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An Exploration of Food Intolerance in the Primary Care Setting: the GPs  
perspective

Mia Nelson and Jane Ogden

Department of Psychology, University of Surrey

Address for correspondence:

Mia Nelson  
Department of Psychology  
University of Surrey  
Guildford  
GU2 7XH  
Surrey

Email: [M.Nelson@surrey.ac.uk](mailto:M.Nelson@surrey.ac.uk)

## **Abstract**

Food intolerance is one of medicine's modern enigmas. Its aetiology and mechanism are unclear and the subject of constant debate, while estimates of its prevalence vary widely from 2% to over 20% of the population. Using Interpretive Phenomenological Analysis (IPA), this study explored the phenomenon of food intolerance in primary care from the GP's perspective. Semi-structured interviews were carried out with 17 GPs from around the UK. Food intolerance was primarily conceptualised as a spectrum of medical conditions in a hierarchy of clinical importance. For the GPs these conditions also represented hierarchies of the authenticity of the patients' experience, and the ease that they would have in making a diagnosis. Since each of the conditions along the spectrum had a medical name that was used in preference to the term 'food intolerance', food intolerance essentially became a 'dustbin diagnosis'. It was used when no pathology could be found in a patient who had symptoms, attributed to food, that were of personal but not clinical importance. Despite their scepticism about food intolerance as a distinct condition, the uncertainty of having no label or explanation for a patient's symptoms generated a critical moment in the GP/patient relationship. Rather than risk damaging the relationship by implying or expressing disbelief, the GPs chose to work with the patient's belief. As a result, whether due to placebo effect, secondary benefit, or as a biophysical result of excluding a food from the diet, the GPs acknowledged both personal and therapeutic benefit in working with the patient's belief in food intolerance and behaviours associated with it.

## **Introduction**

Food intolerance is one of medicine's modern enigmas. It is a condition that is poorly understood and is viewed in scientific circles with scepticism. Claims are made implicating food intolerance in chronic and recurring conditions such as Chronic Fatigue Syndrome (Valesini, Priori, and Conti 1994), Irritable Bowel Syndrome (Dainese et al 1999; Atkinson et al 2004; Monsbakken, Vandvik and Farup 2006), headaches (Mansfield et al 1985), neuropathies and psychological disorders (XX), and many of the recurring and non-specific symptoms that are seen in primary care (XX). Equally, there is literature refuting any role for food intolerance in these conditions (Ortolani et al 1999).

Explanatory models of adverse reactions to food have focused on causal mechanisms. They locate and define food intolerance as non-toxic and non-immune mediated, placing it with a section labelled 'unknown' (Ortolani and Vighi 1995). The models state that they have purposely excluded psychological reactions to food, such as aversion, in their modelling. So, although 'unknown', the mechanism of food intolerance is held as a physical process.

The European Academy of Allergy and Clinical Immunology (EAACI) regard the double blind placebo control food challenge (DBPCFC), combined with a detailed history, as the gold standard diagnosis of food reactions (Mabin 1996). The blind trials and use of placebos are intended to provide objective evidence and differentiate between psychological and biophysical reactions to foods. Studies employing this method of diagnosis suggest that the prevalence of food intolerance is between 1 and 2% (McGowan and Gibney 1993; Young et al 1994; Woods et al 2002). However, the usefulness of the DBPCFC is disputed in the case of food intolerance. Food intolerance is suggested to be dose responsive in many cases, requiring quantities larger than practicable in a DBPCFC. Other scenarios suggest that

symptoms occur only with specific combinations of foods, or have a reaction time too prolonged to be considered definitive in a DBPCFC test (Ortolani and Pastorello 2006).

There are other diagnostic tests, in vitro and in vivo, available on the market, but these are regarded as unproven and the use of them controversial (Jenkins and Vickers 1998, Ortolani et al 1999). The scientific and medical communities therefore remain sceptical about the existence of food intolerance.

