

[研究論文]

# A pilot Study of the Efficacy of a Support Program for Families with a Young Child with a Developmental Disorder

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## Abstract

**Aim:** A support program for family of a child with a developmental disorder based on the family systems theory (Wright & Leahey, 2005) and previous studies by our research group, was designed to foster the family's problem-solving ability. This study aimed to examine the efficacy of this program.

**Methods:** The effectiveness of the program was evaluated with the one-group pretest and posttest design using "the ability to problem-solving rating scale for families" developed by research group. This scale consists of 26 items and 4 subscales and its reliability and validity were largely confirmed (Hamazono & Moriyama, 2011), so that this scale can be considered useful for the measurement of ability to problem-solving of families with a young child with a developmental disorder. The participants consisted of 13 families, all of whom attended a four-day training session.

**Results:** The total score increased significantly immediately after the program compared with before the program and was maintained after one month. After the program, the average values for each subscale at three time points were scores for "Sense of self-control regarding parenting" tended to increase significantly.

**Conclusions:** The results reported here demonstrate that our support program for families is effective in enhancing their problem solving abilities. It is necessary, however, to examine why intervention did not produce significant improvement in some aspects of the program and to perform a follow-up for spousal relationships one month after the intervention.

**Keywords:** family systems theory, problem-solving ability, support programs for families, young children with developmental disorders, intervention study

## Introduction

Families of children with developmental disorders are forced to cope with characteristic behaviors such as panic of children caused by the characteristics of the disorders, trouble with other children, and adherence to their own rules, and face problems such as childcare stress, decreased QOL, and deterioration of family relationships (Miyamoto, 2007; Hamazono, 2012). In particular, nurturing families with infants and toddlers must also meet family development challenges, such as obtaining parental roles, readjusting the division of roles between husband and wife, and adjusting relationships with relatives and social resources, while having difficulties accepting the disorder of the child (Friedman, 1986; Mochizuki, 2000). In addition, many of families in the parenting stage are nuclear families, making it difficult for them to obtain support from others and to be isolated, today's. Therefore, in order to support families with these many problems, it is necessary to improve the problem-solving ability of families themselves. Previous studies have shown that the problems of families with young children with developmental disorders arise from a vicious cycle in which a mother who is distressed by the characteristic behavior of her child suffers from new anxiety

and loneliness due to her husband's lack of understanding or cooperation, and becomes increasingly unacceptable of her child (Ishizuka, 2007; Nagai & Hayashi, 2004). It is not difficult to imagine that couples who have lost confidence in raising their children in this vicious circle are likely to become isolated because they cannot build good relationships with their relatives, neighbors, and medical and welfare experts. In other words, the parent-child problem caused by the child's disability affects the marital relationship, which in turn affects the parent-child relationship and the relationship with the community. In order to support such families, we decided to make use of the Family System Theory (Wright & Leahey, 2005), which focuses on the context (interaction, communication chain, and brief) that causes problems, rather than attributing them to children's disorders or parent-child relationships. As a first step, in a previous study, we examined the components of problem-solving ability of nurturing families with children with developmental disorders using the framework of family system theory, and extracted 4 factors: "Cooperative relationship between spouses", "Sense of self-control regarding parenting", "Ability to use social resources", and "Belief regarding the roles of spouses" (Hamazono & Moriyama, 2011).

In this study, we developed a family support program based on these four factors, incorporated the intervention technique of family system theory, and examined its effectiveness.

The program was implemented in a multi-family setting. This is because beliefs about the role of couples are particularly important in solving the problems of families raising children with developmental disorders, and community support for marital relationships is inadequate (Hamazono & Moriyama, 2011), the following 2 effects are intended. First, when participants become aware of their own gender biases and resist the transformation, they are encouraged to learn by identifying them as a group of men for husbands or a group of women for wives (Sato, 1983). Second, while there is a risk of hesitation about exposing the family's private affairs to other family members, there is an opportunity for participating families to deepen their interaction and to support each other as peer support in the future.

### **Study Aim**

Development and implementation of support programs to enhance the problem-solving ability of families with children with developmental disorders and to examine their effectiveness.

