

Article

Patients' experience of a regional allergy service

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Although there is a great deal of information available about allergy on the Internet, in the media and via word of mouth from family and friends, unfortunately a fair proportion of this is misleading, inaccurate and even potentially dangerous. The main role of a specialist allergy service is the diagnosis and management of allergies and patient education during the consultation. This audit of patients diagnosed with type 1 allergy showed that a small but significant proportion may not have understood or accepted their diagnosis, others may not be confident in coping with their allergy, and over half had further symptoms after discharge from the clinic. The effectiveness of specialist allergy services will be diminished if there is no longer-term follow-up of patients. Public health education is also important so that patient expectations about the role of allergy services are realistic.

Abstract

Background. The principle reason for referral to specialist allergy clinics is to establish diagnoses and provide treatment plans to help patients manage their allergy. If patients do not accept, understand, or remember diagnoses or treatment, clinic visits may have been a waste of time. Few specialist allergy clinics follow up patients after diagnosis.

Design and Methods. This was a postal survey to assess patients' i) perception of usefulness of specialist allergy clinic visits, ii) understanding of their allergy, iii) confidence in managing it, and iv) response to joining a regional online forum. Data for patients with confirmed allergy who attended the Peninsula Allergy Service (PAS) from 1998-2009 were extracted from consultant letters to general practitioners. Postal questionnaires were sent to 933 patients; 39% (336) responded.

Results. Two-thirds (63%) thought their clinic visit useful and resulted in them being more *in control* of their allergy; 9% thought it useful but they still had problems, 26% thought it had not been much use. One in six (16%, 55) respondents had major differences in their view of their allergy compared to that recorded by PAS. Over half (56%) had had further symptoms since their clinic visit and 120 patients, who were not confident in coping with their allergy, listed aspects of their lives that gave concern.

Conclusions. Specialist clinics need routine feedback from patients if they are to monitor their effectiveness and some better form of follow up for patients is needed to reinforce education and support patients. Public education is important.

Introduction

The prevalence of allergic diseases worldwide is rising dramatically

in both developed and developing countries and is becoming a serious public health problem with about 30-40% of the world population now being affected by one or more allergic conditions.¹ A high proportion of this increase is occurring in young people; thus, as this young population reaches adulthood, the burden of allergic diseases is expected to increase even more. In many countries, attempts to tackle these problems on a national basis are widely variable and fragmented, resulting in decreased quality of life, increased morbidity and mortality, and considerable cost to patients with allergic diseases.² An estimated 21 million adults in the UK suffer from at least one allergy in their lifetime.³ Allergy incidents and their increase have an adverse effect on the European economy due to both direct costs (for asthma alone, pharmaceutical cost stands at €3.6 bn per year and those to healthcare services at €4.3 bn) and costs to patients. Allergic disease costs NHS Scotland (population 5.3 million) over £130 million annually with the majority of this cost being for asthma.⁴

Severe allergic reactions (anaphylaxis) are responsible for approximately 3000-5000 admissions to A&E in each Strategic Health Authority in the UK each year,⁵ of which approximately 19 patients die.⁶

Food allergy clearly affects a patient's health related quality of life.⁷ There have been a number of recent studies among children with food allergies showing that food allergy and food hypersensitivity have an impact on psychological distress and on the quality of life (QoL) of children and adolescents, as well as their families.⁸⁻¹² However, there have been fewer studies among adults.¹³

The main purpose of referral to an allergy clinic is to obtain a clear diagnosis and to identify whether or not the patient suffers from type I allergy or some other related condition.⁵ Once a diagnosis of a type I hypersensitivity has been made, the patient is given a treatment plan which generally involves recommendations as to what allergen(s) to avoid and what to do in case of accidental exposure to the allergenic trigger. In most cases this necessarily involves a life-style change which is often associated with a degree of anxiety and personal costs. The life-style change is necessary in order to prevent exposure to the offending allergen and triggering a further allergic reaction. The degree to which patients have developed a correct understanding of their diagnosis and treatment is crucial here and will depend on the interaction between patients and doctors during consultations. If the patient's understanding of the diagnosis and treatment is incorrect this could result in either a risk of the patient suffering a further event or the patient leading unnecessarily restricted lives. Compounding this will be the degree of anxiety associated with the diagnosis which, if excessive can also adversely affect the patients' quality of life.

