Effectiveness of a Family Management Intervention Program among Families of Children with Autism: A Randomized Controlled Trial

*Thi Lan Anh Mai, Nujjaree Chaimongkol**

Abstract: An increasing number of children are diagnosed with autism, affecting their family's quality of life and various burdens to family caregivers. Several studies have evaluated the effectiveness of interventions to improve the health conditions of children with autism, but few on family outcomes. This two-group randomized controlled trial determined the effectiveness of a 4-week family-management intervention program on family quality of life and burden among family caregivers of children with autism. Forty caregivers of children diagnosed with autism in Hanoi, Vietnam, were randomly assigned to an intervention (n = 20) and a control group (n = 20). The intervention group received a Family Management Intervention Program, in addition to routine care, while the control group received only routine care. The Beach Center Family Quality of Life Scale and the Caregiver's Strain Questionnaire were used to measure the outcome variables at three-time points; baseline (week 0), post-intervention immediately (week 4), and follow-up (week 8). Descriptive statistics and 2-way repeated-measures ANOVAs were used to analyze the data.

The findings revealed that the participants in the intervention group had a significantly higher family quality of life and significantly lower caregiver burden than those in the control group after attending the intervention and remaining overtime. Results provided evidence that the family-management intervention program improved outcomes for families of children with autism. This program needs further testing. After this, nurses and healthcare providers responsible for families and children with autism can integrate this program as part of their services.

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Introduction

Autism is a lifelong disability that affects a person's social interactions in both verbal and nonverbal communication and is often characterized by restrictive and repetitive behaviors. In the last ten years, the worldwide prevalence of autistic disorders has increased more than 100%, and in the United States, its prevalence was 18.5 per 1,000 (one in 54) among children aged eight years and below.[1] This may be due to a more effective diagnosis of autism across the spectrum. The General Statistics Office has estimated there are more than 500,000 people with autism in Vietnam, of whom two-thirds are children under 15 years of age, with a prevalence rate of 1%.[2]

Families of children with autism play an essential role in a child's ability to adapt and function in everyday life and receiving appropriate treatment. Families report high burdens and poorer family quality of life when caring for a child with autism by taking on various roles.[3-5] Children with autism do not always exhibit the same characteristics as adults. Signs and symptoms of autism range from mild to severe and commonly include difficulties making eye contact, no response to their name, deficiencies in attention, poor skills in daily life, and problems with nonverbal communication.[6,7] A child's autistic behaviors have reciprocal effects on the family in that these can generate family stress, increase caregiver burden, and decrease the family's quality of life, which in turn impacts the levels of stress and quality of life for the child.[5,8] These effects illustrate the importance of learning to work and cope with the child's behaviors by supporting the entire family to achieve a better quality of life and lower the caregiver's burden.[9] Relatively few studies have evaluated the broad impact of this approach on family quality of life and the burden of giving care for children with autism. Most studies have evaluated the effect of interventions on a child's outcomes, such as mood, language, sensory perception, behavior, play, and social skills,[10-12] but few have evaluated the parents' or the family's outcomes. Thus, this study sought to answer whether the Family Management Intervention Program (FMIP) could increase the family quality of life and reduce the burden among family caregivers of children with autism.

Conceptual Framework and Review of Literature

This study was guided by the Family Management Style Framework (FMSF).[13] This conceptualizes three key components of family members' efforts to manage a child's medical condition and incorporate these into daily living activities. First, the situation component is information about the causes, severity, and prognosis of the condition; difficulties and challenges in implementing treatment regimens; and the ability to manage the child's condition effectively. It also includes the family caregiver's perspective on the condition of the child. Second, managing the condition is a component of family members' efforts to cope with family interactions and how families incorporate the challenges of living with and managing the condition into their daily lives. The third component, perceived consequences, focuses on the family's awareness of having a child with a health condition in the family's life. The family management style is a result of the responses of family members to these three components. It is conceptualized as a mediation of individual and family system outcomes.[13-14] In our study, the family system outcomes were defined as the family caregivers' perceptions of the family's quality of life and burden.

Families living with a child with autism potentially experience changes in family social dynamics and resources. Evidence points to these changes as altering the family's quality of life[15-17] and caregiver burden.[5,9] Research on interventions about family management approach indicates their effectiveness varies. Evidence shows that three aspects of interventions are essential for a family with a child showing autistic behaviors: psychological, technological, and educational.[18-21] The psychological aspect is about activities related to supporting mental and emotional health. A family management intervention that includes social support reduces mental health problems and other adverse outcomes for children with autism.[18] A technology-based intervention has been shown to provide families with sufficient support mediated by technology despite a geographical distance or other logistical difficulties with health care service systems.[19] The educational aspect is associated with an increased likelihood for a family's better mental health related to the quality of life, family functioning, and child outcomes.[20] Research results provide evidence that an education intervention for families can improve important outcomes, including parents' self-efficacy, coping, parent-child shared management, family quality of life, and depressive symptoms. Education interventions strengthen parents' capacity to manage their own lives and the life of a child with autism or a chronic illness for a better outcome.[21]

Factors that could affect family quality of life and the burden of families of children with autism include the severity of autism, presence of psychiatric disorders in the family, relationships among family members, time since autism diagnosis, and the child's use of behavioral interventions.[22-23] Good management of family problems can improve family life and burden quality, so the main components of family interventions should be focused on these. Such components include effective family-management strategies, managing family caregivers' emotional dimensions and the child's life, supporting family relationships, and providing resources for transitions into a meaningful life. Interventions related to family management in Vietnam have been rarely studied; hence this study was undertaken.

