#### **ORIGINAL ARTICLE**

# A Family-Engaged Educational Program for Atopic Dermatitis: A Seven-Year, Multicenter Experience in Daegu-Gyeongbuk, South Korea

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Background: It is important to educate families of pediatric patients with atopic dermatitis (AD) so that they have a correct understanding of AD. Objective: The purpose of this study is to introduce, evaluate, and improve our family-engaged educational program. Methods: Children suffering from AD and their families have participated in a half-day educational program called "AD school" with catchy slogans such as "Enjoy with AD Families!" every year since 2005. Educational lectures were conducted for parents. For children with AD, various entertaining programs were provided. A feedback survey about AD school was administered for the purpose of evaluation. Results: A total of 827 people (376 patients and 451 family members) participated in this program over 7 years. On-site surveys showed a positive response (i.e., "excellent" or "good") for the prick test (95.1%), emollient education (78.4%), educational lecture (97.0%), drawing contest and games (90.2%), and recreation (magic show; 99.0%) respectively. Telephone surveys one year later also elicited a positive response. Conclusion: We herein introduce the experience of a half-day, family-engaged educational program for AD. Family-engaged education programs

\*These authors contributed equally to this work.

for AD such as this AD school encourage and validate family participation in the treatment of their children's AD. (Ann Dermatol 27(4) 383~388, 2015)

#### -Keywords-

Atopic dermatitis, Education, Family, Survey

## **INTRODUCTION**

Atopic dermatitis (AD) is a common, chronically relapsing inflammatory skin disease caused by multiple genetic and environmental factors<sup>1</sup>. Long-term and persistent management of AD is necessary; therefore, AD families and society experience a significant economic burden<sup>2</sup>. The chronically relapsing nature of this disease and unsatisfactory treatment experiences cause frustration and disappointment in patients and their family members, which in turn may negatively influence the course of the disease<sup>3</sup>. However, AD families frequently do not know much about the illness or its consequences. From this point of view, one of the most important considerations is family education in the proper treatment of AD. In addition, children with AD have a fear of hospitals. Therefore, for children, it is important to reduce the fear of hospital visits.

We herein introduce an annual half-day, family-engaged educational program entitled "AD School in Daegu-Gyeongbuk, South Korea" with the slogan, "Enjoy with AD Families!" Our AD school has three characteristics that differentiate it from other AD educational programs. First, not just one organization but all of the local university hospitals came together for this program. This enabled us to easily recruit

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#### YH Jang, et al

patients with AD and their family members, and to develop a sense of cooperation. Second, for maximum efficiency, educational sessions were conducted for parents only and entertainment was designed specifically for children with AD. Third, we performed on-site surveys and follow-up telephone surveys (years later) for the purpose of evaluating and improving our program. The purpose of this study is to introduce our half-day educational program for pediatric patients with AD and their family members, and to evaluate the impact of our program based on the on-site and telephone surveys.

## MATERIALS AND METHODS

#### **Participants**

Children with AD (between 3 and 10 years of age) and their family members participated. All participants were asked for their verbal informed consent. AD was diagnosed by dermatologists and the severity of AD was not considered. A total of 827 people (376 patients and 451 family members) took part in this program over 7 years  $(2005 \sim 2011)$ .

#### AD school programs

AD school was held as an annual continuing educational program on a Saturday afternoon. The program composed of eight sessions, including a skin prick test, emollient education, educational lectures, and recreation (Fig. 1, Table 1).

## 1) Registration and emollient education

At the registration area, children with AD and their families received nametags and token gifts such as colored pencil sets. After registration, families participated in an emollient education program, in which dermatologists explained the appropriate application method for an emollient.



Fig. 1. Composition of our atopic dermatitis (AD) school program. (A) Dermatology residents explain the appropriate application method for emollients. (B) Dermatology residents conduct skin prick tests and explain the results of these tests. (C) While parents listen to educational lectures, children with AD play games in another room. (D) A professional magician performs a magic show.

Overview of activities	Guide	Participants	Total duration (min)
Registration & emollient education	Dermatology residents	Children & parents	30
Opening ceremony	Dermatologist	Children & parents	10
Prick test	Dermatologist	Children & parents	60
Educational lecture for families	Dermatologist	Parents	90
	Pediatrician		
	Psychologist		
	Dietician		
Drawing contest and games*	Art teacher	Children	60
Movie & snack time*	Dermatologist	Children	30
Recreation (magic show)	Magician	Children & parents	40
Awards & closing	Dermatologist	Children & parents	20

Table 1. An overview of activities including guides, participants, and durations

\*While parents listened to educational lectures, children participated in a drawing contest, watched a movie, and had snacks in another room.

#### 2) Opening ceremony

After the emollient education, participants attended the opening ceremony, which conveyed a positive image of the event. During the opening ceremony, the goal of the program and its connections to the academic community (and thus its reliability) were described to participants.

## 3) Skin prick test

Dermatology residents conducted skin prick tests and explained the results. Skin prick tests were performed using a battery of the four common allergens (milk, egg, peanut, and house dust mite). Skin prick tests can be helpful for daily functioning in that they provide information about substances that patients should avoid. Emergency medical kits were prepared in case of accidents during the skin prick tests. However, the emergency situation did not occur even once.

