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ABSTRACT

Introduction: Food-induced anaphylaxis is a serious and potentially fatal reaction occurring in individuals with severe food allergies. A questionnaire study conducted at RPAH recently investigated a range of issues regarding the management of children at risk of anaphylaxis (Cohen, 1999)¹.

Aim: To identify the main issues that arose from the questionnaire survey and explore them in greater detail using focus group methodology.

Methods: Conducted in three parts: **I.** After comparison, 25 late questionnaires were pooled with those collected by Cohen, and the total of 237 re-analysed. **II.** Thirty participants were sent 3 questionnaires (General Health Questionnaire, GHQ; State and Trait Anxiety Index, STAI-X; and Eating Disorder Inventory, EDI). A Parenting Stress Index questionnaire (PSI) was also administered. **III.** Five focus groups were conducted. The discussion was taped and analysed for main themes.

Results: **I.** Findings supported those of Cohen. **II.** Analysis of GHQ, STAI-X, and EDI indicated that the eating behaviour, and psychological status of participants was within the normal range. Mean PSI (251.3) was higher than normal population (222), suggesting that there are issues and concerns facing parents in the management of food allergies. **III.** The focus groups revealed valuable information, under the four main themes: (i) Family and social support. (ii) EpiPen® use. (iii) Food labelling, and (iv) Education.

Discussion: The results highlighted the need for better information for parents, and educational programs directed at: schools; the food industry (manufacturers and hospitality); and the medical profession (doctors, nurses, and other specialists).

¹ D. Cohen. Management of Children with Food-Induced anaphylaxis. (MNutDiet dissertation) Human Nutrition Unit, Department of Biochemistry, University of Sydney. June 1999.

INTRODUCTION

Food allergies affect approximately four to six percent of infants, one to two percent of children, and less than one percent of adults (Swain et al, 1996). There are different types of allergies, and a range of manifestations. Broadly defined, a food allergy is an abnormal immune response to a food protein. Anaphylaxis is the most serious food allergy reaction, and can be fatal if emergency treatment is not administered promptly.

Food allergy

Food allergy reactions are characterised by the presence of high levels of food protein specific immunoglobulin (IgE) antibodies in individuals with allergies (Snyder and Poland, 1993). Sensitisation usually occurs early in life when weaning foods are first introduced, or more often when protein fragments absorbed from the mother's diet are transmitted to the infant via breast milk, resulting in the production of IgE antibodies (Cohen, 1999). The foods most likely to cause an allergic reaction in children are nuts, eggs, cow's milk, and fish. Peanuts and tree nuts are especially of concern since they were the allergen implicated in most of the first serious reactions in all age groups, from the questionnaire survey (Tables 12-15). Another study found that peanuts and tree nuts were responsible for 5 of 7 near-fatal and 10 of 13 fatal food-induced anaphylactic reactions (Sicherer et. al, 1998).

The allergy becomes evident subsequently when the child comes into contact with the allergen that they have been sensitised to, which results in the activation of mast cells and release of histamine and other mediators (Snyder and Poland, 1993). This release can manifest in many different ways, including gastrointestinal, respiratory, and skin related responses.

Anaphylactic shock

The most serious form of food allergy is anaphylaxis. An anaphylactic reaction can involve a number of symptoms, such as: urticaria and angioedema, dyspnea, wheezing, dizziness, hypotension, nausea, vomiting, diarrhea, cramping, flush, upper airway edema, headache, and rhinitis (Middleton et. al, 1998). Adrenaline is the

preferred first line treatment in the event of an anaphylactic reaction (Fisher, 1995). However, due to the rapid onset of symptoms adrenaline should be self administered in the form of an EpiPen® (a pre loaded dose of adrenaline), before reaching medical attention.

ISSUES IN MANAGING FOOD-INDUCED ANAPHYLAXIS

There have been few studies that have investigated the issues relating to the management of severe food allergies. Some aspects such as the use of adrenaline, schooling, and hospital emergency cases of anaphylaxis have been explored (Sampson 1992; Yunginger 1988; Stewart 1996). The findings of these studies formed the basis for the present research (in particular a recent study conducted by Cohen, 1999), and reinforced the need to develop a greater understanding of the circumstances surrounding the management of such a condition.

Emergency treatment

Previous studies have found that fatal reactions are more likely to occur outside the home, and in the absence of available adrenaline (Vickers et. al, 1997; Sampson et. al, 1992). In one study examining thirteen cases of anaphylaxis, of the six patients who died only two received adrenaline within the first hour. This was compared to the patients who survived, where all but one received adrenaline within thirty minutes after the onset of the reaction (Sampson et. al). Anderson (1997), observed from case studies, that the rate of survival in the event of an anaphylactic reaction was directly related to the time at which adrenaline was administered.

One of the main findings from Cohen (1999), was the anxiety respondents had in relation to the EpiPen®. This could lead to parents being reluctant to use the device in an emergency situation. One of the aims of the present study was to explore reasons for this anxiety in order to develop strategies to overcome these problems. Other research studies have found that parents are not aware of the correct procedure for administering the EpiPen®, resulting in ineffective treatment (Huang, 1998).

Education and schooling

In many cases, starting school can be a very stressful time for parents. This has been highlighted as an issue of particular concern in the management of food allergies, since it has been documented that day care centres, pre-schools, and schools have not always been supportive of the needs of the child (Cohen, 1999).

The preventative measures implemented by schools is an area that requires further exploration. In some countries, the problems encountered by parents of children with severe food allergies have been identified, and policies have been put in place in the school system to address their concerns. There has been minimal research conducted to investigate the Australian school system in relation to institution of preventative measures, and identifying problems parents are encountering. In particular, medication and the use of the EpiPen® has been raised as a possible difficulty in the school environment, for the child, parent, and teachers involved (Vickers et. al, 1997).

Hospital and emergency

Often the hospital is the initial place of medical contact for parents following their child's first anaphylactic reaction. Evidence suggests that anaphylaxis is a condition that is under-recognised by the medical profession. Klein et. al (1995) found that while four patients were diagnosed as having an anaphylactic reaction, another thirteen patients presenting with clear symptoms of anaphylaxis were not recognised as such. Other studies have examined the role, route, and dose of adrenaline (Hughes and Fitzharris, 1999; Fisher, 1995).

Social impact of food allergy and food-induced anaphylaxis

Few studies have investigated the impact that a severe food allergy has on social and family life. The most recent finding by Cohen (1999), suggests that parents are avoiding some social occasions on account of their child's food allergy, and the present study aims to explore the reasons for this in more detail.

AIMS

Food-induced anaphylaxis is a serious form of food allergy, which can be fatal if appropriate treatment is not administered. There are many issues and circumstances involved in managing a child at risk of anaphylaxis. The **overall aim** of this project was to identify the main issues arising from the previously conducted questionnaire survey (Cohen, 1999) and explore them in greater depth using focus group methodology.

SPECIFIC OBJECTIVES:

To assess:

1. Psychological status of the parents of children with a history of food-induced anaphylaxis.
2. Whether these parents have higher stress levels than the normal population.

To describe:

3. Areas of concern parents have in managing their child's food allergy.
4. Parental attitudes and practices in using the EpiPen®.
5. Parental anxieties and barriers to using the EpiPen®.
6. Parental strategies employed in the management of food allergies, within the context of family and social life.
7. Strategies parents believe would reduce the stress and anxiety involved in managing children with severe food allergies.

METHODS

This research project was conducted in three parts, which will be outlined in the following sections as:

- Part I: Questionnaire survey
- Part II: Recruitment of parents for focus groups, and questionnaires
- Part III: Focus group methods and procedures

PART I: QUESTIONNAIRE SURVEY

Twenty five late returns were received from the questionnaire survey, conducted by Cohen (1999). These questionnaires were first analysed using the same methods to ensure consistency between the two sample groups. The analyses conducted were frequency distributions and descriptive statistics, using the Statistical Package for Social Scientists (SPSS® for Windows, release 8.0, Chicago: SPSS Inc, 1998).

Since the results from the 25 questionnaires were comparable to the previous 212 analysed, it was considered valid to pool the two groups together. The findings of the total 237 sampled were tabulated, and are included in the appendix (F-S).

