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Including young children in their food allergy care: A pilot study

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ABSTRACT

Rationale: Food allergy education is often directed toward adult caregivers. However, once children go to school, they must participate in their food allergy care to remain safe. The purpose of this study was to assess food allergy knowledge and test an educational intervention targeted toward the child. We hypothesized that child-based teaching will be equal in safety and knowledge outcomes compared with standard parental education.

Methods: Twenty-nine children between the ages of 5–11 years and their caregivers were enrolled. Child subjects completed a food allergy knowledge questionnaire. Each caregiver/child dyad was randomized to receive parent-targeted education (control) or child-targeted education (treatment) and was given an educational booklet. Six weeks later, the child completed the same knowledge questionnaire. At the end of the semester, the caregivers were asked to report allergic reactions that occurred at school.

Results: There were no differences between the groups on age or type of school attended. All the subjects demonstrated a statistically significant increase in allergy knowledge from time 1 (completion of survey 1) to time 2 (completion of survey 2) ($t = -6.301$; $p < 0.001$). There was no difference in knowledge between the groups at time 2 ($t = -1.782$; $p = 0.089$) and no difference between the groups on allergic reactions during the study period ($\chi^2 = 2.33$; $p = 0.13$).

Conclusion: This pilot study, with a small sample size, demonstrated that child-based education was comparable with education targeted toward caregivers, with no difference in allergic events. Children can take an active role in education and management of their food allergies at school.

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Food allergies are a common and increasing problem, and affect 5.6 million children in the United States.¹ A food allergic reaction can occur anywhere, but 16–18% of children reported a reaction at school.² Most reactions that occur in school occur in the classroom (~80%) and lunchroom (~15%), other locations include field trips, playgrounds, and bus transportation.^{2,3} Because a reaction can occur anywhere, children must always be diligent about their food allergies. Fear related to the management of food allergies can affect school attendance. One-third of respondents in a U.S. study reported a significant impact on their child's

school attendance, and 10% of the study group home schooled because of food allergies.⁴ Children and adolescents who are food allergic report being harassed or bullied due to their food allergies.

In one sample, 31.5% of children 8–17 years of age reported being bullying due to their food allergy.⁵ Food allergies can have a detrimental effect on quality of life, and a large amount of stress can be placed on the child to manage food allergies while at school.⁴ Empowerment of the child to manage food allergies can come from proper education. However, education is often directed to the parent or another caregiver. It is not clear how much information is disseminated to the child, especially a young child, nor how much is subsequently retained. Education for the management of food allergies includes avoidance of the inciting food, emergency preparedness, and use of epinephrine autoinjector when a reaction occurs. Education of not only the parent but the child can help lessen the burden of going to school with a food allergy as well as to empower the child to manage his or her food allergy.

In 2013, Simons et al.⁶ assessed caregivers' perceptions of the earliest age at which children could take care of their own food allergies. They found that caregivers expected children ages 6–8 years to be responsible for anaphylaxis recognition and ages 6–11 years to be responsible for epinephrine autoinjector usage. Pediatric allergists, however, did not expect child responsibility of anaphylactic recognition until ages

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9–11 years and self-anaphylaxis treatment at ages 9–14 years.⁶ If parents believe that their children are capable but children are not being taught the information, this may present a missed opportunity for younger school-aged children to participate in their own allergy management. This study tested an educational intervention developed for young children against the standard educational practice that targets the parent or caregiver. We hypothesized that child-based teaching will be equal in safety and knowledge outcomes compared with standard parental education.

METHODS

This pilot study was approved by the institutional review board of Children’s Mercy Hospital (IRB 17030229). The study was conducted via paper and online survey. Subjects were recruited from a convenience sample of patients scheduled in the allergy clinic during summer break. Children were included if they were ages 5–11 years, had been diagnosed with a food allergy, and attended school outside of the home. For this pilot study, only English-speaking children and parents were included. Exclusion criteria were home-schooled children, and those with developmental delays.

All child subjects completed a food allergy knowledge questionnaire at baseline while in the clinic, with the questionnaire being read to the child if the child could not read. Each caregiver/child dyad was randomized to receive parent-targeted education (control) or child-targeted education (treatment), and all the participants were given an educational interactive food allergy booklet. This booklet was created by the author (J.S.) in collaboration with allergy clinic staff for the patients to review at home. There were no scripted instructions given on how often to review the booklet, but the families were encouraged to complete interactive activities of the booklet at home. These activities included writing the child’s allergens, reading sample food labels, and selecting photographs of being safe at school. Six weeks later, the child completed the same questionnaire electronically at home, with questions read by the parent. Training on the use of an epinephrine injector was given to the child (treatment) and to the parent (control) by

using the teach-back method. Children in the target group also received a pictorial handout on how to use their epinephrine injector device. The pictorial handout was specifically designed for this study by the author (J.S.), in collaboration with the allergy clinic staff. This handout was created with the same characters and design as the educational booklet to be used in conjunction after study completion. At the end of the school semester, the caregivers were asked to report allergic reactions that occurred at school.