The general public seem, however, to hold a different viewpoint. Research based on self-report measures of food intolerance state much higher prevalence rates. It is reported that 14.7% of the UK population perceive themselves as food intolerant (Young et al 1994), as do 16% of Americans (Altman and Chairamonte 1996) and 19.1% of Australians (Woods et al 2001). The prevalence is higher still in specific sub-groups of the population with 25-65% of patients with irritable bowel syndrome perceiving themselves to be food intolerant (Dainese et al 1999; Atkinson et al 2004; Monsbakken, Vandvik and Farup 2006). Further, the public are acting on their beliefs and the demand for products that are free of various food constituents such as gluten, dairy products, and wheat has increased by 165% from 2000 to 2002. This sector of the food industry, worth £55.6m in 2003 grew to £90m by 2005 and is estimated to be now worth £138m (XX BBC).

So while the scientific community debate the aetiology, mechanism, definition and diagnosis of food intolerance and claim a low prevalence rate, a large number of the general public not only believe that they have food intolerance but are changing their eating behaviour accordingly. It appears that the two worlds are at odds. Primary care is often the first port of call for many people seeking help for a range of problems. General Practitioners therefore

act as an interface between the scientific world and the lay public and are the gatekeepers to the national health services. This study examines how GPs conceptualise food intolerance.

## **Method**

### **Design**

A qualitative design with in-depth interviews was used.

### **Approach**

An Interpretive Phenomenological approach (IPA) was considered appropriate. The method is based on Husserl's phenomenological philosophy (XX) and can allow an exploration of the participants' perspectives on the phenomenon being studied (Conrad 1987, Smith 1996). It is particularly appropriate in this study as it emphasizes 'sense making' (Smith & Osborn, 2003).

### **Participants**

A strategic selection of GPs was used with the aim of providing a range of views and experiences. 17 GPs, 2 women and 15 men, were interviewed between May and July 2006. All interviewees were currently working as GPs with direct patient contact, 1 as a locum, 1 as a private GP and the remaining 15 based within NHS general practices. They qualified between 1973 and 2000 and all undertook their medical training in the UK.

As well as being GPs, 8 participants held substantive or honorary roles in academia (Research Fellow; Senior Lecturer; Course Leader; Head of Department), 1 held a position in a Primary Care Trust, and 1 GP was also a school medical officer. 6 GPs described themselves as generalists, while the remaining participants variously expressed specialist

interests in osteoporosis, MS, sexual health, drug use, respiratory disease, dermatology, occupational health, muscular skeletal disorders, and Caribbean health. No participants expressed any specialist knowledge or interest in nutrition, diet, or eating behaviour.

The participants were based in practices located in Scotland (2), Northern Ireland (1), Cambridgeshire (1), Oxfordshire (1), Sussex (1), Greater London (5), and Central London (6). The practices' sizes ranged from 2,600 to 15,000 patients and the number of GPs working in the practices from 2 to 15.

### **Procedure**

Semi-structured interviews were conducted over the telephone and were tape-recorded. The same interviewer conducted all the interviews and the interviews lasted between 16 and 49 minutes. The recordings were transcribed verbatim.

### **Interview schedule**

The participants were asked the following questions:

*'What do you understand by 'food intolerance'; 'Have you seen patients experiencing it'; 'What did you do/ how do you manage patients that believe they have a food intolerance'; 'What do you think the patients want from you'; 'Who gets food intolerance'; 'Why do the patients have food intolerance'; 'How do you feel about managing patients who believe they have a food intolerance'.*

The interview schedule was used as a guide and the interviewer was free to follow the paths of responses chosen by each participant.

### **Data analysis**

The recordings were listened to and the transcripts read and reread so that a holistic familiarity with the data was achieved. Emerging themes were organised into clusters and

checked against the data to ensure the allocations of views to themes were grounded in the participants' own narratives. The themes were refined accordingly and examined for connections (Smith and Osborn 2003).