PART II: RECRUITMENT and PRE FOCUS GROUP PROCEDURE

Recruitment

As part of the questionnaire survey, parents were asked to indicate their interest in participating in a focus group study. Those parents who expressed interest were contacted by phone. The aim of the study and what would be involved was explained, and the group times and venues outlined.

Following phone contact, the parents who agreed to participate were sent a package containing the following:

- An information sheet, confirming details of the study, venue, date, and time of the focus group session that was chosen by the participant (Appendix A)

- A series of validated questionnaires utilised to address eating behaviours/attitudes, and current psychological status, (Appendix C)
 - ⇒ Eating Disorder Inventory (EDI)
 - ⇒ General Health Questionnaire (GHQ)
 - ⇒ STAI-X (State and Trait Anxiety Index)

The participants were asked to fill in the questionnaires at home, and bring them to the focus group. In addition, a Parenting Stress Index (PSI) questionnaire was administered before the commencement of each group session.

Questionnaires

Eating Disorder Inventory (EDI)

The EDI consists of sixty four questions, which aims to recognise preoccupation of body weight or other eating disorder psychology (Garner and Olmsted, 1984). There are eight individual subscales targeting different areas, with each receiving a score to measure:

1. Drive for thinness (high scores indicate preoccupation with weight and dieting)
2. Bulimia
3. Body dissatisfaction
4. Ineffectiveness (measures insecurity and feeling of lack of worth)
5. Perfectionism
6. Interpersonal distrust (hesitation to form close relationships or express emotion)
7. Interoceptive awareness (inability to identify own emotions)
8. Maturity fears (measures the desire to return to the safety of childhood)

General Health Questionnaire (GHQ)

This is a self administered twenty eight item questionnaire, with the aim of looking at short term changes in psychological status (Goldberg). The four scales measured are: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression.

STAI-X (State and Trait Anxiety Index)

This questionnaire was used to explore anxiety in participants (Spielberger et. al). State anxiety looks at current tension, nervousness, worry, and apprehension. Trait anxiety identify's a participants disposition to respond to psychological stress and their anxiety tendency.

Parenting Stress Index (PSI)

The PSI is used to identify parent-child systems that are under stress (Abidin, 1995). A parent score of ≥ 260 for total stress generally indicates a need for professional guidance. The total stress score is a combination of two domains:

1. Child domain: high scores in this domain suggest the characteristics and behaviours of the child are making it difficult for the parent to fulfil their parenting role. The child domain has six subscales that identify the child's distractibility and hyperactivity (DI), adaptability (AD), their ability to reinforce the parent (RE), demandingness (DE), mood (MO), and acceptability (AC).
2. Parent domain: high scores in this domain suggest that the stress in the parent-child system is attributable to parental factors. The seven components within this domain are competence (CO), isolation (IS), attachment (AT), health (HE), role restriction (RO), depression (DP), and spouse (SP).

Scoring and Analysis of Questionnaires

The questionnaires were scored according to their specific scoring system. The GHQ, STAI-X, and EDI were scored via appropriate computer programs. The PSI was scored manually, and descriptive statistics were performed.

PART III: FOCUS GROUP METHODS AND PROCEDURES

Focus group technique and limitations

A focus group is defined as a group interview — centred on a specific topic ('focus') and facilitated and co-ordinated by a moderator or facilitator — which seeks to generate primarily qualitative data, by capitalising on the interaction that occurs

within the group setting (Sim, 1998). Focus groups allow the opportunity to recognise main themes, as well as a range of thoughts and feelings within a particular subject matter. The limitation that results from focus group methodology is the inability to determine how group dynamics will affect the discussion, or if the interactions that occur between the participants places a bias on the outcome. Such biases can be minimised by identifying main themes which recur frequently in different groups.

Focus group locations and participants numbers

A total of thirty parents participated in five focus groups. The groups were conducted in different areas of Sydney, in order to make it convenient for participants to attend a session of their choice. Two groups were conducted at the Royal Prince Alfred Medical Centre, one at Westmead Hospital, one in St Ives, and one in Castle Hill.

Each group consisted of four to eight participants. It was decided that the first two groups would have a smaller number of parents, to give the researchers an opportunity to become familiar with running an effective focus group session. The group location, date, and number of participants are summarised in table one.

Table One: Focus group location, date, and number of participants

Location	Number of parents	Date
1. RPAH	4	22/08/99
2. Westmead Hospital	4	26/08/99
3. St Ives	8	29/08/99
4. RPAH	7	02/09/99
5. Castle Hill	7	09/09/99

Subjects

Parents were members of the Food Anaphylactic Children's Training and Support (FACTS) group, and/or had a child who had been previously assessed at the Allergy Unit.

There were thirty parents involved, with twenty nine children between them:

- The children had range of allergies (peanut, milk, egg, fish, and sesame were all represented). The average number of allergies per child was three. Nine children had outgrown one or two allergies, but only one child had completely outgrown all allergies.
- The children ranged in age from 2 to 17 years.
- The majority (76%) of the children had experienced one or more major anaphylactic reactions.

The subjects participating in the study represented different situations and stages that are faced by parents and families. As a result, the insight gained from the focus groups consisted of a full range of experiences in managing food allergies. The diversity of the group ensured that the main attitudes and opinions given were not from just one particular sub population, validating the findings of this research study.

Interview Schedule

The questionnaire survey that was conducted by Cohen (1999) (Appendix B) formed the basis of the focus group questions, which sought to explore areas of special concern. The questions were developed in collaboration with the physicians and dietitians at the RPAH Allergy unit, and the President of the FACTS group (Appendix D).

The parents were asked to comment on:

- Concepts of and attitudes to anaphylaxis
- Issues relating to EpiPen®
- Prevention and impact the food allergy has had on their family and social life
- The child's schooling and education

Focus group procedure

Prior to the commencement of the discussion verbal consent was obtained from the participants to tape record the session and take notes. An information statement was read out (Appendix A) to explain the process, to reinforce that taking part was voluntary, and to give assurance that the data would be kept confidential. Each session ran for approximately fifty to ninety minutes, depending on the size of the group.

Analysis

Data was analysed by listening to the audiotaped discussion. Partial transcription took place, and extensive notes were developed. The issues were categorised into main themes, and a range of attitudes, opinions, and experiences were recorded. One focus group was fully transcribed to ensure consistency, but due to time constraints this could not be done for all five.

Ethical approval

Ethical approval was received from the Ethics Review Committee (RPAH Zone) of the Central Sydney Area Health Service.

Presentation of findings

To maintain consistency with the methods section, the results and discussion sections of this paper will also be presented as Parts I, II, and III. Due to the nature of the research conducted, the findings for Part II and Part III are better presented by combining the results and discussion within each section.

RECRUITMENT OF SUBJECTS

1. Questionnaire study asked participants to indicate if they would be interested in a focus group study
2. Those who expressed interest were contacted by phone and asked if they would like to participate. Participants selected time and venue that was convenient



PACKAGE SENT

Containing:

Information sheet and confirmation of time, date, and venue for the focus group

General Health Questionnaire

STAI-X (State and Trait Anxiety Index)

Eating Disorder Inventory

Reminder call made two days prior to group to confirm numbers



DATA COLLECTION

- i. Late questionnaires were returned via mail
- ii. Participants brought questionnaires to their group, and also filled in a parenting stress index questionnaire before commencing session
- iii. Focus groups were taped and scribed notes taken, with permission from the participants



DATA ANALYSIS

Figure 1: Diagram of Study Methodology

PART I: QUESTIONNAIRE RESULTS

Following the study conducted by Cohen (1999), a further 25 questionnaire's were received past the due date which have been analysed utilising the same methods. These results will be reported here in similar format to ensure consistency, and as a background for the more detailed information that was asked from the focus group participants. These calculations are combined with Cohen's results in the appendix section of this paper (Appendix F-S).

GENDER AND AGE OF SUBJECTS

In the group of 25 surveyed, 68% were male and 32% female. The mean age was 6.5 years, ranging from 1 to 16 years of age.

FOOD ALLERGIES

There was a range of allergies reported in the questionnaire, diagnosed either by a skin prick test (SPT) or a radioallergosorbent test (RAST). Present and outgrown (past) allergies are outlined in table 2.