Study Aim

This study aimed to determine the effectiveness of a FMIP on family quality of life and caregiver burden.

Methods

Study design: A randomized controlled study was employed and reported using the CONSORT 2010 checklist of information.

Sampling and Setting: This study was conducted at an outpatient department in a tertiary children's hospital in Hanoi, Vietnam. The participants were dyads of family caregivers and children with autism. The inclusion criteria of the family caregivers were having a biological relationship with the child; providing care to a child without receiving a wage or payment; living in the same house with the child at least six months before data collection; able to read Vietnamese; and having no severe mental health or physical conditions. The exclusion criterion was being unable to complete all sessions of the intervention. The inclusion criterion of the children was four to nine years of age with autism, and the exclusion criteria were having clinical characteristics of impaired social and communication and some behavioral problems diagnosed by a child psychiatrist at the hospital.

The G*Power 3.1.9.2 software was used to calculate the desired sample size to achieve statistical power.[24] The effect size of family management support from a previous study was used to calculate the sample size. Thus 0.30.[25] with a medium effect size at a significance level of 0.05 and a power of 0.80, the minimum total sample size required was 30 participants.[26] Considering attrition of 20-25 %, an additional 10 participants were recruited. Therefore, the total sample size required was 40 (20 participants per group).

Of the 283 caregivers assessed for eligibility, 71 declined the invitation. Seventy-six were excluded due to being unable to participate in all implementation, leaving 145 family caregivers who met the study inclusion and exclusion criteria. Forty of these volunteered to participate and were randomly assigned to either the intervention (n = 20) or control group (n = 20) using a random number assigned by a research assistant blinded to group numbering. The intervention group had the implementation sessions in the morning, and routine care was provided in the afternoon (Figure 1).

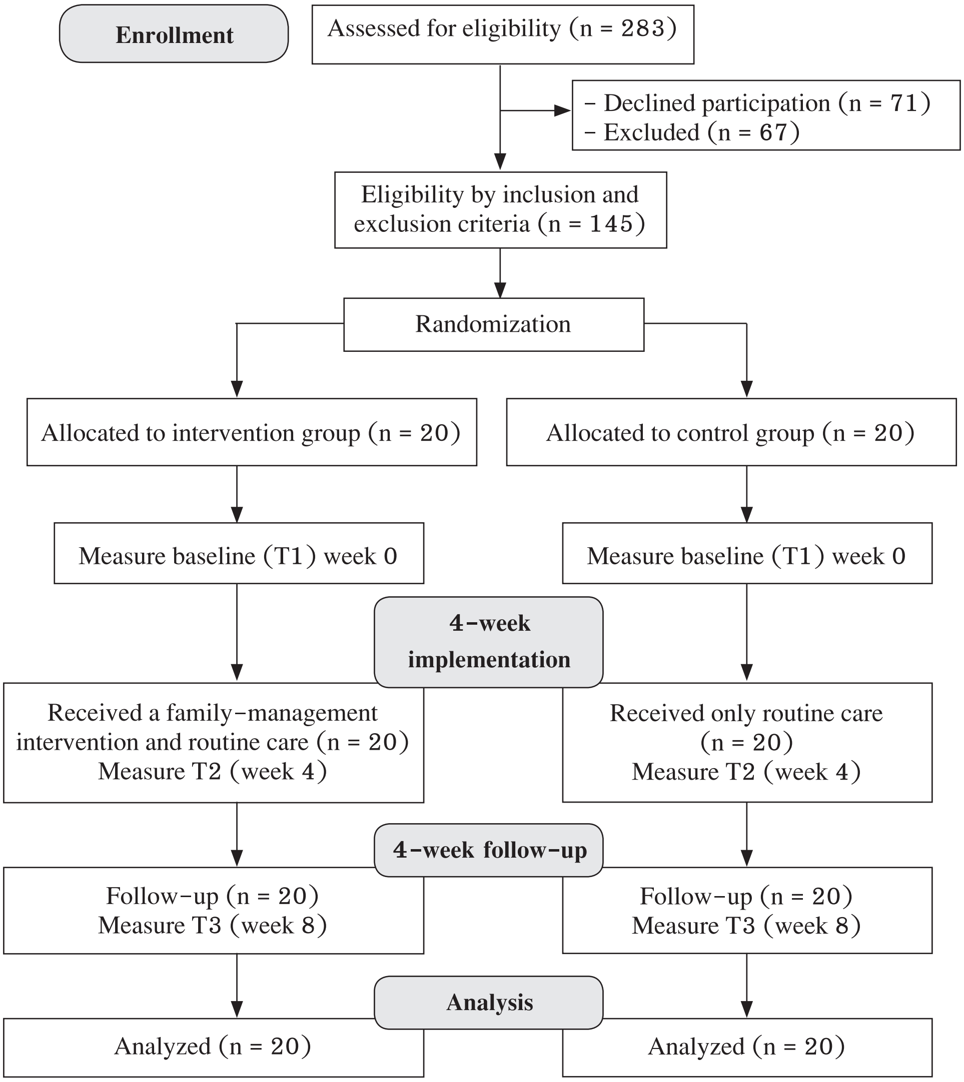

Figure 1 Consort flow chart of participants through the RCT

Research instruments: Three self-report instruments were used for data collection, a demographic questionnaire, the Beach Center Family Quality of Life (FQoL) Scale, and the Caregiver's Strain Questionnaire (CSQ).