The success or otherwise therefore of a clinic visit is dependent on the patients' understanding of their allergic condition. However, very little research has been published on patients' knowledge of their own allergy. Patients' understanding of their allergies does not only include the specific diagnosis and the means to deal with it in the best possible way, but also should include an idea of their personal risk should they be re-exposed to the allergen.

Plymouth Hospitals NHS Trust (PHNT) provides a regional service for allergy for Devon and Cornwall. The Peninsula Allergy Service (PAS) currently receives referrals for 800 new patients per annum from 200 GP practices. Our recent audit of referrals to the PAS identified 961 patients in Devon and Cornwall who had an allergy diagnosed at PHNT during the last 11 years.¹⁴ Few secondary care allergy clinics in the UK follow up patients after return to their GP to see how well patients cope with their condition once they have a diagnosis.

This project aimed to i) follow-up patients diagnosed with a type 1 hypersensitivity at PAS, over an 11 year period, to assess the impact of their diagnosis and how they have been coping with their condition, and ii) to establish an Internet support group for patients with allergy who have attended PAS.

Design and Methods

Ethics and approval

The study, carried out by the Clinical Lead of the PAS on his past patients, was reviewed and approved as *service evaluation* by the chair of the NHS South West 1 ethics committee, the PHNT research governance manager, and PHNT research and development officer in February 2011.

Patient sample

The main source of data was consultant letters to GPs summarising the diagnosis of patients, archived from September 1998 to September 2009. These letters were for patients who, following the taking of a detailed history, were confirmed as having an allergy (type I hypersensitivity) on the basis of a *positive* skin prick test or specific IgE test in the clinic. A skin prick test was considered positive when the diameter of the wheal exceeded the diameter of the negative control by 3 mm and when a flare reaction was also present. A specific IgE test was considered positive when the value exceeded 0.7 kUA/L. We did not include borderline positive results as positive. Letters were reviewed, extracting the clinic date, doctor seen, patient's name, gender, date of birth, postcode, GP, and diagnoses. The characteristics of these 961 patients were described in detail elsewhere.¹⁴ The mean age of patients at referral was 35 with considerably more females (65%) than males (35%). Three-quarters (72%) had one or more non-food allergy and 43% had one or more food allergy; 15% had both food and non-food allergy. Nuts, fruit, and seafood (including fish and crustaceans), were the most frequent food allergies. Of the non-food allergies, airborne allergies were the most frequent and of these house dust mite, pollen, and animal hair all occurred frequently.¹⁴

In 2011, the file of 961 was checked against the hospital index to see if any patients had died and to find more recent addresses. Eight were not found on hospital index and were excluded leaving 953 patients referred between September 1998 and September 2009 by a total of 541 GPs.

Contact with general practitioners

Four GPs, medical officers each having referred one member of the Armed Services to the PAS, were excluded. We contacted 537 GPs who had referred 949 patients, asking for their help in contacting past patients of the PAS. They were sent details of their patients and asked to check these records against their own, to provide updates to contact details, and to indicate if any patient should not be contacted.

Postal questionnaire

Unless they had been excluded by their GP, all patients were contacted with a postal questionnaire (Appendix) asking (mainly in open

questions) for information about their attendance at the PAS and whether it made any difference, if any, to their lives, their allergy and how they coped with it and how confident they were in so doing.

Data analysis

We compared subgroups [age, gender, type of allergy (food *versus* non food), year of visit] using χ^2 , t-tests, or analysis of variance as appropriate. Analysis was carried out using SPSS v20. Groups for content analysis of open questions were agreed between AO and RJ: AO coded the data with RJ checking a 20% sample. Difficult or ambiguous cases were discussed and coding agreed.

Patients' statements on their allergy were compared with information extracted from the consultant's letter to their GP. We classified these as agreement if patient listed the same allergens as the PAS letter (allowing for minor differences such as patient saying *nuts* when PAS letter more specifically recorded *pecan and cashew nuts*). We calculated the number of *differences*, where a difference may be the patient failing to identify a confirmed type allergen documented on the hospital letter (*omission*) or where patients identified allergies not listed on the hospital letter (*commission*). Although we refer to these disagreements as *errors* of omission and commission, we discuss later these may be errors in our hospital derived data as well as errors in the patient's understanding. For ease of presentation we aggregated our data using arbitrary groups into zero differences, 1-3, and 4 or more difference between hospital letter and patient perception. Coding was carried out by AO with a 20% sample and unusual cases being checked by RJ. For cases with extreme discrepancies we audited the trail of data from original sources, to ensure there had been no study data handling errors (such as mismatched records).