Table 2: Present and Past Food Allergies

Food Allergy	% Current (N=25)	% Past (N=25)
Peanut	68	4
Egg	44	12
Dairy	32	36
Tree Nuts	28	4
Soy	20	8
Sesame	16	8
Fish	16	12
Shellfish	8	0
Wheat	4	8

Of the 25 children, 82% were allergic to more than one food, while 39% also suffered reactions to other foods not specifically tested for. Other problem foods reported included: frankfurts, meat, poultry, BBQ sauce, banana, peas, prawns, sunflower seeds, oats, and rye.

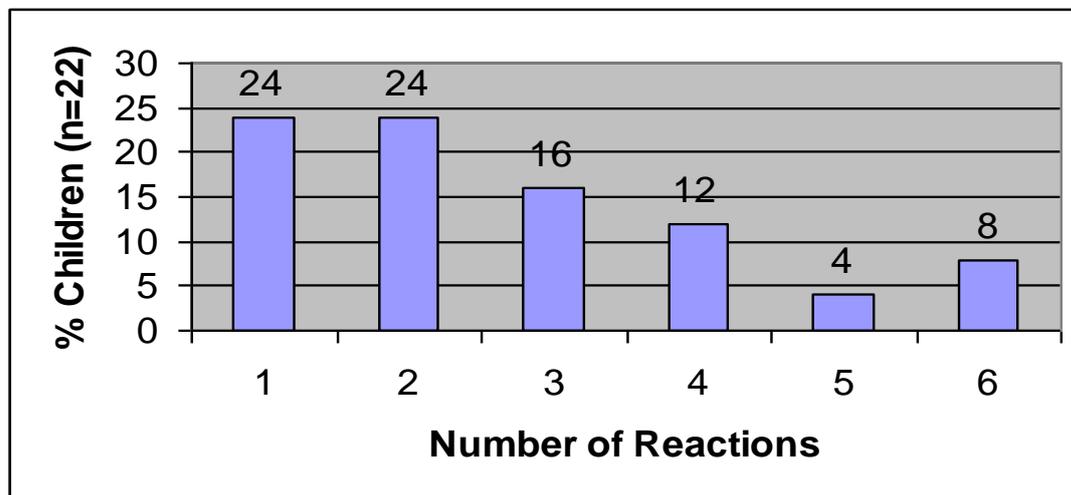
OTHER ALLERGIC CONDITIONS

In addition to the food allergies, the majority of children also have recurrent episodes or previous symptoms of eczema (75%), asthma (71%), and rhinitis/hayfever (39%).

ANAPHYLACTIC REACTIONS

Of the 25 children, 22 had experienced at least one anaphylactic reaction (88%). Three children had not experienced an anaphylactic reaction (12%). A total of 59 (22 initial and 37 subsequent) reactions were reported between the 22 children where the average age of the first reaction was 11 months, while for second reactions it was 2.7 years. The number of reactions per child is shown in figure 2.

Figure 2: Number of Anaphylactic Reactions Per Child



LOCATION OF REACTIONS

The locations where the reactions took place are outlined in table 3. Other locations reported include: shopping centre, beach, hotel, restaurant, hospital, and car.

Table 3: Location of Reactions

Location	% Initial (N=22)	% Subsequent (N=37)
Child's home	63.6	43.2
Home of friend or relative	9.1	24.3
Day care/preschool/school	4.5	13.5
Other	22.7	18.9

PRINCIPAL CARER

The principal carer of the child when the reaction occurred is shown in table 4. In both the initial and subsequent reactions the main carer (77.3% and 54.1%) was the child's mother.

Table 4: Principal Carer at time of Reaction

Principal Carer	% Initial (N=22)	% Subsequent (N=37)
Mother	77.3	54.1
Both parents	18.2	18.9
School staff	4.5	10.8
Father	0	5.4
Grandparents	0	5.4
Doctor	0	5.4

FOOD TRIGGERS

Food allergens that were responsible for the initial and subsequent reactions are listed in table 5. Since many children are sensitized to more than one food, it was not always the same type of food that caused the second or third reactions. In most cases the parent was unaware of the child's allergy to that particular food.

Table 5: Foods involved in causing anaphylactic reaction

Food	% Initial (N=22)	% Subsequent (N=37)
Peanut	40.9	27
Cows milk/dairy	22.7	21.6
Egg	9.1	5.4
Fish	9.1	10.8
Sesame	9.1	0
Soy	0	2.7
Goats milk	0	2.7
Unknown/other	9.1	29.7

Of the food allergens causing the initial anaphylactic reaction, 72.7% were consumed as a part of a commercially prepared product (59.1% packaged; 13.6% not packaged), 13.7% were consumed as the whole food, and 13.6% as an ingredient within a homemade food. Of those foods involved in the subsequent reactions, 73% were consumed as part of a commercially prepared product (59.5% packaged; 13.5% not packaged), 16.2% as whole food, and 10.8% as an ingredient within a homemade food.

Table 6: Types of Food

Type of Food	% Initial (N=22)	% Subsequent (N=37)
Peanut Butter	31.8	18.9
Dairy (other than milk)	18.2	16.2
Whole (eg. Milk, egg, nut)	13.6	21.6
Meat or Vegetable dish	13.6	13.5
Confectionery	9.1	8.1
Savoury snack	9.1	5.4
Baked product (eg. Bread)	4.5	8.1
Unknown	0	8.1

In initial reactions, 90.9% of the foods were knowingly consumed since, at that stage most parents were unaware of the child’s allergy. In subsequent reactions, 59.5% of foods were knowingly consumed, but in over half the cases (54.1%) it was not the same allergen that caused the initial reaction. The other reactions took place following accidental exposure to a known allergen or deliberate challenge.

ROUTE OF EXPOSURE

In most instances the anaphylactic reaction followed after the allergen was swallowed/ingested. In some cases where the child was highly sensitive even contact with the food allergen on the child’s skin, around the eye area, or inhaling the allergen was enough to cause a serious reaction. Route of exposure is shown in table 7.

Table 7: Route of Exposure to Food Allergen

Route of Exposure	% Initial (N=22)	% Subsequent (N=37)
Swallowed	77.3	83.8
Skin contact	13.6	10.8
Skin and eye	4.5	0
Eye contact only	0	2.7
Unknown	4.5	2.7

EMERGENCY TREATMENT

Administration of adrenaline in response to a reaction before medical intervention, occurred in only 22% of total reactions (13.6% in initial and 21.6% in subsequent reactions).

The most common reason (81.5%) for not using adrenaline was that it had not been prescribed, since most only became aware of the allergy as a result of the reaction. Other reasons for not using adrenaline were: symptoms had subsided (10.2%); fear and uncertainty (3.4%); EpiPen® prescribed but not yet purchased (1.7%); used other medication (1.7%); and adrenaline not on hand (1.5%).

In reactions where some form of adrenaline was used, an ampoule of adrenaline and syringe was used in 6 cases, an EpiPen® in 3 cases, and a metered-dose inhaler in 3 cases.

Other medication used before medical treatment included oral antihistamines (37.3%), ventolin (8.5%), and corticosteroids (3.4%).

An ambulance was called in 10.2% of cases, and 33 visits (55.9% of total reactions) were made to a hospital or doctor. Of those children that were taken to a hospital or a doctor, adrenaline was used in 25.4% of cases as part of the treatment given.

ADRENALINE

In this sample of 25 surveys, every participant reported having one or more EpiPen® syringes in case of a reaction. In addition to an EpiPen® one also had an ampoule and syringe, and one has a nebulizer and ampoule.

The average number of EpiPen® syringes per household was two, and 72.7% of parents said that at least one EpiPen® was with the child at all times. Reasons reported for not always having an EpiPen® with the child: too young and not needing it in certain situations. The questionnaire asked participants to indicate who knew how to use the EpiPen® in case of an anaphylactic reaction. These are listed in table 8.

Table 8: People Who Know How to Use the EpiPen®

Person	% Response (N=25)
Child's Mother	100
Child's Father	95.5
Day care/Preschool/School Staff	72.7
Child	54.5
Other relatives	31.8
Friend	13.6
Babysitter	9.1

Participants were also asked about the training and advice they received in relation to the EpiPen® and its use. Most (90.9%) were shown by a doctor or nurse, had practiced with a trainer (81.8%), had received written material (59.1%) and/or had watched a video (22.7%). With regard to the training experience, 86.4% said it was very useful, 9.1% fairly useful, and 4.5% did not think it was useful. Only 18.2% of the participants received assistance in training others to use the EpiPen® (such as school staff and relatives).

