

Attributes and views of families with food allergic children recruited from allergy clinics and from a consumer organization

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A significant body of food allergy research has been conducted with families recruited from consumer organizations (COs). However, there has been no systematic comparison of the characteristics of such families with those attending specialist allergy clinics (ACs), nor have parental views on food allergy COs been examined in detail. To address these questions, 44 families with food allergic children recruited from hospital clinics and 25 families recruited from a CO: (i) completed a survey with items concerning demographic details, allergy features, and sources of allergy information, and (ii) participated in qualitative interviews and focus groups concerning their experiences. Significant differences were found in reported number of food allergies and nut allergy, seeking of second opinions, adrenaline autoinjector possession (but not use) and sources of food allergy information. Parents valued COs as sources of practical information and emotional support, but viewed advice which did not acknowledge their individual circumstances and heightened anxiety from contact with other anxious parents as being unhelpful. Research conducted with CO members is valuable, but may have limited generalizability to other populations. To supplement the information and support provided by ACs, all parents should be given the opportunity to join a CO, with guidance from their clinician towards those aspects of membership which are most likely to be helpful.

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In Western countries there appears to be a significant increase in childhood food allergy and consequent need for specialist services, parental education and community-based interventions (1). Addressing these needs requires an understanding of parental experiences and of the adequacy of health services, which requires the participation of affected families in research. Being highly motivated and well informed, allergy consumer organization (CO) members are a valuable source of participants, with registries of members being formed for this purpose (2). In recent times, CO members have contributed to research concerning the preva-

lence of food reactions in the community (2–5), impact of food allergy on quality of life (6), and effect of community interventions such as food labelling (7). Additionally, parents may benefit from the collective experience of CO members in the practical daily management of food allergy (8).

However, little is known about the comparability of CO members to other groups of interest to clinicians, such as families attending allergy clinics (ACs), or of parental views concerning allergy COs. We report here the results of a survey and qualitative study comparing attributes and views of families recruited from a

national allergy CO and from three paediatric ACs.

Method

Families ($n = 44$) were recruited from three specialist clinics which together provide the bulk of paediatric allergy services in the state of New South Wales (NSW), a population of 6.7 million (9). Families presenting with a child for food allergy evaluation were consecutively sampled; of 48 who were invited, four refused or were excluded as the child did not have allergy. Families ($n = 25$) were also recruited from Anaphylaxis Australia Incorporated (AAI), the peak Australian CO devoted to food allergy and anaphylaxis awareness, education, and patient support. AAI parent groups which were geographically proximate to the clinics were invited so as to match the population likely to attend those clinics. All invited groups agreed to participate, and all participants had attended at least one of the clinics.

A questionnaire, including items on demographic features, characteristics of the child's food allergy including previous reactions and their treatment, and food allergy information sources was administered to all families. This questionnaire was reviewed by paediatric allergists at the three clinics and piloted with parents attending the clinics. Responses were collated and analysed using Fisher's exact test (two tailed), with p -values < 0.05 considered significant.

Semi-structured interviews were conducted with clinic recruited families and focus group discussions with AAI recruited families concerning parental experiences dealing with food allergy. All interviews and group discussions were audio recorded, transcribed verbatim, and analysed using the constant comparative method (10) with the assistance of MAXqda2 (11), a qualitative data analysis software program. Sampling continued until theoretical saturation (no new themes) appeared in the data (12). The study was approved by the human research ethics committees at all three institutions.

Results

Table 1 summarizes the demographic variables for families. The majority of participants were mothers, (AC recruited = 71%, CO recruited = 89%) with the remainder being fathers and one grandmother. The modal age range for children in both groups was pre-schoolers (2.5–5 yr) and the modal family size was 2 children, with the

Table 1. Demographic variables of families

Variables	Allergy clinic	Consumer organization	p-value
Number of families	44	25	n/a*
Average age carer (yr)	37.9	37.8	NS**
Average age child (yr)	5.5	5.0	NS
Age range child (yr)	0.6 to 15.2	2 to 7.4	n/a
Tertiary education	69%	78.6%	NS
Health or educational occupation	43.1%	32.1%	NS
Culturally and linguistically diverse***	36.2%	10.7%	0.019
Inner metropolitan place of residence	66%	96%	0.006

*n/a, not applicable.

