ORIGINAL ARTICLE

Parental food allergy information needs: a qualitative study

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Arch Dis Child 2007;**92**:771–775. doi: 10.1136/adc.2006.114975

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Accepted 20 April 2007
Published Online First 8 May 2007

Objective: To examine information needs and preferences of parents regarding food allergy.
Design: Qualitative study including in-depth semi-structured interviews and focus group discussions. Data were audio-recorded, transcribed verbatim and analysed using the constant comparative method, aided by participant checking of interview summaries, independent reviewers and qualitative analysis software.
Participants: 84 parents of children with food allergy.
Setting: Three paediatric allergy clinics and a national consumer organisation.
Results: Most parent participants had received third level education (72%) and 39% had occupational backgrounds in health and education. Parents experienced different phases in their need for information: at diagnosis when there is an intense desire for information, at follow-up when there is continuing uncertainty about allergy severity and appropriate management, and at new events and milestones. They preferred information to be provided in a variety of formats, with access to reliable individualised advice between clinic appointments, within the context of an ongoing relationship with a health professional. Parents wished to know the reasoning behind doctor's opinions and identified areas of core information content, including unaddressed topics such as what to feed their child rather than what to avoid. Suboptimal information provision was cited by parents as a key reason for seeking second opinions.
Conclusion: Parents with children with food allergies have unmet information needs. Study findings may assist in the design and implementation of targeted educational strategies which better meet parental needs and preferences.

The prevalence of food allergy appears to be increasing[1] with paediatricians consequently experiencing an increased demand for specialist allergy services.[2] It is widely agreed in expert reviews and practice guidelines that comprehensive parental advice and education is a cornerstone of food allergy management.[3–6] Limited parental knowledge has been documented in relation to using adrenaline autoinjectors[7–12] and reading food labels.[13] Clinical audits have revealed suboptimal levels of information provision[14–15] and that parents have a number of common concerns regarding food allergy.[2] However, little is known about parental preferences for information content and delivery, particularly given the complexity of the strategies required to manage food allergy risk.[16] Previous research has demonstrated the value of qualitative methods in ascertaining parental information needs concerning allergic conditions such as atopic dermatitis and peanut avoidance in pregnancy.[17 18] This study examined the information needs and preferences of parents with children with food allergies through a multimethod qualitative approach.

METHODS

Families were recruited from three paediatric allergy clinics in New South Wales (NSW), Australia. Together, these clinics provide the bulk of such services in NSW, which has a population of 6.7 million.[19] In common with a worldwide shortage of allergy services,[20] families wait up to 6 months for appointments at these clinics, where typically, 30 min is allocated for initial medical consultations.

Families presenting with a child for evaluation of food allergy were sampled purposively to include a range of allergy types and severity, children's ages and length of time since diagnosis. Of 48 families invited to participate, four refused or were excluded from involvement as it emerged that their child did not have an allergy. Within a month of the clinic visit, in-depth semi-structured interviews were audio-recorded with parents concerning their child's food allergy, usual management strategies, what they had learned from the clinic visit and suggestions for improving information provision. Summaries of these interviews were returned to parents for checking, with a follow-up interview to ensure coverage of all key concerns. To confirm and extend findings, four focus groups were held with parents who were members of the consumer organisation Anaphylaxis Australia Incorporated (AAI). AAI is the peak Australian consumer body for food allergy and anaphylaxis awareness, consumer support and education. All parent groups who were invited agreed to participate, and all participants had attended at least one of the three clinics. These discussions covered similar topics to those in the interviews and were audio-recorded. Following qualitative data collection, a brief survey was administered to all parents regarding demographic details, the child's food allergy characteristics and sources of food allergy information.

All audio-recordings were transcribed verbatim and imported into MAXqda2 (VERBI Software, Berlin, 2004) for analysis using the constant comparative method.[21] The data were read repeatedly and codes developed from units of meaning as expressed by participants. These codes were refined through comparison between cases with contrasting and similar attributes, such as stage of diagnosis. From these, thematic categories were developed, from which data were systematically coded. Sampling of families continued until theoretical saturation, or no new themes were found. To validate the thematic categories, a selection of contrasting cases was independently read by six expert reviewers from allergy and non-allergy specialist, general practice, sociology, consumer and lay backgrounds. The study was approved by the human research ethics committees at all three clinics and written informed consent was obtained from all participants prior to interview.