The primary investigator (PI) developed a demographic questionnaire for both the children and family caregivers. The children's one included age, gender, number of siblings, duration since diagnosis, and birth order. The family caregiver questionnaire included relationship to the child, gender, marital status, education, and occupation.

The Beach Center Family Quality of Life (FQoL) Scale measures a family representative's perceived satisfaction with the family unit's quality of life. It was developed in English by Hoffman et al.,[27] and was translated into Vietnamese with permission using the World Health Organization guidelines.[28] The back-translation process was conducted by three bilingual experts who were Vietnamese-English teachers in a nursing university. Before data collection, the translated scales were tested for language understandability with 30 caregivers who met the same criteria as the prospective participants. The FQoL Scale comprises a 25-item scale that has five domains (subscales) of family life: family interaction, parenting, emotional wellbeing, physical/material wellbeing, and disability-related support. Each item has a 5-point satisfaction response option: 1 (very dissatisfied), 2 (dissatisfied) 3 (neither), 4 (satisfied), and 5 (very satisfied). Two examples of items are "My family members teach the child how to get along with others" and "My family can handle life's ups and downs." The total summed scores can range from 25 to 125. Each of the five subscales is summed separately and higher scores indicate a better perceived family quality of life by the family's representative. In this study, Cronbach's alpha reliability of the FQoL scale was 0.78.

The Caregiver's Strain Questionnaire (CSQ) measures the perceived degree of burden related to the difficulties, strains, and other negative effects of caregiving. It was developed in English by Brannan et al.[29] to measure strain in caring for elderly family members. It was previously translated into Vietnamese and adapted and used to measure the burden of family caregivers of children with autism in Vietnam.[23] This 21-item scale has five domains: employment, financial, physical, social, and time. Each item has a 5-point response option: 1 (not at all), 2 (a little), 3 (somewhat), 4 (quite a bit) and 5 (very much). Examples of items are "Disrupted family relationships" and "Feeling worried /child's future." Scores are summed and divided by 21 to provide the mean score. The total summed scores range from 1 to 5 and higher scores indicate more burden in giving care. The CSQ has demonstrated good internal consistency and validity.[29] In our study, Cronbach's alpha was 0.82.

The Family Management Intervention Program (FMIP): The 4-weeks of program content was adapted from the Building on Family Strengths program[21] and guided by the FMSF.[13] It included the following five content areas: basic knowledge related to autism and current interventions; managing the family caregivers' emotional dimensions; supporting family relationships, improving family communications and parenting; finding available resources; and transitioning into a more meaningful life. The content was put in a booklet containing an overview of the program's schedule of sessions, presentation content with references, key class concepts, examples of successful strategies in managing children who display autistic behaviors, an action plan template for weekly planning, and an evaluation form. In addition, telephone logs were developed and provided for the intervention group in the first week. The logs were used to track progress and interaction with the participants. The PI phoned each participant every Saturday. Based on the week's content presentation and related behavior challenges, the participants answered five short questions about their action plan during the week, including, "What did you do?"; "When did you do this?"; "How much did you do?"; "How often did you do this ?" and "How confident were you in carrying out the action plan?" For example, if the behavior was a toilet training issue, participants needed to respond to all the above five questions, like "Toilet training to the child," "In the morning at the same time after breakfast," "Very much," "Every day," and "Very confident."

The FMIP was validated by three content experts: a pediatric psychiatrist, a maternal-newborn nurse, and a pediatric nursing instructor. A pilot study was conducted to test the feasibility of the intervention. The PI provided four sessions to five caregivers who met the inclusion criteria at OPD in the site hospital in the pilot study. Other details of the intervention and activities of the PI and the participants are shown in **Table 1**.