The questionnaire asked how anxious the parents felt about using the EpiPen® in the event of an anaphylactic reaction. Some were very anxious (13.6%), others moderately anxious (31.8%), somewhat anxious (22.7%), and not at all anxious (31.8%). When asked how confident they were about the EpiPen® as treatment for their child, 72.7% were very confident, 22.7% moderately confident, and 4.5% indicated that they were not at all confident.

DAY-CARE/PRE-SCHOOL/SCHOOL

Of the 25 children in the survey, 72% attended either a day-care, preschool, or school. In all cases staff were aware of the child’s allergies, and in the majority of places (72.2%) there was an emergency action plan outlined to manage a reaction and/or policies set up in order to prevent the possibility of accidental exposure.

Participants were asked about the measures that were in place at their child’s centre or school that decreased the risk of an anaphylactic reaction.

Table 9: Measures Promoting Prevention at Day-care/School

Preventative Measure	% Response (N=25)
Information about child displayed	72.2
Children taught not to share food	50.0
Information sent home to parents	38.9
Day-care/Preschool/School allergen free	33.3

The questionnaire also asked how much support the parents felt they were receiving from the centres and schools involved with their child’s education. The overall opinion was that day care centres, pre-schools, and schools were very supportive (83.3%) of the child with food allergy; 5.6% were moderately supportive; 11.1% were somewhat supportive. There were no respondents that indicated there was no support at all. Although many centres and schools were considered supportive, 27.8% of respondents had been denied access at some stage in their child’s education, and 11.1% felt that the presence of the food allergy had compromised their child’s schooling to some extent.

NUTRITIONAL IMPACT OF FOOD-INDUCED ANAPHYLAXIS

In terms of the diet changes that needed to be made as a result of the food allergy, 79.2% of participants felt that their child’s diet was nutritionally adequate. The nutrients that concerned parents most were calcium and vitamin C, and to a lesser extent vitamin A, fat, iron and B vitamins.

Also addressed in this area were any problems that had been experienced in providing substitutes for the foods that had to be eliminated from the child’s diet. The results from this question are listed in table 10.

Table 10: Problems Experienced in Providing Food Substitutes

Problem	% Response (N=25)
Expensive to buy	29.2
Difficult to find in shops	25.0
Difficult to prepare	25.0
Child refuses to eat	25.0
Time consuming	8.3
No problems	41.7

SOCIAL IMPACT OF FOOD INDUCED ANAPHYLAXIS

Of this sample 50% said that they felt anxious all the time when their child ate food outside the home, 20.8% most of the time, 16.7% some of the time, and only 12.5% said they never felt anxious when their child ate foods prepared outside the home.

Half the participants said that it was either somewhat (20.8%), moderately (20.8%), or very difficult (8.3%) to prepare meals that were safe and acceptable for the whole family. One quarter of the group said they did not avoid social occasions on account of the food allergy, although 58.3% said they did some of the time, and 16.7% avoided such occasions most of the time. In relation to eating out, 83.3% of respondents said they avoided the restaurant, café, and fast food environment.

FURTHER RESULTS

In addition to the results reported from the data collected from the questionnaires, information documenting the age and implicated allergen of the first anaphylactic reaction was generated. These results are listed below for the total survey sample.

Survey Sample: 237

From 237 there were 186 first reactions, therefore 79.5% have experienced at least one anaphylactic reaction.

Table 11: Age of First Reaction

Age Range (yrs)	% (N=186)
0-1	56
1-2	25
2-5	14
> 5	5

Table 12: Allergen in First Reaction

Allergen	% (N=186)
Peanut	48
Milk/Dairy	23
Egg	17
Other	7
Unknown	5

Within each age group a similar pattern developed where peanut was most commonly implicated in first reactions, followed by milk and egg. In the < 5 age group, egg did not cause any first reactions, and there were more unknown causes of anaphylactic reactions compared to other age groups. Tables 13-15 show the different age groups and the allergens that caused first reactions.

Table 13: Anaphylactic Reactions (0-1 yrs)

Allergen	% (N=104)
Peanut	40
Milk/Dairy	28
Egg	23
Other	6
Unknown	3

Table 14: Anaphylactic Reactions (1-2 yrs)

Allergen	% (N=46)
Peanut	52
Milk/Dairy	17
Egg	17
Other	9
Unknown	4

Table 15: Anaphylactic Reactions (2-5 yrs)

Allergen	% (N=27)
Peanut	70
Milk/Dairy	15
Unknown	11
Other	4

Of the 90 reactions due to nut allergies (48% of the total first anaphylactic reactions), almost three quarters (74%) occurred before the age of two years. Most (47%) were in the first year of life, 27% in the second year, 21% in the 2-5 year age group, and 6% in the over the age of 5.

PART II: QUESTIONNAIRE RESULTS and DISCUSSION

The purpose of the questionnaires was to determine whether having a child with severe food allergies has had an impact on the psychological status of parents, and whether it alters their eating behaviours and attitudes.

Eating Disorder Inventory

The results for the EDI subscales are shown alongside established norms in fig 3. The raw scores of the participants were within the normal range for seven of the eight subscales, with perfectionism showing a slightly higher value for the study population.

The EDI was used to assess the eating behaviours and attitudes of the parents involved in the study. The mean scores for all eight subscales were similar to the mean values of the normal population, indicating that this group had no abnormal eating behaviours or attitudes.

Even though the mean scores indicated no problems, it was observed that some individuals did score highly in certain areas. Seven participants scored highly within the body dissatisfaction subscale, with one respondent scoring 24, and two others scoring 23 out of a possible 27. Although these individuals may have some preoccupation with weight and dieting, it is unlikely that this is associated with their child's food allergy.

General Health Questionnaire

The GHQ is used to assess how an individual perceives their current general health. The questionnaire consists of four categories (somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression), each receiving a score out of seven. The total result is out of twenty eight. It is worth noting that even though the mean of the group is within the normal range, this questionnaire is designed to measure short-term changes in general health (ie. the past 3 weeks). This indicates that at the time of filling out the questionnaire there was no significant impact on the

general health status of the participants. The mean scores for each category are shown in table 16.

Table 16: General Health Questionnaire Results

Category	Mean Score (N=30)	S.D
Somatic symptoms	1.8	2.33
Anxiety and insomnia	1.5	2.01
Social dysfunction	1.3	1.69
Severe depression	0.3	0.94
Total	4.9	5.72

A total score of greater than 12, indicates that there may be a significant psychiatric problem. From the sample group of 30, five (16.7 %) of the parents scored higher than 12, two parents scored 11, one scored 10, one scored 9, and one scored 6. This suggests that there may be some underlying emotional problems within this group.

STAI-X (State and Trait Anxiety Index)

The STAI-X is used to ascertain whether participants are experiencing any current anxiety ('state'), or if they have a predisposition to be anxious ('trait'). The range of possible state and trait anxiety scores is between a minimum of 20 and a maximum of 80. The scores received by the participants were within the normal ranges (Table 17).

Table 17: STAI-X results

	Mean Score (N=30)	S.D
State	37.9	9.96
Trait	39.8	10.46

State anxiety is defined as a score of greater than 49, and trait anxiety a score of greater than 48. Four participants had scores of more than 49, suggesting that currently they are experiencing some tension, nervousness, worry, and apprehension.

Five participants scored greater than 48 for trait anxiety, indicating that they are prone to experiencing anxiety.

The results from the GHQ and STAI-X, suggest that at present these parents are no more anxious than the normal population, and their general and psychological health was not perceived as any worse than their usual.

Parenting Stress Index

The PSI is a combination of the two domains: child and parent. Tables 18 and 19 report the mean, standard deviation, and range in each of the sub-components. In both cases the mean for the participants was higher than that of the normal population, although the mean for total stress was below 260 (the score that indicates that some professional intervention may be needed).

