

Impact of suspected food allergy on emotional distress and family life of parents prior to allergy diagnosis

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Abstract

Background: Food allergy is associated with psychological distress in both child and parent. It is unknown whether parental distress is present prior to clinical diagnosis or whether experiences at clinic can reduce any distress present. This study aimed to assess anxiety and depression in parents and the impact of suspected food allergy on the lives of families before and after a visit to an allergy clinic.

Methods: One hundred and twenty-four parents visiting an allergy clinic for the first time to have their child assessed for food allergy completed a study-specific questionnaire and the Hospital Anxiety and Depression Scale; 50 parents completed these 4–6 wk later in their own home.

Results: Most parents (86.4%) reported suspected food allergy had an impact on their family life prior to clinic attendance; 76% had made changes to their child's diet. 32.5% of parents had mild-to-severe anxiety before their clinic visit; 17.5% had mild-to-moderate depression. Post-clinic, 40% had mild-to-severe anxiety; 13.1% had mild-to-moderate depression. There were no significant differences in anxiety ($p = 0.34$) or depression scores ($p = 0.09$) before and after the clinic visit.

Conclusions: Anxiety and depression is present in a small proportion of parents prior to diagnosis of food allergy in their child and this does not reduce in the short term after the clinic visit. Identification of parents at risk of suffering from distress is needed and ways in which we communicate allergy information before and at clinic should be investigated to see if we can reduce distress.

Food allergy affects around 5–8% of children and causes distressing symptoms such as oedema, skin rashes, breathing difficulties and gastrointestinal symptoms; in severe cases, anaphylactic shock can occur (1, 2). At present, there is no cure for food allergy and treatment involves strict avoidance of the allergen and emergency treatment of symptoms caused by accidental ingestion. Vigilance and continuous risk assessment is therefore needed to avoid these symptoms, and a number of studies have found that food allergy can have a big impact on the quality of life (QoL) of children and adult sufferers as well as their immediate family (3). For example, Valentine and Knibb (4) found that children with food allergy had poorer emotional and social QoL, compared to children with no food allergy or other chronic illness. The primary caregiver also had a lower overall QoL than caregivers not looking after a child with food allergy and lower QoL concerning social relationships. Marklund et al. (5) found that food hypersensitivity in school children had a significant impact on parental emotions, parental time and family. Food allergy has also been found to

be related to high levels of stress and anxiety, particularly in mothers (6, 7).

The majority of studies conducted with parents of children with food allergy focus on the impact of allergy after diagnosis. Specialist allergy services in the UK have been identified as insufficient to meet the rise in prevalence in allergy and knowledge in General Practitioners is recognised as inadequate (8), which can result in parents waiting for long periods of time before receiving a referral and a diagnosis of food allergy in their child. The impact of *suspected* food allergy on the lives of children and parents and whether parental distress is present prior to receiving a clinical diagnosis is unknown. This study measured anxiety and depression levels of parents before and after attendance at allergy clinic to have their child diagnosed for suspected food allergy. Lifestyle changes such as difficulties eating out, checking food labels and taking time off work, dietary changes made before and after clinic attendance, and informational and general knowledge sources of food allergy were also measured.

Methods

Design and participants

This was a questionnaire-based study with participants completing measures in clinic and 4–6 wk later at home. Participants ($n = 124$) were all parents of children referred to one of two secondary care allergy clinics in the Midlands, UK, for the first time. The questionnaires measured demographic and food allergy information, anxiety, depression, sources of knowledge and information regarding food allergy and lifestyle and dietary changes experienced by the family. Ethical approval was obtained from the local ethics committees for both NHS trusts responsible for the hospitals within which the clinics resided, and all participants gave written informed consent before taking part in the study.

Materials

Study-specific questionnaires

A study-specific questionnaire was completed by the parents at the clinic to gather demographic information about the child and parent completing the scales, the foods parents suspected their child was allergic to, the symptoms they had, how they had been referred and how long they had waited for a referral. Parents were asked about lifestyle and dietary changes they had made prior to attending clinic because of the suspected food allergy in their child. These were standardised lists of changes developed through examination of published literature regarding previously reported impact on diet and lifestyle and were also based on a questionnaire used in the previous published research (9). Lifestyle changes included checking food labels and difficulties eating out; dietary changes included avoiding the suspected allergen or using nutritional supplements.