#### 4) Educational lecture

Educational lectures were presented to parents on general topics pertaining to AD, such as "Causes, management, treatment, and symptoms of AD." Special topics, such as "Psychological approaches to AD" were also presented.

#### 5) Drawing contest and games

While parents participated in educational lectures, children participated in a drawing contest in another room. Kindergarten teachers were present to supervise playtime.

#### 6) Movie and snack time

After the drawing contest, children watched animated movies and had snacks.

#### 7) Recreation (magic show)

A professional magician was invited to present a magic show to help parents and children relax.

#### 8) Awards and closing

Awards were presented for the drawing contest and a photo was taken.

#### On-site and telephone surveys

During AD school, an on-site survey was conducted using questionnaires assessing satisfaction with AD school as well as with each specific session. In addition, after more than a year had passed, a telephonic interview assessed satisfaction with AD school, disease progression, overall effect on life (comprehension/improvement/management of the disease), and willingness to participate again in AD school.

## **RESULTS**

#### **Participant surveys**

#### 1) On-site survey

The on-site survey was conducted with a subset of the participants. One of the family members (a caregiver) participated in the on-site survey. Therefore, results were obtained from 102 participants. The satisfaction rate (i.e., "excellent" or "good" responses) was 95.1% for the skin prick test session, 78.4% for the emollient education session, 97.0% for the educational lecture, 90.2% for the drawing contest and games session, and 99.0% for the recreational session (magic show). When compared to the other sessions, the satisfaction rate for the emollient education session, session, was relatively low (Table 2).

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Activity	Excellent	Good	Satisfactory	Poor
Prick test	66 (64.7)	31 (30.4)	4 (3.9)	1 (1.0)
Emollient education	34 (33.3)	46 (45.1)	20 (19.6)	2 (2.0)
Educational lecture	65 (63.7)	34 (33.3)	2 (2.0)	1 (1.0)
Drawing contest and games	61 (59.8)	31 (30.4)	9 (8.8)	1 (1.0)
Recreation (magic show)	68 (66.6)	33 (32.4)	1 (1.0)	0 (0)

Table 2. Satisfaction with atopic dermatitis school: on-site survey (n = 102)

Values are presented as participant number (%).

Table 3. Satisfaction with atopic dermatitis school: follow-up telephone survey (n=96)

Program characteristic	Value
Educational value	
lt was very helpful	17 (17.7)
lt was quite helpful	66 (68.8)
It was somewhat helpful	12 (12.5)
lt wasn't helpful	1 (1.0)
It wasn't helpful at all	0 (0)
Interest	
lt was very enjoyable	8 (8.3)
lt was quite enjoyable	66 (68.8)
It was somewhat enjoyable	17 (17.7)
lt wasn't enjoyable	5 (5.2)

Values are presented as participant number (%).

#### 2) Follow-up telephone survey

We obtained telephone survey results from 96 family members.

**Satisfaction with AD school:** In terms of overall satisfaction with AD school, 99.0% found it helpful, and 94.8% found it enjoyable (Table 3).

Disease progression and overall effect on life: In terms of disease progression and effects on life since AD school, 69.8% of parents agreed that their understanding of the disease had improved, 34.4% agreed that they had changed their frequency of using complementary and alternative medicine, and 56.3% agreed that they had tried to improve their home environment after AD school. Of the children, 55.3% agreed that their disease had improved since AD school, and 50.0% agreed that their attitude toward hospital treatment had improved. However, most children with AD chose a neutral response about the improvement of relationships with friends (75.0%) and learning ability (77.1%). In terms of whether they were trying to apply the ointment/emollient adequately, 83.2% of parents and patients agreed that they did. However, most responded neutrally about whether there were better relationships between family members (Table 4).

Willingness to participate again in the AD school: Of all

participants, 63.5% were willing to attend the next AD school and 93.8% indicated that they would recommend AD school to their friends or relatives (Table 5).

#### DISCUSSION

Educational interventions have long been recommended and used as a critical adjunctive treatment method for patients with AD to enhance the effectiveness of therapy<sup>2</sup>. There are some international studies about educational programs for the management of childhood AD. The Berlin model is a well-known educational program for parents of children with AD. This program aims to improve parents' management skills with regard to their child, and to positively impact the course of the disease as well as the family's quality of life. The program consists of six 2-hour group sessions conducted at weekly intervals. Group sessions are guided by a multi-professional team of pediatricians, psychologists, and dieticians<sup>4</sup>. The Italian model is another educational program for parents of children with AD. This program consists of six 90-minute weekly meetings involving a pediatric allergist, a dermatologist, and a psychologist<sup>5</sup>. A 2-hour educational program based on the Australian model was evaluated by comparing a randomized educational intervention group with a control group, with the goal of measuring outcomes of educational interventions including severity of eczema and patient quality of life<sup>6</sup>. In addition, another Korean study showed positive effects of programmed education delivered by dermatology specialists on the management and knowledge of  $AD^{\prime}$ . Overall, the aforementioned studies are positive because educational programs were shown to contribute toward a comprehensive, family-oriented approach to the management of childhood AD, and are a helpful adjunct to dermatological treatment. However, these programs were family oriented, but not family engaged.