Table 18: Child domain score, and its sub-components

Component	Mean (N=30)	S.D	Range
Distractibility and Hyperactivity (DI)	25.0	6.51	12-36
Adaptability (AD)	28.4	8.98	13-46
Reinforces Parent (RE)	11.3	4.21	6-26
Demandingness (DE)	26.1	6.09	14-35
Mood (MO)	12.0	4.29	6-22
Acceptability (AC)	13.1	3.75	7-22
Child Domain	115.9	25.03	67-180

Table 19: Parent domain score, and its sub-components

Component	Mean (N=30)	S.D	Range
Competence (CO)	32.2	7.31	20-46
Isolation (IS)	12.7	3.56	6-21
Attachment (AT)	12.5	2.99	8-19
Health (HE)	14.6	4.04	7-21
Role Restriction (RO)	20.5	5.58	8-31
Depression (DP)	22.3	5.60	9-31
Spouse (SP)	20.6	5.47	7-31
Parent Domain	135.4	24.26	77-181

The total stress index for the group was 251.3, with a standard deviation of 44.78, and a range of 157-352. For most of the sub-components, there was a wide range of scores which indicates different levels of parental stress from child vs. parent sources. The mean scores of the parents within this study were compared to those of the normal population, and are presented in figs 4 and 5. The mean life stress score (representing other major life events, such as a death in the family) was eight.

The PSI is an instrument that aims to identify stress within parent-child systems. The total stress score can give an indication of overall stress, due to the incorporation of all the subscales that make up the two domains. From this group of thirty parents, one third had a raw total stress score of greater than 260, indicating that they are experiencing significantly higher stress levels in parenting than the normal population. A further eight participants scored higher than the average, revealing that over half of this group are more stressed than normal.

These results suggest that there may be issues in managing food allergies that affect parental stress levels, even though general anxiety levels do not appear to be significantly elevated. Higher stress scores may also be due to personality traits, and as a result a particular individual may always have higher stress and anxiety despite receiving assistance with the problem at hand. The focus groups offered an opportunity to gain insight into some of the main issues and concerns surrounding the management of food allergies, identifying where some of the parental stress is originating. However, further research is required to explore how individual personality contributes to parental stress levels, in this setting.

PART III: FOCUS GROUP RESULTS and DISCUSSION

INTRODUCTION

The questionnaire survey aimed to investigate some of the issues involved in the management of children at risk of food-induced anaphylaxis. Several main issues were identified:

- Only a small percentage of reactions were treated using adrenaline
- Respondents reported that there was anxiety associated with use of the EpiPen®
- Day care centres, pre-schools, and schools were not always supportive, and some parents felt their child's education had been compromised as a result of having a food allergy
- Social occasions were being avoided by the participants

Having identified these areas of concern from the questionnaire survey, focus groups were conducted to obtain a greater understanding of the factors contributing to these problems.

The goal of this analysis was to recognise key themes and describe a range of responses expressed by the participants. From the groups conducted it became apparent that even though each parent was faced with a unique situation, many common issues emerged that were considered important in managing food induced anaphylaxis. This consistency allowed for the identification of main concerns faced by parents in both past and present experiences with their child's food allergy, and the following sections discuss these under four categories:

1. Family and Social support
2. EpiPen® use
3. Food labelling
4. Education.

1. FAMILY and SOCIAL SUPPORT

In a situation such as coping with food-induced anaphylaxis, family and social support is crucial. The focus group questions sought to explore some of the issues relating to family life, as well as the support received in the child's schooling. In addition to these two areas, unexpected insight was also gained into the attitudes and feelings that participants held towards the medical profession in assisting with severe food allergies. The findings are presented under four sub-headings:

- a. Family cooperation
- b. Social occasions and eating out
- c. School and education
- d. Medical staff and assistance

FAMILY COOPERATION

Overall, the participants in the focus groups felt that their families and friends were supportive, and were grateful for the assistance that they were receiving. However, many participants reported that when members of the extended family had witnessed an anaphylactic reaction first-hand, they became more vigilant than before in preventing accidental exposure to the food allergen implicated:

"They don't believe it till they see it." (#25, FG 5)

The way in which participants perceived the degree of support also varied, depending on the type of cooperation given by family and friends. Those that received more active support agreed that it assisted in relieving their stress:

"I've been fortunate. My son has a group of friends that he's grown up with. They all know, and as I've learnt, they've learnt." (#29, FG 5)

I'd say that we have had a pretty good run with 95% of family and 95% of friends. Anyone who wanted to have the kids to birthday

parties would really avoid having any peanut products at the party for the sake of one child. They've really been fantastic.” (#25, FG 5)

Others had not had the same experience. Even in company of friends and family they needed to be on full alert, increasing the stress in these situations:

“I suppose they're supportive, but I just feel they don't really understand the extent that it's life threatening if she has exposure to egg.” (#22, FG 4)

*“I thought I had explained it quite well to members of my family — in fact one of them works in a child care centre where there are children — and we went to a social thing, and there were the nuts!”
(#28, FG 5)*

Impact on Siblings

An unexpected finding was the concern parents expressed about the impact on their other children, and the way in which they adjust and cope with the situation. In four focus groups this issue was brought up without prompting as a crucial topic, exploring the way in which family dynamics impact on siblings when one child may need more attention, and the importance of this as a consideration in the management of a child with a severe food allergy. Participants commonly related stories of other siblings pretending to be unwell or being happy when they were sick, because it made them more like their brother or sister. Parents are aware that emotionally it can be hard for the other members of the family, and that some siblings take it on themselves to be responsible in caring for their brother or sister:

“She actually was touched by a child that had peanut butter on his hands at school the other day, and I was told she was in a mess ... (she went in) tears ... (to) the teacher (saying) that she'd been touched with peanut butter and (now) she can't touch her sister.” (#24, FG 5)

“My daughter definitely has anxiety about her brother’s allergy and (is) fearful. I’ve seen her little diary that they write, and she showed me that if she’s got a wish, it’s that he could grow out of his allergies. She checks on him at lunch times, and that’s lovely, but I don’t like to put that responsibility on her.” (#10, FG 3)

SOCIAL OCCASIONS

From the questionnaires it was revealed that half of the parents avoid social situations some of the time, while 15% avoided them most of the time, and a few (1.7%) all of the time (Appendix S). Specific questions asked in the focus group were designed to investigate why parents feel the need to avoid social occasions. Participants discussed that one of the strategies in reducing the risk of another anaphylactic reaction was to carefully select the ‘safer’ places to go. Even though they were generally appreciative of the efforts of family and friends, they found it too stressful to attend all events:

“... I guess I did limit our social activity quite considerably when he was very young and (in the) toddler years ... he just couldn’t be told, and he used to race around and grab everything ... I found that extremely stressful for him and the family situation, constantly saying no, no, no!” (#4, FG 1)

“We went to a BBQ a couple months ago ... and they were serving satay sticks, and I’m, like, I can’t believe it! These are close friends of ours who knew he was anaphylactic to peanuts.” (#30, FG 5)

In addition to the previous results, over two thirds (68.5%) of respondents avoid eating out. The main concern for parents was the risk of not knowing how the food was prepared (in terms of contamination), and the ingredients that were used. Some participants have been able to find a restaurant that will cater to their needs:

“We don’t eat out very often. Now and again we do, and we have found a Pizza Hut that is very accommodating ... he feels very special that he can eat out.” (#6, FG 2)

However, most admit that it is easier to eat at home where they are in control of menu selection and meal preparation.

Birthday parties were considered one of the biggest traps in managing and preventing anaphylaxis, since being out of the home parents felt they lose much of the control they have there. Many parents in this sample group of thirty talked about their homes being “allergen free” and the reduction in stress associated with this preventative measure. Some families do have the food that the child is allergic to in the home, in order to make the child aware of what these products look like, but they also have procedures in place to prevent accidental exposure. The experiences described with birthday parties ranged from:

- “no stress” (when the party was allergen free)
- parents attending the parties to directly supervise their children
- parents letting the child stay at the party without them, but sitting in the car around the corner prepared for action if necessary.

The overall feeling was that having a food allergy makes socialising more limiting for both the child and the parents. However, the participants were able to laugh at some of their experiences as they shared their stories.

In the family and social environment all of the participants were doing what they believed was necessary to reduce the risk of their children having reactions, and were using strategies that worked for their specific situation. They were educating their family and friends in order to increase their awareness about food induced anaphylaxis, and had explained the preventative measures needed when the child was in their company (especially if in another home). There was a range of comments made about how much support these parents felt they were receiving from family and friends, and the fact that there was at times a lack of understanding and skepticism as to how serious the problem actually was.