Patients were asked for their email addresses and whether they would want to join an online discussion forum. As we aimed to recruit patients to an online community to support their follow-up we wanted to know if those who might form this community were more or less likely to be those with differences with their PAS-recorded allergies.

Results

Final sample and response

Less than half (235/537) GPs responded with information concerning 428 patients. GPs asked us not to contact twelve patients: seven patients whose GP was on long term sick leave, two patients who were very ill, one patient who had died, and two patients who were students who were not contactable. A further four students in temporary accommodation were excluded making 16 of the 949 patients that were excluded; 933 were sent information about the study and asked to complete questionnaires. These comprised 416 patients whose GPs had checked their details and did not object to us contacting them for the purpose of the study, and 517 patients who we wrote to using information held by the PAS, but whose GPs had not responded. Completed questionnaires were returned by 336 (Table 1), 66 questionnaires were

Table 1. Age and gender of 336 respondents.

Age range	Participants (%)	Males (%)	Females (%)
<30	46 (13.7)	16 (34.8)	30 (65.2)
30-50	156 (46.4)	38 (24.4)	118 (75.6)
51-70	111 (33.0)	36 (32.4)	75 (67.6)
>70	23 (6.9)	12 (52.2)	11 (47.8)
Total	336	102	234

returned to sender, person gone away, and there was no response from 531. The response rate therefore was between 35% (336/961: original sample) and 39% (336/867: sent questionnaires not gone away).

There was no difference in response rate by year of clinic attendance but older patients were much more likely to respond than younger [54% of 71 + reducing to 21% of the under 30s responding; $\chi^2(3)=40.3$; $P<0.001$], and females were slightly more likely to respond than males [38% vs 32%; $\chi^2(1)=3.8$; $P=0.05$]. There was no difference by food vs non-food allergies in response rate, amongst responders 42% had a food allergy (possibly plus non-food allergy) and 58% had a non-food allergy only.

Memory of their allergy clinic visit

Although most patients (84.2%) *definitely* remembered their clinic visit, 42 (12.5%) only vaguely remember and 11 (3.3%) did not remember at all. Those aged under 70 were more likely to definitely remember their clinic visit [65% vs 86%; $\chi^2(1)=6.7$; $P=0.01$], as were those with a food allergy [90% vs 80%; $\chi^2(1)=6.0$; $P=0.01$]. Not surprisingly being able to definitely remember the clinic visit was strongly related to the year of the visit [94% of those with visits 2006-2009, 81% 2002-2005, and 70% 1998-2001; $\chi^2(2)=24.5$; $P<0.001$].

Knowledge of their allergy

Patients were asked whether they had an allergy and to state what it was. Most (321, 95.5%) said they had an allergy, but 11 said they did not, and 4 did not know or did not answer. According to PAS records, the 11 who claimed not to have an allergy all had type 1 sensitivity to airborne allergens such as grass pollen, tree pollen, house dust mite, and dog hair. From their comments it appears that three (of 11) patients had other symptoms at the time of referral (one with irritable bowel syndrome and two with angioedema) that were diagnosed as not type 1 sensitivity. Another 15 out of 321 did not state an allergy or gave a vague response such as *too numerous to mention - many things I have no contact with and I am sensitive to many things*.

