

Abstract

Background

Adverse reactions to cow's milk are common in infants and children. Infants and children present with a myriad of dietary, health and social issues. There are two types of adverse reactions to cow's milk, cow's milk allergy and cow's milk intolerance. Little is known about the similarities and differences between these two groups.

Aim

To describe the spectrum of nutrition, health and social issues surrounding infants and children who have been diagnosed with either cows milk allergy or cows milk intolerance, so that best practice management guidelines can be developed for each group.

Design

A questionnaire was sent to infants and children who had presented with adverse reactions to cow's milk (allergy or intolerance) at the Allergy Unit at Royal Prince Alfred Hospital. Questions covered the child's current diet, past diet, health problems, health professional advice, support from care outside the home, nutrition and cooking and family and social support. Responses were analysed using SQL Query Analyser and Microsoft Excel. Descriptive statistics and Student T-tests were used.

Results

Data from 169 patients was analysed. Adverse reactions to milk were not isolated problems. Children with cow's milk allergy were often allergic to egg and peanut. A range of intolerances was seen in both the allergic and intolerant children, the most tolerated foods had a low chemical level and the least tolerated foods had a high chemical level. Skin, gastrointestinal and behavioural symptoms were the most commonly reported in each group. Children with milk allergies reported significantly more cases of skin symptoms and children with milk intolerance reported significantly more cases of gastrointestinal symptoms. The presentation of both gastrointestinal and behavioural symptoms pointed towards milk intolerance. Diet was found to significantly improve symptoms. Although some health professionals gave useful information, early childhood nurses and GPs were not seen to be useful resources. Parents felt that they were very supported by carers and immediate family members but other family members and friends were not so supportive.

Conclusion

Adverse reactions to cow's milk are not isolated problems and cannot be diagnosed purely from a clinical history. Investigation into co-existing allergies and/or intolerances is vital to ensure best practice management. Management strategies must incorporate dietary, health and social issues.

Introduction

Parents commonly report adverse reactions to cow's milk and infant feeding formulas (based on cow's milk) ^[1]. Studies have estimated that between 0.3-7.5% of children have adverse reactions to cow's milk, whether it be cow's milk allergy or cow's milk intolerance. ^[2,3,4,5,6,7,8]

The distinguishing feature between those children diagnosed with cow's milk allergy from those with cow's milk intolerance in this study was a positive skin prick test (greater than 3mm in diameter). Other studies, generally, do not make such distinctions. Studies are commonly based on objective challenges to cow's milk in clinical settings, from which three groups are established. ^[9,10,11,12]

The first group comprises those patients who react within minutes to cow's milk, presenting with symptoms such as urticaria, eczema, wheezing and anaphylaxis. In the second group vomiting and/or diarrhoea developed several hours after the ingestion of cow's milk. The third group of patients are late reactors who frequently tolerated normal volumes of cow's milk for up to 24 hours before eczema or gastrointestinal or asthmatic symptoms developed. In these studies it was found that only the immediate reacting patients and patients with eczema in the third group showed evidence of IgE hypersensitivity to cow's milk protein. ^[9,10,13]

Because health professionals commonly refer to all adverse reactions to cow's milk as 'allergies' little is known about the similarities and differences, in the nutrition and health of children with cow's milk allergy and cow's milk intolerance. This has led to an inaccurate assessment of the problem. ^[14]

For the purpose of this study the term 'allergy' was kept for those reactions known to have an immunological basis.^[14] Skin Prick Tests (SPT) or RAST (Radioallergosorbent test) blood tests were used to diagnose food allergy in combination with a clinical examination and dietary modification.^[15]

Food reactions that do not invoke an immune response were classified as intolerances. Food intolerance is diagnosed by an elimination diet with subsequent food or capsule challenges.^[14] Challenges at the Allergy Unit at Royal Prince Alfred Hospital (RPAH) are based on groups of food chemicals: salicylates, amines, glutamate, food additives, rather than individual foods. Some elimination diets are based on individual foods rather than food chemicals. Within the RPAH elimination diet, foods are categorized according to their overall content of natural chemicals, which allow foods to be grouped into four categories 'low', 'moderate', 'high' and 'very high'.^[6]

Symptoms of milk allergy, urticaria, angioedema, vomiting, breathing difficulties and anaphylactic shock, usually appear from about one month or six weeks of age. Hospital based studies by Hill and Hosking, which are more likely to reflect the more severe end of the spectrum, suggest that clinical symptoms, which persist longer may be associated with intolerance to a wide range of foods. Children with persistent cows milk allergy frequently develop eczema, asthma and rhinitis.^[17] Reactions that start in the first week of life, irritable behaviour, restless sleep, nappy rashes, reflux, or loose stools can be sign that the child has milk intolerance rather than milk allergy.^[18]

A study by Host, on cow's milk protein allergy and intolerance in infancy found that infants typically have 2 or more symptoms involving 2 or more body systems. 50-70% of infants

experienced skin problems, 50-60% had gastrointestinal symptoms and 20-30% experienced respiratory symptoms. ^[19]

Typically, children who react adversely to milk (allergy or intolerance) lose their sensitivity by 2-3 years of age ^[20,21,22] Host, Jacobsen and others found that cow's milk allergy remitted by 45-56% at 1 year and by 71-87% at 3 years. ^[21] Another study, by Host, found the remission rate to be 45-50% at 1 year, 60-75% at 2 years and 85-90% at 3 years. ^[19] Bishop, Hill and Hosking found in a cohort of 97 children found that 28% tolerated cow's milk at 2 years, 56% at 5 years and 78% at 6 years. ^[3]

A study, by Iacono et al, found that children with persistent cow's milk allergy had the following characteristics:

- A family history of atopic disease
- A change in symptoms over time
- An increase in the delay between cow's milk consumption and symptom onset
- A very high frequency of multiple food intolerance and allergic disease. ^[23]

Cow's milk intolerance also appears to remit with age. A study by Schrandt, Oudsen, Forget and Kuijten of 88 infants with cow's milk protein intolerance found that at the age of 1, 2, 3 and 4 years respectively, 15%, 26%, 51% and 67% of children could tolerate cow's milk. ^[24]

Adverse reactions to cow's milk are not usually a single food issue. Host found that 50% of children who reacted to milk also had adverse reactions to other foods. ^[19] In a previous study by Host and others it was found that adverse reactions to egg, soy, peanut and citrus developed in 41-54% of subjects who had reacted adversely to cow's milk. ^[25] Bishop, Hill

and Hosking found that 75% of the children in the cohort (n=97) had multiple food reactions.^[3] The skin test results of 298 children with cow's milk allergy, at the Allergy Unit (RPAH), showed that only 9% of these children reacted to cow's milk alone.^[14]

The adequacy of the diet becomes a concern in children who react adversely to cow's milk. A study by Henriksen et al, of 16 children on a cow's milk restricted diet found that they were at risk from malnutrition, unless precautions were taken to replace the valuable nutrients from milk in the diet. Parents of children on milk-free diets need advice about food choices in order to reduce the risk of low intake of energy, fat and protein. Supplements of calcium, vitamin D and riboflavin were required.^[26,27]

Concern about nutrition increases when multiple allergies and intolerances are present. Some highly sensitive infants develop intolerances to extensively hydrolysed casein, whey or soy formulas.^[28,29] When hydrolysed formulas are inappropriate an elemental formula is required to ensure that the child maintains an adequate nutritional status.

Neocate® is an elemental formula. It is a hypoallergenic, nutritionally complete infant formula composed of individual amino acids and other nutrients. Neocate® has been shown to be clinically and biochemically tolerated.^[30,31] Feeding with Neocate® has shown to decrease symptoms and improve weight gain in both allergic and intolerant infants.
[7,28,30,32]

The social impact of adverse food reactions has been shown to have a significant impact on general health perception, emotional distress in parents, and family activities.^[33]

Aim

To describe the spectrum of nutrition, health and social issues surrounding infants and children who have been diagnosed with either cows milk allergy or cows milk intolerance, so that best practice management guidelines can be developed for each group.

Objectives

To determine

- whether adverse reactions to milk are isolated food problems and if not what other allergies or intolerances typically coexist.
- the common symptoms associated with adverse reactions to cow's milk and whether diet plays a significant role in the management of these symptoms.