Table 1 Implementation sessions of the Family Management Intervention Program

Week/ Session	Objective	Activities
Week 1		
Session I: The impact on family life of living with a child with autism 1 hour (9-10 am)	Introduction to intervention	• Welcome to the program • Introducing the participants • Program overview • Managing family life while living with autism • Muscle relaxation • Introduction to action plans
Week 2		
Session II: Management of family caregivers' emotional dimension and the child life 1 hour (9-10 am)	Explore how having a child with autism can impact the family's emotion and coping skills; how to support the child's skills in their daily life.	• Feedback/problem solving • Impact on you and your emotions • Impact on child • Feeling exploration • Managing hard feelings • Action plan
Week 3		
Session III: Supporting family relationships, family communications and parenting 1 hour (9-10 am)	Support the impact of having a child with autism on parents' relationships, family communication, and parenting; manage the impact using fundamental communication and leadership skills.	• Feedback/problem solving • Explore the impact on your relationships • Impact on your parenting • Introduction to communication and listening skills • Coping skill: distraction • Self-massage • Action plan
Week 4		
Session IV: Finding available resources and transitions into having a meaningful life 1 hour (9-10 am)	Support caregivers in obtaining support from available resources; explore the process of going through major life transitions into having a meaningful life.	• Feedback/problem solving • Working with health care personnel and schools • Community resources • Transition timeline • The family plan • Your transition out of class • Action plan • Program evaluation

Routine care: This consisted of the nurses at OPD sending caregivers a weekly report of their child's progress and providing brief guidelines on how to support their child at home.

Ethical considerations: This study was approved by the Institutional Review Board (IRB) of Graduate Study, Faculty of Nursing, Burapha University, Thailand (#02-04-2562) and the hospital in Vietnam where the study was conducted (#VNCH-RICH-2019-61). The 40 participants were informed about the study's purpose, data collection procedures, benefits and risks, and confidentiality of information. They had the right to participate voluntarily, withdraw during data collection and the intervention, or terminate the study without penalty. They were given code numbers instead of their names for data reporting purposes.

After indicating their willingness, they gave signed informed consent.

Data collection procedures: The data collection was carried out from November to December 2019. The two research assistants (RAs) were Vietnamese nursing instructors who worked at the site hospital's outpatient department. They did not know the experimental status of the participants. They were trained how to collect data using the three research instruments. One RA collected informed consent, and the other made appointments by phone with the participants to complete questionnaires at baseline (week 0, T_1). All aspects of the intervention were held in a hospital classroom by the PI. After the four implementation sessions (post-intervention week 4, T_2), the same RA interviewed the participants of both groups by phone to complete the FQoL Scale and the CSQ and scheduled an appointment for the follow-up phone-call measurement at week 8 (T_3).

Data analysis: Frequencies, means, and standard deviations were used to describe the characteristics of the participants, children, and outcome variables. Comparisons between the control and intervention groups of participants' characteristics were analyzed using t-tests for continuous variables and chi-square for categorical variables. We used two-way repeated-measures ANOVAs to examine differences in family quality of life, and caregiver burden mean scores between the intervention and control groups. All assumptions were met for within-group, between-group, and between-within group (mixed) ANOVAs. Data were analyzed using IBM® SPSS® statistical software, version 26, and the statistical significance level was set at $p < .05$.

Results

Almost all participants were married and were the parents of the children with autism. A fifth (20.0%) of the participants in each group were male. The intervention group was slightly better educated. Most participants have been caring for their children since birth. Most of the children were boys, about six years of age, with one or two siblings. They tended to be the firstborn in the family and had been diagnosed with autism about two years prior to the data collection. There were no significant differences in participant characteristics between the two groups (**Table 2**).

Table 2 Comparison of characteristics of family caregivers and children with autism between two groups

Characteristics	Group				t	χ^2	p-value
	Intervention (n = 20)		Control (n = 20)				
	n	%	n	%			
Family caregivers							
Age (years)	M = 35.3 (±6.14) range = 24-46		M = 37.5 (±11.38) range = 29-72		-0.78		.44
Duration of care (years)	M = 6.1 (±1.91) range = 4-9		M = 5.4 (±1.78) range = 1-8		1.21		.23
Relationship with child							
Parents	20	100	18	90		2.5	.15
Grandparents	0	0	2	10			
Gender							
Female	16	80	16	80		0.00	1.00
Male	4	20	4	20			
Marital status							
Married	13	65	15	75		.54	.76
Single	1	5	1	5			
Divorced	6	30	4	20			

Table 2 Comparison of characteristics of family caregivers and children with autism between two groups (Cont.)

Characteristics	Group				t	χ^2	p-value
	Intervention (n = 20)		Control (n = 20)				
	n	%	n	%			
Education							
Primary school/lower	0	0	4	20		5.09	.28
Middle school	4	20	2	10			
High school	2	10	1	5			
Diploma/college	6	30	5	25			
University or above	8	40	8	40			
Occupation							
Government officers	14	70	10	50		3.81	.28
Farmers	2	10	6	30			
Industrial workers	3	15	4	20			
Housewife	1	5	0	0			
Children with autism							
Age (years)	M = 6.1 (±1.90) range = 4-9		M = 5.6 (±1.35) range = 4-8		0.86		.40
Number of siblings	M = 1.6 (±0.51) range = 1-2		M = 1.1 (±0.22) range = 1-2		4.01		<.001
Duration since diagnosed (years)	M = 2.5 (±1.57) range = 1-5		M = 2.5 (±1.23) range = 1-4		0.11		.91
Gender						3.13	.08
Boy	15	75	19	95			
Girl	5	25	1	5			
Birth order						0.14	.71
1st	16	80	15	75			
2nd	4	20	5	25			