This aside, some family and friends do have genuine concerns about caring for the child with anaphylaxis. One parent described this well by saying:

“I’ve had (#6’s) son stay over-night, and we only had his peanut problem. In our house our son (is) peanut and egg anaphylactic, (which) catered for that. I found it so stressful having him over-night and being responsible for another child, and it gave me a lot of insight how our relatives and friends feel about that.” (#7, FG 2)

SCHOOL AND EDUCATION

School attitudes play a vital role in relation to parental stress. Most of the parents in the group spoke of the feelings that were associated with their child growing up and becoming more independent, and the anxiety associated with the loss of the controlled environment that is in place when the child was under their direct supervision. For this reason many found it difficult to face the school situation, and found it even harder when adequate support was not present:

“I’m actually even more nervous now as she gets older, because when she was younger I could control everything that she ate, whereas now I’m actually more nervous for her because she is exposed to more foods.” (#23, FG 4)

As with family life, there was a broad range of attitudes and experiences described by the participants in relation to pre-school, primary school, and high school. Although the children of these parents were at different levels of education, many common stories were expressed about present and past problems associated with their children going to school.

Of the twenty three schools involved, six of them have introduced policies for establishing an allergen-free environment for managing the needs of the child they have in their care (eg. no food out in the playground; allergen-free classroom; supervisors to watch the child). Such support enables a safe transition from home to the first stage of the education process. This is especially necessary in the toddler

years when the child is dependent on the understanding of an adult who is in control of their circumstances. For example, in one of the focus groups one parent talked about the precautions taken at the day care centre where her son attends:

“They give him his own chopping board, his own knife, his own butter and Vegemite.” (#29, FG 5)

Some parents decided to hold their child back a year giving them the opportunity to find a facility they were comfortable with, where the staff was prepared to deal with the problem. One of the main concerns parents stated was that the child’s needs were not taken seriously, increasing the likelihood of a reaction. Not surprisingly, participants were at times emotionally intense while discussing matters of education and schooling:

“That’s what frightens me the most, the fact that they don’t see it — they become blasé about it — and when they don’t see it they think ‘Oh its not a problem, it will be fine.’ You don’t want to see a problem — that’s the whole point of avoidance!” (#24, FG 5)

Some pre-schools, day care centres, and schools have cooperated well in accommodating such children and some of the experiences related within the groups acknowledged this. Many parents who had experienced problems previously were grateful for the relationship they had now developed with their schools. As in the family situation, it was often not until staff at the centre or school had actually witnessed a reaction that they changed policies and altered the way in which they managed the child, usually by implementing an allergen-free environment.

A finding of concern was that some parents avoided explaining anaphylaxis to the school, mainly because they did not want their child to be treated differently by others:

“I haven’t got any negative experience as far as school is concerned. I’ve probably not really ever mentioned the word ‘anaphylactic’ to start with. I’ve sent information about food allergies, but I haven’t gone into

any horrid details. I don't want my son to be singled out and seen as different — I want him to have a normal education and that's the risk I've taken.” (#1, FG 1)

Denial of Access and Lack of Cooperation

One of the aims of conducting focus groups was to explore the problems and concerns parents were having in order to develop possible solutions to eliminate the risk some parents are taking in concealing their child's allergy. From the various comments brought forward, two main factors emerged that contributed to the problems parents were experiencing in the school and child care system:

- (i) rejection or obstructionism at the centre or school, and
- (ii) issues surrounding the administration of the emergency EpiPen® treatment by staff.

(i) Rejection/obstructionism: On the occasions when a child was denied access to a facility, it was mostly at the day care and pre-school level of education. Those who were denied access or were having trouble reaching an understanding with the staff after they were accepted found it extremely stressful to cope, fearing that their child would miss the opportunity to develop social skills and early learning:

“He was too high risk, and no one would take the legal liability (of) having him on board ... I was very depressed at that time — you know, a real lack of support in the community, not finding the access to what I thought should be normal things for my child.” (#4, FG 1)

One of the issues facing parents was the reluctance of day care centres and pre-schools to make their facilities peanut-free (especially of peanut butter). Analysis of the questionnaires showed that peanut was the allergen that caused the greatest number of first anaphylactic reactions (Table 12), and 74% of the peanut reactions occurred before the age of two years (when attendance at day care and pre-school is frequent). Parents had commonly been told that other children would “starve” if they could not serve peanut butter, since this was the only food that they would consume:

“... and the reaction was, ‘Well other children don’t eat anything but peanut butter, they’re going to starve’...” (#2, FG 1)

Some were told that peanut butter would only be removed on the days that their child was present. However, this could still create problems due to contamination of the environment:

“...(you have to think about such things as) the touch and the residue on toys, on other children.” (#30, FG 5)

One parent reported that initiatives have been taken in other countries to protect allergic children at school:

“I lived in Canada most of my life, and I am very aware of schools there going anti-peanut —I’ve got a niece there who’s an anaphylactic child. They’re just not as open here, I mean people are just not informed and it’s going to be a long time before we see schools accepting.” (#25, FG 5)

Participants in this group wondered why, if other countries were taking action, they in Australia were still struggling to safeguard our children.

(ii) Staff attitudes towards the EpiPen®: Participants described a range of experiences. Some staff were willing to take emergency action if necessary, and in one case, where day care staff had to manage a reaction, the parent said they did “everything right” to assist her son’s recovery. In some schools certain teachers agreed to administer treatment whilst others refused, and the child was supervised and taught only by those particular teachers who were confident they could use the EpiPen® if needed.

By contrast, some centres would not undertake to administer emergency treatment, a situation which parents found frustrating and stressful:

“... (after) a lot of letter writing and legal consultation, (it) still came down to the fact that they would not guarantee any treatment would be given other than that provided by the ambulance.” (#13, FG 3)

In one focus group (FG 3) two of the parents were teachers and they spoke of the fear some of their colleagues expressed about repercussions that may occur if they administered treatment and something untoward happened to the child as a result. This is a logical concern for teachers who in many cases do not feel that this is part of their job description, and consequently they, too, require education, support and reassurance to increase their confidence. In the United Kingdom an Anaphylaxis Campaign has been running since 1994 with the aim of addressing areas where problems have been encountered, and within the school section a protocol has been developed for principal carers to outline the procedures that should be taken if a reaction occurs (Appendix E). Most importantly the protocol stresses that the council will indemnify teachers against negligence claims, if they act “within the scope of their employment, have been provided with adequate training, and are following the LEA’s guidelines” (Anaphylaxis Campaign: <http://www.anaphylaxis.org.uk/whom.html>).

The questions about education provided insight into situations where parents feel they lack support from the education system. From many of the comments made, it appears that one of the factors in making the school experience successful was the additional time, effort, and support given by the parent. Examples include going on school excursions, spending the first three weeks of the year at the school with the child, choosing smaller schools and schools with no canteen, and also providing allergen-free food for their child to eat when there are special occasions:

“Our school experience has been a good one. I think it’s been a good one because I’m always available (during) school hours. I’ve decided that I will do that for my child so that he doesn’t miss out on anything.” (#6, FG 2)

MEDICAL SUPPORT

The questions put to the focus groups did not ask about participants' experiences with the medical profession. However, without any prompting in four groups, and with minimal prompting in the fifth group, parents expressed an overwhelming need to discuss the lack of medical support that they had received.

