
Evaluation of a group intervention for children with food allergy and their parents

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Background: Children with food allergy and their parents may experience substantial stress related to the risk of serious reactions and the demands of allergy management.

Objective: To evaluate a group intervention for children with food allergy and their parents designed to increase parent-perceived competence in coping with food allergy and to decrease the parent-perceived burden associated with food allergy.

Methods: Sixty-one children aged 5 to 7 years with food allergy and their parents attended 1 of 4 half-day workshops, with parent and child groups run concurrently. Parents completed self-report measures of perceived competence in coping with food allergy at 3 time points: preworkshop (within 8 weeks of the intervention), postworkshop (immediately after the intervention), and follow-up (4–8 weeks after the intervention). Parents completed a measure of burden associated with food allergy at preworkshop and follow-up. Parents and children also completed evaluations of the study intervention.

Results: Parent-perceived competence in coping with food allergy increased significantly from preworkshop to postworkshop and follow-up, and parent-perceived burden associated with food allergy decreased from preworkshop to follow-up. Parent and child evaluations of the workshop were favorable.

Conclusions: These findings provide preliminary support for the effectiveness and feasibility of a group intervention for children with food allergy and their parents and suggest the importance of controlled evaluations of group interventions in this population in the future.

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INTRODUCTION

Food allergy affects 1% to 2% of children and seems to be increasing in prevalence.^{1,2} Manifestations of an allergic reaction may include dermatologic, gastrointestinal, and respiratory symptoms and possible anaphylaxis and even fatality. Management of food allergy depends on strict allergen avoidance and ready availability of self-injectable epinephrine for emergency management. Avoidance of food allergens requires significant knowledge and vigilance and advanced planning for even routine events.

Given the demands associated with allergen avoidance and the potential for severe allergic reactions, children with food allergy and their parents may experience substantial stress. Children may experience anxiety about having a reaction or participating in food-related activities and significant limitations in normative social and school activities.^{3–5} Parents not only have the task of promoting their children's safety and well-being but also must manage their own anxiety and

stress. Studies^{6,7} examining the impact of food allergy on quality of life have found increased levels of parental distress and worry and family tension compared with normative and other disease samples. Parental beliefs may also affect child and family well-being. In other pediatric populations, parent-perceived competence and self-efficacy in managing a child's illness have been associated with adaptive family functioning, increased adherence, and decreased parent distress,^{8–10} whereas the parent-perceived burden of a child's illness has been associated with maternal psychological distress.¹¹

A group intervention may be particularly useful for supporting positive adaptation for children with food allergy and their parents, as families may experience feelings of isolation in dealing with food allergy. Groups for parents of children with medical conditions offer opportunities to obtain informational and emotional support from professionals and from other parents in similar situations.^{12–14} For children with medical conditions, group interventions provide opportunities for relating to peers who share similar circumstances.¹⁵

The primary aim of this study was to develop and evaluate a group intervention for children with food allergies and their parents. The intervention, a half-day workshop, was designed to support families in coping with the practical and emotional demands of childhood food allergy and to enhance children's connections with peers with food allergy. We expected that parents would demonstrate higher levels of perceived competence in supporting a child and family coping with food allergy immediately and 2 months after participation in the

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workshop than before the workshop. We also hypothesized that parents would report lower levels of burden associated with food allergy at follow-up than before the workshop.

METHODS

Procedure

Children aged 5 to 7 years with a diagnosis of food allergy who had visited their allergist in the past year were identified through the Allergy Program at Children's Hospital Boston. Non-English-speaking children and those with a severe developmental disability that would preclude active participation in the workshop were excluded. Eight weeks before each workshop, eligible families were contacted via a letter sent to the home. An effort was made to recruit both of the child's parents for participation.

Interested families were asked to complete the following assessments: (1) *Preworkshop*—In the 8 weeks before participation in the study workshop (mean [SD], 3.4 [2.4] weeks), parents attended an in-person research visit. Written parent consent and child assent were obtained in accordance with Children's Hospital Boston institutional review board guidelines. Parents completed self-report questionnaires. (2) *Postworkshop*—Immediately after participation in the workshop, parents completed a subset of the study questionnaires. Parents and children also completed evaluations of the workshop. (3) *Follow-up*—Follow-up questionnaires were mailed to parents, to be returned in a postage-paid envelope. These measures were completed approximately 4 to 8 weeks after the workshop (mean [SD], 5.4 [1.6] weeks).