### **Methods**

#### ***Study design***

It is desirable to set a control group in order to examine the program effect. For the purposes of this study, however, it is necessary to select families within a limited area (so that participating families can continue to interact and support each other). This study used a self-control design because it is ethically difficult to select an intervention group that participates in the program and a control group that does not participate in the program in the same nursing home.

#### ***Subjects***

The number of participating families was considered reasonable at 6 ~ 7 families per 1 course, based on the consideration of ensuring the quality of intervention techniques by researchers and the safety of the childcare environment for children with developmental disorders and their siblings. The participating families were recruited after the researcher participated in the association of Families with Children with a Developmental Disorder in the Kinki region of central Japan and

explained the outline of the research verbally and in writing. As a result, 13 families (Implemented 1 course and 2 courses in 6 ~ 7 families) who were able to participate in the program on the entire schedule as a couple and had no missing answers to the questionnaire were included in this study.

### *Study period and number of times*

The family support program consisted of 4 1 courses at 1 ~ 2 week intervals (Done in 2 Months) in 11 – December 2009 and in 7 – August 2010. The event was held on weekends so that all family members could participate in the event, avoiding the peak season of childhood infectious diseases and influenza and the month of events at nursing facilities, kindergartens and nursery schools.

### *Content of the intervention*

#### ***Program Contents (Table 1)***

Programs are a component of family problem-solving skills (Hamazono & Moriyama, 2011). The following 4 points were made to be a goal by incorporating. The first is to change family perceptions of child disorder. The second is to develop relationships and communication with children. The third is to promote emotional interaction between couples and to change perceptions of family roles, such as child rearing and housework. The fourth is to learn how to use social resources to reduce anxiety about the future and to improve the ability to deal with external problems.

The program began with a theme of nurturing issues with similar experiences and circumstances, so that participating families could build a relationship of trust and increase their sense of peace. Part 1 ~ 2 provided the correct knowledge and information on the abilities of children with developmental disorders, their growth and development despite their disorders, and the implications of their distinctive behaviors. If there were a couple who had already practiced how to deal with the characteristic behaviors of their children, they would be allowed to learn from other couples, and they would intervene so that they could recognize the need for cooperation between the couple in raising their children. The third session covered the developmental stages and challenges of the family, as well as the vulnerable family situation. After the lecture, they worked to strengthen the bonds between husband and wife by using "memory card". Specifically, each husband and wife fills out a card for "each other's strengths" "motive for marriage" "expectations for marriage" and "Why we're attracted to each other, and how we're still attracted to each other" and exchanges them. The fourth session covered special needs education, the types and functions of support institutions, how to use them, the roles of related jobs, and points for building relationships. After the lecture, if there were any concerns or problems about going to school, they were asked to give a presentation, and if there were a couple who had already practiced how to cope, other families could learn how to do and think about it.

Furthermore we intervened them to recognize the need for cooperation between couples by themselves in dealing with the issue of school attendance of their children.

Table 1 Intervention : contents of the support program

Day	Theme	Lecture	Discussion
1	Change in the negative perceptions and feelings that family has about their children's disorder	Characteristics of developmental disorder (Visual symptoms and development of awareness )	The issues that family face involved in raising their children
2	Cut through the vicious circle of parents' communication with the child.	Characteristics of behavioral symptoms indicating that a child has	Coping with the problem involved in raising their children
3	Strengthen the parents' relationship	Characteristics of and tasks for family with a young child	Remember their histories by utilized memory cards
		Improve a vicious circle of the communication in the couple	Remember the quarrel that happened recently in couples
4	Utilization of societal resources for education for their child	Utilization of societal resources for their child's school attendance	Coping with unease about their child's school attendance

### *Intervention method*

The intervention utilized techniques used in family systems theory. Specifically, they provide information and knowledge about problem solving, ask cyclical questions (Prompt to refresh), and strengthen the family's strengths. Using these intervention techniques, they focused on specific problems that families suffered in their lives, identified and patterned repeated chains, and identified the context (especially the briefs) that constituted the problem. Later, when problems did not occur or there were exceptions that had already been resolved (experience of family differences), we focused on the situation and compared it with the problem situation that did not work and found patterns of resolution with the family. When there were no exceptions, reframing (belief conversion) was encouraged by hypothetical and futuristic questions (circular questions) about the belief that caused the problem. While repeating this process, we also acknowledge and appreciate the negative feelings of the family toward the problem (mostly related to the disability of a spouse or child) and support the positive aspects of the family's behavior so that a new pattern of behavior toward problem solving becomes entrenched.