To investigate

- where parents received education about food allergy and intolerance and the usefulness of such information.
- parents attitudes about the care their child receives outside the home, whether it be day-care, preschool or school
- difficulties parents face in terms of providing adequate nutrition and cooking for a child with a restricted diet
- the social impact and support available for parents who have a child who has adverse reactions to cows milk.

Methods

Ethics Approval

Ethical approval was sought and granted by the Ethics Review Committee of the Central Sydney Area Health Service (RPAH Zone).

Subjects

Subjects were selected for inclusion in the study if they had attended the Allergy Unit at Royal Prince Alfred Hospital (RPAH), as infants, with either cows milk allergy or cows milk intolerance. The parents/guardians of 422 infants and children were invited to be part of this study. Two hundred and five subjects had been diagnosed with cows milk allergy and 217 with cow's milk intolerance. All subjects first attended the Allergy Clinic between 1985 and 2000 (60% between 1999-2000). 58% of subjects were male and 42% female. The subjects were aged between 5 months and 20 years, however the average age was 4 years and median 3.3years.

Research Design

The research design is outlined in figure 1. Preliminary information was gathered from the medical/dietetic notes of children and from previously compiled data files to allow children to be placed into one of four groups.

1. Cow's milk allergy prescribed Neocate®
2. Cow's milk allergy not prescribed Neocate®
3. Cow's milk intolerance prescribed Neocate®
4. Cow's milk intolerance not prescribed Neocate®

Information was collected via a written questionnaire. The questionnaire (appendix 1), designed specifically for this study, was sent to the parent/guardian of each subject. No

validation process was undertaken of the questionnaire before use. The questionnaire called for a mixture of closed and open responses and was split into 7 sections.

- **Section A** '*Current diet and foods causing reactions*' investigated the child's tolerance to breast milk, infant formulas, milk and milk products, milk substitutes, cereals, protein foods, fruit and vegetables.
- **Section B** '*Past Diet*' investigated the past diet of the child, covering breast feeding, infant formulas and weaning foods
- **Section C** '*Health Problems*' investigated the health problems/symptoms experienced by these children and the effect of a change in diet on such conditions.
- **Section D** '*Health Professional Advice*' investigated where parents had attained information about adverse reactions to foods and the usefulness of this information.
- **Section E** '*Day-Care/Pre-School/School*' investigated the support and practices of the centres where these children attended.
- **Section F** '*Nutrition and Cooking*' investigated parental perceptions of the child's diet and the difficulties surrounding feeding.
- **Section G** '*Family and Social*' investigated parents perceptions about how supportive family and friends were of their child's condition as well as what would be useful ways to provide support for parents with children who react adversely to cow's milk.

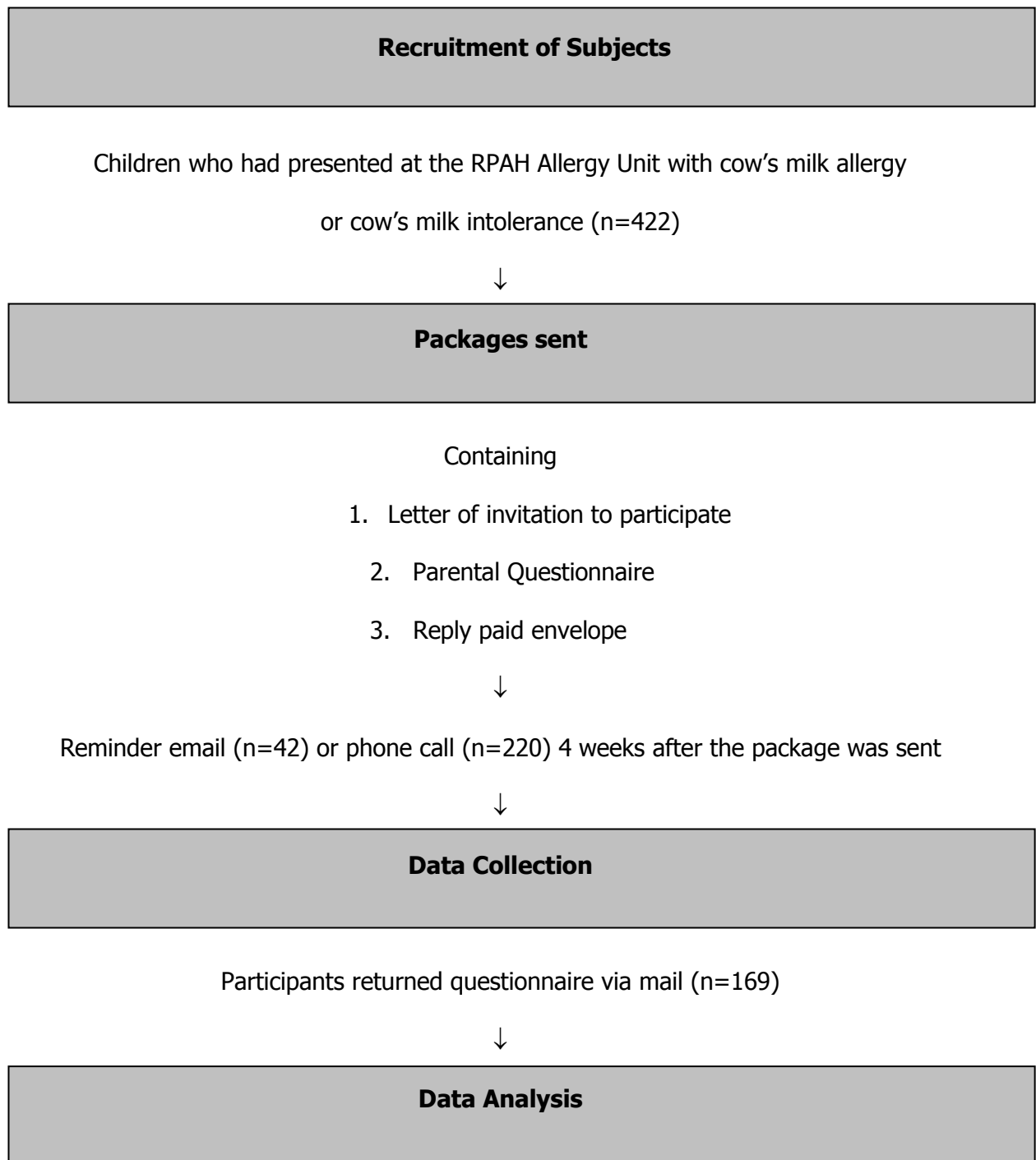
A letter (appendix 2) of invitation and a reply paid envelope was sent with the questionnaire. Consent for inclusion in the study was assumed by the completion and return of the questionnaire.

Those subjects who had not replied within 4 weeks were contacted via email (n=42) or phoned (n=220) to determine their interest in the study. The questionnaire was posted on 15th March 2001 and those returned by 10th May 2001 were included in the results.

Data collation and analysis

Data from the questionnaire was entered into a secure database at the Allergy Unit at RPAH. Data was analysed using SQL Query Analyser and Microsoft Excel 2000 (Microsoft Corp USA). Descriptive statistics were compiled and student's t-tests were used to determine if there were any significant differences between cow's milk allergy and cow's milk intolerance. Graphs were generated from spreadsheet data in Microsoft Excel 2000.