General Practitioners

The common concern described by the majority of parents was the casual response of doctors when first consulted about the problem of food allergy. Often it took a long time (in one case three years) to find out exactly what the problem was, the range of allergens involved, and a medical practitioner who could provide appropriate support to reduce parental anxiety:

“... I visited my GP, and we talked about it. He was very casual about the whole thing ... he did say to me that there have been cases reported where the child needed a dose of adrenaline, but it was almost like: ‘It’s not going to happen to you so don’t worry about it...’”
(#2, FG 1)

“My son had his first reaction when he was twelve months old, but it took us another two years before doctors accepted the fact that this was serious.” (#6, FG 2)

It is noteworthy to mention that in the United Kingdom guidelines issued by the Department of Health advises doctors that if allergy is suspected, “every case should be referred to an allergy clinic ... to identify the degree of risk, should it exist.” (Anaphylaxis Campaign: <http://www.anaphylaxis.org.uk/whom.html>)

Participants felt that in many instances they had to explain to doctors what the term anaphylaxis meant, and that there was not enough guidance given about how to cope with the situation:

“I’ve found myself explaining anaphylaxis to a lot of GPs, and I really feel like there is a lot of medical people out there that just don’t know about it.” (#13, FG 3)

Specialists

The RPAH Allergy Unit statistics show that 90% of children with food allergies suffer from atopic eczema, and many parents had consulted a dermatologist for this. A common concern was the way in which dermatologists treated the problem, and the feeling these parents had towards them. The common view was that dermatologists were not accepting of the part that food allergy plays in childhood eczema, and their lack of appropriate advice made parents feel angry. They emphasised that without medical support, managing the problem and increasing the awareness of others is almost impossible:

“The dermatologist that I got referred to ... supposedly head of some school of dermatologists, said ‘diet played no part’.” (#20, FG 4)

“I was explaining to the dermatologist: ‘if you put milk on my daughter’s skin she will break out in hives’, and she was disbelieving me totally — ‘not possible, can’t happen’. (She) wrote a letter back to my doctor saying I was neurotic, (and) had no idea what I was talking about. I was furious, because if they’re not willing to accept it, it’s so much harder for the normal people out there to believe there is a serious problem.” (#1, FG1)

Hospital and Emergency Units

Some parents needed to take their child to an emergency department following a reaction, where problems occurred in receiving treatment and they felt that no one was in control of the situation. This issue was highlighted by the head of the Intensive Therapy Unit at the Royal North Shore Hospital, in a paper describing how an emergency department failed to effectively cope with his five year old daughter’s reaction:

“... my daughter and I were left alone in a cubicle ... I shouted for adrenaline ... no adrenaline forthcoming. Casualty officer fumbles through pages of a book to figure out adrenaline dosage ... child still having a lot of difficulty breathing — I do not wish in any way to criticise my colleagues ... but I think that the management of her acute anaphylaxis left something to be desired.” (Fisher 1995)

In some cases the hospital was the first contact parents had with the medical profession when their child had their first reaction. On discharge from hospital parents felt that they did not receive much information to advise them about the condition, the medication they should use for emergency treatment, and where they should go for specialist follow up.

Many parents also said that in their experience it was not only the doctors that did not appear to be confident in managing anaphylaxis, but that the nurses in Emergency Units were not attuned to the condition and its treatment. In one case the nurse did not have enough knowledge about the use of adrenaline as first-line treatment for a reaction, and rudely questioned the parent about the EpiPen® and the fact that someone had actually given it to her son:

“In the end I just yelled and said: ‘how dare you speak to me like this!’ — you know I’m stressed as it is, and I was in tears, and I was yelling at her because she had no idea.” (#8, FG 2)

In summary, parents felt that it was important to voice the problems they had faced in relation to the medical profession and nursing staff, and the anxious feelings that had resulted. The main issue, aside from the well being of their children, is the need for support and acceptance in order to make management of food induced anaphylaxis easier for parents as well as assisting in the education of others.

2. EPIPEN® USE

In the event of an anaphylactic reaction adrenaline is the preferred treatment, and should be administered before symptoms have progressed to the point where the outcome may be fatal. Sampson et. al (1992) documented the use of adrenaline in thirteen cases of anaphylaxis, and found that the six patients who died had symptoms within 3 to 30 minutes but only two received adrenaline in the first hour. All of the patients who survived had symptoms within 5 minutes and all but one received epinephrine within 30 minutes.

Of the 237 families surveyed in the present questionnaire study, a total of 362 anaphylactic reactions were reported. At the time of the initial reaction most parents were not aware of their child's allergy, therefore the EpiPen® had not yet been prescribed. However in the 176 subsequent reactions, when 88% of participants had an EpiPen®, it was only used as emergency treatment in 13 cases (3.6% of total reactions, or 7.4% of subsequent reactions; Appendix M). When asked whether parents felt anxious about using the EpiPen®, the majority felt either very, moderately, or somewhat apprehensive about using the device, whilst only a minority (17.7%) said they were not anxious at all (Appendix P). Since confidence in using the EpiPen® is crucial, it was considered important to identify the concerns parents have in relation to its use. The focus groups provided parents with an opportunity to express these concerns.

Attitudes towards the EpiPen®

In general most of the parents were grateful to have the EpiPen®, knowing that they had an effective emergency treatment on hand to tide the child over until medical assistance could be obtained. Some parents found that carrying an EpiPen® created additional tension, since it was necessary to educate all those that care for the child:

“(you’re) burdened with the bloody EpiPen®, because you’ve got to find people willing to administer it. (I) can’t leave (her) for a few hours

because (I) have to teach someone how to use it in case they need it!"
(#28, FG 5)

Many parents commented on the size of the EpiPen®, finding it too big and bulky. Parents who had boys were especially concerned that it would be too awkward for their sons to carry the device everywhere when they grew older, and that they might therefore decide to abandon the EpiPen®.

Another attitude expressed about the EpiPen® was the cost involved in its purchase. Parents are often advised to have a minimum of two EpiPens® for the child, and many feel that they should be subsidised:

"... everybody says (it's) a small price to pay, but I'm thinking: Why do we have to pay \$80 to \$120? Why isn't it on the NHS?" (#16, FG 3)

The EpiPen® also has a limited shelf-life (1-2 yrs), and if it is not used within that certain time it must be discarded and replaced, increasing the costs.

Administering the EpiPen®

Concern surrounding the administration of the EpiPen® has contributed to the anxiety reported by the participants. In particular parents raised questions such as: Will it work? How should I give it?, How will I know when to use it?

Will it work? Some parents perceived adrenaline to be a powerful drug and were concerned about the side effects if given to the child, while many other parents feared that the EpiPen® may not be sufficiently effective to help their child recover from a serious reaction:

"My fear is more: Will it work? ... Is it going to be enough to save my child?" (#1, FG 1)

“I’ve never had to use it — my only concern is that it won’t work when it has to.” (#15, FG 3)

A few of the parents carry extra EpiPen® syringes with them ‘just in case’, being aware that the effects of adrenaline wear off in five to fifteen minutes and that repeat injections may be necessary.

How should I give it? There is a set procedure that needs to be followed when the EpiPen® is administered, and there have been many cases reported where the correct technique has not been used leading to ineffective treatment. Alarming one study found that many patients are not instructed in the use of EpiPen® when the prescription is given (Huang, 1998).

From the questionnaire, almost every participant (98%) was given some formal training and instruction on how to use the EpiPen® (Appendix O). However many parents were still unclear about how and where on the thigh to inject, and feared that when confronted with the situation they may not apply the correct method:

“... I wish I could get my son a tattoo on exactly the spot where I (should) do it, because I’m always worried I’m going to miss this huge muscle...” (#27, FG 5)

In response to anxious comments made by other parents, one mother bought up the “EpiPen® trainer” and recommended that these parents use it in order to become more comfortable with the device:

“Having the training pen is fantastic, because you can practice, (and) practice, ... it gave me a lot of confidence.” (#19, FG 4)

How will I know when to use it? The EpiPen® can be life-saving treatment in the management of an anaphylactic episode, although it is important that it be administered promptly. The focus groups revealed that parents often wait and see if their child’s reaction progresses before deciding whether or not to use the EpiPen®.

Alternatively, they are relying on other medication (eg. antihistamines) as the preferred treatment. Many parents said they would be more confident about using the EpiPen® if they could identify a set of circumstances that indicated the need for the injection, since they were concerned about giving adrenaline unnecessarily. They admitted to being hesitant and not sure of which signs and symptoms to look for:

“I don’t have a fear of giving it. He should have had it once, but I wasn’t educated in the signs and symptoms of anaphylaxis — and I’m a registered nurse ... I really wasn’t aware that he was in shock, and neither was the doctor in the accident and emergency department.” (#6, FG 2)

“... are there a certain set of circumstances that you know: ‘At this point I’m going to put the needle in’...?” (#2, FG 1)

Needle phobia

Some parents identified needle phobia as an issue that increased their anxiety about the EpiPen®. Two of the focus groups did not share this concern, since there were several parents who were nurses and felt comfortable with needles. Other members of the same groups also seemed to be relaxed about needles, and it is unclear if group dynamics may have prevented them from expressing their true feelings.

