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When doctors disagree: a qualitative study of doctors' and parents' views on the risks of childhood food allergy

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In the quoted material, italics indicate the speaker's emphasis, square brackets de-identified material or clarifications, an ellipsis a long pause or edited material. Editing of repetitious phrases has been performed to clarify the speaker's intended meaning.

Abstract

Objective To examine the views of doctors which underpin clinical practice variation concerning an uncertain health risk, and the views of parents who had sought advice from these doctors, using the example of childhood food allergy.

Study design Qualitative study involving in-depth interviews and participant observation over 16 months. Focus groups and consultation audio-recordings provided corroborative data.

Setting Three specialist allergy clinics located in one metropolitan area.

Participants Eighteen medical specialists and trainees in allergy, and 85 parents (from 69 families) with food allergic children.

Results Doctors expressed a spectrum of views. The most divergent views were characterized by: scientific scepticism rather than precaution in response to uncertainty; emphasis on quantifiable physical evidence rather than parental histories; professional roles as providers of physical diagnosis and treatment rather than of information and advocacy; libertarian rather than communitarian perspectives on responsibility for risk; and values about allergy as a disease and normal childhood. Parents held a similar, but less divergent range of views. The majority of parents preferred more moderate doctors' views, with 43% (30 of 69) of families expressing their dissatisfaction by seeking another specialist opinion. Many were confused by variation in doctors' opinions, preferring relationships with doctors that recognized their concerns, addressed their information needs, and confirmed that they were managing their child's allergy appropriately.

Conclusions In uncertain clinical situations, parents do not expect absolute certainty from doctors; inflexible certainty may not allow parental preferences to be acknowledged or accommodated, and is associated with the seeking of second opinions.

Introduction

It is accepted that uncertainty is inherent in medical practice and commentators have described a modern paradox of increasing uncertainty despite greater medical knowledge than ever before.[1,2] Rapid growth in medical interventions with marginal therapeutic effectiveness, together with societal expectations of cures,[3] community ambivalence towards scientific knowledge and questioning of professional expertise have been cited as reasons for this situation.[1,4] This complexity suggests that medical uncertainty has different dimensions, leading to dissenting interpretations and approaches.[5,6]

From the decision analytic perspective, uncertainty is inevitable as clinical decisions must always be made with incomplete knowledge of decision outcomes.[7] From the biomedical perspective, uncertainties arise from limitations in medical knowledge. These include: disease definition, such as ill-defined thresholds between normal and abnormal results when investigations are used liberally; treatment of risk factors or early signs of illness without knowing that they will prevent disease; varying abilities of individual clinicians; and erroneous application of population averages to individual cases.[8] From a humanistic perspective, the unique interactions in each doctor–patient relationship create uncertainty.[9,10] From a moral and legal perspective, uncertainty may paradoxically be increased by the failure of doctors to disclose uncertainty.[11]

From the perspective of patients, uncertainty is intimately associated with the experience of illness;[12] chronic illness in particular causes a ‘biographical disruption’ in the trajectory that one expects to follow in life,[13] and the unpredictability of acute exacerbations adds further uncertainty. Another source of uncertainty is incomplete or confusing information; despite widespread agreement that patients should be better informed, many lack knowledge or seek it from sources outside the consultation room.[14,15] Medically unexplained symptoms are yet another frequent source of uncertainty and dissatisfaction with consultations.[16,17]

These cumulative uncertainties have myriad effects,[18] of which the most studied at the population level is unexplained practice variation.[8,19] Such variations suggest unnecessary care as they are not associated with measurable benefits in health outcomes,[20] and increasing patient participation in treatment decision making where there is no clearly superior option has been shown to reduce the use of unwarranted interventions.[21] However, doctors’ practices vary in relation to patient participation[22] and little is known about the ‘idiosyncratic beliefs’ or personal values of doctors that drive practice variation.[20] To explore this question, childhood food allergy was chosen as a critical example of medical uncertainty, characterized by high stakes, unpredictability[23] and disagreement between experts on the risks of life-threatening allergic reactions or anaphylaxis.[24,25]