Table 2 compares patient-stated with PAS recorded allergies. Just over a third of all respondents exactly matched the PAS record. Two out of five had less than four differences but 55 had four or more differences in their view of their allergy compared to that recorded by the PAS. A simple count of differences may obscure the *importance* of the difference, for example, one patient with one difference had cited allergies of *two types of dust mites, dogs, cats, grass, pollen, nuts, baked beans* which was the same as the PAS record apart from the addition of pollen. On the other hand another patient with one difference stated *Shellfish – lobster, prawns, crab (but not bi-valves-mussels/oysters/scallops)* whereas the PAS letter said *prawns and aspirin*. A few patients had some extreme differences such as one who had diagnosed allergies

to grass pollen, tree pollen, cat, dog and house dust mite but listed *Penicillin, cephalixin, trimethoprim, dosycycline, aspirin, clarithromycin, loratadine, plasters, cats, dogs, horses, cows, sheep, alpaca, llama, buffalo, guinea pigs, ants, raw onion, facial hair, all Sure products, Lilley & Skinner shoe dye, solid soap, solid deodorants, fungal spores, dust mite, tree pollen, yew, grass, glue on hospital name bands, hamsters, deep heat rub*.

Men were more likely than women [49% vs 31%; $\chi^2(1)=9.7$; $P=0.002$] to agree with their PAS diagnosis. People over 70 were more likely to have a major number of disagreements with their PAS diagnosis [44% vs 16%; $\chi^2(1)=7.8$; $P=0.005$]. We also examined the nature of differences; errors of commission, where people think they are allergic to items not listed by PAS are perhaps inconvenient for the patient in that they may be avoiding those items, but are unlikely to have major clinical impact. Errors of omission may be more important, if for example, someone is allergic to peanuts but has not realised or has truly forgotten. Omission of a source of pollen is not particularly important. Table 2 shows that 24 people omitted one or more food allergies including peanuts, tomato, banana, and melon. Some patients had both errors of omission and commission, for example (Table 2) one patient claiming allergy to dust mite, dog/cat fur, dander, tree pollen, grass pollen not on the PAS record but missing PAS-recorded allergy of cladosporium and agreeing on allergy to dairy products. Another example is a patient who agreed on allergy to latex, claimed allergy to pollen not recorded on PAS, but omitted PAS-recorded allergies of tomato, banana, and melon.

Impact of consultation

Thirty three people had no recollection of their clinic visit, or did not respond, or made a comment that was not in response to *If you remember attending the clinic, what difference to your life, if any, did it make?* Of the 303 who answered 191 (63%) patients responded with comments suggesting that the clinic visit had been useful (Table 3) and that as a consequence had altered their behaviour in some way to cope with their allergy. Examples of comments that illustrate this *copying* or behaviour change included: *It made a huge impact to have allergies confirmed (I thought I was going mad). The advice I was given assisted me in dealing with my allergies; They help identify what my allergy was thus enabling me to stop taking steroids and reduced pain; A very positive difference as I was told about my allergy and what to do about it; Yes had made a huge difference as found out I was allergic to kiwi and latex, so had to be very careful; A huge difference as I did not have any days when I was unable to work or go out as I did before attending clinic; The medication I was advised to get has really helped*.

A quarter (76) did not find the clinic visit of much use. People with non-food allergies were slightly more likely to have found the clinic visit not useful [34% vs 21%, $\chi^2(1)=5.2$; $P=0.02$] than those with food allergy. Some of these claimed to already know their diagnosis (*e.g. No*

Table 2. Comparison of patient-stated allergy with PAS record showing number of differences and examples of omissions or commissions for individual patients. (Note that some patients had both omissions and commissions and will be counted in more than one column).

Numbers of differences between patient and PAS record	Patients omitting an allergy that was on the PAS record (omission)		Patients claiming an allergy that was not on the PAS record (commission)		Total
	Food	Non food	Food	Non food	
0 agreement					123 eg, (36.6%)
1-3	11 eg, peanuts	41 eg, latex, dogs	57 eg, egg, yolk	64 eg, dogs, horses	132 (39.3%)
4+	13 eg, tomato, banana, melon	37 eg, dogs, cats, grass, pollen	44 eg, kiwi, apples, apricots	38 eg, dust mite, dog/cat fur, dander, tree pollen, grass pollen	55 (16.4%)
Vague answers					26 (7.7%)
Total	24	78	101	102	336

difference as avoided nuts prior to attending PAS so still avoid nuts; None - I already knew what I was allergic to), while others may have expected some form of cure (e.g. None, I am still suffering with a nasal problem, None really, apart from now I know what I'm allergic to).