The questionnaire was created by the author (J.S.) based on current literature and clinical expertise. It was reviewed by the institution’s family advisory board and teen patients with food allergies. The same questionnaire was used for all the subjects regardless of age. For some children without the ability to read, the study personnel read the questionnaire to the child. The questionnaire scored a Flesch reading ease of 83.8 of 100 and a Flesch-Kincaid grade level of 4.3. Sample topics on the questionnaire included identifying their food allergy, listing parts of the body that could be affected during a reaction, and reporting the steps of using an epinephrine autoinjector. There were situational questions that asked the child what he or she would do if given food by someone other than your caregiver and what he or she would do if a reaction started to occur. Also, questions with regard to feeling scared about attending school or being bullied were asked. The questionnaire contained a total of 12 questions, and a higher score indicated more knowledge. Demographic and outcome measures were reported by using descriptive statistics. The groups were compared by dependent variables by using t-tests, the Mann-Whitney U test, or the χ^2 test.

RESULTS

Twenty-nine children between the ages of 5 and 11 years, and their caregivers were enrolled. The mean age of the entire sample was 7.31 years, 7.40 years for the treatment group, and 7.21 years for the control group. Twenty-four of the children attended public school and five attended private school. Children were in grades kindergarten through fifth grade. There were 14 children in the control group and 15 children in the

Table 1 Group differences

Measure	Treatment Group	Control Group	t	χ^2	U	p
Age (median, IQR*)	8.0, 6.0–9.0	7.5, 5.0–9.0			99.5	0.81
% Public School	93	71		2.44		0.12
Knowledge – 1 (mean)	5.87	5.5	0.35			0.73
Knowledge – 2 (mean)	9.36	7.92	1.78			0.89
% School Reaction (n)	0	28 (2)		2.33		0.13

*IQR = Interquartile range.

treatment group. Peanut was the most frequently reported allergen ($n = 15$), and three children did not know their food allergen at baseline. Nine children could not identify a body part affected during a reaction. Before the intervention, the children did most poorly on the items that measured knowledge of body systems affected by an allergic reaction and use of the epinephrine injector.

On the second questionnaire, all the children were able to identify their food allergen and had the ability to identify at least one body part affected by a reaction compared with nine of the children (30%) before the intervention. The mean baseline knowledge score was 5.5 in the control group and 5.8 in the treatment group. The mean post knowledge scores (scores tabulated on 2nd survey, post intervention) were 7.9 in the controls versus 9.3 in the treatment group. Although not statistically significant, both groups showed an improvement in knowledge score. In addition, there was an improvement on how to use an epinephrine injector among all the participants. On the first questionnaire, 15 children were unable to identify any steps for use of an epinephrine injector. On the second questionnaire, this number decreased to four.

Of all the respondents at baseline, 29% reported being scared or nervous about going to school. This increased to 56% in the second survey. Seventeen percent reported, at baseline, being bullied, which increased to 30% in the second survey. At the end of the semester, there were only two reported reactions at school and both occurred in the control group. Table 1.

DISCUSSION

Although this study provided novel findings on the ability of school-aged children to be active in their food allergy management, limitations remain. This study was a small pilot study and, therefore, limited demographic information was collected. We recognize that other factors may contribute to the children's knowledge or lack thereof, including caregiver educational level, history of reactions, severity of those reactions, previous education that was given to the child, and the child's educational level. A larger study could address these factors. We also recognized that the second questionnaire was completed at home and there could have been caregiver involvement when answering the questions; however, we believed that home completion of the questionnaire was the most feasible way to maintain participation in the survey. Subject attrition may also account for some unmeasured nonresponse bias. We also recognized that feelings of being scared to attend school and reports of bullying increased from the first to the second questionnaire. These increases could potentially be due to situ-

ational awareness not previously recognized and attrition of six subjects.

This pilot study suggested that children at a younger age than previously thought can take an active role in the education and management of their food allergies. The researchers demonstrated that young children can be involved to some degree with their health care and integration of child-based education into clinical practice as young as age 5 years, without serious safety concerns. The amount of involvement may be dependent on the child's level of understanding, but we should not assume that younger children do not have the ability to learn about their disease state. As practitioners, it is important that the child is learning correct information and that this leads to more engagement in self-care as the child ages. A small pilot study in Australia also found that child's knowledge of his or her food allergy and ability to communicate the need for help may help him or her stay safe at school and are vital in the transition to school.⁷

CONCLUSION

As a result of this study, patient teaching at this organization has expanded to include the young school-aged child, with education focusing on the recognition of a reaction and epinephrine injector training. Although complete independence in self-administration of epinephrine may not always be expected, knowledge in this area is paramount. Knowledge of food allergies and self-management could potentially lead to increased quality of life, a concept that could be addressed in a larger study in the future. Overall, these findings highlight the need to involve and teach our younger population about management of their food allergies.

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