ABSTRACT

Background: Professional dietetic input is essential to ensure children with diagnosed food allergies have an individualised 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 centre for dietary advice for their food allergic child. A number of issues around food allergy dietary advice needs were explored and analysed 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 their 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 by giving them 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, providing information, practical advice and support, and emotional support.

Keywords: Diet, nutrition, food allergy, qualitative
INTRODUCTION

The long-term management of food allergy involves dietary elimination of the relevant food(s) and the treatment of any reactions occurring due to accidental exposure. Recently published guidelines from the US, UK, Europe and World Allergy Organisation\textsuperscript{1-4} 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, individualised dietary management advice and monitoring is therefore seen as a key component of food allergy care\textsuperscript{1-4,7}.

Hence, 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 for monitoring and evaluating the impact of such interventions on a range of relevant outcomes\textsuperscript{8}. Where food allergy is concerned, this includes providing individualised advice and education about how to manage an elimination diet and monitoring the impact 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\textsuperscript{9-11}. Although these studies do not focus in detail on the dietary aspects of parents’ information needs, they do indicate that parents are concerned about the impact of food allergy on the growth and nutritional status of their child. They also suggest that parents need advice not only about a range of issues related to allergen avoidance and providing their food-allergic child with a healthy diet\textsuperscript{9}. 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 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; parents of children with a diagnosis of food allergy were invited to take part, and the aim was to sample a range of experience (e.g. 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 six to eight participants in each focus group, to ensure both that a range of views/experiences were represented and that all participants were given an opportunity to discuss their experience in sufficient depth.

Procedure

Focus groups were conducted at local venues (community centre, hotel and allergy centre) and refreshments provided. They were facilitated by HM, who has conducted qualitative food allergy research but does not have expert knowledge on dietary advice. Two observers (JG and GG) were responsible for taking notes of the discussions.

Before commencing the focus group, 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 emphasised. A topic guide was used to guide the discussion (Table 1); however priority was given to interaction between participants. Ethical approval was granted by the Southampton and South East Hampshire NHS Research Ethics Committee (B). Data were stored in accordance with the Data Protection Act (1998).

Data 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: (i) becoming familiar with the data (ii) generating initial (empirical) codes (iii) searching for themes (iv) reviewing themes (v) defining and naming themes (vi) producing the final report (14). The data was 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 towards a comprehensive analysis of the whole (15).
RESULTS

Characteristics of participants and their children

Three focus groups were conducted consisting of between four and seven participants (N=17, who had a total of 19 children with food allergy) and lasted between 1 hour 20 minutes and 1 hour 40 minutes. Although both parents were invited to participate, only mothers responded. A minority of the participants had met before (as their children were at the same school). The sample represented a range of experience, and was cared for by a number of dietitians (see Table 2). All had received at least one consultation with a dietitian about their child’s food allergy.

Themes

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

A. Helps me to protect my child and keep them healthy

It was important to mothers to protect their child and they employed various strategies to ensure their child did not ingest food allergens (A1 & A2). It was also important to mothers to keep their child healthy; many worried that their child’s diet was boring, insufficient or nutritionally inadequate particularly if their child had multiple food allergies. To overcome this, mothers cooked extra meals, often from scratch (A3).

The mothers described several ways in which dietitians (as health professionals) helped them protect their child. Mothers commonly referred to the role of the dietitian as both ensuring, and reassuring them, that their child was receiving a nutritionally balanced and sufficient diet despite restrictions imposed by food allergies (A4). For some, it was also valuable to have their child’s food allergy monitored so that they could be reassured they were not avoiding
B. *Teaches me to become an expert*

From the mothers’ perspective, one key aspect of the dietitians’ role was to act as a teacher, helping them to become experts in food allergy. Immediately after diagnosis many mothers felt daunted by how much they had to learn (B1). In the crucial period immediately after diagnosis mothers particularly valued information dietitians gave to ‘get them started’, particularly that which helped them to cater for their child’s food allergies such as ‘safe food’ lists. However, the majority of mothers found the first meeting a little overwhelming and the volume of information difficult to absorb. Hence, they appreciated having written information to take away (B2).

Dietitians were also viewed as someone who could provide accurate expert knowledge (tailored to their child) (B3) and were consequently often cited as the mothers’ most trusted source for food allergy advice. Over time all mothers acquired expert knowledge about food allergy. However, although generally able to, mothers did not always feel in a position to answer their child’s queries about food allergies (B4). Similarly, they reported gaps in their own knowledge (see Table 4) of which they had become aware since their last dietary consultation and about which they wanted some advice.