Parents were also asked about their sources of general knowledge about food allergy and where they go to get their information about food allergy. Standardised lists were provided for parents to tick all applicable sources, which included family; friends; media sources such as the Internet, book and magazines; medical sources such as the G.P., nurse or other healthcare practitioner; and support groups. The questionnaire asked parents to rate their perceived level of knowledge about food allergy on a scale of 0 (no knowledge) to 10 (very knowledgeable).

A post-clinic questionnaire was also completed by the parents, which asked them to state the result of any food allergy tests that had been conducted at the clinic, their experiences at the clinic, lifestyle changes they had made post-clinic, their self-rated knowledge levels and their sources of knowledge of food allergy now they had been seen by a clinical specialist.

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of anxiety and depression, which asks how a person has been feeling over the previous week (10). Items are measured on a Likert scale with total scores ranging from 0 to 21 for both anxiety and depression subscales. Higher scores indicate greater anxiety and depression and it has cut-off scores to detect clinical cases of anxiety and depression. Score

ranges of 0–7 are classified as normal, 8–10 as mild, 11–14 as moderate and 15–21 as severe anxiety or depression. The measure has excellent internal consistency with alphas of 0.93 for anxiety and 0.90 for depression and the scale has good construct validity (11).

Procedure

Parents attending clinic with their child for investigative tests for suspected food allergy were approached by the study researcher while in the waiting room of the clinic and asked if they would like to consider taking part in the study. They were given an information sheet and then left alone to decide whether they would like to take part. They were able to take as long as they liked to decide whether to take part while at clinic. If they wanted to participate they were given a consent form and a questionnaire pack to complete in private before they went home. This included the study-specific questionnaires and the HADS. At the end of the questionnaires was a question asking them whether they would like to receive a further questionnaire four to 6 wk later, which would be posted to their home. If so they were asked to provide their name and address. Children at allergy clinic had a clinical history taken and skin prick tests for the suspected allergen (which is standard practice for diagnosis of food allergy in these clinics). No child received a double-blind food challenge. The follow-up questionnaire asked the parents to report the results of the skin prick tests, asked about any further lifestyle changes parents had made and included the HADS. Parents were provided with a stamped and addressed envelope with which to post these back to the lead researcher.

Data analysis

Data were analysed using SPSS version 18 (SPSS Inc. Chicago, IL, USA). All tests were two-sided with alpha set at 0.05. Categorical data were analysed by Chi-square, pre- and post-clinic food allergy knowledge levels, and HAD scores were analysed using paired samples *t*-tests; comparisons with published norm data for the HADS were made using one sample *t*-tests. Relationships between anxiety, depression, knowledge levels and number of dietary and lifestyle changes, age of child and length of time for referral were investigated using Pearson's bivariate correlations. Based on the previous published research showing high anxiety in parents of children with peanut and/or nut allergy, anxiety and depression levels for parents who suspected their child had a peanut and/or nut allergy were compared with levels for those parents who suspected their child had other types of food allergy, using independent samples *t*-tests. Main and interaction effects of variables on anxiety and depression were analysed using ANOVA. Questionnaires returned with missing data for the HADS were removed from the analysis.

Results

Participating parents ($n = 124$) reported that their children were attending clinic for the first time for investigative tests for

suspected food allergy and had been referred by their general practitioner (59.2%), the hospital (32.8%), a community paediatrician (3.2%) or school nurse (3.2%). The majority of respondents were mothers (80%), with the remainder being fathers. The majority were of white British ethnic background (77.6%). Children had an age range of 5 months to 16 yr with a mean age of 5.5 yr (s.d. = 4.00); 72 were male (58%), 53 were female (42%). Parents reported foods and symptoms typically associated with allergic reactions (Table 1). Parents had waited for an average of 4.05 months for their clinic appointment after receiving their referral (s.d. = 2.92; range 0–14 months); however, they reported suspicion of food allergy in their child for an average of 2.64 yr (s.d. = 3.01; range = 0–14 yr). Parents who returned the second set of questionnaires (n = 50) were not significantly different in their demographic details.