Food allergy in childhood – a clinical quandary

Up to one in 15 children may be food allergic,[26] but the rate of fatal anaphylaxis in UK children is documented to be one in 16 million children (0–15 years) per annum.[25] However, there is no reliable clinical or laboratory method to predict which food allergic children will be at risk of life-threatening anaphylactic reactions.[24] Skin prick tests can diagnose sensitivity to specific food allergens but cannot predict the severity of reactions if the child were to ingest the food.[27] Oral food challenges, which are considered the gold standard for diagnosing food allergy, can only confirm whether a child will clinically react, and not that the allergy is sufficiently severe to result in anaphylaxis unless it is inadvertently induced by the test. Frequently, challenges have equivocal results.[28]

Accordingly, clinicians are presented with a quandary when making management recommendations. Daily management relies on the avoidance of allergen(s) and prompt treatment of reactions, but the degree to which children should avoid allergens is unclear,[29] given potential cross reactions between food types[30] and the ubiquity of precautionary food labelling ‘may contain traces’.[31] Stringent avoidance may be the safest option,[29] but can lead to dietary insufficiencies[32] and family life becoming centred around the continual burden of food preparation,[33] with accumulating evidence that the quality of life of families with food allergic children is significantly compromised.[34] Nor is it agreed which children should be prescribed adrenaline autoinjectors for the emergency treatment of reactions, with the prescription of such devices incurring significant responsibilities for carers, including teachers and child care workers, to be educated in their use and have them available at all times.[35,36] There is no experimental evidence, nor is there likely to be, that having autoinjectors or strict avoidance of trace allergens will save lives, as such a trial would be ethically unacceptable.[23]

Consequently, there is persistent debate in the literature about whether the risks have been 'exaggerated'[24,25] or 'underestimated',[37] and whether autoinjectors are 'vastly overprescribed'[38,39] or their provision 'good clinical practice'.[40] This study aimed to explore the basis of these differences in medical opinion, focusing on the values that doctors invoke to justify their responses to uncertainty, and the views of families who have consulted them.

Methods

The study was conducted in three paediatric allergy clinics, located in one metropolitan area. Together, they provided the bulk of such services to the region, a population of 6.7 million.[41] The setting was chosen because firstly, it provided a comprehensive snapshot of paediatric allergy practice in the region, and secondly, despite being a highly specialized area where practice variation would be least expected, it was known within the local medical and consumer community that practices varied between the clinics. Table 1 describes some key differences between them; in particular, hours per week spent consulting allergy patients, the ratio of medical and allied health staffing and whether food challenges were performed. All 18 doctors at the three clinics were invited, and agreed to participate. On arrival at the clinic, families presenting for assessment of their child's food allergy were sequentially and purposively sampled until patients of all the doctors were represented (n = 57 parents from 44 families) and theoretical saturation was achieved on preliminary thematic analysis. To further confirm and extend the analysis, parent groups from the national consumer organization Anaphylaxis Australia Inc. who had also attended the clinics were invited to participate (n = 28 parents from 25 families). With the exception of two clinic families, who felt that their child did not have food allergy, all families who were invited agreed to participate.

Data collection included: (a) Semi-structured interviews lasting from 0.5 to 2 h with all participants, conducted by W.H. For doctors, initial interviews were conducted in their offices, to lessen interruptions from clinic duties, and additional interviews in the clinic setting (49 interviews). For parents, interviews were conducted in their home, the majority within 2 weeks of their clinic visit, with follow-up interviews conducted by telephone (100

Table 1 Clinic characteristics

	Clinic A	Clinic B	Clinic C
Patient type	Adult and paediatric	Paediatric only	Paediatric only
Referrals accepted from:	All doctors	All doctors	Paediatricians and dermatologists only
Medical staff (n = 18)	4	4	10
Nurses and technicians	3	2	5
Dietitians	7	1	1
Consulting sessions (number per week)	12	6	11
Oral challenges (approx. per week)	Nil	6	6

interviews). (b) Structured field notes and audio-recordings of the clinic families' consultations, each visit lasting 2–8 h. These were intended to provide evidence of the actual, rather than self-reported, usual practices of doctors in relation to food allergy and confirm that there was significant practice variation. (c) Four focus groups with consumer group parents, using question prompts that explored themes which had emerged from the interviews. The groupings comprised the parents' usual support group membership so as to encourage free discussion and exchange between participants. (d) A brief written survey was administered to all parents at the end of the initial interview or focus group to gather descriptive demographic data.

