

Assessment of quality of life in children with peanut allergy

Avery NJ, King RM, Knight S, Hourihane JO'B. Assessment of quality of life in children with peanut allergy.
Pediatr Allergy Immunol 2003; 14: 378–382. © 2003 Blackwell Munksgaard

Children with a peanut allergy (PA) are faced with food and social restrictions due to the potentially life-threatening nature of their disease, for which there is no cure or treatment. This inevitably impacts upon their quality of life (QoL). QoL of 20 children with PA and 20 children with insulin-dependent diabetes mellitus (IDDM) was measured using two disease-specific QoL questionnaires (higher scores correspond to a poorer QoL). One questionnaire was designed by us and the other was adapted from the Vespida Allergy QoL questionnaire. We gave subjects cameras to record how their QoL is affected over a 24-h period.

Response rates for both questionnaires were 100%. Mean ages were 9.0 and 10.4 years for PA and IDDM subjects, respectively. Children with a PA reported a poorer quality of life than children with IDDM: mean scores were 54.85 for PA subjects and 46.40 for diabetics ($p = 0.004$) in questionnaire 1 and 54.30 and 34.50 ($p \leq 0.001$) in questionnaire 2. PA children reported more fear of an adverse event and more anxiety about eating, especially when eating away from home. Photographs fell into seven common categories: food, management, environment, away from home, physical activities, restaurant and people. Most photographs related to food and management issues and revealed difficulties for both groups regarding food restrictions. PA subjects felt more threatened by potential hazards within their environment, felt more restricted by their PA regarding physical activities, and worried more about being away from home. However, they felt safe when carrying epinephrine kits and were positive about eating at familiar restaurants. The QoL in children with PA is more impaired than in children with IDDM. Their anxiety may be considered useful in some situations, promoting better adherence to allergen avoidance advice and rescue plans.

Natalie J. Avery¹, Rosemary M. King², Susan Knight³, and Jonathan O'B. Hourihane^{1,2}

¹Division of Infection Inflammation and Repair, University of Southampton, ²Wellcome Trust Clinical Research Facility and ³Psychology Department, Southampton University Hospitals NHS Trust, Southampton, UK

Key words: quality of life; peanut allergy; children

Dr J. O'B. Hourihane, Division of Infection Inflammation and Repair, University of Southampton, Mailpoint 218, Southampton University Hospitals NHS Trust, Tremona Road, Southampton, SO16 6YD, UK

Tel.: +44 23 80794989

Fax: +44 23 80795023

E-mail: J.Hourihane@soton.ac.uk

Accepted 18 March 2003

Peanut allergy (PA) is responsible for the largest proportion of fatalities due to food-induced anaphylaxis (1). PA has an unpredictable nature: subjects who have had only mild reactions may have a severe or even fatal reaction on subsequent re-exposure (1–3). A variety of settings are potentially hazardous to PA subjects and they must be extremely vigilant. Only a minority of foods labelled as 'may contain peanuts' labels actually do contain significant traces of peanut (4). Issues that arise around food shopping, meal times and social eating have obvious implications for the

quality of life (QoL) of both the peanut allergic patient and his family.

High levels of anxiety have been shown in the parents of a peanut allergic child (5, 6). Clinical observation suggests the anxiety is constant though exposure is only sporadic, akin to hymenoptera allergy (allergy to bees, wasps and hornets). In contrast to the anxiety they both induce, only hymenoptera allergy has a curative treatment available: allergen-specific immunotherapy, which improves the QoL of those treated (7, 8). There is no such treatment for PA at present (9).

To date only two studies have attempted to measure the impact food allergy has on the quality of life in children (5, 6). This is in contrast to asthma and rhinitis which have been studied extensively (10). In both studies of food allergy the parents of children with peanut/food allergy completed generic health-related QoL questionnaires. Our objective therefore was to ask children directly how they perceive their PA affects their QoL, and to use disease-specific questionnaires, which are sensitive to small changes in health-related QoL in a given disease state (10).

Children with insulin-dependent diabetes mellitus (IDDM) were used as our control group. There are sufficient parallels between the two groups to make IDDM subjects ideal for comparison with PA: food choices, social restrictions, issues relating to school, the carriage and/or use of a syringe kit and the chronicity of the condition (11).