Dietary and lifestyle changes

A total of 76% of parents had made changes to their child's diet prior to clinic attendance, and 35.2% had made changes to their whole family's diet; only 35% had been given advice about these changes. Parents mostly removed the suspected food completely from the child's diet (Table 2). A total of 72.5% of parents continued to make changes post-clinic attendance with 45.1% making changes to the family diet. 30.3% had been referred to a dietician, but only 50% of these parents had seen a dietician when completing the post-clinic questionnaire. 86.4% had reported an impact on their lifestyle prior to clinic attendance, although only 60.8% reported an impact on their lifestyle on the post-clinic questionnaire (Table 2).

Knowledge and information sources

Parents reported a mean knowledge level of food allergy of 5.63 (s.d. = 2.55) at clinic. This was significantly higher after attendance at clinic (mean = 6.54, s.d. = 2.03), $t(45) = -4.15$, $p < 0.001$. A greater level of pre-clinic self-reported knowledge significantly correlated with more pre-clinic lifestyle changes

Table 1 Foods and symptoms reported by parents at clinic

Foods	n (%)	Symptoms	n (%)
Peanuts	59 (22.3)	Diarrhoea	14 (3.8)
Other nuts	55 (20.8)	Vomiting	47 (12.9)
Fish	12 (4.5)	Eczema	37 (10.1)
Shellfish	12 (4.5)	Urticaria	78 (21.3)
Hens' eggs	32 (12.1)	Asthma	23 (6.3)
Cows' milk	27 (10.2)	Breathing difficulties	44 (12.0)
Wheat	8 (3.0)	Rhinitis	12 (3.3)
Fruit	8 (3.0)	Facial swelling	79 (21.6)
Additives	16 (6.0)	Behavioural	16 (4.4)
Other	15 (5.7)	Migraine	3 (0.8)
Unknown	21 (7.9)	Other	10 (2.7)
		Unknown	3 (0.8)

Table 2 Lifestyle and dietary changes reported by parents pre- and post-clinic visit

	Pre-clinic n (%)	Post-clinic n (%)
Lifestyle change		
Checking food labels	89 (71.2)	28 (54.9)
Eating in restaurants is difficult	28 (22.4)	11 (21.6)
Leisure activities, parties, etc. are a problem	23 (18.4)	5 (9.8)
Child has to have own meals at school	40 (32.0)	10 (19.6)
Have had to take time off work	34 (27.2)	6 (11.8)
Dietary change		
Remove food	84 (67.2)	25 (50.0)
Reduce food quantity	8 (6.4)	0
Use alternative food product	21 (16.8)	0
Use nutritional supplements	6 (4.8)	0

Table 3 Sources of information and general knowledge (%) reported by parents

Source	Information	General knowledge	
		Pre-clinic	Post-clinic
Medical	50.4	35.8	30.1
Media	32.1	43.4	49.1
Family/friends	13.9	17.6	17.6
Support Groups	3.6	3.2	3.2

Medical – G.P., dietician, pharmacist, nurse, allergy clinic, immunologist. Media – books, magazines, newspapers, television, Internet.

($r = 0.45$, $p < 0.001$). Those who had made changes to their child's diet before attending clinic also reported higher pre-clinic levels of knowledge (mean = 6.00, s.d. = 2.49) compared with those who had made no changes to their child's diet before attending clinic (mean = 4.30, s.d. = 2.54), $t(112) = 3.09$, $p = 0.003$.

At clinic, parents were asked how they had obtained their general knowledge about food allergy, prior to attending allergy clinic. A significantly greater proportion of knowledge came from non-medical sources such as family, friends and the Internet compared with medical sources such as a G.P., nurse or immunologist ($\chi^2(1) = 48.55$, $p < 0.001$). This significant difference was also found in those who returned their questionnaire pack after clinic attendance ($\chi^2(1) = 57.85$, $p < 0.001$). Parents were also asked where they went to get information about allergy. Parents reported both medical and non-medical sources for where they went to get their information, and there was no significant difference in the source they used (Table 3).

