

1 ABSTRACT

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

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

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

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

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

21 **Keywords:** Diet, nutrition, food allergy, qualitative

22

23 INTRODUCTION

24 The long-term management of food allergy involves dietary elimination of the relevant
25 food(s) and the treatment of any reactions occurring due to accidental exposure. Recently
26 published guidelines from the US, UK, Europe and World Allergy Organisation¹⁻⁴ all
27 highlight the complexities of maintaining an elimination diet and the potential long-term risks
28 for a patient's nutritional status and quality of life. Providing patients with detailed,
29 individualised dietary management advice and monitoring is therefore seen as a key
30 component of food allergy care^{1, 4-7}.

31

32 Hence, it is clear that dietitians have an important role in supporting parents in the long-term
33 management of food allergy. In addition to assessing and diagnosing nutritional problems,
34 dietitians are also responsible for formulating and implementing nutritional and dietetic
35 interventions, and for monitoring and evaluating the impact of such interventions on a range
36 of relevant outcomes⁸. Where food allergy is concerned, this includes providing
37 individualised advice and education about how to manage an elimination diet and monitoring
38 the impact on a range of outcomes including nutrition, growth and quality of life.

39

40 Studies exploring parents' information needs with regard to food allergies have identified a
41 strong need for advice on managing elimination diets⁹⁻¹¹. Although these studies do not focus
42 in detail on the dietary aspects of parents' information needs, they do indicate that parents are
43 concerned about the impact of food allergy on the growth and nutritional status of their child.
44 They also suggest that parents need advice not only about a range of issues related to allergen
45 avoidance and providing their food-allergic child with a healthy diet⁹. More in-depth study
46 of the specific information and support parents require and value from a dietary consultation
47 is therefore required. This can help us to understand how best to support the parents of

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

51

52 **METHODS**

53 Sample and recruitment

54 Participants were recruited using purposive sampling¹²; parents of children with a diagnosis
55 of food allergy were invited to take part, and the aim was to sample a range of experience
56 (e.g. according to the type and number of food allergies, age of child and length of time with
57 food allergy). Potential participants were sent an invitation letter and information sheet, and
58 returned a reply slip and completed consent form if they wished to take part. Participants
59 were telephoned to arrange a convenient time and location for the focus group. Participants'
60 travel expenses were refunded and they were given a £10 gift voucher to thank them for their
61 time. The aim was to have six to eight participants in each focus group, to ensure both that a
62 range of views/experiences were represented and that all participants were given an
63 opportunity to discuss their experience in sufficient depth¹³.

64 Procedure

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

69 Before commencing the focus group, its purpose was recapped (to find out more about the
70 information needs during a dietary consultation of mothers of children with food allergy) and
71 the freedom to withdraw emphasised. A topic guide was used to guide the discussion (Table
72 1); however priority was given to interaction between participants. Ethical approval was
73 granted by the Southampton and South East Hampshire NHS Research Ethics Committee
74 (B). Data were stored in accordance with the Data Protection Act (1998).

75 Data analysis

76 Audio-recordings were transcribed verbatim and field notes added. The transcripts were then
77 imported into NVIVO 8 (QSR International, Melbourne, Australia) for thematic analysis
78 according to the following steps: (i) becoming familiar with the data (ii) generating initial
79 (empirical) codes (iii) searching for themes (iv) reviewing themes (v) defining and naming
80 themes (vi) producing the final report (14). The data was constantly revisited and codes
81 compared across the data to ensure their consistent use. Codes and emergent themes were
82 developed and refined throughout analysis (paying attention to commonality, difference and
83 relationship) working towards a comprehensive analysis of the whole (15).

84

85 **RESULTS**

86 Characteristics of participants and their children

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

94 Themes

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

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

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

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

108 foods unnecessarily.

109 *B. Teaches me to become an expert*

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

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

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

126 There was an underlying theme in many of the mothers' discussions that it was important that
127 their child was able to lead a happy, normal life; to be able to eat a wide variety of foods and
128 take part in activities that children their age did, and to not feel different, or left out, because
129 of their food allergy (C1). Many of the mothers employed a number of strategies (often
130 involving a large degree of forward-planning; see Table 5) to achieve this (C2). The mothers

131 often conducted a balancing act between maintaining normality and safely managing their
132 child's food allergy (C3). Many also highlighted that it was important that the whole family
133 was able to lead a normal life. Mothers described two main ways in which they felt the
134 dietitians were able to help them maintain a normal life and provide a varied diet for their
135 child: (i) helping them to find free-from foods (C4) and (ii) providing allergen-free recipes.
136 Allergen-free recipes that prevented the child from missing out on special occasions (e.g.
137 birthday cake recipes) were particularly valued (C5).

138 *D. Helps to promote my child's independence*

139 Many of the mothers had younger children, and expressed concern about balancing their
140 child's increasing need for independence with ensuring their safety, and, similarly, how to
141 convey the importance of managing food allergy responsibly without scaring their child.

142 The mothers felt supported by dietitians in managing the growing independence of their
143 child. Some also felt it was important to have them reinforce what they themselves had been
144 telling their child e.g. around what foods they could and could not eat (D2).