Methods

The study was approved by the Southampton and South West Hampshire Local Research Ethics Committee (LREC). Written parental and child consent were obtained. Twenty children with PA and 20 with IDDM between 7 and 12 years old were recruited directly in allergy and diabetic clinics or via post from established clinic records. The mean ages were 9.0 and 10.4 years for PA and IDDM, respectively. The male/female ratios for the two groups were 9:11 and 11:9 for PA and IDDM, respectively. The only inclusion criterion, other than age, was that the individual had experienced either an allergic reaction to peanuts or a hypoglycaemic attack, respectively. Patients with co-morbidity such as physical disabilities, non-allergic lung or heart diseases were excluded from the study as they may have an impact on their QoL.

Two disease-specific questionnaires were completed by the child at a clinic or at home if posted to them. A higher score (out of 100) indicated a lower QoL. We designed the first, and the second was adapted from the Vespil Allergy QoL questionnaire, which has been used to measure health-related QoL in individuals with anaphylactic sensitivity to wasp stings (7, 8). The hypoglycaemic attack (hypo) was considered the comparator to the allergic reaction to peanut as it is this which diabetics associate with morbidity and which causes them most anxiety.

Each child received a disposable camera (donated by the Anaphylaxis Campaign) and

notebook, and was asked to record how their condition impacted on their QoL over a 24-h period at a weekend. They commented in the notebooks how they felt at the time of taking each picture. Written consent was obtained from people having their photograph taken.

The pictures taken were categorized: food, management, environment, physical activities, restaurant, away from home and people. A percentage of the total number of PA or diabetics who had taken photographs in each category could then be obtained and compared. Each comment about a photograph was given an arbitrary value according to the sentiment expressed: negative -1; neutral, 0 or positive, +1. Photographs with no comment were scored as neutral, 0.

Data were stored and analysed using SPSS software (Version 10.1, SPSS Inc., Chicago, IL, USA). Differences in mean scores between the two groups in each questionnaire were examined using the independent Student's *t*-test. Questionnaires were compared directly using Pearson's correlation to measure the strength of their linear association. Chi-squared tests and Fisher's exact test were used to examine the differences between the numbers of photographs taken in each category by PA or diabetic subjects. Two-tailed *p*-values of < 0.05 were judged significant.

Results

Questionnaires

One hundred per cent of the questionnaires were returned. Mean scores for questionnaire 1 were 54.85 for the PA group and 46.40 for the IDDM group ($p = 0.004$, Fig. 1). The mean scores for questionnaire 2 were 54.30 for the PA group and 34.50 for the IDMM group ($p \leq 0.001$, Fig. 2). There was a linear correlation between questionnaires 1 and 2 for the PA group ($r = 0.69$, $p = 0.001$) and the IDMM group ($r = 0.67$, $p = 0.001$) showing that the questionnaires can be reliably used independently of each other.

There was a significant difference between the mean scores for the PA and IDMM groups, within the management ($p < 0.001$) and eating subgroups ($p < 0.001$). Children with PA were more afraid of accidentally eating peanuts than diabetics were of having a hypo: five children with PA claimed that they were either very scared or extremely scared of accidentally eating peanuts whereas diabetics only claimed to be moderately scared or less ($p = 0.04$, Fig. 2a).