Figure 1: Flow Diagram of Methodology



Results

Response rate

Of the 422 questionnaires posted 179 questionnaires were returned. Ten patients were no longer at the given address. One hundred and sixty nine questionnaires (40%) were returned completed. Out of the 40% response rate 51% (n=87) had been diagnosed with cow's milk allergy and 49%(n=82) with cow's milk intolerance. (appendix 3)

Age, gender and first attendance

The mean age of the group that responded was 3.2 years (median=2.8) and the range of ages was 9 months to 14 years. The range of ages between those with cow's milk allergy and those with cow's milk intolerance was similar. The mean and median age of those with cow's milk allergy was slightly higher than those with cow's milk intolerance.(table 1) Males comprised 54% of the sample and females 46%. Respondents had first attended the Allergy Unit at RPAH between 1988-2000, however the majority (74%) first attended the unit between 1999-2000. (appendix 3)

Table 1 Age of Respondents

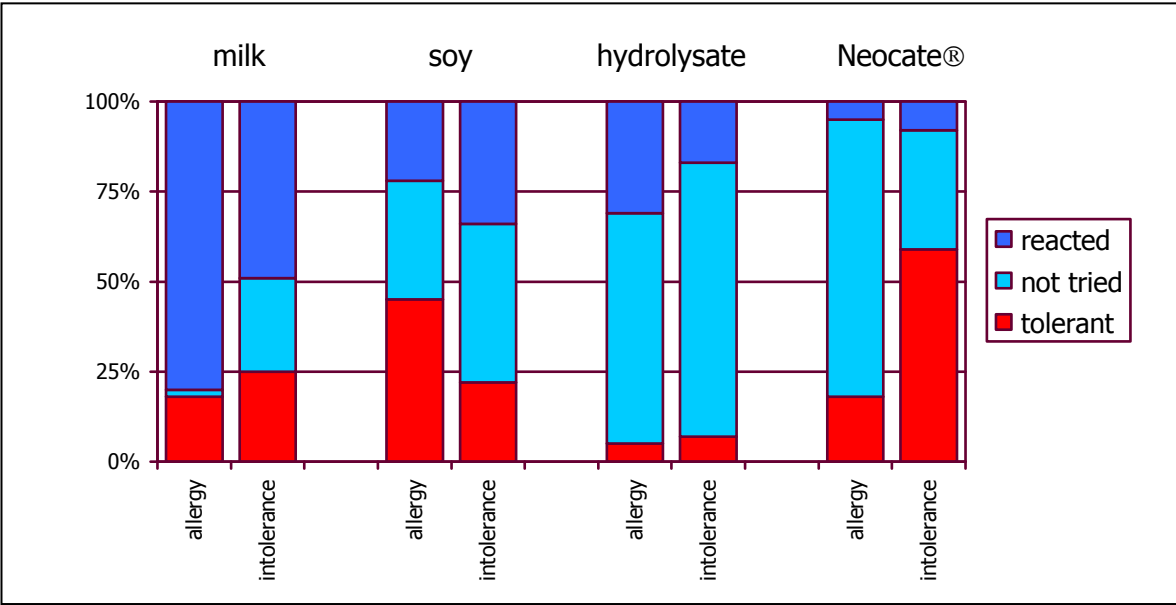
	Number of Children	Av. Age (years)	Median Age (years)	Range (years)
Responders	169	3.2	2.8	0.9-14
Cow's milk allergy	87	3.7	3.1	1.3-10.7
Cow's milk intolerance	82	3	2.2	1.0-14.4

Current diet

Milk, soy and infant formulas

Figure 2 shows the tolerance of milk, soy and infant formulas. Milk, soy and hydrolysate formula were poorly tolerated. It appears that children with milk allergy were more likely to tolerate soy (45%) than those children with milk intolerance (22%). The majority of children had not tried hydrolysate formula, but of those who had tried it, tolerance was low. Seventy-seven percent of children with milk allergy had not tried Neocate®, 18% tolerated the formula and 5% reacted. Only 33% of children with milk intolerance had not tried Neocate, 59% tolerated the formula and 8% had reacted. (appendix 4)

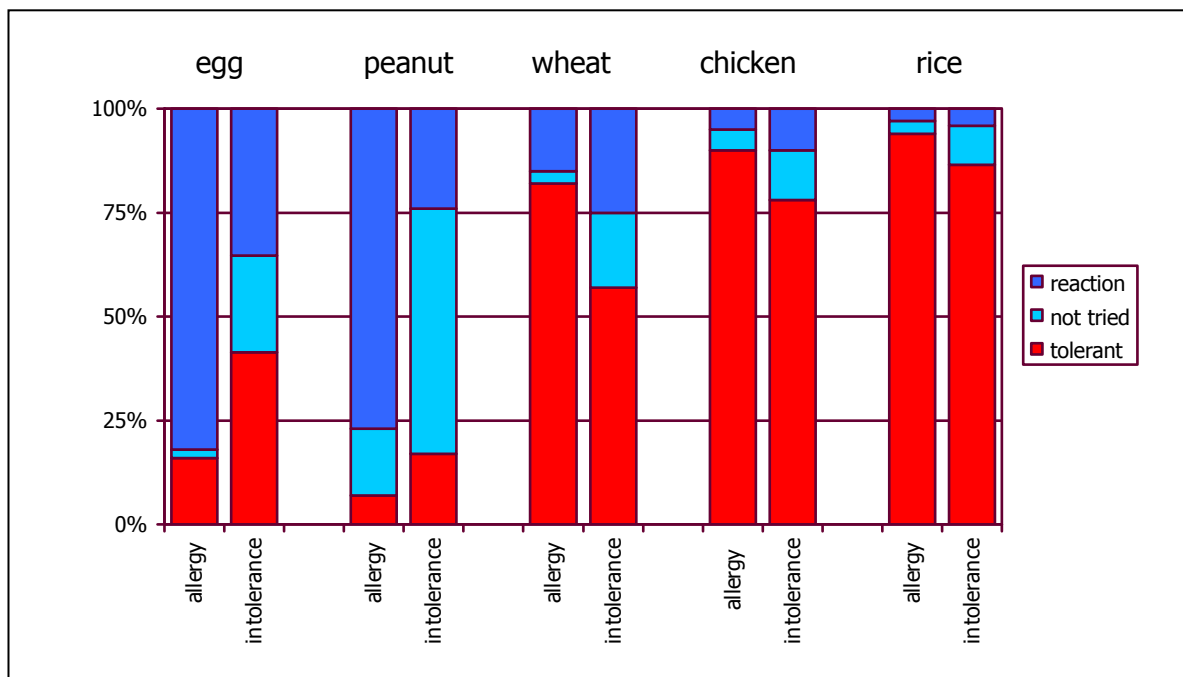
Figure 2 : Tolerance to milk, soy, and infant formula



Other allergens and basis food stuffs

Children with milk allergy were more reactive towards other allergens, egg (82% reacted) and peanut (77% reacted) (figure 3), than children with milk intolerance of whom 34% reacted to egg and 24% reacted to peanuts. Most children in the study were able to tolerate chicken and rice however children with milk intolerance were slightly more reactive to these foodstuffs. Wheat was largely tolerated in the children with milk allergy (82%) and was less tolerated (52%) in children with milk intolerance. (appendix 4)

Figure 3: Tolerance to other allergens and basic foodstuffs



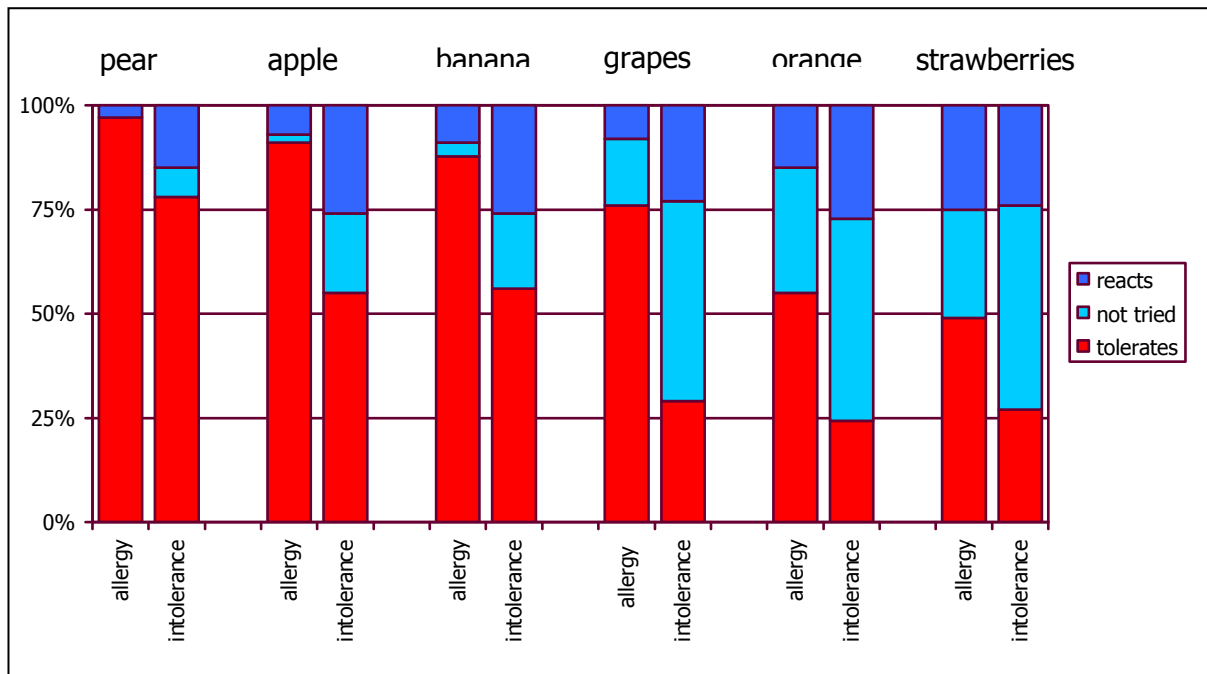
Fruit

Tolerance to fruit decreased as the chemical load within the fruit increased for both children with milk allergy and milk intolerance (Figure 4). However, children with milk allergy are more tolerant of fruit than those with milk intolerance. Ninety-seven percent of children with milk allergy tolerated pear compared with 85% of those with milk intolerance.