Measures

Medical information. Child medical history related to food allergy was evaluated via a brief parent questionnaire administered at preworkshop. Anaphylaxis was defined as either 2 or more body systems involved in an allergic reaction (eg, skin plus respiratory, gastrointestinal, or cardiovascular) or shock occurred (ie, low blood pressure, with symptoms such as fainting and collapse). At postworkshop and follow-up, parents completed a questionnaire about any changes in the child's food allergy-related medical history.

Resource use. Parents completed a brief self-report measure about other resources they have used to cope with and manage their children's food allergies, including membership in national organizations, online resources (eg, Web sites and listservs), and support groups.

Parent-perceived competence. Parents completed the Family Coping With Food Allergy Questionnaire (FCFAQ) at preworkshop, postworkshop, and follow-up. The FCFAQ is an 18-item questionnaire developed by us to evaluate parent-perceived competence in supporting a family coping with food allergy. Items reflect topics that were addressed during the study workshop (eg, teaching my child age-appropriate allergy management skills, problem solving with my child about how to handle difficult situations, finding ways to control anxiety about my child's allergy, and teaching other adults caring for my child about food allergy safety). Parents

rate items on a 5-point scale, from "not at all competent" to "very competent." Questionnaire items are summed and divided by the total number of items to create a total score, which can range from 1 to 5, with higher scores indicating greater competence. The FCFAQ demonstrated strong internal consistency reliability (Cronbach $\alpha = 0.91$).

Parent-perceived burden. Parents completed the Food Allergy Quality of Life—Parental Burden Questionnaire (FAQL-PB)⁸ at preworkshop and follow-up. The FAQL-PB is a 17-item food allergy-specific measure of parental burden associated with having a child with food allergy. Items address the impact of food allergy on domains such as family/social activities, school, meal preparation, health concerns, and emotional issues. Parents rate items on a 7-point scale, from "not limited/troubled" to "extremely limited/troubled." Item responses are summed and divided by the total number of items to create a total score, which can range from 0 to 6, with higher scores indicating greater burden. The FAQL-PB has demonstrated strong internal validity and good construct and criterion-related validity.¹⁶ The Cronbach α coefficient for the FAQL-PB in this study was 0.91.

Parent and child workshop evaluations. At postworkshop, parents were asked to rate how strongly they agreed or disagreed that program objectives were met and that components of the program were useful. Ratings were made on a 5-point scale from "strongly disagree" to "strongly agree." Parents were also asked to respond to open-ended questions about aspects of the workshop that they found helpful or would like to see changed.

At postworkshop, children were asked whether they had fun during the workshop and enjoyed meeting other children with food allergies. Ratings were made by filling in 1 of 3 different-sized circles corresponding to response options (ie, "no," "a little bit," and "a lot"). Children were also asked open-ended questions about what they learned and their favorite parts of the workshop.

Intervention

Four 3.5-hour workshops took place between March and November 2006. Fourteen to 17 families attended each workshop. Child and parent groups were run concurrently.

Parent groups were led by a pediatric psychologist and either a pediatric allergist or a pediatric nurse practitioner. The format for the parent groups consisted of a presentation by the pediatric psychologist, followed by group discussion. Presentation topics included preparing children for food allergy management tasks, helping children cope with challenges related to food allergy (eg, problem solving, managing anxiety, and dealing with teasing), talking to children about safety and risks, educating peers about food allergies, managing parental stress, supporting siblings, and educating other adults about food allergy.

Child groups were led by child life specialists. Goals included providing a safe environment for children to express feelings about food allergy, enhancing connections to other children with food allergies, and increasing children's confi-

dence in age-appropriate allergy management skills. Activities included games aimed at helping children express feelings related to food allergy, collaborative discussions about food allergy management, art projects, children's books about food allergy, and supervised medical play (toy doctors' kits, EpiPen trainers, toy ambulances, and toy food and shopping carts). Medical play was intended to give children a hands-on way to explore medical and food items and increase their sense of control and mastery and to alert facilitators to possible worries or misconceptions. A joint parent-child activity involved watching a brief video, *Alexander the Elephant Who Couldn't Eat Peanuts*.

Statistical Analyses

Because most participants were mothers, only maternal data were used in study analyses ($n = 59$), except for analyses comparing mother and father reports (for 12 families). The following variables were dichotomized owing to skewed distributions: mother's education level, father's education level, time since diagnosis, and number of food allergies.