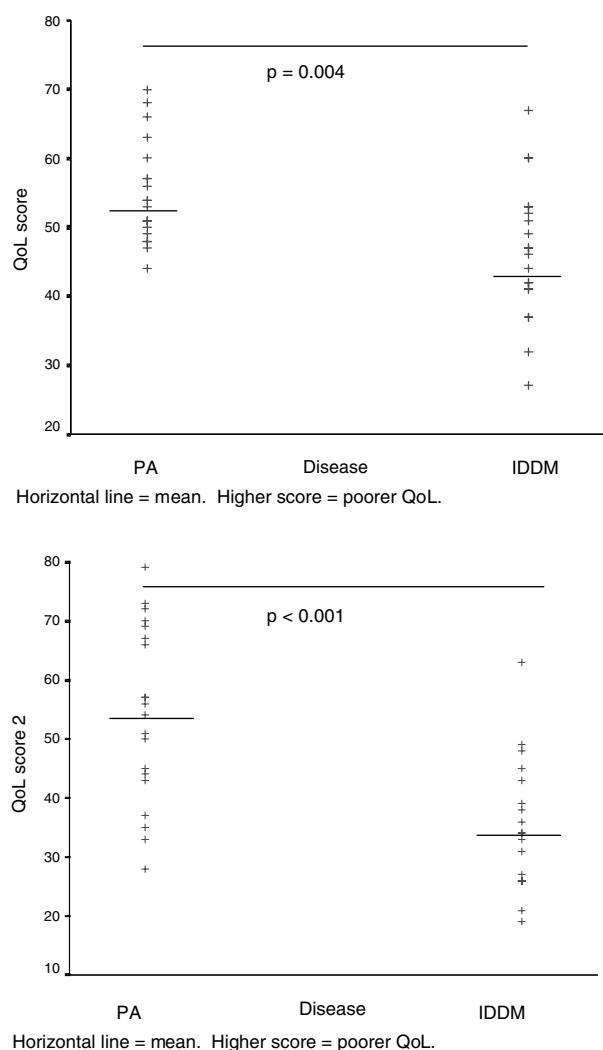


Fig. 1. QoL scores for questionnaires 1 and 2. There was a significant correlation between questionnaire scores for both groups: PA ($r = 0.69$, $p = 0.001$), IDMM ($r = 0.67$, $p = 0.001$).

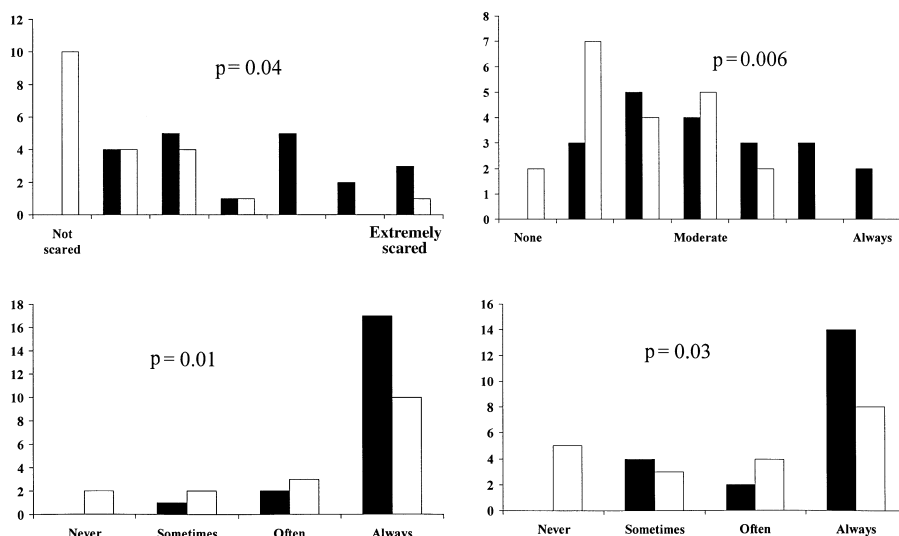


Fig. 2. Comparisons of questionnaire scores for peanut allergy subjects and diabetics. (a) Fear of eating peanuts/having a hypo; (b) chance of having a bad reaction and getting very sick; (c) I have to be careful about what I eat; and (d) I must take care when eating in a restaurant. Black bars denote peanut allergy and clear bars denote diabetes.

This point was reinforced when children were asked what chance they thought they had of having a bad reaction to peanuts/bad hypo and getting very sick, with PA subjects having a mean score reflecting perception of a higher risk than diabetics (4.2 vs. 2.9, $p = 0.006$; Fig. 2b). PA subjects check food labels more often than diabetics ($p = 0.001$). Eighty-five per cent of PA subjects compared with 50% of diabetics felt they always have to be careful about what they eat generally ($p = 0.01$, Fig. 2c), specifically being very careful in restaurants ($p = 0.031$), Fig. 2(d).

Peanut allergics reported significantly higher anxiety than diabetics when they go on holiday ($p < 0.001$), at birthday parties ($p = 0.002$) and when on public transport ($p < 0.001$). Concerns and worries about disease management at home and school were similar in each group.