Ninety-one percent of children with milk allergy tolerated apple and 79% tolerated banana. Children with cow's milk intolerance were less tolerant of these 'moderate fruits', with 55% tolerating apple and 56% tolerating banana.

The fruit in the 'high' (strawberries) and 'very high' (oranges, grapes) category were the least well tolerated. Children with milk allergy were seen to have a greater tolerance of these fruit. Within the group of children with milk allergy, grapes (76%) appeared to be the most tolerated followed by oranges (55%), then strawberries (49%). Children with milk intolerance had similar levels of tolerance to grapes (29%), oranges (24%) and strawberries (27%).(appendix 4)

Figure 4: Tolerance to Fruit



Vegetables

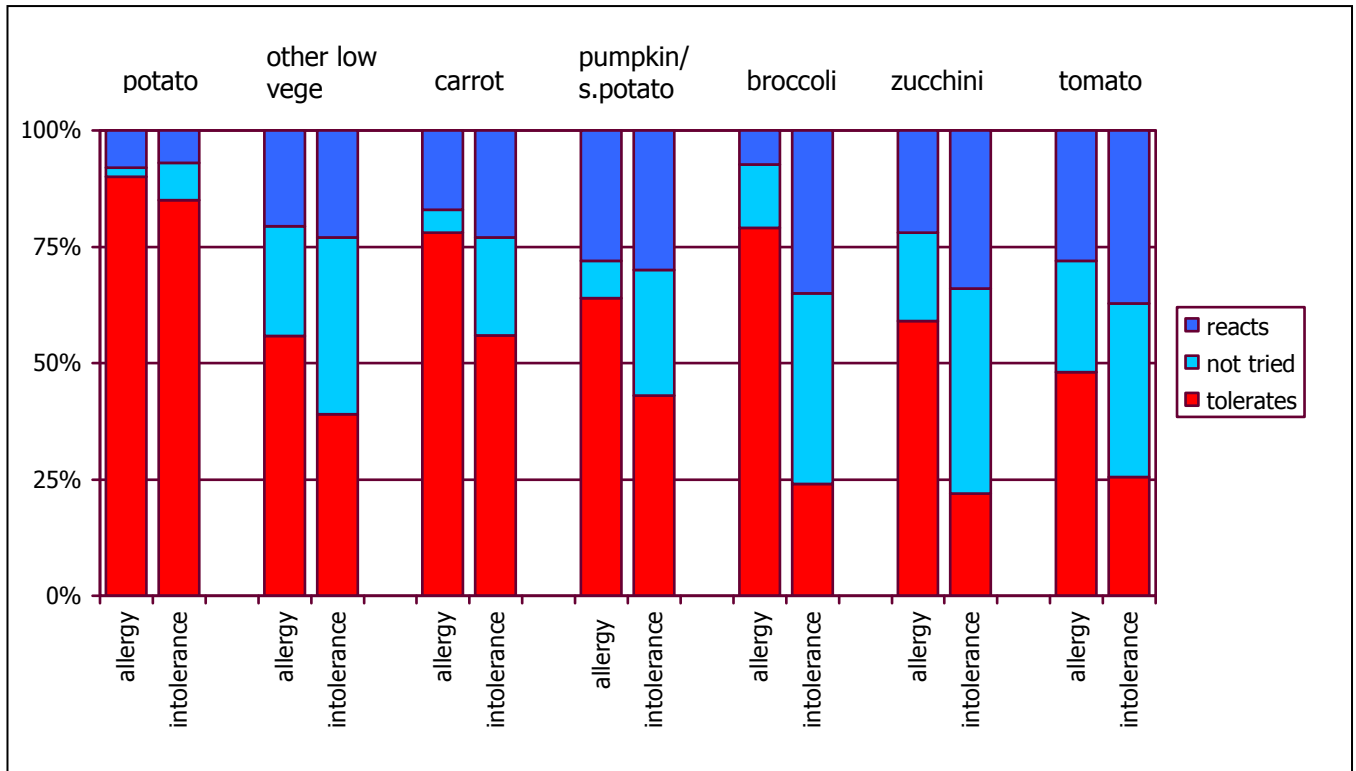
The pattern of tolerance in terms of 'low', 'moderate' and 'high' vegetables, based on their chemical load, was not as predictable as for fruit tolerance. (figure 5)

Potato was the most tolerated vegetable, with 90% of children with milk allergy and 85% of children with milk intolerance able to tolerate it. Surprisingly, the 'other' vegetables from the 'low' category in the elimination diet (swede, cabbage, celery and lentils) were not well tolerated by both children with milk allergy (57%) and intolerance (39%).

The 'moderate' vegetables, carrot, pumpkin and sweet potato, were better tolerated than the 'other low' vegetables, with 78% of children with milk allergy tolerating carrot and 64% tolerating pumpkin/sweet potato. Fifty six percent of children with milk intolerance tolerated carrots and 43% tolerated pumpkin/sweet potato.

Children with milk allergy had a better tolerance of vegetables in the 'high' category of the elimination diet (broccoli, zucchini, tomato). Broccoli was well tolerated (87%) by children who were milk allergic. Fifty nine percent of children with milk allergy tolerated zucchini and 48% tolerated tomato. The tolerance of broccoli, zucchini and tomato in children with milk intolerance was similar, 24%, 22%, 24% respectively and revealed much lower tolerance levels than those children with milk allergy. (appendix 4)

Figure 5: Tolerance to vegetables



Children with cow's milk allergy experienced symptoms of adverse food reactions less commonly than those children with cow's milk intolerance. (appendix 4)

Past Diet

Breastfeeding and the introduction of weaning formulas and food

The infants who were allergic to milk were found to be breastfed for twice as long as those with milk intolerance. (Table 2)

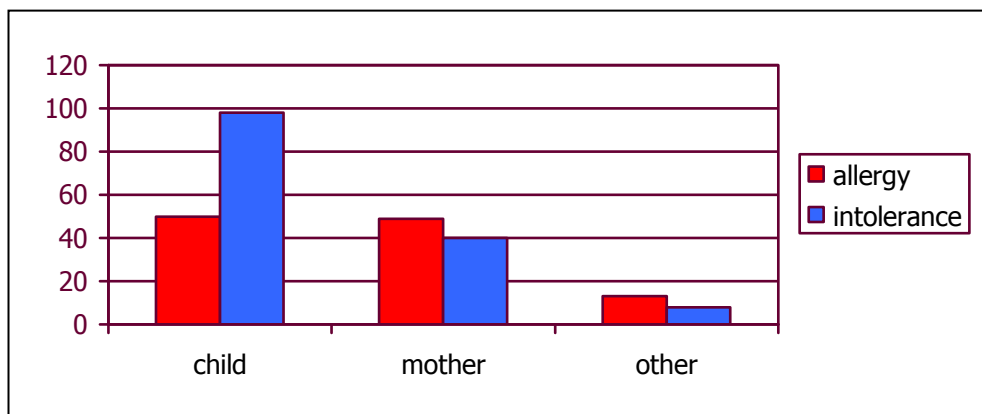
Table 2 Length of breastfeeding (months)

	Range	Mean	Median
Milk allergy (n=80)	Never-40	11	10
Milk intolerance (n=72)	Never-24	6.3	5

The reasons for ceasing breastfeeding were split into 3 categories. 'Child' reasons included the baby being too demanding or hungry, baby not thriving, baby weaned itself, baby pulled away from breast and baby reacted to breast. 'Mother' reasons included mastitis or

bleeding nipples, breastfeeding was too painful and choosing to wean. The most common 'other' reason was work commitments. Mothers of children who were milk allergic ceased breastfeeding for both mother and child reasons, whereas mothers with a child who has milk intolerance mainly ceased breastfeeding for child reasons. (Figure 6)

Figure 6: Reasons for weaning (n=148)



The introduction of weaning formula and foods occurred later in those with milk allergy. The mean age that weaning formulas were offered to infants who were allergic to milk was 6.5 months (median 6 months) compared to those infants, intolerant to milk, who were offered a weaning formula at 4.3 months (median 3 months). The mean age that weaning foods were offered to infants who were allergic to milk was 5.2 months (median 5 months) and those with intolerances to milk were offered weaning foods at an average of 4.8 months (median 4.25 months).