## **Results**

Three superordinate themes were identified from the data. These were; food intolerance as a spectrum of conditions, food intolerance as a 'dustbin diagnosis' and food intolerance as a useful tool. Food intolerance as a spectrum of conditions described how food intolerance was conceptualised in a hierarchy of clinical importance, a hierarchy of the authenticity of the patients' experience, and a hierarchy of the ease with which the GP might make a diagnosis. Food intolerance as a 'dustbin diagnosis' illustrated how the term was used when no pathology could be found in a patient who had symptoms attributed to food and of personal, but not clinical, importance. Food intolerance as a useful tool indicated how the term was used to validate the patients experience and to allow the patient to 'do something' to alleviate symptoms. These three themes will not be described in detail.

### **1. Food intolerance as spectrum of conditions**

All the GPs interviewed were familiar with the term 'Food Intolerance' although they did not generally use it as a diagnosis in itself. Rather, it was used as a blanket term that covered a number of specific diseases and diagnoses. It was repeatedly talked of as a spectrum of medical conditions and the GPs used terms such as '*spectrum*', '*continuum*' and '*range*'. As the GPs listed and ordered the conditions along the spectrum they ascribed values to each and three distinct hierarchies emerged from within the spectrum. The first hierarchy was one of the clinical importance of the condition, consistent with the biomedical paradigm of illness.

*'Um, well I was thinking about this last night, um and um. I suppose I see food intolerance as the kind of, towards the left hand end of the spectrum that runs, runs from food dislike [laugh] to uh, being upset sometimes by odd bits of food and getting indigestion through intolerance of a particular food producing undesirable but not terrible symptoms. Right through to the right hand end of the spectrum, which would be Food Allergy, so I, I, I don't, so I don't, so I thought to myself, should I make this a categorical or a continuous thing and I think it's a continuous thing probably'. (GP16)*

*'On the one side you can talk about people with true food allergy, people who develop an allergic response to foods ... and then on the other side of it you've got people who eat foods and develop a whole host of different symptoms and probably the most well defined is something like gluten enteropathy ... The third much more grey area is this thing where patients come in attributing their symptoms which may be very broad from being light headed right through to abdominal pain through to depressive illness through to um, weight loss'. (GP1)*

The availability of objective evidence was important to the GPs and a second hierarchy, based on the ease and degree of certainty in making a diagnosis, emerged from the spectrum. The GPs described the process of making a diagnosis as ranging from 'definite', 'certain' and 'clear' to 'hazy' and 'vague'.

*'You've got the severe end, where you have people who have anaphylactic reactions to certain foods ... peanuts, um, so that's the sort of serious end of the spectrum, and then there'll be definite diagnoses such as coeliac disease, where*



*people have ah, an intolerance to gluten, um, and that can be diagnosed, and you have a specific test for that. So that's, that's fairly definite. But sort of in the more milder spectrum, um, it's sort of pretty hazy, I think...it sounds sort of as if, um, it could exist, but every time you speak to a specialist ... they're always pretty sceptical.'* (GP10)

*'I suppose at one end of the spectrum there are things like, um, coeliacs where I guess, um, there's a very clear cut and specific intolerance to a very specific ingredient of food, um, and that can be demonstrated objectively and then at the other end of the spectrum, I guess, there are patients who attribute food intolerance to a very wide range of, um, symptoms, some of which seem very unlikely to be related to food intolerance and somewhere in the middle of the spectrum are, I guess there are entities such as intolerance to wheat and milk which I would, you know, recognise as, um, legitimate conditions, if you like.'*  
(GP11)

For some of the GPs there was a final third hierarchy in the spectrum of food intolerance. This presented as a value judgement of the authenticity of the patient's experience. It ran in direct connection with the other hierarchies, placing the conditions in the same order. The GPs used the terms 'legitimate' 'genuine' and 'serious' at the same end as anaphylactic reactions to food, whereas 'fashionable' 'unlikely' and 'collude' were used at the other 'milder' or 'vaguer' end of the symptomatic spectrum.