To evaluate change on outcome measures, change scores were calculated for each participant by subtracting the preworkshop competence score from the postworkshop competence score, the preworkshop competence score from the follow-up competence score, and the follow-up burden score from the preworkshop burden score. Higher change scores reflect improved functioning (ie, increased competence and decreased burden). One-sample t tests were used to determine whether the means of the change scores were centered at 0. Exploratory analyses (Pearson correlation coefficients and independent-samples t tests) were used to examine demographic and medical correlates of change on competence and burden. Paired-sample t tests were used to assess for differences between maternal and paternal preworkshop scores and change scores on outcome measures. All P values are 2-sided and are considered statistically significant at $P < .05$.

RESULTS

Participants

Of 380 families who were contacted to participate in 1 of the 4 workshops, 65 agreed to participate and completed preworkshop measures, yielding an overall participation rate of 17.1%. Four of the 65 families that completed preworkshop measures did not attend the study intervention owing to scheduling conflicts or illness. Therefore, the study sample included 61 children and their parents. In 46 cases (75%) only the mother participated, in 12 cases (20%) both the mother and father participated, in 2 cases (3%) only the father participated, and in 1 case (2%) 2 mothers participated. The demographic and medical characteristics of the participants are summarized in Table 1.

Preliminary Analyses

Differences between completers and noncompleters. All 59 mothers who participated in the study intervention completed study measures at postworkshop. Forty-nine mothers (83%)

Table 1. Demographic and Medical Characteristics of the Study Participants

Characteristic	Value
Child's age, mean (SD), y	6.4 (0.7)
Child's sex female, No. (%)	34 (56)
Child's race, No. (%)	
White	50 (82)
African American	1 (2)
Asian	8 (13)
Other	2 (3)
Child's ethnicity, No. (%)	
Hispanic	2 (3)
Not Hispanic	59 (97)
Mother's education level, No. (%)	
Less than college degree	8 (13)
College degree	20 (33)
Graduate degree	33 (54)
Father's education level, No. (%)	
Less than college degree	11 (18)
College degree	21 (34)
Graduate degree	29 (48)
Food allergies, mean (SD), No.	5.3 (3.8)
Specific food allergies, No. (%)	
Peanut	58 (95)
Tree nut	45 (74)
Egg	40 (66)
Milk	34 (56)
Soy	13 (21)
Shellfish	21 (34)
Fish	6 (10)
Wheat	11 (18)
History of anaphylaxis, No. (%)	44 (72)
Time since diagnosis, mean (SD), y	5.4 (1.4)
Other allergic disease, No. (%)	
Atopic dermatitis	36 (59)
Asthma	11 (18)
Support resources used in past month, No. (%)	
National organizations (eg, FAAN, AAFA)	45 (74)
Food allergy Web sites	41 (67)
Food allergy listservs	11 (18)
Parent support groups	8 (13)

Abbreviations: AAFA, Asthma and Allergy Foundation of America; FAAN, Food Allergy and Anaphylaxis Network.

completed study measures at follow-up. No significant differences were detected between families who did and did not complete follow-up measures based on demographic characteristics, medical characteristics, or scores on outcome measures (competence and burden) at preworkshop.

Differences between workshop groups. There was a significant difference in child age based on which of the 4 half-day workshops was attended ($F_{3,55} = 3.39$, $P = .02$), with children attending the third workshop being younger. There was a significant difference in the number of food allergies based on the workshop attended ($\chi^2_{3,59} = 13.26$, $P = .004$), with children in the fourth workshop having fewer food allergies. No differences were found in preworkshop burden or competence scores based on which workshop was attended.

Therefore, data for participants in the 4 workshops were combined for study analyses.

Changes in child medical variables across time. There were no changes reported in child allergy-related medical characteristics from preworkshop to postworkshop or follow-up (eg, diagnosis of a new allergy or an episode of anaphylaxis).

Descriptive analyses of outcome measures. Mean scores on the parent-reported measures of competence and burden across the study time points are found in Table 2. The mean competence score at preworkshop was 3.8 on a scale from 1 to 5 (3 = somewhat competent and 4 = pretty competent). The mean burden score at preworkshop was 2.4 on a scale from 0 to 6 (2 = somewhat limited/troubled and 3 = moderately limited/troubled).

Relationships between demographic and medical characteristics and outcome measures at preworkshop. Lower levels of maternal and paternal education were associated with higher levels of burden at preworkshop (Table 3). None of the demographic or medical characteristics were associated with competence scores at preworkshop.