Further symptoms since their clinic visit

More than half (178, 56%) of the 317 patients had had further major reactions or troublesome symptoms since their last clinic visit. These included: *Labelled food that should have been safe on flight to Australia!; Rhinitis has got worse all year round. Makes me very miserable as I seem to be permanently blocked up; Some tingling in my mouth and lips swelling. Use inhaler a lot if eat something that may contain traces of nut; Went into anaphylactic shock twice and went to hospital. It was after we ate out and they had not listened to me and put something that I was allergic to; My asthma became worse 2010, ended up hospital collapsed March 2011, anaphylaxis stopped breathing, 1 spoon a small taste of curry and struggling on since then.*

How confident are you that you are coping with your allergy?

Patients were asked to rate their confidence in dealing with their allergy on a scale from 1 (not at all confident) to 10 (totally confident); 319 responded. Two thirds (203, 64%) were very or totally confident (score 8-10) but 10% (31) scored 3 or less (out of 10). There was no dif-

ference in confidence by age (ANOVA) or gender (t-test) but those with food allergy were more confident than those with non-food allergy [8.2 vs 7.1; t (317)=-4.1; P<0.001]. Those who had experienced further symptoms were less confident than those who had not [7.0 vs 8.4; t (317)=-5.0; P<0.001]. Those for whom there was some discrepancy between reported allergies and PAS records were also less confident [7.2 vs 8.1; t (317)=-3.4; P=0.001]. There was no association between experiencing further symptoms and discrepancy in reported allergy and PAS records. Patients concerns (Table 4) included a need for more information, the social aspects of dealing with their allergy in public, the strain placed on family members, and the lack of knowledge of other health professionals.

Online discussion forum

The majority of respondents (314, 88%) had an email address although only half (176/336) were prepared to disclose it to the survey, and only 120 (68%) of these expressed an interest, at that time, in joining an online discussion forum. There was no difference between those with and without email in level of confidence or getting an exact match between PAS and patient-stated allergies. When the survey was complete, and the discussion forum website ready (March 2012) we emailed all those who had given an email address thanking them for their response to the survey and asking if they would like to register. By May 2013, only 45 patients had registered on the PAS website.

Table 3. Patients' views on the value of the clinic visit.

Patients' views	No. patients (%)
Clinic visit useful	
Clinic visit useful - coping (generally a positive/successful experience and have some altered behaviour in some way that suggests coping with allergy)	191 (63.0)
Clinic ok - confirmation of allergy only (no reference to behaviour change or coping)	13 (4.3)
Clinic visit useful - still problems	11 (3.6)
Clinic ok - clear diagnosis not possible	3 (1.0)
Clinic not mentioned	
Clinic not mentioned - life limited to a degree	5 (1.7)
Clinic visit made little difference	
Visit to clinic made no/none/not a lot of difference	76 (25.1)
Clinic not useful, not much help, went elsewhere for advice	4 (1.3)
Total	303 (100)

Table 4. Examples of aspects of life that give patients concern (n=121).

Patient ID (allergy)	Age/sex	What aspect of your life, treatment or condition give you concern?
41 (house dust mite, cat, dog)	67/F	I need to concentrate on avoiding conditions which will trigger my allergy. I also could do with a copy of my skin prick results in order to help myself more in the future.
81 (bananas, melons, cucumbers, red peppers, yellow peppers, tomatoes, plums, silver birch)	36/F	Eating out is still a huge cause for concern for me, as people don't always take my allergies seriously and sometimes still serve foods that I'm allergic to on the same plate. I often get extremely embarrassed about my allergies.
248 (egg, almonds, hazelnuts, peanuts, cat hair, dog hair, grass pollen and house dust mite)	23/M	I don't carry an epipen with me when I go out socially as I find it too bulky to carry in my pockets.
383 (apple, pork, kiwi, milk and orange)	61/F	The whole spectre, my husband's life is very difficult because of me he has to do a lot for me and my family are terrified I will have an anaphylaxis again.
427 (brass pollen, cat hair, dog hair and house dust mite)	45/F	That I am unable to perform normal duties without worrying what environment I am going into and my uncontrollable eczema.
516 (latex)	33/F	Medical staff in hospitals (not [PAS] clinic) don't understand severity, makes my life hell and I honestly believe they think I just say it to make their life difficult. Lack of knowledge in hospitals.