*Um, I suppose a, a spectrum of things, from people who have what I would call genuine food intolerance, um, people who have, say, coeliac disease or who have*

*to avoid things, nuts, or, you know, have an, an allergy to something or other, um, right through from that to what I see as the sort of the, the fashionable food intolerances that sort of started in Surrey and that's spread out to the rest of the, the country, where it's basically they don't particularly like something.*

*(GP5)*

The GPs, therefore, describe food intolerance as existing along a spectrum involving three hierarchies. These appear to embody the different roles that GPs may have: the scholar interested in the clinical importance of the disease, the professional with a duty of care interested in the ease and certainty with which they can reach a diagnosis, and the judgemental being who evaluates patients' experiences and views. Although separate hierarchies, however, their dimensions run parallel with each other and, together, they reflect the traditional medical model approach to health and health care. Accordingly, at the end of the spectrum indicating low clinical significance, symptoms are regarded as mild, uncertain and false, whereas at the end of high clinical significance the symptoms are deemed severe, certain and legitimate.

## **2. Food intolerance as a dustbin diagnosis**

As a reflection of the spectrum and the hierarchies within it the way the GPs described their approach to managing patients who believed they had a food intolerance and their use of the term 'food intolerance' as a 'dustbin diagnosis'. The GPs talked of first looking to exclude the most life threatening conditions and then running tests for diseases that could be diagnosed, confirmed and treated.

*'Inevitably, you tend to work in a traditional biomedical model first, which means, let's just make sure that that bloating isn't because they've got bowel*

*cancer, uh and the headaches are not due to a brain tumour. Having said that, I can't remember when I last saw a patient with either bowel cancer or a brain tumour but you, you look a right berk if you miss it. Um, once I've done that then I would take my normal sort of history and examination as appropriate to make sure that there's, that nothing else, obvious going without fitting, any other nice um, well recognised diagnostic category within which I feel comfortable.'* (GP14)

*'As a doctor you have a duty to rule out significant pathologies... so you need to go through a process of exclusion and an examination, and maybe testing people, um, according your clinical judgement.'* (GP9)

However, each of the conditions that the GP could test for along the spectrum had its own specific name or label and each was very different in terms of aetiology, treatment and prognosis. The umbrella term food intolerance was too broad to be useful so if a test indicated that a patient had coeliac disease or an enzyme deficiency, the GPs used that diagnosis in preference, making the term 'food intolerance' superfluous.

*'So that's really what I'm saying is it is a, it's a term which I wouldn't often use, um without trying to define it down a bit.'* (GP15)

In reality, the term 'food intolerance' only came into play when all the potentially known conditions had been excluded and the diagnostic process exhausted, as there was no certain or better label for the patient's experience. Food intolerance then represented a patient who had symptoms, attributed to food, that were of personal but not clinical importance and in whom no pathology could be found.

*'I say actually this is a dustbin diagnosis. It's a diagnosis when we've shown that you don't have other conditions.'* (GP15)

*'It comes down to being I think a bit of a rag-bag, um, in difficult-to-diagnose individuals.'* (GP4)

This practical experience of food intolerance, as opposed to the theoretical description of the spectrum, had a general air of scepticism about it. The possibility of food intolerance as a specific disease or as the cause of the patients' symptoms was held as doubtful.

*'They want me to agree that the cause of their low mood, say, is candidiasis or whatever, wheat, and that's what I can't give them. It's partly lack of knowledge, admittedly, and it's partly just lack of belief.'* (GP6)

*'You know, I've got an open mind about that. I don't, I don't think that it's all a lot of rubbish, I just think that as a doctor I don't have a lot of evidence to base my decisions on.'* (GP13)

Further, the symptoms and experiences that ended up being labelled as food intolerance were perceived by the GPs as much more likely to be functional or psychological in nature.

*'You do have people who mention it in consultations, oh, well, you know, every time I eat... so-and-so I come up in a rash or I feel, sometimes it's quite non-specific, it makes me feel quite nauseous or quite down and it's those people that*

*you sort of think, you know, something more functional is going on rather than they are actually intolerant to a food type.’ (GP6)*

*‘There definitely is a sort of, um, I don’t think all of the patients that come and see me are looking for solving their problems in terms of food intolerance are wacky but there certainly is a...a...you know, a wacky group there, you know, people who would...who are sort of casting around for all sorts of sort of unusual therapies for their, um, often, you know, psycho-somatic related problems.’(GP7)*

*‘I think when people see they may have a food intolerance, um, or they’re presenting with features of a food intolerance, I generally, um, would see it as kind of a...a proxy for other issues.’(GP12)*

The GPs knew of tests and investigations that were available to the public but the lack of objective scientific evidence to support them or even to support the argument for the existence of food intolerance as a specific condition was important to the GPs and added to their scepticism. Further, the individuals who did proffer tests and treatments were viewed with suspicion and distaste.