Evaluation of Changes in Outcome Measures

One-sample *t* tests indicated significant increases in parent-perceived competence from preworkshop to postworkshop ($t_{58} = 5.90, P < .001$) and from preworkshop to follow-up ($t_{48} = 5.43, P < .001$) (Table 2). Seventy-eight percent of participants showed some improvement in competence scores from preworkshop to postworkshop, and 74% showed improvement from preworkshop to follow-up. There was also a significant decrease in parent-perceived burden from preworkshop to follow-up ($t_{47} = 3.37, P = .002$), with 63% of participants demonstrating a decrease in burden scores.

Larger increases in parent perceptions of competence from preworkshop to postworkshop were found for parents of boys vs parents of girls and for families with lower levels of paternal education (college degree or less) (Table 3). None of the demographic or medical characteristics were associated with change in burden scores.

Evaluation of Mother-Father Differences in Perceived Competence and Burden

For the 12 families in which both a mother and a father participated, no significant differences were detected between mother and father preworkshop competence or burden scores or change scores on these measures.

Workshop Evaluations

Parent ratings of the usefulness of presentation materials were high (mean, 4.2 on a scale from 1 to 5, where 5 indicates strong agreement that topics were useful). Ninety-six percent of parents agreed or strongly agreed that they would be interested in attending another workshop. Seventy-six percent of parents identified the parent discussion and learning how others cope with food allergies to be the most useful aspect of the workshop.

Most children reported enjoying participating in the workshop “a lot” (88%) and meeting other kids with food allergies “a lot” (78%). On open-ended questions about their favorite part of the workshop, 62% of children indicated medical play. When asked about what they learned during the workshop, the most frequent responses were ways to stay safe (25%) and that other children have food allergies too (15%) (eg, “Having food allergies doesn’t mean you’re different, because lots of kids have them”).

DISCUSSION

This study represents the first examination of a group intervention for children with food allergy and their parents. Study findings provide preliminary support for the effectiveness of a half-day workshop in increasing parent-perceived competence in coping with food allergy and decreasing perceived burden associated with food allergy. Examination of factors associated with changes in parent-perceived competence and burden after participation in the study intervention did not reveal differences based on medical factors such as the child’s number of food allergies or history of anaphylaxis. This finding suggests that participation in the workshops benefitted families regardless of the “severity” of the child’s allergy.

Larger increases in parent perceptions of competence from preworkshop to postworkshop were found for parents of boys than of girls, although the reason for this difference is unclear. Larger increases in perceived competence were also found for families with lower levels of paternal education. It is possible that parents with lower levels of education may not have had as much access to support resources before the workshop. A post hoc examination of the association between parent resource use before the workshop (eg, involvement in food allergy organizations, participation in support groups, or use of online resources) and changes in competence and burden, however, did not reveal any significant relationships.

Table 2. Outcome Measure Scores at Preworkshop, Postworkshop, and Follow-up^a

Measure	Preworkshop	Postworkshop	Follow-up
Parent competence	3.8 (0.6) [59]	4.1 (0.4) [59] ^b	4.2 (0.5) [49] ^b
Parent burden	2.4 (0.9) [59]	NA	2.0 (0.9) [48] ^b

Abbreviation: NA, not applicable.

^a Data are given as mean (SD) [No.]. Competence mean scores are based on a possible range of 1 (not at all competent) to 5 (very competent); burden scores are based on a possible range of 0 (not limited/troubled) to 6 (extremely limited/troubled).

^b Significant change from preworkshop at $P < .05$.

Table 3. Demographic and Medical Factors Associated With Outcome Measures and Change Scores on Outcome Measures