C. *Provides me with hints and tips to help maintain normality*

There was an underlying theme in many of the mothers’ discussions that it was important that their child was able to lead a happy, normal life; to be able to eat a wide variety of foods and take part in activities that children their age did, and to not feel different, or left out, because of their food allergy (C1). Many of the mothers employed a number of strategies (often involving a large degree of forward-planning; see Table 5) to achieve this (C2). The mothers...
often conducted a balancing act between maintaining normality and safely managing their child’s food allergy (C3). Many also highlighted that it was important that the whole family was able to lead a normal life. Mothers described two main ways in which they felt the dietitians were able to help them maintain a normal life and provide a varied diet for their child: (i) helping them to find free-from foods (C4) and (ii) providing allergen-free recipes. Allergen-free recipes that prevented the child from missing out on special occasions (e.g. birthday cake recipes) were particularly valued (C5).

D. Helps to promote my child’s independence

Many of the mothers had younger children, and expressed concern about balancing their child’s increasing need for independence with ensuring their safety, and, similarly, how to convey the importance of managing food allergy responsibly without scaring their child. The mothers felt supported by dietitians in managing the growing independence of their child. Some also felt it was important to have them reinforce what they themselves had been telling their child e.g. around what foods they could and could not eat (D2).

E. Advocates, helping me fight my child’s corner

As previously described, in many scenarios the mothers would make adjustments to manage their child’s food allergy, even when their child had arguably been ill-served (in one case a family ate elsewhere after a restaurant refused to serve their child). There were, however, two key scenarios in which many acted assertively to convey the seriousness of their child’s condition: (i) when their child’s school had failed to manage food allergy appropriately (E1) and (ii) when they felt their GP was not sufficiently helpful in the diagnosis or management of their child’s food allergy (E2).

Some of the mothers found it helpful when the dietitian (or other health professional) had
acted as an advocate for them when they were trying to fight their child’s corner; for example, supporting them when they experienced difficulties with other health professionals (E3). Some also found it helpful when the dietitian would either provide them with information to help them explain to other people about food allergies or when they were directly involved in training other people (such as school staff: E4).

F. Provides me with emotional support

Some mothers highlighted the emotional impact of their child having food allergy, particularly before, during and immediately after diagnosis (F1). These mothers described receiving a great deal of support from the dietitians during this difficult period. For example, some highlighted how managing a newborn baby was made additionally difficult by a food allergy diagnosis and provided emotional descriptions of the support they had received (F2). Similarly, many felt that the dietitians understood the anxieties they had as mothers of young children with food allergies. Moreover, by talking with an expert who understood the degree of risk that their child faced (and the need to be realistic about managing food allergy), some mothers felt able to put their concerns into perspective (F3). However, while some reported being able to speak to their dietitian whenever they needed to, others had not realised this was possible.
DISCUSSION

This is the first study to have examined what information and support mothers of children with food allergies require and value from a dietary consultation. The mothers’ perceptions of their own role and experiences of caring for a child with food allergy echo themes reported in previous studies. This study, however, also describes how this relates to their perception of the dietitians’ role, and what they most value about having access to a dietitian.

Importantly, this study highlights the value of specialist dietitians to mothers. As described in previous research, although the mothers felt that over time they grew to understand their child’s food allergy, immediately after diagnosis they felt daunted and anxious. Dietitians were involved with the formulation and implementation of an individualised elimination diet for their child. At this stage, mothers wanted to know as much as possible about the dietary management of food allergies, including how to avoid allergens (e.g. label reading, manufacturing processes), how to manage food-related situations (e.g. restaurants) and also how to maintain a healthy diet. They wanted to know how to provide a healthy, varied, interesting and allergen-free diet for their child. Many felt the advice, education, support and practical help they received was critical to their ability to manage their child’s food allergy in this period. This suggests that it is important to offer dietetic input as soon as possible after the diagnosis of food allergy to ensure that mothers are confidently able to meet their child’s nutritional and social needs and avoid accidental exposure.

It also suggests that, in line with previous studies, dietitians should provide written material (e.g. lists of foods to avoid, alternative allergen names and recipe ideas) to supplement the dietary consultation. This is especially important for the first consultation after diagnosis, when mothers described feeling overwhelmed with the amount of information they needed to remember. However, since research suggests that a significant minority of
parents may not accurately recall dietary advice provided to them\textsuperscript{10}, written advice is likely to be useful for all food allergy consultations. Additional copies may also be useful since some mothers reported that friends and family were not sure how to manage food allergy.

Over time, mothers became more knowledgeable and confident in managing their child’s elimination diet. At this stage they wanted dietitians to monitor the nutritional adequacy of the diet, and provide advice on how to ensure their child had a varied and interesting diet and was able to participate in social occasions involving food. It was important to the mothers that their child could lead as normal a life as possible. Although allergen-free recipes help to introduce variety and reduce the daily burden of catering for a food-allergic child, those that are tailored to special occasions (e.g. birthday cakes) are equally important as they help mothers to maintain normality.