### *Evaluation method*

Questionnaires were distributed to couples before, during, immediately after, and one month after the implementation of the family support program, and collected on the spot or by mail. The contents are background information of the family, a scale to measure problem-solving ability of the raising family with the child of developmental disorder (FPAYCDD26 item:  $\alpha = 0.78$ ), and free description on program contents and method (Other desired lecture themes and comments on multiple family members).

Of these, 26 items of FPAYCDD are five-step Likert scales developed by us (Hamazono & Moriyama, 2011), 4 subscales of cooperative relationship between spouses, sense of self-control regarding parenting, ability to use social resources, and belief regarding the roles of spouses. Each question was answered with a score ranging from (5 -points) "I think so." to "I don't think so at all." (1-point). The possible score range was 26 ~ 130 points, indicating that the higher the overall score for all items, the higher the problem-solving ability of the family. Since the FPAYCDD 26 item was

developed for the mother, it was not carried out for the father this time.

Using the statistical analysis software SPSS 17.0 for Windows, the FPAYCDD scores before, immediately after, and 1 month after the implementation of the family support program were compared by Friedman's test and Wilcoxon's signed rank test, and the significance level was less than 5%. Questionnaire surveys on program objectives, content, and methods distributed during and immediately after the implementation of the Family Support Program included descriptive statistics and content analysis.

### ***Ethical considerations***

The research was conducted at a special support school run by a family association for children with developmental disorders in a city, Hyogo Prefecture. The participants were parents who signed a written statement explaining that the purpose of the study, the expected effects of participation in the program, the content of the program, and participation in the study were voluntary and can be rejected in the middle of the study, that there would be no disadvantage if they refused, and that the data obtained would not be used for purposes other than the study. Also, in order for participating families to be able to take care of their children at the request of their families, sufficient space and safety were provided for children with developmental disorders to be able to work, and they were able to purchase accident insurance. In addition, volunteers were recruited to provide pre-education on children with developmental disorders. Prior to the start of the study, it was approved by the Ethics Committee of Graduate School of Health Sciences, Hiroshima University (approval number; 255 ).

## **Results**

### ***Characteristics of participating families***

Table 2 shows Characteristics of participating families.

Table 2 Characteristics of participating families		
Age of the father	Average	40.15
	SD	6.32
Age of the mother	Average	36.62
	SD	4.41
Presence of another child (siblings)	"yes"	8(61.5%)
	"no"	5(38.5%)
Participated in a seminar or lecture about developmental disorder	"yes"	13(100%)
	"no"	0(0%)
Characteristics of children with developmental disorders		
Age	Average	4.62
	SD	1.33
Age of children when parents noticed their child`s disorder	Mean	1.32
	SD	1.31
Gender	Male	11(84.6%)
	Female	2(15.4%)

***Change in family problem-solving abilities (N = 13) before, immediately after,  
and 1 month after program implementation (FPAYCDD)***

**Average Total Score Comparison (Table 3)**

Table 3 shows the average of the total scores at the three time points. The total score increased significantly immediately after the program compared with before the program and was maintained after 1 month.

Table 3 Comparison over time ;Total score:range26~130 ( N=13)				
	Alpha-value	Baseline	After	1-month
Total score	0.78	93.54 ± 11.33	98.31 ± 11.22	98.31 ± 9.41
			*	
The Alpha-value measured at the baseline. Wilcoxon mached pairs single test : *p<.05				

**Comparison by means of average values for each subscale (Table 4)**

The average values for each subscale at three time points are shown in Table 4. "Ability to use social resources" and "Sense of self-control regarding parenting" showed an increase in scores over time. In particular, "Sense of self-control regarding parenting" showed a significant increase at 2 time points: before, immediately after, immediately after, and 1 month after the program. In contrast, "Belief regarding the roles of spouses" showed little change in scores over time. In addition, the "Cooperative relationship between spouses" score increased immediately after the program compared to before the program, but was not maintained after 1 months.