**NS, not significant, $p > 0.05$.

***Standard Australian Bureau of Statistics term for non-English-speaking cultural background.

most common pattern being an allergic eldest child in a multiple child family.

Reported features of the child's food allergy are shown in Table 2. With the exception of two incomplete responses, all parents stated that their child had been diagnosed with skin testing. In both groups, a minority reported their children having radio allerge sorbent test (RAST) (AC = 27%, CO = 44%) and in-hospital oral challenges (AC = 23%, CO = 20%), with the difference between groups not being statistically significant. Although 34% of AC parents reported deliberately giving their child a food at home to see if they were allergic to it, when compared with only 9% of CO parents, this was not a statistically significant difference.

Nut and tree nut allergy were the most commonly reported allergy for both groups. The next

Table 2. Reported food allergy characteristics

Characteristics	Allergy clinic (%)	Consumer organization (%)	p-value
More than 1 food allergy	47.7	82.7	0.003
Peanut and/or tree nut allergy	66.7	96.6	0.002
Past clinical reaction to food*	93.2	92.0	NS
Past anaphylaxis*	38.6	48.0	NS
Have autoinjector	65.9	100.0	0.0005
Used autoinjector**	10.5	16.0	NS

*The questionnaire included descriptions of allergic reactions (allergic reactions include hives or skin rash, face or lip swelling, abdominal pain or vomiting after eating the food) and anaphylaxis (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) derived from consumer education materials produced by the national professional body for allergists and immunologists (31).

**Of families who possessed autoinjectors at the time of the questionnaire. NS, not significant.

Table 3. Amount of information received at the clinic

Source of information	Allergy clinic (%)	Consumer organization (%)	p-value
Current allergist	78.4	100.0	0.006
Dietitian or nurse	39.2	67.4	0.019
Education session	9.8	42.6	0.001

Table 4. Amount of information received from other sources

Source of information	Allergy clinic (%)	Consumer organization (%)	p-value
Family and friends	39.4	53.6	0.05
Newspapers and magazines	39.2	32.2	NS
Television and radio	25.5	35.7	NS
Internet	56.9	85.7	0.012
GP	41.2	21.4	NS
Other specialist	27.4	42.9	NS
Consumer group	22.7	96.4	<0.001

NS, not significant.

most commonly reported allergy was egg (AC = 33%, CO = 58% and $p = 0.03$), then milk (AC = 16%, CO = 48% and $p = 0.004$). Of the six families (AC = 2, CO = 4) who had administered the autoinjector, five reported their child had experienced anaphylaxis.

The rate of seeking second opinions was significantly different between the two groups. (AC = 29.5%, CO = 56% and $p = 0.041$) Tables 3 and 4 documents differences in the amount of information received from clinic and other sources, with the figures representing the percentage of parents who stated that they had received 'lots' or 'some' information when compared with 'little' or 'no' information from that particular source. No parent stated that they had received all their information from one source. Less than 10% of AC families had been referred to a parent education session. Of these, all stated

that they had received 'lots' of information at the session. About half (53%) of the AC families reported ever being referred to a dietitian. The majority of parents in the study (86%) had internet access and used it to access information. The majority of AC families (63%) had never heard of the CO.

Of the parents who had heard of, and/or come into contact with the CO, the qualitative data revealed that there was little difference between AC and CO families regarding what they found beneficial; this included practical information through newsletters, websites and parent meetings about safe food products, recipes, the latest research and stories of personal experiences, with the latter being particularly helpful for parents when their child was first diagnosed. Such information helped parents to regain a sense of control over the constant uncertainty of acute reactions. Other helpful aspects were emotional support and understanding from similarly affected families, being given a sense of perspective on their child's sensitivities in relation to other children, and the knowledge that there was a group advocating on one's behalf. Negative aspects, only expressed by AC families, included advice that did not take account of their individual circumstances and their child's level of sensitivity, and the anxiety provoking effect of being in contact with parents who were perceived to be overly anxious or stringent with allergy management. Table 5 contains parental quotes illustrating these themes.