The Effectiveness of the FMIP

Means and standard deviations of FQoL and caregiver burden of both groups at three point-time measurements are presented in **Table 3.** The two-way repeated-measures ANOVAs showed a significant main effect of group in both FQoL and caregiver burden (**Table 4**), indicating that mean scores of FQoL and caregiver burden in the intervention and control groups were different. Results from the one-way ANOVAs (**Table 5**) revealed that at baseline (week 0), there were not significantly different FQoL and caregiver burden mean scores between the intervention and control groups. However, immediately after the intervention (week 4) and follow-up (week 8), the mean score of FQoL in the intervention group was significantly higher, and the mean score of caregiver burden was significantly lower than that of the control group. Moreover, there was a significant change in mean scores of FQoL and caregiver burden over time, and the time-group interaction was also significant (**Table 4**). The multiple pairwise comparisons using the Bonferroni test between each point of measurement revealed that, in the experiment group, the mean score of FQoL increased significantly from baseline (T_1, week 0), post-intervention (T_2, week 4), and to the follow-up (T_3, week 8). The mean score of the caregiver burden decreased significantly from baseline (T_1, week 0) to post-intervention (T_2, week 4), but not significantly decreased from post-intervention (T_2, week 4) to the follow-up (T_3, week 8). In contrast, the mean scores of FQoL and caregiver burden in the control group were not statistically significant across three times (**Table 6**)

Table 3 Means and standard deviations of the scores of family quality of life and caregiver burden at three time periods of both groups

Variable	Measured time (T)	Intervention group (n = 20), M (SD)	Control group (n = 20), M (SD)
FQoL	1	37.30 (3.53)	40.90 (5.44)
	2	90.05 (4.98)	45.05 (4.50)
	3	103.90 (3.18)	46.20 (4.38)
Caregiver burden	1	4.13 (0.58)	3.78 (1.18)
	2	2.90 (1.07)	3.90 (0.92)
	3	2.96 (1.13)	3.65 (1.14)

Table 4 Two-way repeated-measures ANOVAs of family quality of life and caregiver burden scores across three time periods

Source	SS	*df*	MS	*F*	*p*-value
FQoL					
Within Subjects					
Time	12,347.52	2.00	6,547.35	248.94	< .001
Time*Group	8,463.35	2.00	2,475.38	328.46	< .001
Error Time	346.38	76.00	11.63		
Between Subjects					
Group	11,374.35	1.00	14,736.25	398.52	< .001
Error	237.74	38.00	12.54		
Caregiver burden					
Within Subjects					
Time	1,392.72	2.00	696.36	211.41	< .001
Time*Group	951.62	2.00	475.81	144.45	< .001
Error Time	250.33	76.00	3.29		
Between Subjects					
Group	2,279.41	1.00	2,279.41	334.95	< .001
Error	161.92	38.00	4.26		

Table 5 Simple effect of groups on family quality of life and caregiver burden between 2 groups at 3-point times

Source	SS	*df*	MS	*F*	*p*
FQoL					
Pre-intervention (T_1, Week 0)					
Between subjects	25.60	1.00	25.60	2.82	0.10
Error	344.80	38.00	9.07		

Table 5 Simple effect of groups on family quality of life and caregiver burden between 2 groups at 3-point times (Cont.)

Source	SS	*df*	MS	*F*	*p*
Post-intervention (T2, Week 4)					
Between subjects	20,295.03	1.00	20,295.03	442.19	<0.001
Error Time	534.75	38.00	14.07		
Follow-up (T3, Week 8)					
Between subjects	34,105.60	1.00	34,105.60	697.78	<0.001
Error	480.40	38.00	12.64		
Caregiver burden					
Pre-intervention (T_1,Week 0)					
Between subjects	2.03	1.00	2.03	0.48	0.49
Error	160.75	38.00	4.23		
Post-intervention (T_2,Week 4)					
Between subjects	2,030.63	1.00	2,030.63	513.91	<0.001
Error Time	150.15	38.00	3.95		
Follow-up (T_3,Week 8)					
Between subjects	2,340.90	1.00	2,340.90	702.64	<0.001
Error	126.60	38.00	3.33		

Table 6 Pairwise comparisons of means of family quality of life and caregiver burden between each time point of both within the intervention and the control groups

Time	M_{diff}	SE	*p*
FQoL			
Intervention group			
T_3 vs. T_1	66.60	0.93	< 0.001
T_3 vs. T_2	13.85	1.18	< 0.001
T_2 vs. T_1	52.75	1.11	< 0.001
Control group			
T_3 vs. T_1	5.30	0.93	0.05
T_3 vs. T_2	1.15	1.18	0.30
T_2 vs. T_1	4.15	1.11	0.08
Caregiver burden			
Intervention group			
T_3 vs. T_1	-1.17	0.05	< 0.001
T_3 vs. T_2	0.06	0.05	0.25
T_2 vs. T_1	-1.23	0.06	< 0.001
Control group			
T_3 vs. T_1	-0.13	0.06	0.23
T_3 vs. T_2	-0.25	0.06	0.18
T_2 vs. T_1	0.12	0.05	0.22