The interview prompts, which covered topics such as the participants' usual management of food allergy and how they came to know the risks, were developed from literature reviews on food allergy and risk perception, and iterative discussion by allergists and consumer organization representatives. Following preliminary data analysis, prompts on emerging themes were added and included in follow-up interviews, so all participants were asked the same questions. For example, in early interviews, participants repeatedly cited the attainment of 'the normal life' as guiding their decisions. Summaries of initial interviews were returned to the participant for checking before re-interview.

All data were transcribed, imported into qualitative analysis software (MAXqda2)[42] and tagged with attributes such as doctor, child's age and allergy type to aid analysis by the constant comparative method.[43] Open codes were derived from initial readings of the data, then refined and grouped on repeated readings by W.H. Using the attributes, negative cases and alternative explanations were sought, and preliminary themes tested. A.K. and C.G. independently reviewed transcripts to confirm that the codings were comprehensive and reproducible. This study was approved by the relevant human research ethics committees, and written informed consent was obtained from all participants prior to data collection.

Table 2 Characteristics of doctor participants

Characteristic	Doctors (*n* = 18)
Gender	
Male	8
Female	10
Position	
Director of clinic	3
Specialist allergist	12
Trainee allergist	3
Years after graduation	
Less than 10 years	2
10–24 years	8
More than 25 years	8

Table 3 Characteristics of parent participants

Characteristic	Allergy clinic recruited	Consumer Organisation recruited
Number of families	44	25
Number of parent participants	57	28
Mothers (% participants)	70.6	89
Mean age parent (years)	37.8	37.8
Mean age of allergic child (years)	5.5	5.0
Tertiary level education (%)	69	78.6
Non-English-speaking background (%)	36.2	10.7

Results

Characteristics of the doctor and parent participants are summarized in Tables 2 and 3. Sixteen of the 18 doctors were qualified specialist allergists with more than 10 years practice experience. The majority of parent participants (71 of 85) were mothers.

Doctors' views

There was a distinctive spectrum of doctors' views, which corresponded with the doctors' usual approach to food allergy management. Views expressed at the extreme ends of the spectrum could be described as *rationalistic* or *moralistic*. Ten doctors expressed values which typified these divergent ends of the spectrum, with the other eight describing an intermediate position that combined values from both ends of the spectrum, although they tended to cite one more than the other.

Rationalistic views were characterized by scepticism; the 'real' risks were low, but their perception magnified by parental anxiety and media reports. This view was associated with restricted provision of autoinjectors (for example only if there had been previous anaphylaxis) and advice that avoiding foods with precautionary labelling was unnecessary.

Moralistic views were characterized by precaution, arguing that this afforded greater safety and security given the uncertainties of food allergy and the tragedy of child deaths. This view was associated with more liberal provision of autoinjectors (for example as 'insurance' against accidental exposures) and advice to avoid exposure to allergen traces, including foods with precautionary labelling. Three thematic groups differentiated these positions.