For many of the parents the main concern was that the child was scared of needles, rather than the parents themselves worrying about giving the injection:

“I think all our children have the needle phobia about the EpiPen®. If there was some other form to get it (into) them it would be much easier.” (#16, FG 3)

Some of the other points brought up included the size of the needle, the question of whether it would hurt the child, and that it was invasive:

“The needle seems invasive, and you kind of put up a barrier.”

(#2, FG 1)

“The needle seemed so huge when he was little. I actually used to worry about, you know, would it go through his whole leg?”

(#4, FG 1)

Parents categorised the EpiPen® as a medical procedure, as it is a needle, and so they wanted more assistance in showing others how to use it. Their opinion was that it should not be the sole responsibility of the parent to show all principal carers how to administer the EpiPen® correctly:

“The other thing I have a problem with in relation to (the) EpiPen®, (is) it’s a medical procedure ... parents shouldn’t do the training.”

(#28, FG 5)

The concerns raised about the EpiPen® contributed to the overall stress parents were experiencing in the management of food-induced anaphylaxis, even though many had not yet used it to treat a reaction.

3. FOOD LABELLING

Packaging

Food labelling was a major concern for parents, and most participants were very cautious about the choices they made when at the supermarket. The confidence participants had in the accuracy of food labels varied, and most were not convinced that what they saw on the label was what they always got.

Parents felt frustrated with blanket labelling, and in the majority of cases did not buy ‘risky’ products:

“... the ‘may contain traces of ...’, does not give confidence in the product.” (#1, FG 1)

One parent spoke of a simple coding system implemented in England, where the warning of certain allergens (eg. peanut containing products are marked with a capital ‘P’ in a circle) was very clearly marked on the front panel of the package, meaning that it was “... *in your face...*” (#17, FG 4)

Many parents said they purchased the products that they had previously tried and knew to be safe, but still checked the labels due to possible changes that may be made. When trying a new food, parents would watch the child consume only a tiny amount of the product to ensure they did not react before adding it as a regular choice for their meals and snacks.

Another issue that concerned parents was the terminology on food packaging, and the risk this posed. Parents described the effort that was needed to investigate the safety of a product. This usually involved many telephone calls to various manufacturers inquiring about an ingredient included in their product. Parents would like to see uniform and simple terminology used on packaging:

“There was a fish thing, and it had ‘beverage whitener’ ... I didn’t know what it was, so I rang Birds Eye and it was milk ... I said that’s ridiculous — why can’t you just say that’s milk — why do you have to call it ‘beverage whitener’?” (#11, FG 3)

Manufacturing facilities

Parents also discussed the manufacturing environment, expressing concerns about possible cross-contamination of products. One participant described two reactions her son experienced as a consequence of his allergen free product being accidentally run on the wrong production line. Other experiences included parents witnessing careless behaviour in the factory setting, where it seemed as though there was a lack of awareness that even the smallest trace of an allergen can cause a reaction:

“We visited a lolly factory, and on the bagging machine there was ... all these nuts just sitting around, and you could actually buy a lolly that didn’t have nuts in it, but (it) was on this bagging machine.” (#5, FG 2)

The overall feeling from these groups was that they wanted manufacturers to guarantee that the product they are buying was safe for their child and that food labels are accurate and easy to interpret.

4. NEED FOR BETTER EDUCATION

Parents and family

The majority of parents in these groups used words such as ‘depressed’, ‘lost’, ‘fearful’, ‘guilty’, and ‘devastated’ to describe how they felt when their child was first diagnosed with a severe food allergy. In many cases they were very concerned about how they were going to cope and manage the situation, as well as worrying about who was going to assist them in protecting their child. In the beginning parents were very anxious about the situation, but most said that after making contact with either the RPAH Allergy Unit, or the Food Anaphylactic Children Training and Support organisation (FACTS) they were able to relieve some of their stress and take control of the circumstances. Even though many of these parents still had anxieties in relation to certain issues, the information they had received was essential for them to become confident and take charge:

“It was a bit of a lonely road till I met FACTS and became a member ... I feel more in control — knowledge is power.” (#6, FG 2)

“When I came here (RPAH) and I found out what the problem was ... I was sort of relieved that we could finally solve some of the mysteries...” (#22, FG 4)

The wider community

In addition to the specific questions explored during the focus group discussions, parents were asked what would make management of their child's food allergy easier? The consensus was: "education". Parents said that by increasing awareness and receiving more support from appropriate sources, many of the anxious feelings they experienced could be greatly reduced or eliminated:

"I would like to share the responsibility a little bit, and I think education is a big thing." (#2, FG 1)

"I think raising public awareness (would make things easier) ... (it's not) until they hear of someone actually dying or being hospitalised — that's when they take it seriously." (#7, FG 2)

The parents in this group were highly motivated, and were doing everything in their power to gain information that might help them manage their child's problem. Many parents asked for wider community education:

"... could you educate more people?" (#29, FG 5)

One of the common views shared by many of the participants was that general awareness of anaphylaxis could be raised by including training in all first aid courses, such as St John's Ambulance. This would result in others learning about what anaphylaxis is, how to treat it, and becoming familiar with the EpiPen® and its administration:

"It should be part of First Aid. I mean, its not just anaphylaxis with food — what about bee stings? I think every school, and anywhere that is legally liable for the responsibility and care of children, need(s) to have procedures in place for dealing with anaphylaxis ..." (#30, FG 5)

Another suggestion made by parents to make the wider community aware of this problem was to encourage the media, as well as doctors and hospitals to highlight information about anaphylaxis and the implications it has for the daily life of susceptible children and their families.

Education policies

Countries such as the United Kingdom, Canada, and the United States of America are implementing programs and policies with the aim of improving community knowledge, in order to make management for parents significantly easier. Such campaigns are directed at many target groups including: schools, medical practitioners, caterers, dietitians, and manufacturers. Some parents knew of these overseas initiatives, and emphasised the need for developing useful educational tools in Australia:

“We talk about the education of teachers and day care centres, but we (also) need the education of doctors, our GP’s ... (and) of nurses in accident and emergency units.” (#6, FG 2)

A study evaluating a training package and proposal for good practice developed in Cambridge reported that parents found it stressful dealing with school staff directly and often felt that the situation was not being taken seriously. Many felt as if they had been labelled as over-anxious parents. (Vickers et. al, 1997)

On the whole, parents in the focus groups supported the view that they were not always taken seriously enough because of the emotional involvement they had in the situation, and they thought it would be better if the education did not always come from them personally:

“... someone to actually go and speak to the schools, mainly ... so that they don’t think: ‘this is the ... neurotic mother’ ...” (#13, FG 3)

“Maybe an awareness program from the Education Department, because then the teachers of schools are getting (it) from a source other than just the parents.” (#19, FG 4)

In relation to the medical profession, parents would like to see more assistance in both general practice and hospital emergency units. They also would like to feel as though specialists are open to the role food can play in relation to allergies:

“I wish there was a course dermatologists (could do) — even six months, to learn about food, not just dust!” (#24, FG 5)

Education was frequently referred to as the solution for many of the problems parents faced in managing food induced anaphylaxis, and whilst many shared concerns were raised by parents within the focus groups, the need for better education was a common theme linking the issues identified.

CONCLUSIONS

This research project was conducted with the aim of identifying the issues and concerns parents have in managing children at risk of anaphylaxis.

Overall, it was found that the food allergy did not significantly impact on the general health or anxiety levels of the parents, nor did it contribute to changes in eating behaviour and attitudes, to food. However, the findings do suggest that parents whose children have severe food allergies have had experiences that result in higher stress levels than that of the 'normal' parent.

The focus groups (using the questionnaire survey as a base) have been successful in identifying many of the issues, concerns, and problems parents are experiencing in the management of food allergies. Parents felt that:

- there is lack of support from teachers and health care professionals.
- there is a need for increased community awareness of the potentially serious nature of food allergy and anaphylaxis.
- despite the training currently received, they still have considerable anxiety about using the EpiPen®.
- there is a continuing need for constant vigilance in social settings and when eating out etc.

In conclusion, the focus groups highlighted the need for better information and advice for parents, and the development of policies and/or educational programs targeted at:

- Family and friends
- Day care centres, pre-school, and schools
- Doctors and nurses
- Food industry and hospitality
- The general community (eg. via first aid courses and media involvement)

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