



# Information and support from dietary consultation for mothers of children with food allergies

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## ABSTRACT

**Background:** Professional dietetic input is essential to ensure that children with diagnosed food allergies have an individualized avoidance plan and nutritionally adequate diet. However, it is not clear what dietary information and support parents require.

**Objective:** To explore what information and support parents of children with food allergies require from a dietary consultation.

**Methods:** Focus groups were conducted with 17 mothers who attend an allergy center for dietary advice for their food allergic child. A number of issues around food allergy dietary advice needs were explored and analyzed using thematic analysis.

**Results:** Six themes were identified. The mothers described how they sought to protect their child from harm, to maintain normality for their child, and to promote child independence. They described needing to become an expert in their child's food allergy and fight their corner when needed. The dietitian supported their needs by ensuring their child's diet was safe and nutritionally adequate and giving information and support to help them provide a normal life for their child. Dietitians also taught mothers about food allergy and provided advocacy and emotional support.

**Conclusion:** Mothers of children with food allergies want to understand how to provide a nutritionally adequate, allergen-safe diet while maintaining a normal life. Hence, mothers value a range of support from dietitians, including monitoring their child's health and providing information, practical advice and support, and emotional support.

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## Introduction

The long-term management of food allergy involves dietary elimination of the relevant food(s) and the treatment of any reactions that occur because of unintentional exposure. Recently published guidelines from the United States, the United Kingdom, Europe, and the World Allergy Organization<sup>1–4</sup> all highlight the complexities of maintaining an elimination diet and the potential long-term risks for a patient's nutritional status and quality of life. Providing patients with detailed, individualized dietary management advice and monitoring is therefore seen as a key component of food allergy care.<sup>1,2,4–6</sup>

It is clear that dietitians have an important role in supporting parents in the long-term management of food allergy. In addition to

assessing and diagnosing nutritional problems, dietitians are also responsible for formulating and implementing nutritional and dietetic interventions and monitoring and evaluating the effect of such interventions on a range of relevant outcomes.<sup>7</sup> Where food allergy is concerned, this includes providing individualized advice and education about how to manage an elimination diet and monitoring the effect on a range of outcomes, including nutrition, growth, and quality of life.

Studies exploring parents' information needs with regard to food allergies have identified a strong need for advice on managing elimination diets.<sup>8–10</sup> Although these studies do not focus in detail on the dietary aspects of parents' information needs, they indicate that parents are concerned about the effect of food allergy on the growth and nutritional status of their child. They also suggest that parents need advice on a range of issues related to allergen avoidance and on how to provide their food allergic child with a healthy diet.<sup>8</sup> More in-depth study of the specific information and support parents require and value from a dietary consultation is therefore required. This can help us to understand how best to

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support the parents of children with food allergies and may also have implications for the training and education of dietitians. Hence, this study aimed to explore what information and support mothers of children with food allergies require and value from a dietary consultation.

## Methods

### Sample and Recruitment

Participants were recruited using purposive sampling<sup>11</sup>; parents of children with a diagnosis of food allergy were invited to take part, and the aim was to sample a range of experience (eg, according to the type and number of food allergies, age of child, and length of time with food allergy). Potential participants were sent an invitation letter and information sheet and returned a reply slip and completed consent form if they wished to take part. Participants were telephoned to arrange a convenient time and location for the focus group. Participants' travel expenses were refunded, and they were given a £10 gift voucher to thank them for their time. The aim was to have 6 to 8 participants in each focus group to ensure that a range of views and experiences were represented and that all participants were given an opportunity to discuss their experience in sufficient depth.<sup>12</sup>

### Procedure

Focus groups were conducted at local venues (community center, hotel, and allergy center) and refreshments provided. They were facilitated by one of the authors (H.M.), who has conducted qualitative food allergy research but does not have expert knowledge on dietary advice. Two observers (J.G. and G.G.) were responsible for taking notes of the discussions.

Before commencing the focus group session, its purpose was recapped (to find out more about the information needs during a dietary consultation of mothers of children with food allergy) and the freedom to withdraw emphasized. A topic guide was used to guide the discussion (Table 1); however, priority was given to interaction among the participants. Ethical approval was granted by the Southampton and South East Hampshire National Health

Service Research Ethics Committee. Data were stored in accordance with the Data Protection Act (1998).

### Statistical Analysis

Audio recordings were transcribed verbatim and field notes added. The transcripts were then imported into NVIVO 8 (QSR International, Melbourne, Australia) for thematic analysis according to the following steps: (1) becoming familiar with the data, (2) generating initial (empirical) codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the final report.<sup>13</sup> The data were constantly revisited and codes compared across the data to ensure their consistent use. Codes and emergent themes were developed and refined throughout analysis (paying attention to commonality, difference, and relationship) working toward a comprehensive analysis of the whole.<sup>14</sup>

## Results

### Characteristics of Participants and Their Children

Participants were divided into 3 focus groups, consisting of 4 to 7 participants each (N = 17, who had a total of 19 children with food allergy), with sessions lasting between 1 hour 20 minutes and 1 hour 40 minutes. Although both parents were invited to participate, only mothers responded. A few participants had met before (because their children were at the same school). The sample represented a range of experience and was cared for by a number of dietitians (Table 2). All had received at least one consultation with a dietitian about their child's food allergy.

### Themes

Six themes that related to how the dietitians supported mothers in their role as caregivers for a child with food allergy were identified (see Table 3 for a summary and related quotations).

#### *Helps Me to Protect My Child and Keep Them Healthy*

It was important to mothers to protect their child, and they used various strategies to ensure their child did not ingest food allergens

**Table 1**

Topic guide used to guide the discussion during the focus groups

Knowledge of managing food allergy
How do you manage your child's food allergy?
Are you clear about which foods should be avoided? <i>If not, what are you not clear about? If so, how do you know?</i>
Are you clear about any emergency medicine that you may need to use? <i>If not, what are you not clear about? If so, how do you know?</i>
Which questions about foods does your child regularly ask you? <i>Do you feel able to answer these? Where did you find out the information to answer these questions?</i>
Are you concerned about any reactions/symptoms that your child may develop? <i>Why? What is your main concern?</i>
Are you concerned about your child not outgrowing the food allergy/intolerance? <i>Why? What information would you like about this?</i>
Managing food avoidance: Reading labels
What are you looking for when you read food labels?
How easy do you find it to read food labels? <i>If not easy, why not? If easy, why is it easy? What could be improved?</i>
Where did you find out about reading food labels?
Managing food avoidance: eating outside the home
What is your experience of eating away from home (eg, in restaurants or at children's parties)?
Do you experience any problems when eating away from home (eg, in restaurants or children's parties)? <i>If so, what?</i>
How you find sorting out the school dinners/lunch boxes? <i>If difficult, why? If easy, why? What does your child think of their lunch box?</i>
Managing food avoidance: going on holiday
Do you experience any problems when going on holiday?
<i>What kind of problems do you experience? What would make it easier?</i>
Effect of managing food avoidance
What is the most difficult aspect of adhering to a food avoidance regime? <i>What could be done to make this easier? Are there any benefits to managing food avoidance?</i>
Do you have any problems or difficulties at home regarding food avoidance? <i>Can you describe these?</i>
Impact of dietitian's advice
What advice did you receive on managing food avoidance?
Did you find the advice from the dietitian helpful and if so, in which way?
Is there anything else you would have liked to have known about?
Did the advice from the dietitian affect your quality of life in any way? <i>If so, how? Can you give me an example?</i>
Round-up
Do you have anything else that you feel is important that we haven't yet discussed?

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