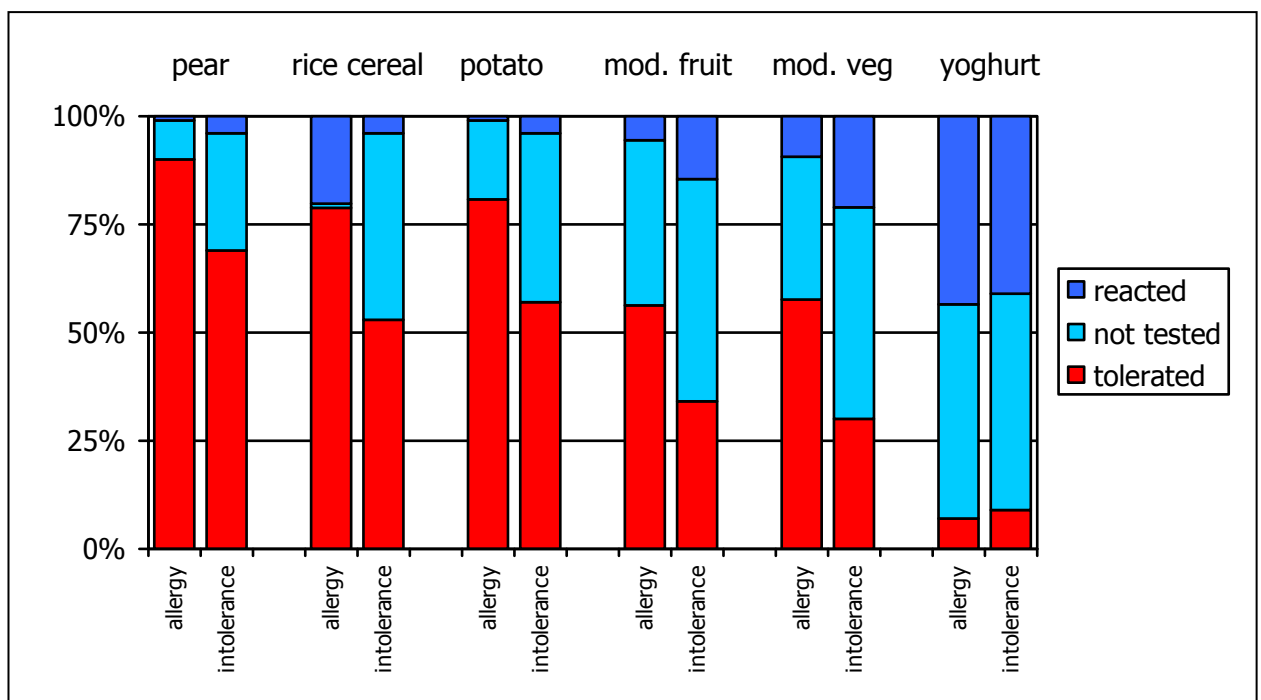
Age when parents first suspected their child was reacted to diet

Parents of children with milk allergy suspected that their child was reacting to something in the diet at an earlier age (mean 5.7 months, median 5.8 months) than those with milk intolerance (mean 13.5 months, median 7.5 months). However these results may be skewed by the poor response rate for this question (milk allergy n=52, milk intolerance n=8)

Tolerance of weaning foods

Tolerance to weaning formulas followed the same pattern as seen in figure 2. (appendix 5) Pear was the most tolerated weaning food for both children with milk allergy (90%) and those with milk intolerance (69%). Tolerance of other foods followed the chemical content of the food with rice cereal and potato being the next well tolerated, followed by 'moderate fruit' (apple, banana) and vegetables (potato, pumpkin, sweet potato). Very small numbers of children tolerated yoghurt. (figure 7) Greater tolerance were seen in children with milk allergy for all weaning foods. (appendix 5)

Figure 7: Tolerance to weaning foods



Benefit of removing food from diet of mother or child

The greatest benefits from the removal of food from the diet was seen in the removal of foods rich in salicylates, amines and preservatives from the diet of children who were intolerant to cow's milk. (Table 3)

Table 3 Percentage of total sample who saw removal of a food as beneficial

(N=169)

Food removed	Mother's diet		Child's diet	
	MA	MI	MA	MI
Breast/soy/cow	23	17	16	62
Eggs/Nuts/cereals	33	22	14	70
Pres/sal/amine	21	27	14	94

Health Problems

Symptoms

Ninety five percent of the children with cow's milk allergy and 96% of children with cow's milk intolerance reported at least one skin symptom. Eighty two percent of children with cow's milk allergy and 96% of children with cow's milk intolerance reported at least one gastrointestinal symptom. The third most commonly reported symptom by both groups was behavioural symptoms with 77% of children with cow's milk allergy and 93% of children with cow's milk intolerance reporting at least one behavioural symptom. Table 4 shows the other symptoms associated with adverse reactions to cow's milk.

Table 4 Symptoms associated with adverse reactions to cow's milk (n=169)

Symptom	Allergy (%)	Intolerance (%)
Skin ¹	95	96
Gastrointestinal ²	82	96
Behavioural ³	77	93
Respiratory ⁴	71	80
Nutrition and Growth ⁵	50	80
Other ⁶	40	71

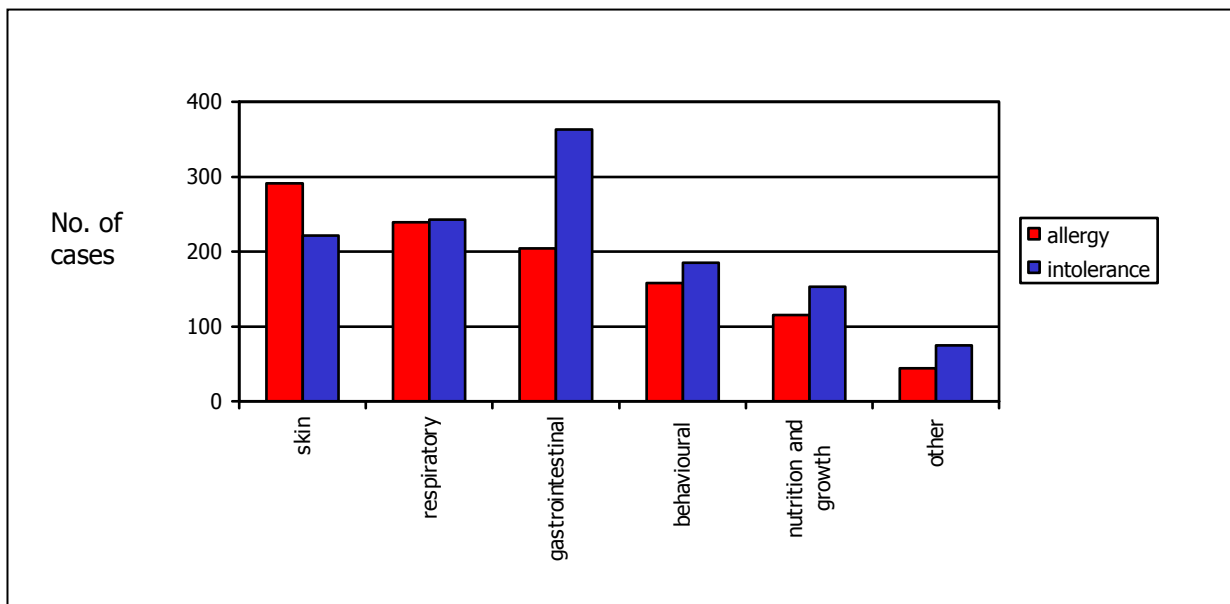
- 1. frequent loose stool, abdominal pain or colic, reflux or regurgitating feeds, constipation, mucus in stools, mucus in vomit, frequent vomiting, intermittent vomiting, blood in stools*
- 2. runny nose, cough, asthma, wheezing, blocked nose, recurrent ear infections, shortness of breath with asthma attack or exercise, glue ears*
- 3. facial eczema, eczema, hives/swelling, nappy rashes, non-specific rashes*
- 4. restless sleep, frequent night waking, irritable moody behaviour, other sleep problems, language delay, ADHD/ADD if over 3 years*
- 5. food refusal, poor weight gain, poor appetite, poor growth*
- 6. difficulty breast feeding, reactions to smells and odours, surgery*

Children with milk intolerance reported more gastrointestinal, behavioural, nutrition and growth and other symptoms (figure 8) than children with milk allergy. There was a

significant difference between the numbers of gastrointestinal (t-test=0.01576, 5% sig) and skin problems (t-test=0.03156, 5% sig) reported between the two groups.