Discussion

The study aimed to examine the effectiveness of a FMIP for children with autism in terms of family quality of life and burden perceived by the family caregivers. The most robust result we found was that combining educational sessions and telephone support in the FMIP effectively improved family quality of life and reduced caregiver burden. The results supported the FMSF[13-14] and previous literature.[5,20-21,30-32] In this study, the PI provided knowledge of autism (definition of situation), a practical management approach for family caregivers (behavior management/action); and raised the family's awareness of having children with autism in the life of the family (the perceived consequences), therefore, enhancing family system outcomes, which were explicitly defined as the family quality of life and burden of caregivers.[20-21]

The FMIP provided knowledge related to autism; management of family caregivers' emotional dimension and the child's life; supporting family relationships, family communications and parenting; and finding available resources and transitions into a meaningful life. Therefore, the FMIP we implemented strengthened the caregivers' perceptions of the family's capacity to manage their daily living. By focusing on family needs, including informational needs and emotional support, the program helped family members learn how to intervene and cope more effectively with their children's difficult behaviors. The results were congruent with previous studies that parental interventions have the potential to reduce tension and anxiety.[30] Educational sessions and support improve the psychological wellbeing of parents and influence the wellbeing of the children with autism and other family members.[31] Although we did not measure the children's outcomes, other evidence suggests that an effective parental intervention can also influence a child's levels of stress and quality of life.[5-7]

Family caregivers completing the FMIP perceived they had less burden. The findings supported that the FMSF guided the intervention on improving family management of children with autism; therefore, the intervention positively influenced lessening family burden. Previous studies support this finding.[30-32] Other techniques could be included in future follow-up or "booster" sessions, such as relaxation techniques and mindfulness-based stress reduction, to improve parenting stress and general health and reduce the parents' depression and anxieties.[30] Mindfulness interventions with self-massage, muscle relaxation, and positive self-talk can be practical tools to manage stress and increase the wellbeing of parents who have children with autism.[32]

A follow-up session was employed to confirm the program's effect. The FMIP provided family foundation knowledge related to autism, discussed in-group for sharing their experiences, involved emotional support, and made action plans for their challenges with problem-solving. The study's family caregivers committed to participating in all the sessions while they waited for their children to receive ongoing follow-up treatment.

In conclusion, the FMIP content and interventional approach toward communicating with family caregivers who have children with autism showed the benefits by improving the outcomes. The expanded FMSF explains that the socio-cultural context affects family issues and difficulties of children with autism.[20] The healthcare providers and health systems also affect the family's ability to manage behavioral issues of children with autism. Family financial resources contribute to the family's decision-making process to select appropriate medical and treatment services for children and families. Parents also need resources from the community.[20-21] To that end, healthcare providers should assess parents of children newly diagnosed with autism as to their interest and readiness to participate in a FMIP. This might be as soon as the family receives their child's diagnosis, at the time when they are most worried and distressed.

Limitations

The study had some noted weaknesses that could be improved in the future. First, collecting data over the phone may be convenient, but may have been intrusive for participants. In addition, the generalization of this study is limited since it was carried out in only one tertiary children's hospital. Although we explored the family caregiver's perspective of the FQoL and burden, other family members may have different viewpoints. Also, the FMSF has been modified recently to include the child's perspective. Future studies should examine the outcome variables on both parents and children, combining data from observation and self-report that would provide a multi-dimensional view of the effectiveness of the FMIP. Longer follow-up should be explored the sustainability of the outcomes. Refresher, mobile-tailored and digital technology/internet-based sessions may be needed to reinforce information and boost the morale of family members managing their challenges effectively over a more extended period.

Conclusions and Implications for Nursing Practice

The FMIP showed the benefits of improving family quality of life and caregiver burden among children with autism. Nurses should assess parents of children newly diagnosed with autism and their interest and readiness to participate in a FMIP. In addition, nurses who work with children with autism should obtain and implement this program as a part of their nursing care with further testing its effectiveness in different situations. However, we recommend further testing of the program before implementation in practice.

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References

1. Maenner MJ, Shaw KA, Baio J, et al. Prevalence of autism spectrum disorder among children aged 8 years — autism and developmental disabilities monitoring network, 11 sites, United States, 2016. MMWR Surveill Summ 2020;69 (No. SS-4):1-12. doi: 10.15585/mmwr.ss6904a1.
2. General Statistics Office of Vietnam. Alarming: children with autism in Vietnam are increasing [Internet]. 2019 [cited 2021 Aug 20]. Available from: https://tuoitre.vn/tre-em-tu-ky-tai-viet-nam-gia-tang-phan-lon-khong-duoc- tri-lieu-giao-duc-phu-hop-20210406132735649. htm (in Vietnamese)
3. Bozkurt G, Uysal G, Düzkaya DS. Examination of care burden and stress coping styles of parents of children with autism spectrum disorder. J Pediatr Nurs. 2019;47:142-7. doi: 10.1016/j.pedn.2019.05.005.
4. Alenazi DS, Hammad SM, Mohamed AE. Effect of autism on parental quality of life in Arar city, Saudi Arabia. J Family Community Med. 2020;27(1):15-22. doi:10.4103/jfcm.JFCM_157_19.
5. Bayoumi M, Ezzat O, Samarkand O. Quality of life and subjective burden on family caregiver of children with ASD. Am. J. Nurs. Sci. 2017;6(1):33-9. doi: 10.11648/j.ajns.20170601.15.
6. Muris P, Ollendick TH. Current challenges in the diagnosis and management of selective mutism in children. Psychol Res Behav Manag. 2021;14:159-67. doi:10.2147/PRBM.S274538.
7. Celik H, Acikel SB, Ozdemir MAF, Aksoy E, Oztoprak U, Ceylan N, Yuksel D. Evaluation of the clinical characteristics of children with autism spectrum disorder and epilepsy and the perception of their parents on quality of life. Epilepsy Res. 2021;172:106599. doi: 10.1016/j.eplepsyres.2021.106599.
8. Ten Hoopen LW, de Nijs PFA, Duvekot J, Greaves-Lord K, Hillegers MHJ, Brouwer WBF, Hakkaart-van Roijen L. Children with an autism spectrum disorder and their caregivers: capturing health-related and care-related quality of life. J Autism Dev Disord. 2020;50(1):263-77. doi: 10.1007/s10803-019-04249-w.