145 *E. Advocates, helping me fight my child's corner*

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

153 Some of the mothers found it helpful when the dietitian (or other health professional) had

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

159 *F. Provides me with emotional support*

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

171 **DISCUSSION**

172 This is the first study to have examined what information and support mothers of children
173 with food allergies require and value from a dietary consultation. The mothers' perceptions of
174 their own role and experiences of caring for a child with food allergy echo themes reported in
175 previous studies^{9, 16-18}. This study, however, also describes how this relates to their perception
176 of the dietitians' role, and what they most value about having access to a dietitian.

177 Importantly, this study highlights the value of specialist dietitians to mothers. As described in
178 previous research¹⁷, although the mothers felt that over time they grew to understand their
179 child's food allergy, immediately after diagnosis they felt daunted and anxious. Dietitians
180 were involved with the formulation and implementation of an individualised elimination diet
181 for their child. At this stage, mothers wanted to know as much as possible about the dietary
182 management of food allergies, including how to avoid allergens (e.g. label reading,
183 manufacturing processes), how to manage food-related situations (e.g. restaurants) and also
184 how to maintain a healthy diet. They wanted to know how to provide a healthy, varied,
185 interesting and allergen-free diet for their child. Many felt the advice, education, support and
186 practical help they received was critical to their ability to manage their child's food allergy in
187 this period. This suggests that it is important to offer dietetic input as soon as possible after
188 the diagnosis of food allergy to ensure that mothers are confidently able to meet their child's
189 nutritional and social needs and avoid accidental exposure.

190 It also suggests that, in line with previous studies⁹⁻¹¹, dietitians should provide written
191 material (e.g. lists of foods to avoid, alternative allergen names and recipe ideas) to
192 supplement the dietary consultation. This is especially important for the first consultation
193 after diagnosis, when mothers described feeling overwhelmed with the amount of information
194 they needed to remember. However, since research suggests that a significant minority of

195 parents may not accurately recall dietary advice provided to them¹⁹, written advice is likely to
196 be useful for all food allergy consultations. Additional copies may also be useful since some
197 mothers reported that friends and family were not sure how to manage food allergy.

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

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

214 Many of the mothers needs fall clearly within the traditional remit of a dietitian, in particular
215 the formulation and implementation of a nutritional intervention (in this case an elimination
216 diet, and the advice and education associated with this), and in monitoring and evaluating the
217 impact of the intervention on outcomes⁸ such as dietary variety, growth and nutritional status.
218 However, it was clear that the mothers also strongly valued the emotional support provided

219 by dietitians who understood the difficulties involved in managing an elimination diet, and
220 the advocacy provided by dietitians who liaised with their child's school and GP when
221 needed. Although allergy dietitians are well trained to provide parents with a range of advice
222 on how to manage food allergies, they may not be as well prepared to manage the emotional
223 needs of parents of children with food allergies. As the mothers describe, coping with a
224 child's food allergy can be emotionally demanding particularly early after diagnosis. It may
225 be therefore that there is a need for dietitians to receive training on how to provide
226 appropriate emotional support or for psychologists to be part of allergy clinics. At the least it
227 may be useful for dietitians to be able to offer either written guidance for parents on how to
228 cope, or to be able to signpost them to relevant support.

229 Taking all the findings into account, and the potential adverse effects of an elimination diet in
230 infants and children with food allergy²⁰⁻²⁸, dietary advice should be provided to all parents of
231 food allergic children. However, in the UK only a minority of parents have access to a food
232 allergy dietitian²⁹. There is scope to widen access to specialist dietitians for families dealing
233 with food allergy, and to ensure that there is more targeted training and education available to
234 dietitians. Although such methods could not hope to replicate the support offered by
235 specialist allergy dietitians, it may be that, at a minimum, primary care services need to be
236 equipped with appropriate resources (such as information packs) to help parents who do not
237 have access to specialist services manage the dietary needs of their child.

238 *Strengths and limitations*

239 A qualitative approach has enabled us to gain an in-depth understanding of the information
240 needs of mothers attending a dietary consultation. It allowed mothers to discuss the role of
241 the dietitian as they perceive it and to identify what they have found useful and what
242 additional information or support they need. It is also important to note that the sample was

243 composed of parents whose children were a range of ages, and types, number and severity of
244 food allergies.

245 There are, however, some limitations which must be considered. Firstly, although both
246 parents were approached only mothers consented to participate in the study. Given that
247 mothers tend to take greater responsibility for managing their child's food allergy this is
248 perhaps not surprising. Thus, the findings are likely, in most cases, to be relevant to the main
249 caregiver of a food allergic child. Nevertheless, evidence suggests that mothers of children
250 with food allergies experience greater impact on their quality of life, perceived stress and
251 anxiety than do fathers³⁰. It is therefore possible that fathers (and other family members) may
252 have fewer and/or different dietary information needs than the mother. Secondly, as this is a
253 qualitative study the findings may not be generalisable and the effectiveness of interventions
254 suggested by the findings should be formally evaluated. In particular, although the area from
255 which participants were recruited was diverse in terms of socio-economic, educational and
256 ethnic background, given the size of the sample, this diversity may not be fully represented in
257 this study. Furthermore, this study is limited to those parents who have received support from
258 a group of allergy dietitians based at a dedicated allergy clinic. Further research is required to
259 establish what questions those parents who do not have access to specialist care have about
260 dietary management of their child's food allergies, particularly those who have not seen a
261 dietitian or an allergy specialist dietitian.

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

267 *Conclusion*

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