Photographs

Sixteen PA subjects and 19 IDDM subjects returned cameras ($p > 0.05$, NS). The only significant difference in category of subjects photographed was that more PA subjects than IDDM took photographs within the restaurant category ($p = 0.05$, Table 1) (1).

Restaurant category. Unexpectedly, 60% of PA subjects made mostly positive comments about restaurants. The majority did clarify, however, that they always go to the same restaurant because they cater for people with PA. Only two diabetics made comments relating to restaurants: both neutral in tone.

Table 1. Photograph categorization results

	Categories						
	Food (%)	Management (%)	Environment (%)	Physical activities (%)	Restaurant (%)	Away from home (%)	People (%)
PA (n = 16)	100	75	25	31	44*	19	38
IDDM (n = 19)	84	89	16	47	11	11	16

*p < 0.05.

Table shows the percentage of people from each group who took photographs within each category.

Food category. All PA subjects and 85% of diabetics took photographs of food-related issues. The overall feeling from both groups in this category was negative but different themes were observed between the groups. Two PA subjects stated they were scared of dying when they knew peanuts were nearby, for example, in the supermarket. Diabetics commented on restricted foods that their siblings were allowed eat or their own helping size but none mentioned a fear of death.

Physical activities category. PA subjects were negative about physical activities, feeling restricted and unable/not allowed to do things that other people could do. Diabetics felt that physical activities help with the control of their diabetes and therefore were positive in this respect.

People category. The PA group made neutral comments in the people category but the common feeling for the diabetics was positive. A common positive theme for both groups was that of friends who also had PA/IDDM and understood how they felt. 'My sister is also diabetic, I'm happy she knows how it feels'. PA subjects made some negative comments with respect to people not understanding about their allergy. 'My Grandma buys my brother and me sweets but she forgets about my allergy and buys things that I can't have. It's really annoying'.

Discussion

We have shown that children with PA have a poorer QoL than children with diabetes. This appears to be related to anxiety. It appears that PA subjects are aware that their condition might be fatal but children with IDDM may not be aware of the long-term implications of their condition. PA subjects' higher levels of disease-related anxiety especially when outside a home or school environment could be interpreted as helpful or protective as it increases their compliance to a management plan – the strict avoidance

of peanuts – in the absence at present of any meaningful curative treatment. Anxiety may be unhelpful if the restrictions in lifestyle are unrealistic or unfounded, e.g. avoiding supermarkets because of a fear of death. Anxiety can lead to mental health problems in children.

Peanut allergic children have to be constantly aware of allergen hazards in their environment and must carry an injection to 'possibly save their life' should they accidentally encounter peanut. For IDDM subjects, disease control is based on eating the right foods, performing regular blood tests and taking insulin. Although this strategy can be a burden, it does give them some control over their disease.

Our study expands on the previously available literature (5,6) in several ways. The two preceding studies used generic health-related QoL questionnaires, completed by parents and Primeau's study used a control group of children with musculoskeletal disorders. We used disease-specific questionnaires, completed by the children themselves, and cameras, which are a child friendly tool, to gain an insight into the personal experiences and the perceived burden of PA and IDDM. Our control group appears more comparable than Primeau's to the peanut allergic study group, as it comprises ambulant, pain-free children who have issues similar to peanut allergies relating to food, independence and the need for injected medication, albeit daily insulin subcutaneously rather than epinephrine intramuscularly in an emergency, while under great physical and emotional stress.

Limitations of this study included the recruitment of patients from regional allergy and diabetic clinics from the same hospital. The study does not therefore allow for differences between clinics and varying practice between clinicians, which may influence a patient's management of their disease. We concentrated on issues in diabetes self management that mimicked issues in PA. It is possible or likely that there are other issues in the management of diabetes in general (renal or eye problems) that may affect QoL but which we have not measured. In

generally healthy children such long-term complications of diabetes probably do not have a great impact on a child's QoL. This pilot study only involved a small number of patients and could be performed on a larger scale. Perceived issues of data protection and privacy prevented us from approaching schools to allow inclusion of a school day in our study. School is a major part of a child's life and appears, despite parents' worries to the contrary, to be associated with less risk of food allergen exposure than out of school activities (12), so this may limit the widest interpretation of our findings.