Discussion

Our study is the first to systematically describe similarities and differences in the attributes of families recruited from ACs and from a CO. There was little difference in parental and allergic child's average age, and family size. All parents in

Table 5. Typical parental views concerning the consumer organization

It is good to hear about other people's experiences, and not to feel so isolated, like (another group participant) was saying, that, your life does totally change. And you know, you can just feel a bit pissed off about it, sometimes? Until you find out that you're not the only person.
Mother no. 11, consumer organization
It was really good to talk to them, and get lots of normal information, you know, everyday information? And also, to put your little family, into perspective, with the bigger picture? Of how serious it can be, and how, possibly serious, (my son's allergy) <i>isn't</i> ?
Mother no. 24, allergy clinic
I think we probably know a lot more, than a lot of people out there, who have kids who are anaphylactic, because we keep in touch with all these people.
Mother no. 5, allergy clinic
I think they do a lot of good stuff, but I actually do think they scared a lot of people too, to start with...it took a little while, but I started to work out that (avoidance of casual contact) was a bit of an overreaction and maybe an overexaggeration, and that they needed to be very clear about every case (being) different?
Mother no. 36, allergy clinic
I said but, you know this is all very new to me, and she just, absolutely bamboozled me, with you know...my kids allergies are bigger than yours (laugh) I just thought, no, I can't. I don't want to, I thought that she would make me more anxious, than anything else, so I just didn't (join them).
Mother no. 1, allergy clinic

the study had high levels of tertiary education, comparable with the 70.9% rate of post-school qualifications in the NSW population between 24 and 54 yr (13–15). Notably, the proportion of parents in both groups with occupational backgrounds in health or education (including nursing, medicine, dentistry, dietetics, psychology and childcare), is higher than in the general population. In NSW, 10.4% of females have occupational training and 21.1% are employed in the health and education sectors (14). It is possible that this is typical of families who attend specialist paediatric clinics, but there were no data to confirm this. It appears that parents who seek specialist paediatric food allergy services tend to have a professional interest in children's health and welfare, which may influence their health information needs and demand for services.

Allergy clinic families were more likely to self-identify with a non-English-speaking cultural background. This may influence the types of allergies that are likely to be found (16, 17), and ability to seek alternative sources of health information. For example, the English proficiency of six AC parents meant that their responses required continual clarification during interview and none had heard of the CO. The predominance of metropolitan residence in CO parents is an artefact of the sampling procedure, but also reflects the geographical reach of specialist clinics, which include rural and remote regions. These differences suggest that AC families may be pre-disposed to have less access to health information.

Consumer organization families reported a greater number of allergies, including nut, egg and milk allergies. This may be because families with more severely allergic children are more likely to seek the support offered by a CO, or that CO parents tended to report allergies on the basis of skin testing, as the questionnaire did not ask participants which allergies had been confirmed by clinical reactivity or formal challenges. The presence of multiple, and nut allergies may increase anaphylaxis risk (18, 19) and could explain the universal possession of autoinjectors in CO families. However, CO parents were no more likely to report anaphylaxis or acute allergic reactions in their children. This could be due to effective allergen avoidance or similar clinical sensitivities in children across the two groups. In Australia, autoinjectors can be purchased without a doctor's prescription, and as medical opinion regarding the appropriate prescription of autoinjectors varies (20, 21), it cannot be assumed that possession of an

autoinjector indicates a particular level of allergy severity, with some parents stating that they had obtained an autoinjector after learning about them through the CO. While CO recruited families may be skewed towards those with children who are more highly allergic to food, it is also possible that membership of a CO is a factor in the decision to obtain an autoinjector.

Although not a statistically significant difference, of interest was the number of parents who reported deliberately trialling a food at home. The qualitative data revealed that in at least three AC families this was against medical advice. The lower proportion of CO families who reported doing so perhaps reflects a greater awareness of the risks. Concurring with this interpretation was the greater likelihood of CO parents being more informed by a range of information sources, including parent education sessions, dietitians, nurses and the CO, as well as the internet, friends and family. The significantly lower proportion of AC parents receiving substantive amounts of information from clinic sources reflects a lower reported rate of referral to education and dietetics services. This contrasts with the high proportion of all parents who sought and received information from the internet, suggesting that parents needed more information than had been provided elsewhere.