9. Picardi A, Gigantesco A, Carolla E, et al. Parental burden and its correlates in families of children with autism spectrum disorder: a multicentre study with two comparison groups. Clin Pract Epidemiol mental health. 2018;14:143-76. doi:10.2174/17450179018140 10143.
10. Pacia C, Holloway J, Gunning C, Lee H. A systematic review of family-mediated social communication interventions for young children with autism. Rev J Autism Dev Disord. 2021;1:1-27. doi: 10.1007/s40489-021-00249-8.
11. Rojas-Torres LP, Alonso-Esteban Y, Alcantud-Marín F. Early intervention with parents of children with autism spectrum disorders: a review of programs. Children (Basel). 2020;7(12):294. doi:10.3390/children7120294.
12. Fuller EA, Kaiser AP. The effects of early intervention on social communication outcomes for children with autism spectrum disorder: a meta-analysis. J Autism Dev Disord. 2020;50(5):1683-700. doi:10.1007/s10803-019-03927-z.
13. Knafl K, Deatrick JA, Gallo AM. The interplay of concepts, data, and methods in the development of the Family Management Style Framework. J Fam Nurs. 2008 Nov;14(4):412-28.doi:10.1177/1074840708327138.
14. Knafl KA, Deatrick JA, Knafl GJ, Gallo AM, Grey M, Dixon J. Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. J Pediatr Nurs. 2013 Nov-Dec;28(6):523-35. doi: 10.1016/j.pedn.2013.03.006.
15. Frantz R, Hansen S, Machalicek W. Interventions to promote wellbeing in parents of children with ASD: a systematic review. Rev J Autism Dev Disord. 2018;5(1), 58-77. doi: 10.1007/s40489-017-0123-3.
16. Wang H, Hu X, Han ZR. Parental stress, involvement, and family quality of life in mothers and fathers of children with autism spectrum disorder in mainland China: a dyadic analysis. Res Dev Disabil. 2020;107:103791. doi:10.1016/j.ridd.2020.103791.
17. Mello C, Rivard M, Terroux A, Mercier C. Quality of life in families of young children with autism spectrum disorder. Am J Intellect Dev Disabil. 2019;124(6):535-48. doi:10.1352/1944-7558-124.6.535.
18. Bechet AK. Positive thinking training intervention for caregivers of persons with autism: establishing fidelity. Arch Psychiatr Nurs. 2017;31(3):306-10. doi: 10.1016/j.apnu.2017.02.006.
19. Marino F, Chilà P, Failla C, et al. Tele-assisted behavioral intervention for families with children with autism spectrum disorders: a randomized control trial. Brain Sci. 2020; 10(9):649. doi:10.3390/brainsci10090649.
20. Deb SS, Retzer A, Roy M, Acharya R, Limbu B, Roy A. The effectiveness of parent training for children with autism spectrum disorder: a systematic review and meta-analyses. BMC Psychiatry. 2020;20(1):583. doi:10.1186/s12888-020-02973-7.
21. Kieckhefer GM, Trahms CM, Churchill SS, Kratz L, Using N, Villareal N. A randomized clinical trial of the building on family strengths program: an education program for parents of children with chronic health conditions. Matern Child Health J. 2014;18(3):563-74. doi: 10.1007/s10995-013-1273-2.
22. Özgür BG, Aksu H, Eser E. Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. Indian J Psychiatry. 2018;60(3): 278-85. doi: 10.4103/psychiatry.IndianJPsychiatry_300_17.
23. Anh, TML. Factors related to burden among caregivers of children with autism in Vietnam [master's thesis]. [Internet]: Burapha University; 2015 [cited 2021 Aug 20]. Available from: http://digital_collect.lib.buu.ac.th/dcms /files/56910323.pdf
24. Faul F, Erdfelder E, Buchner A. G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behav Res Methods. 2007 May;39, 175-91. doi: 10.3758/BF03193146.
25. Iadarola S, Levato L, Harrison B, et al. Teaching parents behavioral strategies for autism spectrum disorder (ASD): effects on stress, strain, and competence. J Autism Dev Disord. 2018;48(4):1031-40. doi:10.1007/s10803-017-3339-2.
26. Polit DF, Beck CT. Nursing research: generating and assessing evidence for nursing practice. 10th edition, Philadelphia: Wolters Kluwer Health, 2017.
27. Hoffman L, Marquis J, Poston D, Summers JA, Turnbull A. Assessing family outcomes: psychometric evaluation of the Beach Center Family Quality of Life Scale. J Marriage Fam. 2006 Oct;68:1069-83. doi: 10.1111/j.1741-3737.2006.00314.x.