*‘So I would try, and I would also gently steer people away from um spending a load of money on getting private tests, because my understanding is that these tests are not well, um they’re not reliable, and in fact some of them, they may be almost fraudulent.’ (GP15)*

*'I suppose I'm post-modern in my old age so I think it's fine if that's what they want to do, um, I suppose my main concern is, um, that people administering these sorts of tests are often, um, I do think they are pandering to people's needs for a panacea and I think there is often a, um, quite a lot of dogma, lot of quasi science and that they get glossy brochures and, um, so it really is, um, smoke and mirrors of ten, I think. Um, so in terms of the validity of the tests, that particular technology I think is complete garbage.'* (GP12)

*'It bothers me somewhat if people are going off and getting inappropriate and/or frankly dangerous advice on the High Street from people with relatively little qualification or training in these matters'*(GP14).

This scepticism was, however, tempered by an element of self-awareness and an awareness of the limitation of modern medicine. With the transitional nature and constant evolution of medical knowledge several of the participants entertained the idea that this condition might be recognised and understood in the future.

*'A little bit of me is inward-looking. I think actually, I don't know enough about this. Who am I to say it is not? For other diseases I can say categorically, it is not cancer. I know you've had all sorts of tummy trouble but we've now done the tests and you do not have a stomach cancer. I can't be like that with an [intolerance], you do not have an [intolerance], I can't be like that. So I realise my own limitations.'* (GP2)

*'I mean maybe in 30 years' time we'll be saying oh well, 'exorbia', you know, how to do your arthritis much worse, or you know, milk, oh no, I shouldn't be drinking cow's milk. I have that kind of eczema. But I don't think there's any evidence for it at the moment'.(GP10)*

*'When people are unwell and medicine fails them and I know we often do and I think in ten years' time I'll be biting my lips saying, oh, my God, you know, it's so obvious that food intolerances exist and they do cause all these things.'(GP6)*

Thus, although the GPs initially portrayed food intolerance in a theoretical manner as the whole broad spectrum of conditions, their conceptualisation of food intolerance in practice was limited to one specific subgroup of patients within the spectrum. They were the patients at the mild, uncertain and, to a minority of the GPs, the illegitimate end of the spectrum. The GPs were sceptical that food was truly the cause of these patients' experiences while simultaneously acknowledging that a body of knowledge may yet evolve to support the definition of food intolerance as a recognised medical condition in the future. They did not have trust in the validity of current tests and investigations that claimed to diagnose food intolerance as a specific condition and expressed misgivings about the motivations of those who promoted them.

### **3. Food intolerance as a useful tool**

Despite their scepticism the GPs described a conscious decision to work with the idea of food as a cause of the symptoms, at least as a starting point, if that was what the patient believed. The GPs made a distinction between initiating such a diagnosis, which they would not do,

and allowing the patient to act on their beliefs when there was no evidence of any other disease process occurring and when no harm would result.

*'I am usually willing to give at least saying I'm not sure what's going on here, but I can understand why you say this, and I'm willing to work with that diagnosis.'*  
(GP15)

*'Belief systems are very precious, they just have a ten minute appointment with me, what right have I got to upset their belief system, if they seem locked into a belief system and it is that, a food allergy, I feel that perhaps I'll go along with that'.*(GP2)

*'Food intolerance is not the sort of thing I would ever say, oh you are intolerant of food X, Y or Z. It would be patients, a patient will come in and see me who says whenever I eat this, this is what happens to me. And if he doesn't, and often it won't fit any, any precise diagnostic metric that I can put a, make a nice biomedical diagnosis on and I, I have to say my... My usual response is, well if that food upsets you then don't eat it.'* (GP14)

The decision to work with the patients' beliefs was initially portrayed by the GPs as a way of preserving the doctor-patient relationship. Rejecting a patient's understanding and interpretation of their symptoms, in the absence of any confirmed diagnosis, was held by the GPs as tantamount to rejecting the patient.