RESULTS

A total of 84 parents drawn from 44 clinic recruited and 25 consumer organisation families participated. Tables 1 and 2 list

Table 1 Demographic details of parent participants

Age range	23 to 55 years
Average age	37.9 years
Third level education	72%
Health or education occupation	39%
Non-English speaking background*	27%

*Parents were asked which culture they identified with. Using standard Australian Bureau of Statistics terminology, ''Australian'' was the most commonly identified English-speaking background, and ''South European'' the most commonly identified non-English-speaking background.

demographic features of the sample and characteristics of the child's food allergy reported by parents. Most participants were mothers (n = 69), with the remainder being fathers. Of the clinic families, 22 were visiting the clinic for the first time and 22 for follow-up appointments, with the time since diagnosis ranging from 0 to 8.5 years. Of all families, 39% (n = 27) had sought second opinions regarding their child's food allergy. Table 3 contains data extracts illustrating parental views on information provision as described in the following sections.

Phases in information needs

Parents described three distinct phases in information seeking: on initial diagnosis, at follow-up and at milestones. When food allergy was first diagnosed, many parents described a period of disbelief and distress concerning the severity of the allergy and need for avoidance measures, accompanied by an intense desire for information. Parents reported great variation in the amount of take-home information provided by clinics, ranging from a package containing many printed pages of written information, illustrated booklets and videos at one clinic, to no information at others. The majority of parents requested that more information be given at the first visit, with only two parents stating that they were given too much information.

At follow-up visits, parents who had lived with the diagnosis for more than a year typically wished to know about their child's current allergic status, recent scientific developments, new food products and whether they were managing their child's allergy with the appropriate level of concern and vigilance. The latter was particularly important given persistent uncertainty about the seriousness of their child's allergy, especially for parents whose children had not experienced anaphylaxis. Parents felt caught between the need to keep their child safe from accidental allergen exposures but not overly restrict their child's life and social opportunities.

Other information-seeking phases were those triggered by the anticipation, or occurrence, of new events and milestones, such as further acute reactions, starting childcare or school and travel. These raised questions about precautionary strategies such as educating teachers and carers, treatment procedures for acute reactions and ensuring a safe food supply, particularly if the parent could not be present and had to entrust the care of their child to another.

Table 2 Parent-reported characteristics of child's food allergy

Age range of allergic child	0.6 to 15.2 years
Average age of allergic child	5.1 years
More than one food allergy	59%
Peanut or tree nut allergy	76%
Previous anaphylaxis*	42%
Have autoinjector	77%

*This was defined in the survey as ''An anaphylactic reaction is the most serious type of allergic reaction. The person can have trouble breathing, swelling of their tongue or throat, difficulty talking or a hoarse voice, noisy breathing, wheeze or persistent cough, loss of consciousness or collapse, or go pale and floppy'', and is taken from parent education materials developed by the Australian professional body for allergists.[34]

Information content needs

Parents described needs regarding two aspects of information content. The first concerned the reasoning behind the doctor's judgments about their child's allergy, including the likelihood of anaphylaxis, and the recommended management. When parents did not understand the basis of the doctor's opinion, they would continue to speculate after the consultation, for example by presuming that the size of the skin test correlated with the risk of anaphylaxis and requirement for an autoinjector.

The second type of information concerned basic medical facts and practical advice related to daily management. These core areas, as identified by parents, are listed in table 4. These needs clearly persisted after the clinic visit, with the interview triggering queries about topics such as techniques for using the autoinjector, the meaning of skin test results and the need for follow-up visits. Most of all, parents whose children had significant food allergies talked at length about needing information regarding what they should feed their child, as distinct from what they should avoid. Dietary management was one of the most life-changing aspects of food allergy and there was continual concern over the effect of restrictive diets on the child's nutritional status and growth. There was also considerable confusion over the extent to which parents should exclude allergens from the child's diet and environment. Examples included whether foods labelled ''may contain traces'' should be avoided, or whether all foods from a group (eg, tree nuts), should be avoided if there was an allergy to one food (eg, peanut). A minority (n = 6, 27%) of newly diagnosed families had been referred to a dietician.