Appendix 6 outlines the symptoms in each category and how many cases of each symptom were reported.

Figure 8: Number of symptoms reported in each category

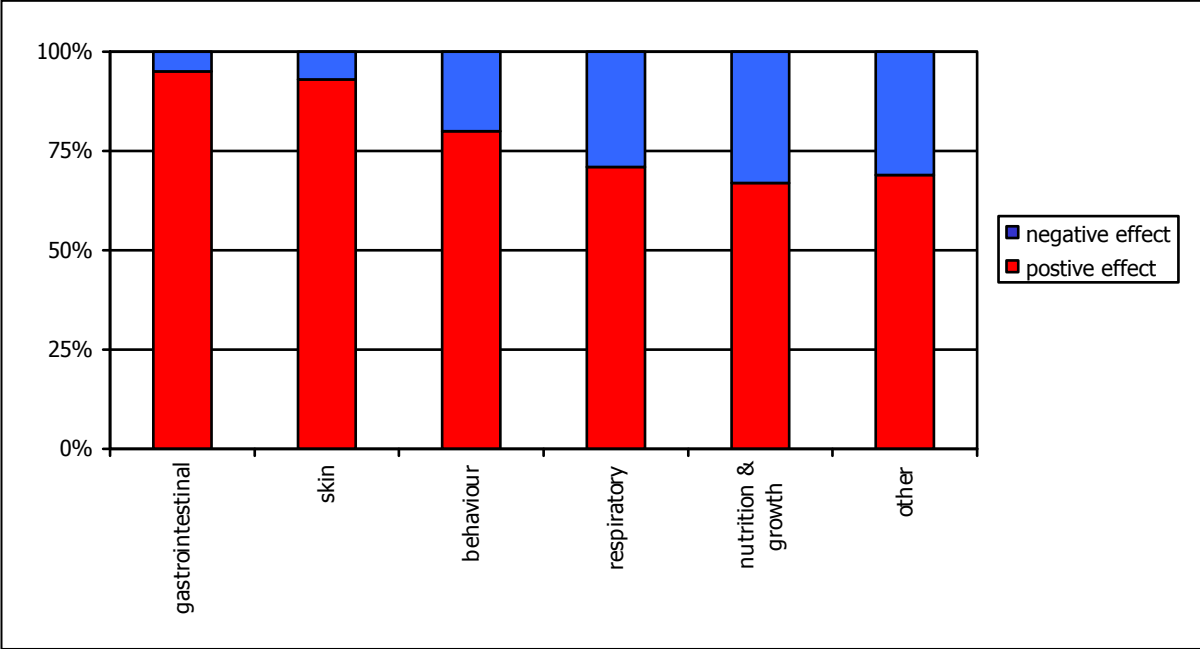


It was found within this sample that 91% of children with milk intolerance presented with both a gastrointestinal symptom and a behavioural problem, whereas this common denominator was only seen in 63% of children with milk allergy.

Effect of diet on symptoms

A change in diet was found to significantly improve symptoms (t-test=0.018835, 5% sig). The positive effect of diet can be seen in figure 9 on each type of symptom. Most symptoms were improved by the changes in diet. (appendix 7)

Figure 9: Effects of diet on symptoms



Health Professional Advice

Parents received information about adverse food reactions from a variety of sources (table 5) and no single source was extensively utilized. Specialists were the most commonly used (38%) by parents of atopic children (table 3), but were less commonly used (24%) by parents who had non-atopic children (table 3). Dietitians were seen to be significant points of contact for both atopic (37%) and non-atopic children (29%) (table 5).

Table 5 Where people received advice about adverse reactions to food

Information source	Allergy n=87	Intolerance n=82
Specialist	38	24
Dietitian	37	29
Paediatrician	31	29
GP	29	13
Early childhood nurse	25	16
Hospital	14	8
Other	8	27
Food industry person	0	4

Early childhood nurses provided information that tended to be 'not at all useful' for food allergy (52%) and food intolerance (62%). General Practitioners also proved to be 'not at all useful' for information about allergy (55%) and intolerance (63%). The usefulness of information from Pediatricians ranged from 'very useful' to 'not at all useful'. Forty-six percent provided 'very useful' information about food allergy and 32% provided information that was 'not at all useful'. Forty-six percent of the information parents received about food intolerance from Pediatricians was 'very useful' and 43% found the information 'not at all useful'.

Previous Diagnosis

The previous diagnoses that children had received can be seen in Table 6. Children with cow's milk allergy received a smaller number of other diagnoses. Lactose intolerance had been diagnosed in 21% of children, reflux in 23% and a range of 'other' diagnoses in 31%. Eighty-eight percent of the 'other' diagnoses were allergies other than cow's milk. Children with cow's milk intolerance more commonly received other diagnoses. Children with cow's milk intolerance were commonly diagnosed with cow's milk allergy (41%). The three most common diagnoses were lactose intolerance (48%), reflux (46%) and silent reflux (46%).

Table 6 Other diagnosis that that children received

Diagnosis	Cow's milk allergy % (n=87)	Cow's milk intolerance % (n=82)
Milk Allergy	100	41
Lactose intolerance	21	48
Reflux	23	46
Silent reflux	5	46
Breast milk colitis	3	5
Eosinogastroenteritis	3	5
Toddler Diarrhoea	7	9
Other Diagnosis	31	35

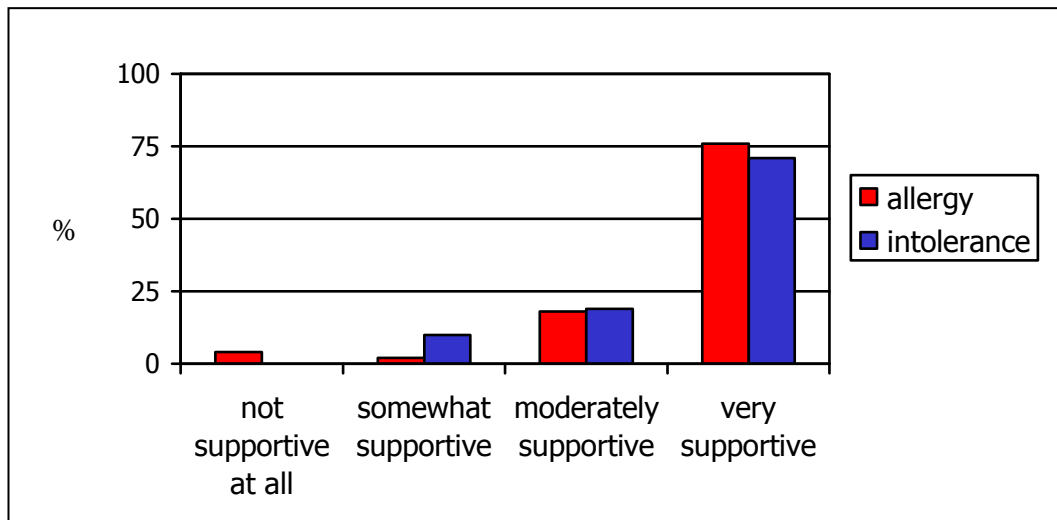
Centres for Parental assistance

The majority of parents (66%) had not attended centres for parental assistance. Of those who attended these facilities, 54% found that there was no improvement in the child's health or behaviour as a result of the intervention. Twenty-six percent found the intervention provided a temporary benefit and 20% believed there was a permanent benefit. The most useful advice people received from these facilities was about settling and sleeping techniques.