Orientation to risk, uncertainty and evidence

The rationalistic viewpoint privileged evidence that was physically measurable, reproducible, quantifiable and published in medical journals. Aggregated data from which objectively proven reactions, fatalities and generalizable factors could be calculated were valued over the concerns of parents:

> What people are *most* worried about is what is the risk that their child will *die* from a serious allergic reaction. OK? That risk seems to be very remote. Some [published] estimates suggest that in Australia, in children less than 5 years of age, *one* child in the next 30 years will die due to food allergy. (Doctor 17)

Accordingly, parents' anecdotal stories had to be interpreted according to scientifically demonstrable pathophysiological mechanisms, as laypersons tended to ascribe any symptom to allergy. Anaphylaxis risk arose from the biology of individuals, so the best way to assess risk was with a controlled experiment such as challenge:

> Well, [the child]'s got eczema and she's going to come up all the time. So if the *mother* is conscious that the doctor said [that] she might be allergic to egg ….the eczema flares up and she thinks, oh yeah, but there was the egg this morning on the table. So we *cut through* all that, with a challenge. (Doctor 5)

From the moralistic perspective, risk was not just biology; anaphylactic events were an unpredictable confluence of circumstances, including the actions of uninformed adults:

> I am constantly amazed at how *unpredictable* the events are, when a child has a severe reaction. How you would never have imagined that *that* was the day, or the time, or the place, that it would have happened….. Because it's not just your household, but at grandma's house. Grandpa's getting a bit dotty, he puts the knife in the margarine into the peanut butter, and into the margarine again, and the child goes over [and has] margarine. (Doctor 3)

Parents' stories were consistent and to be believed; challenges could not comprehensively assess risk as they did not reflect real-life conditions. The history, detailing the child's environment and family situation, was thus the key to risk assessment. Anaphylactic reactions should be investigated as accidents, with lessons to be learnt from each case:

> …the precise circumstances in which a child experiences an anaphylaxis, or the circumstances in which somebody has died from anaphylaxis, it's just like doing an analysis of the circumstances in a car accident. There are many contingencies that come into play … any of which, if they had not been there, might have prevented that accident from happening. (Doctor 2)

Professional role and responsibility for risk

From the rationalistic perspective, the doctor's role was principally that of physical diagnosis, treatment and cure, centred on a prescribing decision:

> In essence I see it largely as about whether you give this [autoinjector] or not, I mean that's what I'm weighing it all up to. Do I or don't I do that - that's the action I've got to take. (Doctor 10)

As there was no rigorous proof for the effectiveness of interventions, there was no obligation to provide them, and economic arguments were invoked to support this position:

> These are costly interventions, they're *unproven* interventions, well it's certainly unproven that they're *necessary*. So giving [autoinjectors] to absolutely everybody because there *might* be a

> miniscule risk of them anaphylaxis is not *responsible* use of health resources, to my way of thinking. (Doctor 11)

Providing autoinjectors was to be guided by their pharmacological effect and the known frequency of fatal anaphylaxis, and as these were small, autoinjectors should be provided sparingly. Liberal provision imposed societal costs and social restrictions for many, compared to questionable life-saving benefits for a few:

> If I give them an [autoinjector], I'm *imposing* lifestyle issues. I'm making it more difficult for the child to go and stay with friends and extended family, putting a burden on her school … I'm probably making the allergy a bigger part of this child's life, by having this *object* that's got to with the child at all times. (Doctor 5)

Parental anxiety was the key problem, so the doctor, as scientific expert, should correct their misperceptions. The responsibility for preventing anaphylaxis lay *primarily* with individual parents and older children, rather than burdening others, for example through food bans at school and childcare centres.

> They're in an age group where they're not responsible for their own diet. No 4 year old is going to go out and buy themselves a jar of peanut butter. So you would *hope*, that their diet is controlled, either by their parents, or their carers. (Doctor 7)

From the moralistic perspective, the key problem was lack of awareness. Consequently the doctor's role was to warn of the dangers, instruct parents thoroughly in management strategies and publicly advocate for affected families:

> …if I have not told somebody that there's a conceivable risk, and that if you're concerned about this, that you can carry this [autoinjector], and then they have a reaction, I haven't done my job properly, whether they sue me or not. And I can't tell you how often people come into our clinic….*outraged* about….the child having had an anaphylaxis and not being warned that this could happen. (Doctor 2)

Parental anxiety was understandable because risk arose from complex events and the actions of many, which could not be controlled by parents acting alone. Therefore, communal precautions such as school bans reduced the chance of delayed treatment and accidental exposure, so that responsibility for risk was shared by all. The provision of autoinjectors was to be guided as much by social and psychological, as well as physical benefits, and as events were unpredictable, autoinjectors were a necessary precaution:

> The problem is that it's a bit like saying; I won't be struck by lightning, unfortunately. And [the autoinjector] is just like wearing a safety belt. It's no more than that. I'm not saying that you *have* to use it, but the problem is that you *may*. And it'd be silly not to have it if you needed it. (Doctor 12)

Notions of disease, food and childhood

The rationalistic view regarded food allergy as a mild disease with few physical manifestations, compared to other paediatric illnesses:

> I see a wide range of food allergies and other allergies and also a range of other immunologic problems. That means that I'm actually exposed to …. a range of severity of diseases, in which allergy is not necessarily as bad as a lot of other things that I see. (Doctor 14)

The allergic child was a healthy normal child who occasionally had reactions from which no permanent damage resulted:

> I tend to think of death or the risk of death in terms of [being the] bad outcome, because in essence if you don't die from it and you're not left a vegetable due to hypotension, you're probably not going to have any adverse effect at all. It's not as though you're going to have a lingering effect. (Doctor 10)

Children's diets were under parental control and avoiding allergens was straightforward; the social consequences of over stringent food restrictions were to be avoided. These restrictions affected what should otherwise be a normal childhood, which should be a time of freedom and exploration. The parents of food allergic children appeared to an example of anxious modern parenting:

> [It's] the way children are brought up nowadays, more fearful of things that are happening. Whether it be risks of travel, risks of cars, or what have you, and we….*mollycoddle* our kids, much more than we were ever mollycoddled, you know. (Doctor 11)

From the moralistic viewpoint, food allergy was a chronic disease causing significant morbidity, including psychological effects from the unpredictability of reactions. Modern food production processes meant that allergen contamination could easily occur and avoidance required complex knowledge. Autoinjectors and strict avoidance were therefore a way to regain certainty and control:

> The experience of witnessing an anaphylaxis in a small child and not being able to do anything about it is very frightening for many parents. They describe a sense of powerlessness. Helplessness - and desperation, to be able to do something. Watching their child choking. It doesn't have to be fatal to fill people with a sense of terrible anxiety, having experienced this … So it's also a means of empowering patients, to have control within their life, providing them with an [autoinjector]. (Doctor 2)

Food allergy was conceptualized as a chronic condition and daily restrictions were to be accepted as being no different to the management of other chronic diseases. Aspiring to the 'normal life' was unrealistic and incurred unacceptable risks to the child's health. By nature, children were vulnerable and impulsive, and today's children were exposed to many different environments; ensuring their safety and protection was an obligation that required precautionary approaches at a societal level.

Parents' views

Parental views also varied, but not as markedly as the doctors'. However, as their overall experience was one of uncertainty and concern for their children, they tended towards precautionary or moralistic views. The majority were aware of varying medical opinions, which they found confusing and incomprehensible, adding to the uncertainties they already felt in dealing with food allergy:

> You get the extreme advice of avoid all traces. Or you get the advice that small traces might even - a little bit is good, because it slowly desensitises them. And *that*'s why it's very confusing? As a parent, you either wholly believe in one, and not the other. Or you try and keep an open mind and get even *more* confused. (Parent 38)

Parents expected that each child should be treated as an individual, but they wondered why there was not more consistency, and about the reasoning behind differing recommendations. Parents were not confident if advice was either 'over the top', or 'too blasé', and inconsistencies eroded trust:

> The doctors actually do say things about, each other, oh you don't want to listen to [them, they're] a nutcase, you know? And so….yeah, *surely* there's got to be a way of getting consistency in information, so that patients can have some level of trust in what they're being told. (Parent 56; Focus group)

Of the families, 36% (16 of 44) of the clinic and 56% (14 of 25) of the consumer organization families had sought another specialist opinion, and in all cases, they had first consulted doctors in the study who had expressed markedly rationalistic or moralistic viewpoints. What parents disliked were doctors' views that were too inflexible; either disavowals that the risks were real and that parental concerns were legitimate, or absolute and strict management advice that they could not refuse as it could endanger their child's life to do otherwise:

> Parent 39 (Mother): They make me feel like, I'm too anxious, or ….especially when they write a letter to the doctor saying 'mother is anxious' [laughs] Parent 82 (Father): Cause it's not that we were anxious, but I suppose we were just trying to find out the facts about anaphylaxis … you're just trying to get the facts straight, rather than you're panicking.
>
> I suppose the best way to describe it was sort of like, school principal-ish? Um, like you will do, and you will do, and you will do and there will be *no*….no room for - oh I *can*'t do this, and I can't do that? (Parent 43)

Most parents accepted that there were uncertainties in food allergy and did not expect absolute certainty from their doctors:

> I don't think anybody's is going to be able to give me all the answers. I don't know if anybody can say to me *yes*, you must prevent him from eating *any* thing that *may* contain a product. Or that it's probably quite *safe*….nobody can give me that certainty. (Parent 27)

The acknowledgement of uncertainty, particularly over management options which affected daily life, allowed parents latitude in which to make decisions:

> What [my doctor] has said to me is that there isn't evidence. That if you strictly *avoid* the traces, or if you do let them have small amount, that it makes a *significant* difference. Um, so *that* probably makes it a little easier for me - to think that when I do let [my child] have some of the food that says may contain traces of nuts, that I'm not - I don't feel as though I'm really jeopardising [my child's] chances. (Parent 38)

What parents valued were more moderate views and relationships with doctors characterized by validation of their concerns, confirmation that they were managing their child's allergy appropriately and accommodation of their needs, particularly concerning information about their child's condition and its practical management.

> We don't know how much we've worried and panicked over things or not. That's the thing. But when the specialist worries with you, you go *good*, we're not being over anxious here……
>
> …… It's always, these are what we can do, and what do you think, we're allowed to say yes or no. …. I feel like it's a team work thing? In terms of [our son's] medical management, [our doctor] holds a really special place for us. … we really look forward to seeing [the doctor] each year. Cause [our doctor] gives us the information, helps us make the decisions. (Parent 20)

Discussion

This study documents a spectrum of doctors' views concerning a controversial health risk and parental views of this variation in opinion. The doctors expressed key differences concerning what was regarded as legitimate evidence, the professional role of doctors, norms of childhood, health and disease, and what could be described as individualistic libertarian compared with social communitarian worldviews, about who should bear responsibility for risk. It appears that in highly uncertain clinical situations, doctors will draw on personal values to support their position.

Limitations of the study

For clarity of presentation, the findings have been presented as divergent 'ideal' types. These form the ends of a spectrum depicting differences in emphasis as expressed by participants, which were then observed to be associated with distinctive clinical approaches to food allergy. The spectrum is a descriptive framework for doctors' responses to uncertainty, rather than being a predictive model for the management decisions of specific individuals.

The terms 'rationalistic' and 'moralistic' also risk being over-generalizations for what is a complex situation, and should be seen as apt but limited conceptual labels for key characteristics of the ideal types. Doctors who espoused rationalistic views described their approaches as being logical, analytical, objective, reproducible, reasonable and 'scientific'. Doctors who expressed moralistic views described their approaches in terms of duty, obligation and principle, invoking the need to protect and advocate for the weak and vulnerable. All doctors described experiencing uncertainty but those who expressed more extreme views were more certain and emphatic about what they thought should be done.

The study was conducted in a discrete setting with limited participant numbers. The doctors comprised a 'natural' and comprehensively recruited sample, but findings may not be generalizable to other settings and non-allergic conditions. Nevertheless, there were similarities between their views and those in published debates[24,25] and to variations in doctors' responses to uncertainty in other clinical conditions.[44,45] Parents were sampled until theoretical saturation, or no new themes, occurred, but findings may comprise, particularly with consumer organization participants, the views of a subset of all families with food allergic children. Parent participants recruited from the clinics and from the consumer organization had comparable demographic characteristics except for cultural background, but all parents could competently conduct the interview in English.