Table 3 Data extracts concerning parental information needs and preferences

Just naturally [as parents], I think we crave information, especially when it's something … that affects your children, and there's not much other information out there, your doctor's pretty much, the primary source. And you need to get the answers from them, because if you don't, then you risk, you know, trying to search the internet, getting information from current affairs programs, where it's not always relevant to your situation. And you can start making assumptions, and getting carried away, and getting worried about things that you don't need to be worried about. Tess (mother, clinic recruited)*

Initially, nobody actually starts with, what is anaphylaxis? Because well, for me, I mean, I'd never heard of it. I've no medical background, I had no idea what they were talking about. Lori (mother, consumer organisation)

And just nobody ever really explained that. […] I've been involved with my son's allergy for over two years, and I have *never* understood any of this…. and as I came home from that [nurse education session] I said to my partner….in a sense I felt like a real weight had been lifted? Because when you understand something you feel like you have a little bit of control over it. Sabrina (mother, clinic recruited)

It's a sort of a stressful time, when you're up there, with a child, particularly when they're young … because they're jumping around the room, and they're either tired, because it's their sleep time, or whatever it may be. And it's very hard to try to remember all your questions, concentrate on what they're saying, concentrate on keeping your child quiet, so you can hear [laugh]. Melinda (mother, clinic recruited)

Yeah, it's really reassuring when [the doctor] comes along and says, I don't think you should have that. […] We don't know how much we've worried and panicked over things or not – that's the thing. But when the specialist worries with you, you go, *good*, we're not being over-anxious here. Robyn (mother, clinic recruited)

*Pseudonyms are used for all participants.

Table 4 Core information needs identified by parents

- What is anaphylaxis? What is *not* anaphylaxis?
- Recognising symptoms of allergic reactions, the timescale of reactions.
- How accidental exposures occur and how to manage risky situations.
- What to feed your child (rather than what to avoid), maintenance of nutrition.
- Practical allergen avoidance: label reading, shopping, cooking, social events, eating out and travel. How to find allergen-free products.
- When and how to give the autoinjector. Revision of techniques at each visit.
- How to educate extended family, other carers and adults who may give the child food.
- Risks and benefits of skin testing and oral challenges. Interpretation of results.
- When follow-up is required, and why.
- Where more information may be found, eg nurse-led education sessions, consumer organisations, contacting the clinic.
- How to educate your child.
- Background information about allergy, the relationship between asthma, eczema and food allergy, natural history of food allergy.

Preferences for information delivery

Three key aspects were described in relation to information delivery. The first concerned clinic procedures and accessibility. Clinic visits were often prolonged by multiple encounters, including initial allergist consultation, skin testing with a technician, and the allergist again, sometimes with the addition of dietician and nurse-led education, a process that lasted some hours. As a result, when final opinions and advice were presented by the allergist, parents were often distracted by a tired and bored child. Parents also consistently requested a method through which they could have their queries addressed between clinic appointments, preferably by a health professional familiar with their case.

A second aspect related to information formats. Written take-home information was strongly preferred, as it was difficult to recall details about food ingredients and products, but not as a substitute for talking with a health professional. Parents also spoke highly of videos, which they found essential for educating their child, extended family, child care workers and teachers. A desire for more information led many parents to search the internet, which 73 (87%) parents reported using as a source of food allergy information. However, they questioned its reliability, preferring to receive more trustworthy information from their doctor. Parents who had been referred to nurse-led education sessions consistently found them valuable, particularly if they had time to formulate questions between the consultation and the session, and have them answered. However, only a minority (9.8%) of clinic parents had been referred to and attended such sessions.

The third and most important aspect was the doctor–parent–child relationship. The most common reasons for seeking a second opinion were insufficient information provision, difficulty having questions answered, advice that was perceived to be either too restrictive or too cavalier, and non-acknowledgement of the child as the patient. Parents noted that doctors who provided more information would readily answer their questions and spent more time with them. What parents valued was consistent information given in the context of a long-term partnership that acknowledged their uncertainties and concerns.

DISCUSSION

This study has shown that parents with children with food allergies have unmet information needs which continue after clinic visits. In common with other qualitative studies concerning parental experiences with allergic conditions,[17 18] the study has found persistent uncertainties concerning the daily management of allergies. There are also similarities with findings from interview studies conducted with parents of children with non-allergic long-term conditions, where participants preferred information provision to be part of a trusting and ongoing relationship with health professionals.[22 23] Our findings, however, are new in relation to families with children with food allergies. They document how information needs may change over time, and include parental preferences concerning the content, format and delivery of information.