The great majority of parents in both groups reported receiving substantial amounts of information from their current allergist. However, a notable proportion had also sought second opinions, with CO parents more likely to have done so. The qualitative data suggests that unmet information needs were a key reason for seeking another opinion, with families seeking out allergists who were more informative. Less than half of the parents in both groups reported receiving substantive information from their general practitioner (GP) or non-allergy specialist. These findings agree with research on health COs, where members are often united by unsatisfactory experiences with health professionals, and the desire to improve awareness and diagnosis in primary care (22). The CO parents in this study may therefore represent a subgroup of parents attending clinics who tend to be more proactive in their search for information and engagement with health service providers. This sense of self-efficacy has been reported by patients to be a result of CO membership (23). A prospective study found that parental awareness of the CO was a significant factor for correctly recalling the procedure for administering an adrenaline autoinjector (24), and our study suggests that

this may be related to a greater interest in, and ability to, find health information outside of that provided by the clinic.

Members of health COs report the benefits of membership as being greater disease knowledge and psychological support, and reduced isolation, with a minority reporting negative effects, such as pre-occupation with the disease and association with severely affected persons reported by 1–4% of members (23). Our study confirms that this range of effects occurs in an allergy CO, as well as in non-members. In addition, for some parents, contact with more severely affected children was reassuring. However, it appears that families recruited from COs have important differences from those attending ACs, with implications for the generalizability of research conducted in one group to another.

Increasingly, COs are involved in the design and conduct of research (25), but the representativeness of their members to all consumers with the same condition has been questioned (26), with members often being well educated, middle class professionals (22). However, parental expertise may be invaluable in evaluating the quality of paediatric services (27, 28), particularly if, as in our sample, there is experience of different health services. Importantly for health service improvement, the qualitative data revealed that information provision was a key issue for all families, and CO families were more able to describe the specific information that parents required. Conversely, if CO families have children who are more highly allergic, then their reaction experiences may not be generalizable to other groups. For example research on self-reported reactions to peanut during airline travel in CO members (29) may not be applicable to the general clinic population. Lending weight to this proposition, systemic reactions to inhaled and topical peanut have not been reproduced in children recruited from clinics who were selected for their likelihood to have such reactions (30).

Limitations of the study

The aim of this study was to describe attributes of families with food allergic children recruited from different sources, rather than to compare clinic populations with CO members *per se*. The qualitative data showed important effects from contact with the CO, but the study did not find, and was not designed to measure differences in outcomes such as the severity and the frequency of reactions as a result of this contact. The study was conducted in discrete settings with a selected population; therefore its applicability to other

settings is untested. However, despite the restricted sample, and a minority ($n = 5$) of AC recruited families also being CO members, there were sufficient differences for statistical significance to be achieved for some attributes. There are several alternative explanations for the observed differences. One is that the study findings are based on parental recall and perceptions and these may differ systematically between the two groups. However, self-reports are typical of studies conducted with CO members (3–5). Another is the time since diagnosis; as AC recruited families included those who were newly diagnosed, it could be expected that these families would have accumulated less information. However, nearly a third of AC families had sought second opinions, and the younger age range of children from CO families does not support a longer time period since diagnosis. A larger sample would allow multivariate analysis of these factors and confirm preliminary findings such as the practice of trialling foods at home.

Conclusions

This study has provided evidence concerning the similarities and differences between families recruited from a CO and from ACs. Families were similar in parental age, educational level and occupational backgrounds with nut allergy being the most commonly reported allergy. Families recruited from the CO may be better informed about food allergy and its risks, and have children with more severe allergies. Knowing the characteristics of both groups can assist clinicians to apply research findings to families presenting to their clinical service. Parents report a range of effects from contact with an allergy CO. On balance parents view contact as beneficial, so all parents should be given the opportunity of joining such organizations to supplement the information and support provided through ACs. Clinicians may need to guide parents to those aspects which are likely to be helpful, such as information about daily management. The benefits of consumer group membership may be more apparent for knowledge levels, satisfaction and quality of life, rather than for outcomes such as reaction severity and frequency.

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