Discussion and Conclusions

Two thirds of patients thought their clinic visit had been useful and resulted in them being more *in control* of their allergy. Comments from these patients suggested that this had made a major difference to their lives. We have not been able to find other publications to compare this *satisfaction rate* but although this appears reasonably satisfactory there is clearly room for improvement and it is likely that other specialist allergy services will face similar challenges.

The quarter of patients who did not find their clinic visit useful are clearly an important group to focus on. Possible explanations could include i) complex cases with multiple allergies, ii) the doctor not having sufficient time to clearly explain things to the patient, iii) the patient having high anxiety, not having the intellectual capacity or sufficient time in the consultation to absorb the information given, iv) lack of explanatory materials (leaflets etc.) at an appropriate level for patients v) unreasonable expectations on the part of the patient – *e.g.* expecting to be cured when this is not possible. For this reason, in an ideal world, follow-up consultations should be routine. However, the NHS like many health services lacks sufficient resources and there is often pressure to discharge patients once a diagnosis has been made. Public (mis)understanding of allergy in the UK may have played a role both in dissatisfaction with the clinic visit and in their continuing lifetime concerns. More than half of the patients experienced troublesome symptoms after their visit. Misuse of the term allergy in everyday English to include many signs and symptoms of unknown origins may diminish appreciation of the health risks of a true Type I allergic reaction. Although the resolve of patients to carry an adrenaline autoinjector (Table 4) may be reinforced by further follow up and education, part of the solution may lay in more understanding public attitudes. Similarly, a better common understanding of allergy, so that patients referred will have better expectations (*e.g.* that there is no *cure*), will mean that the message put across in specialist clinics is more effectively received. The continuing education of GPs and secondary care physicians and nurses about allergy is also important. The importance of public education to change attitudes has been well demonstrated by the *Dementia Friendly Communities* movement and perhaps similar public health approaches to allergy are needed.⁶ Only just over a third gave their allergy as an exact match of what was recorded in PAS records. Differences in what patients reported and what was recorded by PAS may have occurred because of omission (*i.e.* patients missed an allergy listed by PAS) because i) patients have omitted it from the questionnaire but knew about it, or ii) patients had forgotten or never understood that they were allergic to this substance. Other mismatches were of commission (*i.e.* patients gave an allergy that was not listed by PAS). There could be three reasons for this i) patients had more than one visit to PAS and we only extracted data for one visit (*i.e.* a research data error), ii) patients had visited another clinic or PAS outside of the data collection period and received confirmation of another allergy, iii) patients had visited an alternative practitioner or had developed their own ideas on their allergies. Of these errors, errors of commission, where people think they are allergic to items not listed by PAS are perhaps inconvenient for the patient in that they may be avoiding those items. This could have a major psychological impact and impact on quality of life if people are avoiding a range of foods they are not allergic to. In extreme cases this could cause nutritional deficiencies if not managed properly. Errors of omission may be more immediately life threatening, if for example, someone is allergic to peanuts but has not realised or has truly forgotten. In an ideal situation all patients would leave the clinic with a clear and accurate understanding of their allergies, how to cope with it, and be confident in their ability to do so. It was surprising that people with food allergy were MORE confident than those with non-food allergy. It

is perhaps a good thing that those who had discrepant ideas on their allergy were less confident; having a mistaken understanding about allergy but being confident is probably the worst combination.

Limitations

Although the response rate (39%) is low, it is fairly typical of surveys of this type and included responses from people who had clinic visits more than 12 years ago. Older people were more likely to respond to our survey so we may under-represent the experience and views of younger people with allergy. Clearly the length of follow up (up to ten years) means that patients' memories of their clinic visit may be vague even if present.

Implications of our findings

This audit of patients diagnosed with type 1 allergy showed that a small but significant proportion may not have understood or accepted their diagnosis, others may not be confident in coping with their allergy, and over half had further symptoms after discharge from the clinic. More needs to be done to follow up and support patients with type 1 allergy and to reinforce education. Specialist clinics need routine feedback from patients if they are to monitor their effectiveness. We had hoped that an online forum would help to both reinforce clinic education with longer term discussion, and to extend this to more general public health education about allergy, but our attempts to date have not been successful. Nevertheless, there are allergy online communities and further exploration of these, linked to other media such as TV, magazines, and school health education are needed.

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