*'I think, you know, that requires a little bit of, um, careful work because if you pooh pooh the idea then you basically dismiss the patient at the same time. Now, that applies I think to some areas of perceived food intolerance.'* (GP8)

*'I think it's, it's not a good, you know, it's not ah, even if you think it's ridiculous, it's not a good thing to dismiss it out of hand. You need to work with people.'*  
(GP10)

*'I think if you...if you're working strictly within a bio medical frame, then when you're presented with a symptom like that, you can very quickly see that there's not much I can do here and then you become, I would describe it as nihilistic in terms of, well, I can't do tests, therefore there's nothing wrong with you and I think the relationship very quickly, um, terminates and the patient goes elsewhere. Um, I suppose I would try and find a bit of ground. Obviously I don't want to, um, engage necessarily in lots of wacky referrals and tests and start treating them, you know, for cancers and all that sort of jazz, um, but I do try and, um, respect their, respect their sort of, their model.'* (GP12)

*'You know, you take your patients symptoms seriously. You don't dismiss them as being, you know but at the same time, whilst listening to the physical story, you're also listening to the psychosocial story as well.'* (GP16)

Other benefits from working with the patient's belief in food intolerance were described, not least of which was the fact that many patients did feel better for acting on their belief and excluding foods from their diet. It also took the onus of responsibility for treatment away

from the GP and placed it instead in the hands of the patient. This was of particular importance where the GPs felt that the symptoms were psychological but the patient was unable to accept this. Acceptance of food intolerance and the dietary and lifestyle changes it seemed to the patient to require were, in comparison, a good option.

*'I'd like to be convinced because when I see the patients, they're very plausible and they come to me with symptoms which I often have very little to offer and they seem to have found the cure themselves by working at it, so in another sense, I am quite happy for them to do that, because to me, they are de-medicalising their symptoms. They're saying their symptoms aren't in your domain, they're in my domain; I can take control of them.'*(GP2)

*'So if they are making lifestyle changes with a pure and obvious beneficial effect to them, where there's little or no chance of an unpleasant downside. I'm quite happy with that and actually I'm happier with that than handing out all sorts of pills to people because within reason, you're not going to do yourself any harm by manipulating your diet.'*(GP14)

*'If these people have taken themselves off to a complementary therapist... In fact most of these people would probably count as alternative therapists and they are, they are getting some general sensible advice from a sensible person who is providing a useful listening ear and the stuff that they're doing for them is not actually harmful. It is probably a good thing in that it's keeping these folk away from the health service and the medicalisation of whatever's going on with them because the worst thing that could happen to these folk is end up in hospital*

*outpatients. Where they will end up having zillions of tests done on them and large amounts with potential risks, that half of them are actually going to find something that's a coincidental find.'*(GP14)

The GPs, when unable to identify a definitive cause for patients' experiences, expressed an understanding for the anxiety that such uncertainty would cause and the need that the patients had to do something to relieve their symptoms. The GPs interpreted patients' belief in food intolerance as a way of working at some solution in the absence of another diagnosis.

*'We all look for an explanation to something that we think we can either cure or control... and in contrast to that if you imagine patients who, um, aren't able to control their situation, the degree of anxiety and loss of control and the impact that that has on their lives is so negative.... I think that's why they do it, because it's their way of trying to regain control on a situation that they don't understand'.*(GP1)

*'Well, I think that people, um, would like an understanding and a solution that explains their position, so in the first place I think they want...they want an understanding, and they want an understanding that might lead to a solution... It's a way of understanding and seeing what's happened to them, which is appealing because it provides a single hypothesis which, um, might lead to a single solution.'*(GP8)

*'I think there are people who genuinely have problems that, you know, often we haven't been able to help them with very much and they're just kind of seeking around for something that might be helpful.'*(GP7)

At the end, however, any improvement from acting on the belief in food intolerance was attributed by the GPs to several other mechanisms such as placebo effect, secondary gain, or the simple acknowledgement of their distress, rather than to any direct biophysical mechanism.

