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ORIGINAL ARTICLE

Evaluation of an educational programme with workshops for families of children with food allergies



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KEYWORDS

Patient education; Food allergy; Anaphylaxis; Patient engagement; Quality of life; Patient empowerment; Health education

Abstract

Background: When a child is diagnosed with a food allergy, prevention and patient education are the key interventions for maintaining the child's health and quality of life and that of his or her whole family. However, health education activities for the families of children with food allergies are very limited, and most of these activities have not been evaluated. Therefore, the objectives of the present study were to develop an educational programme, to empower its participants through workshops, and to evaluate its results.

Methods: Several types of educational materials were created specifically for the programme, called "Proyecto CESA" ("STOP-FAR Project: Stop Food-Induced Allergic Reactions"). The programme was carried out in seven Spanish cities and was attended by parents and caregivers. The workshops were led by physicians specialising in allergies and by expert patients. Afterwards, participant learning and satisfaction were evaluated based on questionnaires that were completed both before and after the workshops.

Results: A significant improvement was observed in 29 items out of 40 (McNemar's test). Participant satisfaction with the programme was also very high: 90% rated the course between 8 and 10 points out of a possible 10 (41% rated it as a 10).

Conclusion: The face-to-face workshops, which included utilisation of educational materials, had positive results in terms of learning as well as in levels of satisfaction in participating families.

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Introduction

Food allergy is one of the most common chronic diseases in childhood, affecting 4–8% children.^{1–3} In certain cases, its symptoms are serious and even life-threatening, ^{1,4,5} causing a noticeable decrease in quality of life (QoL) as it relates to health.⁶ However, with education and appropriate care, food allergy-related morbidity in children is generally low, and mortality is relatively rare.⁷

Although the principal treatment for food allergy still consists in avoiding the allergen, oral desensitisation may be recommended in certain cases. 8-10 Following diagnosis, parents and children often experience a period of adaptation and psychosocial reckoning. 11 In particular, the whole family's activities are limited because of the child with food allergy. Additionally, Sicherer et al. found that parents' perceptions of their family's general health diminished if they had a child with food allergy when compared with parents of children in the general population. 12

To avoid allergic reactions, parents and caregivers must have information about certain tools to manage the condition. Therefore, when a child is diagnosed with food allergy, patient education is a key intervention for maintaining the health and QoL of the child and of his or her whole family. 1,14

The objective of education about food allergies is to train parents and children to manage the condition. This entails giving them the knowledge and skills needed both to prevent reactions and to know how to treat these reactions in the event that they do occur. Although school-aged children are able to learn self-management skills for their allergies, they need their parents to share responsibility for managing the condition.

The principal frustrations that parents experience include a lack of social comprehension, inconsistent medical information, and inadequate product labelling.¹²

Patient education for the families of children with food allergies should be offered as a standard part of treatment. Nevertheless, for various reasons, patient education is often unavailable or insufficient. ¹⁶⁻¹⁸ In reality, health education programmes are either very limited or non-existent in the majority of the health centres where these patients are seen. ¹⁹

Greenhawt et al. ²⁰ remind us that as allergy specialists, our responsibilities must also include preparing families to face the difficult task of raising a child with a food allergy. In the school context, it is also necessary to promote collaboration with the non-allergic community to better keep allergic children safe while at the same time imposing the lowest number of restrictions possible.

Families occasionally turn to patient organisations or perform Internet searches in order to meet their needs for information and support. Thus, in many cases, information is acquired in a haphazard way or without the patients having established clear goals. However, the materials used in educational activities are rarely evaluated by professionals. ^{17,21} The objectives of the present study were to develop an educational programme, to empower its participants through workshops, and to evaluate its results.

Materials and methods

Study tool

This educational programme is part of a programme known as "Proyecto CESA" ("STOP-FAR Project: Stop Food-Induced Allergic Reactions"). CESA is a Spanish acronym representing four words: Know, Avoid, Symptoms, and Epinephrine. Workshops were held in seven major Spanish cities (Madrid, Barcelona, Valencia, La Coruña, Murcia, Granada, and Málaga) over two consecutive weekends in November 2012.

The project team was composed of researchers, health professionals, nurses, doctors specialising in allergy treatment, and expert parents of patients (parents of allergic children) who were members of the main Spanish patient associations: AEPNAA, Immunitas Vera, and Elikalte. The team, in keeping with the Participative Medicine model,²² shared in decision-making,²³ held a number of meetings to design the study, developed the educational materials and questionnaires used, and discussed and evaluated the results.

Educational materials

A variety of materials was created specifically for this project, including seven educational videos and additional video support for parents and caregivers, which were developed by physicians specialising in allergies and by expert parents of patients, using the Participative Medicine methodology. These materials were based on a bibliographic review and on expert opinions in allergy and education. All materials used were the same in every city and covered different topics, from clinical aspects to general management of the condition (labelling or school, and so on) (see Table 1). All the items in the evaluation questionnaires were explicitly addressed in the materials.

In addition, an illustrated story was created for children to explain the most important concepts related to food allergies using age-appropriate language. Four storytelling videos and other educational activities were also developed for

Table 1 Units	s of the educational programme.
	Pre-questionnaire
Workshop 1 (2 hours)	Unit 1: Allergy Specialists Workshop • What is food allergy? • Symptoms • Treatment
Workshop 2 (2 hours)	 Unit 2: Expert Parents of Patients Workshop How to avoid allergens The most common allergenic foods Regulations and labelling Balanced nutrition, eating safely, and kitchen management Living with allergies in the family and at school, and relationships with healthcare professionals Post-questionnaire

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