Anxiety and depression

A total of 32.5% of parents reported mild-to-severe anxiety in the week prior to attending allergy clinic, and 17.5% of parents

reported mild-to-moderate depression levels (Table 4). Only 60% had anxiety levels in the normal range post-clinic, with 40% suffering mild-to-severe anxiety; 13.1% of parents reported mild-to-moderate depression levels post-clinic. There was no significant difference between anxiety levels pre- and post-clinic ($t(42) = -1.72$, $p = 0.09$) or depression levels pre- and post-clinic ($t(35) = -1.40$, $p = 0.17$), indicating that attendance at clinic and getting a confirmation or disconfirmation of food allergy in their child did not help reduce anxiety or depression in parents (Table 4).

When compared to norm data for a clinical sample (11), anxiety in parents in the present study in the week prior to attending allergy clinic was significantly higher than those who had just been diagnosed with a chronic illness ($t = 2.59$ (119), $p = 0.01$) (Table 4). There were no differences in overall depression levels. Significantly more parents in this study scored over the clinical cut-off for depression when attending allergy clinic (17.5%) than people in the clinical norm data (8.7%), ($\chi^2(1) = 7.39$, $p = 0.07$).

There were no significant differences in anxiety and depression in parents who suspected their children had peanut and/or tree nut allergy (anxiety mean = 5.99, s.d. = 3.94; depression mean = 2.90, s.d. = 3.07) compared with other types of food allergy (anxiety mean = 7.08, s.d. = 4.65; depression mean = 3.76, s.d. = 3.3) (all $p > 0.05$). Parents who suspected their child had an allergy other than peanut and/or tree nut allergy had significantly higher anxiety levels compared with the anxiety levels of the clinical norm data (Table 3), ($t = 2.52$, $p = 0.01$).

There were no significant relationships between anxiety and depression levels and self-reported knowledge levels, number of dietary or lifestyle changes, age of child, time to referral or length of time parent suspected a food allergy in their child (all $p > 0.05$). We used a median split to put parents into high and low knowledge levels and high and low number of lifestyle changes and ran independent measures ANOVAS to see whether anxiety and depression were different in these groups. We did not find any main or interaction effects with all p values > 0.05 .

Experiences at clinic

Fifty parents (40%) responded to the second questionnaire sent to their home. Of those who responded only 50% reported that their child had a positive skin prick test to the suspected food allergen. Nearly all parents (92%) were happy with the information given to them in clinic. A total of 86% of parents felt that they had been given enough information by the clinic; however, there was a need for more information on how to avoid specific foods, especially nuts, interpretation of food labelling and information on support groups.

Discussion

Prior to diagnosis, suspected food allergy does have an impact on the lives of the child and parents. The majority of parents had removed foods from their child's diet, although only around a third had received advice about this. Very few

Table 4 Anxiety and depression scores reported by parents at clinic and post-clinic

Score range	At clinic		Post-clinic	
	Anxiety n (%)	Depression n (%)	Anxiety n (%)	Depression n (%)
Normal	81 (67.5)	85 (82.5)	27 (60%)	33 (86.9)
Mild	17 (14.2)	17 (16.5)	11 (24.5)	4 (10.5)
Moderate	18 (15.0)	1 (1.0)	6 (13.3)	1 (2.6)
Severe	4 (3.3)	0	1 (2.2)	0
Mean	6.45 (2.55)	3.25 (3.19)	6.35 (3.85)	3.18 (3.10)
score (s.d.)				
Data from clinical population	5.44 (4.07)	3.02 (2.98)	5.44 (4.07)	3.02 (2.98)

replaced the food with an alternative product or introduced nutritional supplements to their child's diet. Of the parents who returned the second questionnaire pack, only half reported that their child had a positive skin prick test; thus, many parents may be removing staple foods unnecessarily from their child's diet, possibly compromising nutrient intake. This is particularly concerning given the time taken for parents to get a referral for suspected food allergy and then the wait for their clinic appointment. In severe cases, removal of foods due to food allergy has been shown to lead to nutritional deficiencies and failure to thrive (12) although no cases were reported in this sample.