*'Um, and I think, you know, that process has its purpose, whatever its purpose may be...in terms of them ... concentrating in sorting out their diet, which then, you know, may actually impose other routines on their life, like, you know, having breakfast or having dinner, or even buying in some, you know, fresh fruit or whatever... I think they're wanting acknowledgement of their upset with life, it may well distract them or whatever, it may well give them an excuse for, you know, not doing something that they don't want to do, there's usually a, a trade-off. It's very often they want an acknowledgement of, you know, all is not settled in their life, as opposed to all is not settled in their tummy.'*(GP5)

*'For some people it can be benefits that are intangible, so for example suddenly, you know, a spouse has to then sort of change the way they cook a meal or cook their meals for example.'*(GP1)

*'Sure enough it's sort of bread-and-butter GP I guess with a bit of bloating, a bit of this and a bit of that, and I guess it's a question of trying to manage it, but you*

*don't always find the solution and while they're seeing us if other things in their lives sort themselves out then perhaps their... the bloating and the, the weight and their fluid and their whatever, um, er, can settle on its own.'*(GP4)

A good working relationship with the patient was presented by the GPs as important in their ability to help, and central to this good working relationship was ensuring the patient had a sense of acceptance. The acceptance that they described was not necessarily of the whole of the patient's belief system or of food intolerance itself, but of the reality of the patient's distress and his/her desire for relief. Allowing the patient to act on a fast-held belief in food intolerance as the cause of their symptoms, in the uncertainty of the absence of an identifiable pathology, had benefits. There was, however, a careful balancing act between supporting the patient while ensuring that she or he, the GP, remained true to her or his scepticism and need of proof.

## **Conclusions**

The aim of this study was to examine the way in which GPs conceptualise food intolerance. Three superordinate themes were found, food intolerance as a spectrum with three identifiable parallel hierarchies, as a dustbin diagnosis, and as a useful tool. Central to these themes was the process of managing uncertainty.

The work of Fox (1957) indicated that uncertainty is inherent in medical practice, born from concerns of personal inadequacy, the limitations of established medical knowledge, and the ability to distinguish between these. However, clinicians have increasingly been pushed towards certainty, not only by medical culture (Atkinson, Medical student stuff, XX, XX), but also by the growing demands of society in general (Fox, 1980; Crawford, 2004). In this

study, the GPs talked of the spectrum of food intolerance in terms of degrees of certainty. Further, in their portrayal of the diagnostic process they again described searching for certainty in the form of test results and objective evidence. The GPs recounted adhering to established routines of investigation, to the extent of testing for conditions even when they considered the existence of these conditions to be highly improbable. By doing this, however, it appeared that they were able to reduce their concerns about personal inadequacy. The GPs in this study were not perturbed by being unable to find a definitive cause for symptoms nor by the absence of a diagnosis *per se*, provided they were confident that the correct investigations had been conducted. Any residual uncertainty was assigned by the GPs to two possibilities, the patient's somatic presentation of emotional distress or the limitations of established medical knowledge, rather than to any personal professional failure on the GPs' part.

In this study the GPs contemplated the idea that though there is not the evidence to support food intolerance as a distinct condition at present, there may be in the future. This finding corresponds with much of sociological work on medical uncertainty which asserts that the information explosion and technological advances of the last century have increased the experience of uncertainty in medicine, rather than reduced it. Such developments highlight how little we still know and understand about our bodies and minds (Sorenson 1974, Douglas and Wildavsky 1982, Wolf, Gruppen and Billi 1985, Slovic 1986, Crawford, 2004). This was implied, as mentioned above, in the GPs' rationalisation of why the patient had symptoms but no diagnoses, and also in why they were reluctant to dismiss completely the patients' belief in food intolerance.