Table 4 Comparison over time ; four subscales ( N=13)				
	Cooperative relationship between spouses	Sense of self-control regarding parenting	Ability to use social resources	Belief regarding the roles of spouses
Range of score	11~55	6~30	5~25	4~20
Baseline	43.48 ± 6.49	19.65 ± 4.25	16.23 ± 3.74	15.38 ± 2.91
After	45.50 ± 5.79 ] *	20.77 ± 2.79 ] **	16.68 ± 3.51 ] *	15.96 ± 2.22
1-month	44.34 ± 5.32	21.96 ± 2.27 ] **	17.54 ± 3.19 ]	15.96 ± 2.22
Wilcoxon mached pairs single test : **p<.01 *p<.05				

**Content analysis of the questionnaire****Other desired lecture themes**

Among 13 families, 2 out of 8 healthy families (61.5%) "I'm always curious about what my siblings think, so I want to know about that." They also cited the burden and feelings of their siblings.

**Feelings about multiple families**

As a result of the content analysis of the questionnaire, the following 5 points were mentioned.

\*It was very good to deal with the specific problem. Useful in real life.

\*I was able to synchronize because I was a parent with the same problem.

\*At first, there was resistance, but it was good that the couple joined together. Since other family members also participated, I was relieved to think that there was a difference of opinion between husband and wife.

\*It was helpful to receive information that I didn't know from other family members.

\*Stories from various experts were important, but sharing information and experiences from other families helped.



## **Discussions**

Focusing on the similarities in experiences and situations of multiple families in a similar situation of "Parents of preschool children with developmental disorders" this time, the following two effects were obtained. First, as a person who shares the same kind of problem, families can form a cooperative relationship. This is the "a parent with the same problem so synchronized" " · · · Other family members participated as a couple, so I was relieved to know that there was a difference of opinion between husband and wife." This can also be inferred from the fact that there were situations in which families communicated with each other, such as when mothers shared their contact information, exchanged information, and fathers exchanged business cards. Second, participating families learned how to cope with the various difficulties associated with children's disorders through mutual interaction. This is because "It was helpful to be informed of information I didn't know." or "It is important to talk with experts from various organizations, but information from parents (other family members) (Experience) was helpful." It can be deduced from the contents of the free description, and it can be said that it was effective to target the multi-family setting that are parents of young children with developmental disorders, or those in similar situations such as fathers and mothers.

In addition, the significant increase in "Sense of self-control regarding parenting " scores at the 3 post-program evaluation points was attributed to the use of family systems theory to focus on "interactions with children" that contribute to parental distress, rather than on children's disorders. In other words, the intervention focusing on specific parent-child episodes to encourage parents to change their cognitive / behavioral patterns, which seemed to give up thinking that the troubled problems that they repeated every day were due to child disorder. This is a support that considers the whole family as a system in which the cause of family distress is not a specific individual in the family, but a vicious circle of communication within the family and the underlying family belief are changed.

Traditional workshops and lectures for families of children with developmental disorders often focus on children's disorders. Therefore, it is possible to strengthen each individual's position of "A child who suffers from a developmental disorder and a parent who is concerned about the relationship between the child and the family" and tightly close the system between parents and children. However, as in this study, providing support based on the belief that family distress is caused not by a specific individual in the family but by a vicious circle of communication within the family is far more productive in solving family problems because parents can acquire new patterns of behavior based on the child's characteristic behavior due to disorders.

## ***Limitations and future issues***

In the program implemented this time, the increase in the score of "Belief regarding the roles of spouses" was hardly recognized, and the increase in the score of "Cooperative relationship between spouses" was only immediately after, and was not maintained until 1 months later. In other words, there has been no clear change in the couple system. In the future, it is necessary to aim at the development and implementation of programs that promote smooth communication not only between parents and children but also between husband and wife.

This time, we did not set up a program for siblings of children with developmental disorders. However, the results of "the free description of the program contents and methods" and the necessity of support were reported in previous studies, so we would like to consider it as a future issue.

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