Suspected food allergy also impacted on the lifestyle of the family, with parents checking food labels and finding difficulties eating in restaurants or taking their child to parties. Almost a third had also taken time off work prior to clinic attendance. A similar impact on lifestyle has been reported in the previous studies of families where children have already been diagnosed with food allergy (4, 5, 13–15); this study has shown that similar lifestyle changes are taking place even prior to getting a diagnosis of food allergy. Now that food allergy-related QoL scales for parents and children are available (16–19) it would be fruitful to investigate whether there is a similar impact on QoL prior to diagnosis.

Parents self-reported knowledge levels regarding food allergy were related to dietary and lifestyle changes, with those professing to know more about food allergy making the most changes. Previous research has similarly found that higher self-reported levels of knowledge in food allergic individuals were related to higher levels vigilance in allergen avoidance (20, 21). These studies also found that higher knowledge and vigilance were related to greater anxiety. This was not the case in the present study where neither knowledge levels nor dietary changes were related to anxiety. This may be because the present study measured parental anxiety rather than anxiety in the allergic individual, but further research in this area would be useful to ascertain the direction of this relationship.

Most of the knowledge in parents in the present study was reported to come from non-medical sources such as friends, family and the Internet, rather than medical sources. It is

therefore not clear if changes being made were based on accurate information. Almost all parents checked food labels prior to attendance at allergy clinic, and the ability to do this has found to be particularly poor in those who have not had proper advice (22). Educational materials provided at clinic have been shown to increase knowledge levels, improve correct use of adrenaline auto-injectors and relate to a reduced annual rate of allergic reactions (23). It has also been reported that parents of children with newly diagnosed food allergy would benefit from access to clear materials to help reduce levels of stress and anxiety (24). Material about food allergy such as this, which is accurate and easy to understand, also needs to be disseminated to the general public in order for parents to be able to make properly informed choices before they attend allergy clinic, if they suspect their child has a food allergy. Self-reported knowledge levels in the present study significantly increased after the clinic visit, but this was measured using just one item and so the validity of this finding and the areas of knowledge increase are not known. Only a third of parents talked to a dietician in this sample, as funding for a full-time dietician was not in place when data were collected for this study. This is something that is now standard practice and can help improve knowledge of food allergy management. Further investigation of levels of knowledge prior to and after clinic and the types of knowledge that is retained after clinic is needed.

Encouragingly a large number of parents scored within the normal range for anxiety and depression and so it seems that the majority of parents of food allergic children manage well, and only a small minority struggle to cope and exhibit higher levels of anxiety requiring help for mental health difficulties; a finding that has been reported elsewhere (25). Some level of anxiety has also been purported to be adaptive for parents of food allergic children and helps maintain a level of vigilance (21, 26–28). In the present study, over a third of parents suffered from some level of anxiety prior to the clinic visit and almost a fifth suffered from depression, and numbers scoring over the cut-off for depression were significantly greater than

seen in a clinical population (11). These levels did not reduce in the short term after the visit to the allergy clinic and so it is clear that anxiety and depression remains in a proportion of parents of food allergic children after diagnosis. We cannot be certain that a suspicion of food allergy in their child has caused the levels of anxiety and depression seen in parents in this study. Consistent findings of high levels of anxiety in this population suggests that food allergy is a causative factor, but longitudinal research following parents over time is needed to ascertain whether food allergy causes anxiety and depression or possibly exacerbates levels of anxiety and depression already present.

The low response rate for the follow-up questionnaire is a limitation for this study as it may be that only those who were still anxious responded. It may also be that the follow-up period was too short, and a longer period of time is needed to develop good food allergy management skills which could reduce anxiety. It would have been beneficial for double-blind food challenges to have taken place to confirm food allergy. These are not routinely carried out in secondary care allergy clinics in the UK and so a small number of false negatives or positives from the skin prick tests is a possibility. As with most studies of this nature, the respondents were predominately white British mothers and investigation of these issues in other ethnic groups would be beneficial.

This is the first study to demonstrate the impact of food allergy on parents prior to diagnosis in their child and those at risk of anxiety and depression need to be identified so that they can be supported in managing their distress levels prior to and after clinic attendance. This may include provision of allergy information prior to clinic, at clinic and after clinic attendance, as has been advised by Hu et al. (29), and it may also be useful for parents to receive information on the ways in which food allergy can affect the family psychologically.

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