In keeping with the findings of other research (XX, XX, XX), this study observed that, although the GPs presented themselves as being comfortable in the absence of a diagnosis, they recognised that not all patients would be at ease with such uncertainty. There are many reasons for the patient to want a confirmed diagnosis, not least of which is that, without it, the individual's rights to the sick role (XX) are limited and potentially illegitimised (Glenton, 2003). A diagnosis has also been found to bring with it hope for resolution, suggesting that now the cause has been identified it can also be treated and the symptoms accordingly reduced (XX). In the absence of a diagnosis, the GPs felt that they could allow the patient him or herself to frame their experience and work towards the relief of their symptoms, by using a broad term, such as food intolerance, as a provisional and experimental basis for treatment. At the same time the GPs could remain true to their own uncertainty on the cause of the patients' experience. The fact that the aetiology and mechanisms of food intolerance are uncertain proved advantageous in such a scenario. Just as food intolerance cannot be specifically proven or diagnosed, neither can it be ruled out.

However, this reluctance to dismiss food intolerance and their tentative willingness to work with it, in the absence any other pathology, was coupled with frustration at what the GPs referred to as the *dogma* and *psuedo-science* of the high street services. To be acceptable to the GPs, food intolerance needed to be seen and acknowledged as unproven, but food intolerance as a lay diagnosis has acquired a momentum that has outreached the control of the medical profession. There are many tests available on the high street, *in vitro* and *in vivo*, and there has been a growth in the food industry for foods free of certain ingredients. It would appear that, as seen throughout the course of medical history (XX), there are now vested interests, in terms of personal and financial gain, in the reification of food intolerance as a distinct condition.

The conceptualisation of food intolerance in this qualitative study found resonance in the complexities of uncertainty that occur in primary care. It embodied the searching for certainty while accepting uncertainty.



## References

Altman, D.R. & Chiaramonte, L.T. 1996 Public perception of food allergy. **Journal of allergy and clinical immunology**, 97: 1247-1251.

Atkinson, W., Sheldon, T. A., Shaath, N., & Whorwell, P. 2004 Food elimination based on IgG antibodies in irritable bowel syndrome: a randomised controlled trial. **Gut** 53, 1459-1464.

Aronowitz RA 2001 When do Symptoms Become A Disease? **Annals of Internal Medicine**. 134:803-808.

XX BBC

Conrad 1987

Dainese R, Galliani E A., De Lazzari F, Di Leo V, & Naccarato R 1999 Discrepancies Between Reported Food Intolerance and Sensitization Test: Findings in Irritable Bowel Syndrome Patients. **The American Journal of Gastroenterology**. Vol. 94, No. 7.

Jenkins M, & Vickers A, 1998 Unreliability of IgE/IgG4 antibody testing as a diagnostic tool

in food intolerance. **Clinical and Experimental Allergy**. 28:1526–1529.

Mabin 1996

Mansfield et al 1985

McGowan and Gibney 1993

Monsbakken KW, Vandvik PO, & Farup PG, 2006 Perceived food intolerance in subjects with irritable bowel syndrome – etiology, prevalence and consequences. **European Journal of Clinical Nutrition**. 60: 667–672

Ortolani and Vighi 1995

Ortolani et al 1999

Ortolani C & Pastorello AE 2006 Food allergies and food intolerances. **Best Practice & Research in Clinical Gastroenterology**. Vol. 20, No. 3, pp. 467–483.

Salmon P, Peters S, Stanley I 1999 Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. **BMJ**. 12:193-201.

Smith 1996

Smith & Osborn, 2003

Valesini, Priori, and Conti 1994

Woods, R.K., Stoney, R.M., Raven, J., Walters, E.H., Abramson, M. and Thien, F.C.K. 2002 Reported adverse foods reactions overestimate true food allergy in the community. **European Journal of Clinical Nutrition**, 56: 31-36.

Woods RK, Abramson M, Bailey M & Walters EH 2001 International prevalences of reported food allergies and intolerances. Comparisons arising from the European Community Respiratory Health Survey (ECRHS) 1991 - 1994. **European Journal of Clinical Nutrition** 55, 298-304.

Young, E., Stoneham, M., Petruckevitch, A., Barton, J., & Rona, R. 1994 A population study of food intolerance. **The Lancet** 343, 1127-1130.

