stress of the primary caregivers of children with severe disabilities is not a measure that can be easily changed in such a short amount of time unless long-term and comprehensive system of care is established.

Conclusions and Implications

Below are the implications for future studies based on the results and the limitations of this study. First, to settle high-quality respite care system in Korea, more replication studies need to be conducted in order to investigate the effects of respite care. Especially, an effort is required to expand the sample size so that the studies can obtain more objective results that can be generalized.

Second, though this study employed a quantitative design only, a qualitative research method can be considered in future studies to describe the outcomes of family support programs including respite care in detail. Through qualitative research, influences of the family support program and experiences of the participants can be understood more in-depth.

Third, in this study, respite care services were provided for 23 weeks. Other studies have usually provided respite care for less than 6 months (e.g., Singer et al., 1989). There are no studies that indicate an appropriate time for respite care. Therefore, in follow-up studies, it is necessary to study the effect of respite care according to its service periods. Also, there is a need to study the best ways to match families with respite care providers in order to maximize the benefits of respite care.

Finally, this study evaluated outcomes of family support based only on the perceptions of primary caregivers. In future studies, effects of family support need to be evaluated from multiple family members.

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