Day-care/Preschool/School

Only one parent (n=102) had not informed the carers of the child outside the home about their child's dietary restrictions. The majority of staff were perceived to be very supportive of the child's needs (figure 10) and most parents felt their child's care had not be compromised (65%).

Figure 10: Level of support provided by carers (n=103)



The methods of preventing an adverse food reaction (allergy/intolerance) within a care setting were as follows; teaching children not to share food (44%), banning foods that the child reacts to (19%), staff education (13%), all utensils and food brought from home (9%), and a separate food/dining area for the sensitive child or having a carer help during meal times (9%). Only 6% of parents reported that no measures were undertaken in the care setting to prevent adverse food reactions. Most of the children in care centres with no measures in place suffered from food intolerances (75%).

Nutrition and Cooking

Parents found it difficult to provide food for their child to eat for a variety of reasons. Sixty three percent of the total sample found that their child refused to eat the food and 59% of the total sample found it difficult to find appropriate food in the shops. Forty-one percent of all the parents questioned found their child's 'special' food' to be expensive and 34% found that they did not have enough time to prepare the food.

Twenty percent of parents encountered 'other' problems, which made it hard for them to provide food for their child. These other problems include:

- a perception that the child was not receiving enough variety
- difficulties in providing food away from the home
- restrictions made it difficult for the whole family
- hard to find recipes
- food was unattractive
- found it hard to read labels on packaged foods.

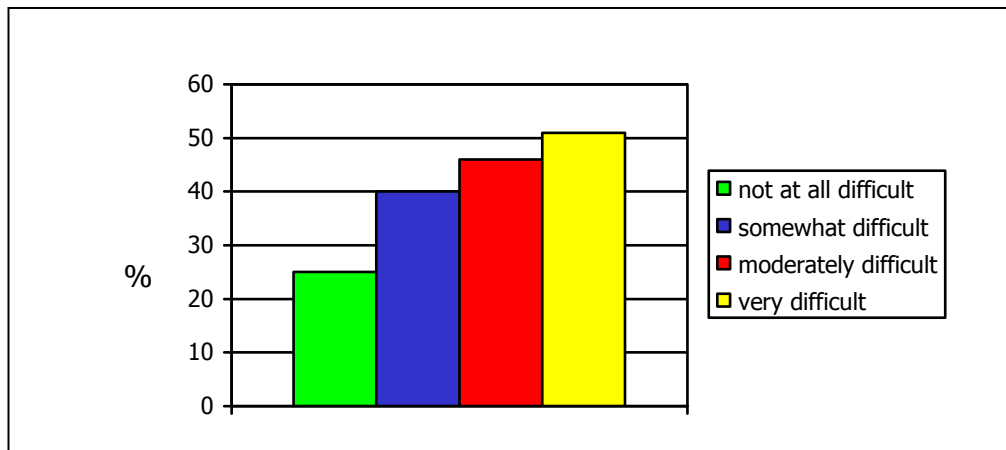
Most parents felt that their child's diet was adequate (Table 7) Only 8 out of the 27 parents who thought their child was lacking in 'other' nutrients stated specific nutrients that they were concerned with. (Table 7) Those stated included: essential fatty acids, fibre and trace vitamins and minerals.

Table 7 Perceived Adequacy of the child's diet

Nutrient	N=	Adequate (%)	Not Adequate (%)
Calcium	158	54	46
Adequate nutrition	156	56	44
Vitamin C	154	63	37
Iron	155	70	30
Vitamin A	150	70	30
Protein	155	74	26
Energy	154	76	24
Other	125	79	21

It appears from figure 11 that it is difficult to provide a meal that is suitable for the whole family.

Figure 11: Level of difficulty in preparing a meal for the whole family (n=162)



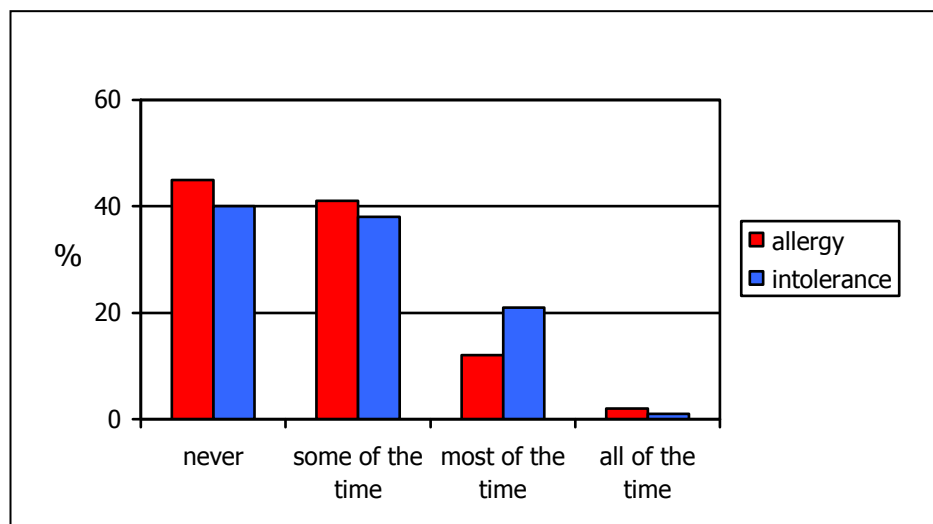
It was found that in 84% of households (n=162) the mother prepared the meals, in 13% of households' parents shared meal preparation. In 1.5% of household the father was responsible for the majority of the cooking, and grandparents were similarly responsible in 1.5% of households.

In 39% of families (n=155) no one else other than the child who had adverse reactions to cow's milk ate food from the elimination diet. Everyone in 30% of families ate the elimination diet food. In 19% of families only the children ate elimination diet food, and in 10% of families the parents of the child who reacted adversely to milk also ate food in line with the elimination diet.

Family and Social

It appears that the majority of families of children with adverse reactions to cow's milk either 'never' or only 'sometimes' avoided social occasions because of their child's adverse reactions to food (figure 12). Although a large number of families do not avoid social occasions, 61% of families with a child who is allergic to milk and 53% of families with a child with milk intolerance avoid eating out.

Figure 12: Avoidance of social occasions (n=169)



The immediate family of children with adverse reactions to cow's milk appeared to be every supportive (figure 13) but other family members and friends seem to vary more in terms of their support towards the families of these sensitive children (figure 14).

Figure 13: Support of immediate family (n= 165)

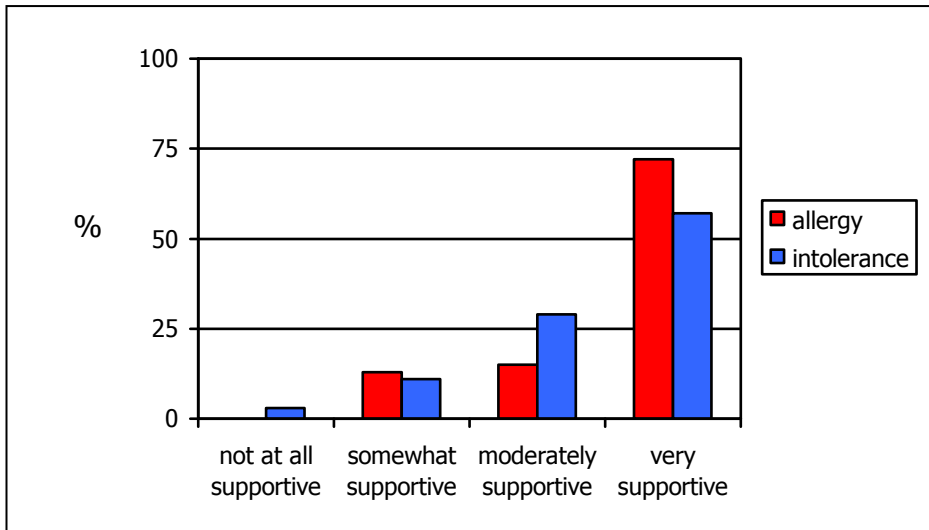
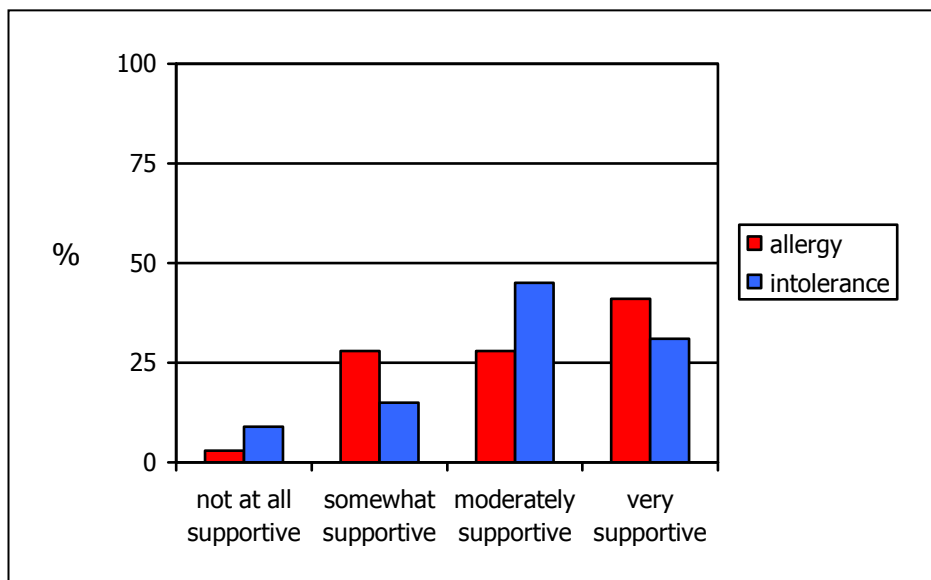