28. World Health Organization. Process of translation and adaptation of instruments. 2016 [cited 2020 Oct 12]. Available from: http://www.who.int/substance_abuse/research _tools/translation
29. Brannan AM., Heflinger CA, Bickman L. The caregiver strain questionnaire: measuring the impact of the family of living with a child with serious emotional disorders. J. Emot. Behav. Disord. 1997;5:212–22.
30. MacKenzie KT, Eack SM. Interventions to improve outcomes for parents of children with autism spectrum disorder: a meta-analysis. J Autism Dev Disord. 2021 Jun 29. doi:10.1007/s10803-021-05164-9.
31. Catalano D, Holloway L, Mpofu E. Mental health interventions for parent carers of children with autistic spectrum disorder: practice guidelines from a critical interpretive synthesis (CIS) systematic review. Int J Environ Res Public Health. 2018;15(2):341. doi: 10.3390/ijerph15020341.
32. Singh NN, Lancioni GE, Medvedev ON, Hwang YS, Myers RE. A component analysis of the mindfulness-based positive behavior support (MBPBS) program for mindful parenting by mothers of children with autism spectrum disorder. Mindfulness (NY). 2020 May 11:1-13. doi:10.1007/s12671-020-01376-9.

ประสิทธิผลของโปรแกรมการจัดการครอบครัวในครอบครัวที่มีเด็กออทิสติก: การทดลองแบบสุ่มและมีกลุ่มควบคุม

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บทคัดย่อ: การเพิ่มขึ้นของจำนวนเด็กออทิสติกในปัจจุบันส่งผลต่อคุณภาพชีวิตครอบครัวและภาระของผู้ดูแลครอบครัว การศึกษาส่วนใหญ่มุ่งประเมินประสิทธิผลของกิจกรรมต่อการส่งเสริมสุขภาพเด็กออทิสติก แต่มีการศึกษาน้อยเกี่ยวกับผลลัพธ์ของครอบครัว การทดลองแบบสุ่มและมีกลุ่มควบคุมแบบสองกลุ่มนี้มีวัตถุประสงค์เพื่อศึกษาประสิทธิผลของกิจกรรม 4 สัปดาห์ของโปรแกรมการจัดการครอบครัวต่อคุณภาพชีวิตครอบครัวและภาระในผู้ดูแลเด็กในครอบครัวที่มีเด็กออทิสติก ผู้ดูแลเด็กจำนวน 40 คน จากครอบครัวที่มีเด็กเป็นออทิสติกในกรุงฮานอย เวียดนามได้รับการสุ่มเข้ากลุ่มทดลอง 20 ราย และกลุ่มควบคุม 20 ราย กลุ่มทดลองได้รับการดำเนินกิจกรรมและการดูแลตามปกติ ในขณะที่กลุ่มควบคุมได้รับการดูแลตามปกติเท่านั้น แบบวัดคุณภาพชีวิตครอบครัวของ Beach Center และแบบสอบถามความเครียดของผู้ดูแลถูกใช้เพื่อวัดตัวแปรผลลัพธ์จำนวน 3 ครั้ง ได้แก่ ก่อนการให้กิจกรรม (สัปดาห์ 0) ภายหลังเสร็จสิ้นกิจกรรมทันที (สัปดาห์ 4) และระยะติดตามผล (สัปดาห์ 8) วิเคราะห์ข้อมูลด้วยสถิติพรรณาและการวิเคราะห์ความแปรปรวนสองทางแบบวัดซ้ำ

ผลการวิจัยพบว่าผู้เข้าร่วมในกลุ่มทดลองมีคุณภาพชีวิตครอบครัวสูงกว่าและมีภาระการดูแลต่ำกว่าในกลุ่มควบคุมภายหลังการเข้าร่วมโปรแกรมการจัดการครอบครัวและคงอยู่ในเวลาต่อมา ผลลัพธ์แสดงหลักฐานเชิงประจักษ์ว่าโปรแกรมการจัดการครอบครัวช่วยปรับปรุงผลลัพธ์ของครอบครัวเด็กออทิสติก พยาบาลและผู้ให้บริการด้านสุขภาพที่รับผิดชอบสุขภาพของครอบครัวและเด็กออทิสติกควรนำโปรแกรมนี้บูรณาการเป็นส่วนหนึ่งของการให้บริการ ตลอดจนการทดสอบประสิทธิภาพของโปรแกรมเพิ่มเติม

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ทะเบียนการทดลองทางคลินิกของประเทศไทย: http://www.thaiclinicaltrials.org/ (TCTR20200610001)

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