This study shows how simple tasks such as shopping or eating in restaurants can be extremely frightening, even perceived as life-threatening. PA children are frightened to eat foods without checking labels and must be extremely vigilant in order to avoid peanuts. IDDM subjects, however, are able to adapt their diet (and insulin dose) to some extent and still avoid any ill effects. Both groups display an element of frustration: peanut allergics are faced with defensive food labelling by manufacturers, limiting the variety of foods they can eat; diabetics must follow a strict diet regime, often forcing them to eat when they do not want to. The unexpected positive reports that PA subjects made about restaurants actually represent a limitation: they indicate a restriction of choice of where PA subjects feel that it is safe to eat.

To ensure continued compliance, while achieving a more acceptable QoL, it is vital that education is geared towards developing a positive attitude and decreasing unjustified levels of anxiety in peanut allergic children, particularly relating to disease management and food exposure, enabling them to follow a less restricted lifestyle.

Peanut allergic and diabetic children both felt reassured by knowing other people had the same problems as them. Camp activities are well established for diabetic children in Britain and such an approach could be a way of supporting food allergic children, who feel isolated and vulnerable. Diabetes clinics are well established in Britain and families often have access to diabetes nurse specialists, psychologists and dietitians. Such services do not appear to be so widely available to families with severe food

allergies. Our study suggests a significant need for such resources to help address major issues of anxiety and lifestyle adaptation in families affected by peanut allergy.

Acknowledgments

We thank Dr Anthony Dubois (Groningen, Netherlands) for sharing with us the Vespider Health Related Quality of Life Questionnaire, Dr Peter Betts and Sr Bridget Smith of the Paediatric Diabetic Clinic, Southampton for allowing us to approach children attending their clinic.

References

1. BOCK SA, MUÑOZ-FURLONG A, SAMPSON HA. Fatalities due to anaphylactic reactions to foods. *J Allergy Clin Immunol* 2001; 107: 191–3.
2. VANDER LEEK T, LIU A, STEFANSKI K, BLACKER B, ALLAN BOCK S. The natural history of peanut allergy in young children and its association with serum peanut-specific IgE. *J Paediatr* 2000; 137: 749–55.
3. PUMPHREY RS. Lessons for management of anaphylaxis from a study of fatal reactions. *Clin Exp Allergy* 2000; 30: 1144–50.
4. MCCABE M, LYONS RA, HODGSON P, GRIFFITHS G, JONES R. Management of peanut allergy. *Lancet* 2001; 357: 1531–2.
5. PRIMEAU M, KAGAN R, JOSEPH L et al. The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children. *Clin Exp Allergy* 2000; 30: 1135–43.
6. SICHERER S, NOONE S, MUNOZ-FURLONG A. The impact of childhood food allergy on quality of life. *Ann Allergy, Asthma Immunol* 2001; 87: 461–4.
7. OUDE ELBERINK JN, DE MONCHY JG, GOLDEN DB, BROUWER JL, GUYATT GH, DUBOIS AE. Development and validation of a health-related quality-of-life questionnaire in patients with yellow jacket allergy. *J Allergy Clin Immunol* 2002; 109: 162–70.
8. OUDE ELBERINK JN, DE MONCHY JG, VAN DER HEIDE S, GUYATT GH, DUBOIS AE. Venom immunotherapy improves health-related quality of life in patients allergic to yellow jacket venom. *J Allergy Clin Immunol* 2002; 110: 174–82.
9. HOURIHANE JO'B. Recent advances in peanut allergy. *Curr Opin Allergy Clin Immunology* 2002; 2: 227–31.
10. THOMPSON A, JUNIPER E, MELTZER E. 'Quality of life in patients with allergic rhinitis'. *Ann Allergy, Asthma Immunol* 2000; 85: 338–44.
11. GARDINER P. Social and psychological implications of diabetes mellitus for a group of adolescents. *Pract Diabetes Int* 1997; 14: 43–6.
12. SICHERER SH, FURLONG TJ, MUNOZ-FURLONG A, BURKS AW, SAMPSON HA. A voluntary registry for peanut and tree nut allergy: characteristics of the first 5149 registrants. *J Allergy Clin Immunol* 2001; 108: 128–32.