Our AD school is a short half-day educational program for pediatric patients with AD and their families. The main purpose of our AD program is to improve knowledge about the disease, improve parents' management skills

Table 4. Comprehension, improvement, and management of the disease: follow-up telephone survey (n = 96)

Survey question	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Comprehension of the disease					
Do you think your understanding of the disease is better?	11 (11.5)	56 (58.3)	26 (27.1)	3 (3.1)	0 (0)
Have you changed your frequency of use of complementary & alternative medicine?	5 (5.2)	28 (29.2)	38 (39.6)	22 (22.9)	3 (3.1)
Have you tried to improve your home environment?	14 (14.6)	40 (41.7)	32 (33.3)	9 (9.4)	1 (1.0)
Improvement of the disease					
Has the patient's disease improved?	6 (6.3)	47 (49.0)	37 (38.5)	6 (6.3)	0 (0)
Have the patient's attitudes toward hospital treatments improved?	2 (2.1)	46 (47.9)	43 (44.8)	5 (5.2)	0 (0)
Have the patient's relationships with friends improved?	3 (3.1)	16 (16.7)	72 (75.0)	5 (5.2)	0 (0)
Have the patient's attitudes toward learning and ability to learn improved due to improvement of the disease?	3 (3.1)	16 (16.7)	74 (77.1)	3 (3.1)	0 (0)
Management of the disease					
Do you apply ointment/emollient adequately?	19 (19.8)	60 (62.5)	15 (15.6)	2 (2.1)	0 (0)
Do you have better relationships between family members?	5 (5.2)	19 (19.8)	67 (69.8)	2 (2.1)	3 (3.1)

Values are presented as participant number (%).

**Table 5.** Willingness to participate again in the atopic dermatitis (AD) school: follow-up telephone survey (n = 96)

Question	Yes	No
Will you participate again? Will you recommend the AD school to others?	61 (63.5) 90 (93.8)	35 (36.5) 6 (6.2)

Values are presented as participant number (%).

with regard to their child with AD, and to positively impact the course of the disease and the family's quality of life. Our AD school became a popular local annual event in Daegu-Gyeongbuk. Through the prick test and emollient education, children with AD and their family members received information about what to avoid and how to correctly use the emollients, which could be helpful in daily life. Educational lectures were provided to adult family members by a multidisciplinary team including dermatologists, pediatricians, psychologists, and dieticians. In contrast with other educational models, we prepared several entertaining programs for children with AD. While parents listened to educational lectures, children enjoyed a drawing contest, a movie, and snacks in another room. Because of this additional program, family members were able to concentrate on the educational lectures and children with AD were able to get to know one another better. The magic show was also prepared to encourage participation and present a positive image for the AD

school.

Through on-site surveys, we verified that most participants were satisfied with our program, but that the emollient education session was not perceived as positively as the other sessions. This may be due to people being able to easily get information on how to use emollients correctly, underestimating of its importance, or dis-satisfaction with the explanation. Results from the follow-up telephone survey about overall satisfaction showed that the AD school was helpful, and 94.8% found it enjoyable. Especially in terms of management and comprehension of AD, the disease improved compared to its status before the AD school. This may be because family members not only received information from a variety of professionals, but could also ask any questions about AD. Most of the responses to the follow-up telephone survey about overall effect on life and disease progression were positive, but several parts of the questionnaire showed a pattern of neutral responding (e.g., using complementary and alternative medicine, learning attitude and ability, and the patient's relationship with friends and family members). With regard to the results about complementary and alternative medicines, almost 60% of the total Korean population has been treated by traditional Korean medicine for chronic intractable diseases like AD<sup>8</sup>. This may be because many Korean people still believe that Oriental medicine is safer than Western medicine.

There are some limitations of our AD school evaluation.

YH Jang, et al

First, we did not consider each patient's disease severity, so we could not evaluate improvements in the severity of the disease after AD school. Second, we did not offer a tailored program for each age group, because a relatively wide range of ages (3 to 10 years) participated in the AD school. Third, our educational team, mainly composed of dermatologists, should have been composed of professionals from a greater variety of fields. Adequate educational programs are of great value when offered in cooperation with dermatologists as well as pediatricians, dieticians, psychologists, and nursing staff<sup>2</sup>. Fourth, the follow-up telephone survey had a low response rate, but we still believe that having this follow-up is valuable. Fifth, because AD school is held only once a year, it may be difficult to change the ingrained habits of families of children with AD. To solve these problems, we are planning to utilize online communication.

In conclusion, even though our AD school for children with AD and their family members is a short half-day program, it contributes to a comprehensive, family-engaged approach to the management of AD and is a helpful adjunct to conventional, stepwise AD treatment.

Our educational program creates an ongoing and comprehensive system for promoting family engagement and improving AD treatment. Therefore, such programs should be considered for integration into routine care.

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