Figure 14: Support of other relatives and friends (n=166)



Sixty six percent (n=151) of parents wished to be linked with others who had similar problems. Of the 60 people who suggested ways to link, 55% would prefer to be linked via the internet or electronic mail, 43% would like to meet with other people in social settings such as support groups, 22% would like to be in phone contact with other people, 17% of

people would like to receive a regular newsletter and 10% would like to have a contact list for people with similar problems.

Discussion

Limitations of the study

The questionnaire was very long and complicated and as a result some sections were poorly answered. This was particularly the case in the last two columns in question 1 where the majority of people did not state when their child stop reacting and started to tolerate the food. It would have been beneficial for such information to be collected from patient files if more time was available.

The questionnaire called for a lot of retrospective information. Parents found it hard to remember what foods their child had reacted to, how much food had caused the reaction, at what age symptoms had started and at what age symptoms had stopped. Therefore some information may have been under or inaccurately reported.

General Discussion

Previous research has shown that children who reacted adversely to cow's milk often present with a myriad of other coexisting food reactions and related symptoms. Such findings were confirmed in this research.

Dietary Issues

Children with cow's milk allergy appeared to be highly atopic with 82% reacting to egg and 77% reacting to peanut. Children with milk allergy were more tolerant of soy, meats, cereals, fruit and vegetables than children with milk intolerance, however food rich in natural chemicals still posed a problem for these children.

Children with milk intolerance could tolerate foods within the low category of the elimination diet, with fewer children tolerating moderate foods and even fewer children tolerating high

and very high foods. An unexpected result presented with children reacting to some vegetables in the low group. Potato was widely tolerated but tolerance of swede, cabbage, celery and lentils was similar to that of vegetables in the moderate category (carrot, pumpkin, sweet potato).

Textbooks often present milk allergy and milk intolerance as isolated problems. If management of these children is conducted in such a way, important and potentially life-threatening (egg and peanut allergy) reactions could be overlooked.

Information obtained from the past diet history, showed that children who had adverse reactions to cow's milk started reacting to food in the first year of life. Such information was reflected in the tolerance of weaning formula and foods, cessation of breast-feeding and suspicions of parents. Deciphering what to feed these infants to ensure adequate nutrition to promote growth becomes an important question.

Soy formula appears to be a valid choice for children with cow's milk allergy but not for children with cow's milk intolerance. Hydrolysate appeared to be better tolerated by children who are intolerant of cow's milk. However, elemental formulas were shown to be least reactive and this is confirmed by previous research.^[34] The tolerance of formulas, from other studies, appeared to be a reflection of the complexity of the child's food intolerances and allergies and the length of time that these intolerances persist for.^[29,35]

Food allergies and food intolerance are suspected to improve over time. Previous research at the Allergy Unit showed that this was the case for those children with cow's milk intolerance (appendix 8). Studies by D. Hill et al ^[36] showed similar trends for children with

milk intolerance. Other research has shown these trends in children with milk allergy [3,20,21,22,19,25]

Health Issues

A child's clinical history is often used to determine whether they have cow's milk allergy or cow's milk intolerance. It was shown in this sample that although children with cow's milk intolerance reported a greater number of symptoms in each category except skin symptoms, there was little difference in the percentage of children who had at least one symptom in each group. The top three symptoms for cow's milk allergy and cow's milk intolerance were the same, i.e. skin, gastrointestinal, and behavioural. It was evident that when behavioural and gastrointestinal symptoms co-existed it was more likely to be an indication that the child had food intolerance. These results highlight that a clinical history of symptoms, by itself, is not a reliable method of diagnosis.

The prevalence of symptoms was higher than in other studies, such as one conducted by Schrandt and associates ^[37] who found the dominant symptoms in children with cow's milk intolerance were gastrointestinal (50%), skin (31%) and respiratory (19%). Table 9 allows comparisons to be made between previous studies in cow's milk intolerance by Hill et al and the Allergy Unit (RPAH) to be made for specific symptoms. Similar trends are seen between the three studies except the percentage of patients reporting frequent loose stools and eczema is much lower in D.Hill et al's ^[32,36] research than in the studies conducted at Royal Prince Alfred Hospital.

Table 9 Frequency of symptoms recorded in three different studies

Symptom	Intolerance=82 (%)	D.Hill et al 1995, 1999 n=18 (%)	Milk and soy intolerance RPAH 2000 n=104 (%)
Irritable moody behaviour	78	67	89
Reflux or regurgitating feeds	62	72	76
Frequent loose stools	80	28	71
Eczema	56	22	52

The patients from the Allergy Unit presented with more symptoms than the other study groups of subjects. This may be a reflection of the severity of their condition.

Diet was found to have a significant role in the management of symptoms and therefore should be recognised as an important aspect of case management.

Social

Parents went to a variety of health professional to attain information about adverse food reactions. Some information was useful, but some was not. Further research into what was useful about this information and what was not would be helpful ensuring the best management of these children. Children often received more than one diagnosis and that diagnosis was frequently reflux or lactose intolerance. Gastroesophageal reflux is commonly associated with milk allergy in infants but as suggested in a study by Iacono et al it is important that the problem is carefully examined to determine whether the disorder is primary or caused by cow's milk allergy. ^[38]

Although parents found it difficult to provide food for their child, the majority of parents were not concerned about the nutritional content of the diet.

The majority of staff at child care centres and schools were perceived to be supportive of the child's condition as were immediate family members. Other family member and friends were found to provide varying levels of support. Despite the positive support parents were receiving 66% would still like to be linked to parents who have children with similar problems.

Conclusions

- Adverse reactions to cow's milk are not isolated problems.
- Cow's milk allergy is commonly associated with egg and peanut allergy.
- Children with cow's milk allergy are generally less reactive to food chemicals than children with cow's milk intolerance
- Children with cow's milk intolerance become more reactive to foods as the chemical load increases
- Children with cow's milk intolerance experience symptoms of adverse food reactions more frequently than children with cow's milk allergy
- Children with cow's milk allergy were breast fed for twice as long as children with cow's milk intolerance and weaning formulas and foods were introduced later
- Mothers with a child who was allergic to cow's milk ceased breastfeeding for mother or child reasons, whereas mothers with a child intolerant to cow's milk ceased for child reasons
- Children with cow's milk allergy and cow's milk intolerance presented with similar symptoms, however there was a significant difference in the number of gastrointestinal and skin symptoms reported by the two groups. Symptoms alone did not give a direct impression of whether the child had an allergy or intolerance to cow's milk. However when gastrointestinal and behavioural symptoms presented together it was more likely to be a case of cow's milk intolerance.
- Diet was found to significantly improve symptoms
- A variety of health professionals provided information about adverse food reactions but not all information was useful
- Carers and immediate family members were found to be very supportive of the child's needs

- Although parents had difficulties feeding their child, most felt that their child was receiving adequate nutrition
- Families of these children did not avoid social occasions but they did avoid eating outside the home
- The majority of parents would like to be linked to other people who are in similar situations via the Internet, support groups or phone.

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