Parent or child characteristic	Mean (SD)/P value ^a				
	Preworkshop competence	Preworkshop burden	Pre/post competence change ^b	Pre/follow-up competence change ^c	Pre/follow-up burden change ^d
Child age	0.04%/.76	−0.10%/.47	0.05%/.70	0.07%/.61	0.10%/.50
Time since diagnosis	−0.05%/.72	−0.05%/.68	−0.01%/.96	−0.11%/.45	−0.27%/.07
Child sex	.16	.18	.03	.61	.95
M	3.6 (0.6)	2.6 (0.9)	0.5 (0.4) ^f	0.4 (0.5)	0.3 (0.7)
F	3.8 (0.6)	2.2 (1.0)	0.2 (0.4) ^f	0.3 (0.5)	0.3 (0.6)
Mother's level of education	.91	.04	.75	.36	.95
College or less	3.8 (0.6)	2.7 (1.0) ^f	0.3 (0.4)	0.3 (0.4)	0.3 (0.6)
Graduate school	3.7 (0.6)	2.1 (0.8) ^f	0.4 (0.5)	0.4 (0.5)	0.3 (0.7)
Father's level of education	.16	.002 ^f	.01 ^f	.43	.96
College or less	3.6 (0.6)	2.7 (1.0) ^f	0.5 (0.4) ^f	0.4 (0.5)	0.3 (0.7)
Graduate school	3.9 (0.6)	2.0 (0.8) ^f	0.2 (0.4) ^f	0.3 (0.4)	0.3 (0.5)
No. of food allergies	.76	.31	.86	.60	.38
≤2	3.7 (0.6)	2.2 (1.1)	0.3 (0.3)	0.4 (0.4)	0.4 (0.5)
≥3	3.8 (0.6)	2.5 (0.9)	0.3 (0.5)	0.3 (0.5)	0.3 (0.7)
History of anaphylaxis	.31	.48	.61	.85	.82
Yes	3.7 (0.6)	2.4 (0.9)	0.4 (0.5)	0.4 (0.5)	0.3 (0.7)
No	3.9 (0.6)	2.2 (1.1)	0.3 (0.4)	0.4 (0.4)	0.4 (0.7)

^a Competence mean scores are based on a possible range of 1 (not at all competent) to 5 (very competent); burden mean scores are based on a possible range of 0 (not limited/troubled) to 6 (extremely limited/troubled).

^b Calculated for each participant by subtracting the preworkshop competence score from the postworkshop competence score

^c Calculated for each participant by subtracting the preworkshop competence score from the follow-up competence score

^d Calculated for each participant by subtracting the follow-up burden score from the preworkshop burden score

^e Pearson correlation.

^f Values indicate significant associations at $P < .05$.

In addition, parents and children rated the program favorably. Most parents stated that they would be interested in attending another workshop. Opportunities to network with other parents of children with food allergy were particularly valued. Children reported enjoying meeting other children with food allergy. The children's strong positive response to medical play suggests that this is an engaging activity for children aged 5 to 7 years. Although formal data on medical play were not collected, the child group facilitators indicated that children particularly gravitated toward use of the EpiPen trainers (eg, pretending to administer the EpiPen to group leaders or to dolls who had "eaten" food they were allergic to). Most children were very accurate in their play (eg, knew to insert the EpiPen into the thigh and counted to 10 before removing it). For children who did not use medical equipment accurately, leaders gently explored and corrected misconceptions.

Several limitations of this study are important. First, because no control group was used, changes in parent-perceived competence and burden cannot be directly attributed to the study intervention. It is possible that other factors, such as the passage of time or familiarity with study questionnaires, may play some role in observed improvements on study measures. Furthermore, the study design does not allow for investigation of what specific components of the workshop may have contributed to observed changes on outcome measures. Fu-

ture studies would benefit from using a control group, such as a wait-list or possibly an "information-only" group, in which participants could be provided with written materials related to coping with childhood food allergy. In addition, although statistically significant changes were found on study outcome measures, it is unclear whether increases in parent-perceived competence and decreases in perceived burden are clinically significant or translate into meaningful differences in families' lives. Note, however, that positive parent and child evaluations of the workshop suggest perceived benefit for participants.

The demographic profile of this sample was skewed toward white, highly educated families. These results, therefore, may not generalize to other study populations. Even in this highly educated sample, lower levels of parent education were associated with higher ratings of burden associated with food allergy at preworkshop. It is possible that the nature of parent discussions might differ if workshops were held with more diverse groups of parents. One of the benefits of allotting significant time for group discussion during the workshops is the flexibility to address issues that are most pertinent for families in attendance.

Despite these limitations, to our knowledge, this study represents the first attempt to develop and empirically examine the benefits of a group intervention for children with food allergy and their parents. Study results, combined with our

experience in performing the study workshops, provide preliminary support for the effectiveness, feasibility, and acceptability of the study intervention. We believe that this brief intervention could be easily adapted by professionals in other institutions and settings.

These results suggest the importance of further efforts to develop and evaluate group interventions in this population. Future research could include development of a randomized controlled study of a multisession intervention, which would allow for greater attention to issues that were frequent topics in parent discussions (eg, managing allergies at school, managing anxiety, experiences with the EpiPen, and strategies for dining out and traveling). Group interventions for older children and adolescents could provide opportunities for instruction in coping skills relevant to living with food allergy (eg, stress management, assertiveness skills, and problem solving) and collection of child-reported data to evaluate intervention effectiveness.

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