Given the low refusal rate, the sample is likely to reflect those who attend specialist allergy clinics. Although the findings concerning variations in usual practice were confirmed by observations and recordings of consultations, they do not include subsequent actions outside the clinic setting.

Implications of this study

There is a tradition of empirical sociological research on doctors' responses to uncertainty, particularly during professional training,[46,47] but previous medical accounts have tended to be theoretical reviews on how doctors should act when faced with uncertainty.[9,11,23] Several recent studies have examined doctors' responses to uncertainty using audio-recordings of consultations concerning women's health[44] and medically unexplained symptoms[45] with real and surrogate patients, but none have examined the values that doctors espouse to support their practices and compared them to the views of patients, or parents, who have consulted with them.

It is widely agreed in the clinical decision-making literature that in such situations doctors should acknowledge uncertainty and that the values of patients, or parents, concerning the impact of illness, management options and participation in decision making, should be accommodated.[11,48,49] Several reviews and studies suggest that disclosing uncertainty to patients may have deleterious effects on the doctor–patient relationship, with patients subsequently devaluing the doctors' competence.[5,50–52] However, these studies have tested real and simulated patients' responses to hypothetical scenarios rather than actual consultations; our findings suggest that many parents prefer openness concerning uncertainty. Conversely, the denial of uncertainty through presentation of fixed views may cause greater loss of trust when alternative viewpoints are discovered.

Our study adds weight to the finding of other studies that denial of uncertainty is a typical response for some doctors.[44,45] These and other studies[16] also suggest, as do our findings, that a more patient-centred approach, particularly aspects such as sensitivity to, and elicitation of, patients' concerns and support or affirmation of the patients' actions, is desirable and may result in greater patient satisfaction. In our study, parents who reported these qualities in their doctors did not subsequently seek second opinions during the 16-month study period. These behaviours may be fostered by training,[16] and it is notable that such training is not part of the specialist training programme where our study was performed.[53]

In contrast to limitations in medical knowledge, our study also implies that there are avoidable forms of parental uncertainty due to limited information provision. Without information, parental participation in decision making and care is impaired. Those doctors who cited informing parents as one of their responsibilities tended to work in clinics where there was a greater ratio of dietitians and nurses and were more likely to refer families for their advice. This finding supports the greater availability of multidisciplinary clinics, which have been shown to improve parental knowledge.[54] Where such services are not readily available, or doctors not inclined to volunteer information, parents may be better prepared to ask questions and doctors to give information through the use of standardized information guides.[55]

There is some evidence that patient satisfaction is increased if there is congruence between patients' preferences and the personal values of their doctors.[56–58] Our study does not contradict this hypothesis, although in practice, whether parents in this study found doctors with congruent values was dependent on where they were referred and their motivation to seek a second opinion. An alternative would be for doctors to have more flexible consultation styles that can adapt to different patients' values. Our findings suggest that if doctors present inflexible opinions that do not accept parental perspectives, then parents will seek medical opinions elsewhere, to the likely detriment of the continuing care of what is often a long-term condition.

Conclusions

Parents in this study did not expect absolute certainty from their doctors, nor that their views should be unquestioningly adopted. Our results suggest that it is possible to have a surfeit of certainty; inarguable certainties are presented by rationalistic views concerning the insignificance of the risks, and by moralistic views about the necessity for rigorous interventions. Paradoxically, some uncertainty may allow parents latitude in which to make decisions in accordance with their own lifestyles and preferences. Supporting earlier work on uncertainty in clinical practice in other conditions, the preferred doctors' response is disclosure of uncertainty, acknowledgement of the patients' concerns and actions, mutual discussion and ongoing negotiation. What this study adds is empirical confirmation for this approach from the patient/parental perspective and an analysis of the personal values invoked by doctors in response to uncertainty. Parents preferred doctors with more moderate views of the risks, and doctor–parent relationships characterized by validation of their concerns, confirmation that their child's condition was appropriately managed and accommodation of their needs, particularly for information.

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