Although the use of multiple data collection methods has enhanced internal validity, our findings are of unknown generalisability as the study was conducted in specific settings with a selected population. Notably, the parents' high level of third level education, and occupational backgrounds in health and education, including nursing, medicine, psychology and childcare, may have influenced information preferences. These may not reflect the information needs of all parents, and less well educated parents may have differing needs which should also be addressed. Educational levels, however, were comparable to the 70.9% of the NSW population of this age range with third level education[24] and it is possible that the occupational backgrounds of parents in the study are typical of families who seek specialist help for childhood food allergies. The low rate of refusal and theoretical saturation suggests that the sample covered the range of parental experiences in the clinic population. The inclusion of consumer organisation members may have also skewed results towards a preference for greater information provision, as patients tend to seek out health consumer organisations to find more information.[25] However, in this study, clinic-recruited parents whose children had significant allergies also consistently requested more information; the difference was that consumer organisation parents had dealt with food allergy for some time and were better able to describe the specific information that parents required. Consumer organisation representatives may also be best placed to understand the intricacies of food allergy daily management.[16]

Our findings suggest ways in which information provision may be optimised. It appears that information content tailored to parental needs at specific times is preferred, and models for health information seeking support this contention.[26] For example, at diagnosis, the list of core information could be used as a checklist for discussion and written materials. However, the complexity and amount of education required suggests that even core information will be difficult to convey within one consultation. This implies a need to ensure follow-up, for example to check parental understanding of dietary advice or skin prick test results, and in particular that a strongly positive result correlates only with the likelihood of allergy and not with the severity of subsequent reactions.[27]

Given shortages of specialist services,[20] alternative methods of information provision that do not necessarily increase the requirement for doctors' time may need to be found. Written information is important but requires explanation and review to ensure parental understanding.[28] Our findings suggest that alternative formats such as video, may have more impact. As only a minority of clinic-recruited families were referred to a

What is already known on this topic

- Comprehensive advice and education is required in order to safely manage food allergy.
- Parents have limited recall and knowledge about food labelling and use of adrenaline autoinjectors, but little is known about their preferences for information provision.

What this study adds

- Many parents experience persistent uncertainty regarding the appropriate balance between keeping their child safe from accidental allergen exposures and not restricting their child's growth, nutritional status and social development.
- Important content areas for information provision include what to feed the food allergic child, rather than what to avoid, and the basis for doctor's judgements concerning the child's risk of anaphylaxis.

dietician or nurse-led education session, greater utilisation of these services may better meet information needs. Previous studies have demonstrated the effectiveness of multidisciplinary approaches in improving parental knowledge.[29, 30] Given the proportion of parents who access the internet for health information both in this study and more generally,[31] it could be better utilised by providing guidance to trustworthy websites. For example, a trained allergy nurse could use email to answer queries and provide reliable individualised information between clinic visits. Streamlining clinic procedures and suggesting that parents attend with another adult for child-minding may reduce parental distraction by children and improve the effectiveness of doctor–parent communication.

Our study findings also suggest that the rate of second opinion seeking may be reduced by better meeting parental information preferences and by addressing discrepancies between parental and allergist views of the risks. The latter are known to differ,[32] supporting parental preferences for doctors to explain the reasoning behind their opinions. Longitudinal studies of clinic populations have had differing results concerning the effectiveness of parent education. One study found that parental education at the time of autoinjector prescription was followed by use of the device in only 29% of anaphylactic reactions.[7] Another study found that detailed advice, written information and regular follow-up was associated with a reduction in the severity and frequency of acute reactions to food in children.[33] An explanation for these discrepancies, as suggested by this study, is that it is not only the quantity and quality of information provision, but also the extent to which it matches parental needs, which will determine its effect.

CONCLUSIONS

The information needs of parents with children with food allergies vary over time but parents consistently request more information provision from their specialist. This has resource implications, but these may be minimised through alternative strategies to provide information. More time spent initially or through more frequent follow-up consultations may also compensate for an even greater use of resources if second opinions are sought. Parents prefer information to be delivered in a variety of formats, and in an accessible, ongoing, parent and child-centred manner. Knowledge of parental preferences may enable clinicians to better fulfil information needs and findings from this study may assist in the development of more effective educational strategies.

ACKNOWLEDGEMENTS

The authors wish to gratefully acknowledge Anaphylaxis Australia Incorporated (AAI) for their assistance with this study.

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Funding: WH was supported by the Australian Allergy Foundation and the National Health and Medical Research Council (NHMRC) of Australia, ID no. 297112. Neither funding body had any role in the study design, collection and analysis of data, or in the writing and submission of this manuscript.

Competing interests: None.

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