In general, at this stage it appears that practical advice (and help) is appreciated. Some mothers reported conducting many checks prior to their child attending a party or going on a school trip. Pro-forma checklists may help expedite this process. Additionally, many mothers reported that queries about their child’s diet sometimes arose between appointments. They were also concerned about their child being adequately equipped to manage food allergy as a teenager. A range of potentially helpful measures were suggested including a frequently asked questions sheet, newsletter (particularly including easy-to-understand summaries of recent food allergy research), a ‘helpline’ e-mail/on-call service and a teenager support group.

Many of the mothers needs fall clearly within the traditional remit of a dietitian, in particular the formulation and implementation of a nutritional intervention (in this case an elimination diet, and the advice and education associated with this), and in monitoring and evaluating the impact of the intervention on outcomes\textsuperscript{8} such as dietary variety, growth and nutritional status. However, it was clear that the mothers also strongly valued the emotional support provided
by dietitians who understood the difficulties involved in managing an elimination diet, and the advocacy provided by dietitians who liaised with their child’s school and GP when needed. Although allergy dietitians are well trained to provide parents with a range of advice on how to manage food allergies, they may not be as well prepared to manage the emotional needs of parents of children with food allergies. As the mothers describe, coping with a child’s food allergy can be emotionally demanding particularly early after diagnosis. It may be therefore that there is a need for dietitians to receive training on how to provide appropriate emotional support or for psychologists to be part of allergy clinics. At the least it may be useful for dietitians to be able to offer either written guidance for parents on how to cope, or to be able to signpost them to relevant support.

Taking all the findings into account, and the potential adverse effects of an elimination diet in infants and children with food allergy, dietary advice should be provided to all parents of food allergic children. However, in the UK only a minority of parents have access to a food allergy dietitian. There is scope to widen access to specialist dietitians for families dealing with food allergy, and to ensure that there is more targeted training and education available to dietitians. Although such methods could not hope to replicate the support offered by specialist allergy dietitians, it may be that, at a minimum, primary care services need to be equipped with appropriate resources (such as information packs) to help parents who do not have access to specialist services manage the dietary needs of their child.

Strengths and limitations

A qualitative approach has enabled us to gain an in-depth understanding of the information needs of mothers attending a dietary consultation. It allowed mothers to discuss the role of the dietitian as they perceive it and to identify what they have found useful and what additional information or support they need. It is also important to note that the sample was
composed of parents whose children were a range of ages, and types, number and severity of
food allergies.

There are, however, some limitations which must be considered. Firstly, although both
parents were approached only mothers consented to participate in the study. Given that
mothers tend to take greater responsibility for managing their child’s food allergy this is
perhaps not surprising. Thus, the findings are likely, in most cases, to be relevant to the main
caregiver of a food allergic child. Nevertheless, evidence suggests that mothers of children
with food allergies experience greater impact on their quality of life, perceived stress and
anxiety than do fathers. It is therefore possible that fathers (and other family members) may
have fewer and/or different dietary information needs than the mother. Secondly, as this is a
qualitative study the findings may not be generalisable and the effectiveness of interventions
suggested by the findings should be formally evaluated. In particular, although the area from
which participants were recruited was diverse in terms of socio-economic, educational and
ethnic background, given the size of the sample, this diversity may not be fully represented in
this study. Furthermore, this study is limited to those parents who have received support from
a group of allergy dietitians based at a dedicated allergy clinic. Further research is required to
establish what questions those parents who do not have access to specialist care have about
dietary management of their child’s food allergies, particularly those who have not seen a
dietitian or an allergy specialist dietitian.

It is important to highlight that since parents were recruited from an allergy clinic, they may
have felt obliged to offer only positive remarks. However, it was made clear to participants
that the researcher conducting the focus groups did not work for the allergy centre and that
the researchers valued their honest opinion. Participants willingly identified areas of good
practice and for improvement, which suggests that they were not unduly influenced.
Conclusion

This is the first study to have examined what information and support mothers of children with food allergies require from a dietary consultation. It found that mothers have a wide variety of needs that they perceived were currently met by the specialist food allergy dietitians. Many of these fell within the traditional remit of dietitian: assisting in the diagnostic process, monitoring their child’s food allergy and nutritional status, providing advice to help them cater for their child safely and support to manage their child’s growing independence. However, the dietitians were also meeting other needs, acting as someone to advocate for the mother and providing emotional support as needed. In addition to contact with a specialist allergy dietitian the provision of practical, written advice to take away from the consultation may be the most useful method by which to support mothers to provide their child with a safe and healthy diet, while maintaining normality.