

A qualitative study of families of a child with a nut allergy

Abstract

Objectives: The aim of this study was to explore, using qualitative methods, the experiences of children and their parents living with nut allergy.

Methods: Children with a confirmed diagnosis of peanut allergy were identified from a database of patients maintained at an allergy clinic at a large teaching hospital. 26 family interviews were conducted involving 11 children, 25 mothers, and 10 fathers.

Results: The diagnosis of nut allergy signalled a critical transition – or biographical disruption – in the life of the family. Parents took on the role of ‘alert assistant’ and sought to create ‘safe places’ where nuts were not permitted, but often struggled when outside the home environment. The option of ‘passing as normal’, often used by people with a chronic illness to avoid stigma, was not available to them. Consequently, parents often reported being treated as faddy, demanding, and neurotic, and children suffered from teasing and exclusion. The social consequences of nut allergy were worsened by poor labelling and control of foods and products containing nuts.

Discussion: In many ways nut allergy may be considered a form of disability, because it imposes social barriers on participating fully in society.

Keywords: food allergy, nut allergy, stigma, disability, food labelling

Introduction

Food allergy is defined as adverse immune responses to food proteins.¹ Peanut allergy is the most common food trigger of anaphylactic reactions,² accounting for two-thirds of all fatal food-induced anaphylaxis.³ The number of deaths resulting from nut allergy is extremely low, but remains a risk. The epidemiology is contested⁴ but studies suggest that the prevalence of peanut allergy is increasing and currently affects around 1-2% of children.⁵ The first allergic response to nuts usually develops between 14 and 24 months of age and typically involves the skin, respiratory system, gastrointestinal system, or cardiovascular system, which vary in severity.² For the majority of children, peanut allergy does not resolve with age.^{1 6} Nut allergy can, for these individuals, be a permanent, potentially life-threatening condition.

The evidence base for best management of nut allergy is limited and considerable regional variation exists.^{7 8} Clinical management typically involves dietary avoidance of all nuts, including traces, and carrying an adrenaline auto-injector (device for administering a dose of adrenaline or epinephrine) for emergency use to treat anaphylaxis following inadvertent nut contact. Children are frequently advised to avoid all nuts even where single nut allergy is present. Though there is a literature focused on psychological concepts such as anxiety and coping mechanisms as well as health related quality of life in relation to food allergies^{9 10 11 12 13 14} and a further literature focusing on 'risk taking' behaviour in relation to food allergy,^{15 16} studies of experiences of nut allergy have been rarer.^{17 18 19 20 21} We aimed to explore, using qualitative methods, the experiences of children and their parents living with nut allergy.

Methods

Children with a confirmed diagnosis of peanut allergy were identified from a database of patients maintained at an allergy clinic at a large teaching hospital in England. Patients on the database are referred with suspected nut allergy to the Children's Allergy Clinic at hospital. Initial assessment aims to establish whether the clinical history is characteristic with that expected for an allergic reaction to a nut. Factors in the history include the child's ingestion of a suspected food immediately prior to the reaction and development of symptoms characteristic of a type 1 allergic reaction. A suspected allergy is then confirmed with a positive skin prick test. The database used for recruitment included all patients with a nut allergy who had been seen at the clinic within two years of the start of recruitment (October 2007).

All eligible patients were invited to participate in order to ensure a cross-section of views and experiences. Participants were sent, by the hospital, a study information leaflet and letter inviting them to participate in the interview study. Replies were sent directly to the research team, thus ensuring that the identity of those taking part was not known to clinic staff. Of the research team, only the interviewer (JW) knew the identity of the participants.

Participating children and young people aged between 8 and 16 years were offered the choice of joint (children paired with their parents) or separate interviews.^{22 23} For children under 8 years old, only parents were invited to participate in interviews, but their children with nut-allergy were often present and contributed to the interviews. Age-appropriate information sheets were provided for those young people aged between 8 and 16 years. Recruitment continued until theoretical saturation²⁴ was reached.

Semi-structured interviews were carried out using an interview prompt guide developed from a literature review, discussions within the project team, input from a consumer representative, members of a local support group and pilot interviews. The prompt guide explored issues relating to obtaining a diagnosis, experiences of being a parent of a child with nut allergy, and experiences of being a child with nut allergy in different contexts including home, school, and social settings. The emphasis was on encouraging children and parents to discuss their own perspectives freely. The interviewer obtained the consent of study participants before starting each interview; children and parents consented separately. Interviews were audio recorded and transcribed verbatim. Participants were given the contact details of the lead clinician at the children's allergy clinic in the event that the interviews raised any concerns for participants.

A systematic and iterative method of analysis based on the constant comparative method²⁴ was used. 'Open codes', representing a mix of descriptive summary, commentary, and second order constructs were initially applied line-by-line to the data to represent the meaning or significance of items of text. Generation of the open codes proceeded sequentially, with no attempt at this stage to impose any framework on the data. Open codes were then incrementally grouped into organising categories or themes. These categories were modified and checked constantly as analysis continued. Data analysis was carried out by two coders and was checked by a third.

Results

Interviews with 26 families with a child with a clinic-diagnosed nut allergy (10 girls and 16 boys) were conducted (Table 1). At least one parent from every family was interviewed, and 11 children were

themselves interviewed. Parents were generally happy to discuss the nut allergy with children present, and vice versa. Children themselves were often very interested in their allergy, as it appeared a frequent focus of discussions within households.

First reactions to nuts and getting a diagnosis

Most parents described the diagnosis of nut allergy as following an incident or series of incidents where their child had a severe allergic reaction after consuming food or coming in contact with food. These incidents were described as very frightening, often requiring emergency medical intervention.

...immediately after doing that <name>'s eye swelled up and the white swelled up completely so you could hardly see his pupil, like in, in seconds...well it scares you death obviously it was so, you know it was immediately in the car and over to casualty . (Interview 22)

Parents were highly motivated to avoid recurrence of these incidents, especially as they gained in realisation that such reactions were potentially fatal. They therefore took steps to get a definitive diagnosis and advice on management.

I sort of wanted to know straight away really 'cos I thought, "oh no this is awful, I've got two other children and", you know, "this is serious". (Interview 23)

In most cases, the process of seeking and receiving a diagnosis was described as straightforward for both parents and children. The medical staff involved in the process of referral and diagnosis were mostly described as helpful. In four cases, however, the GP was reported not to have taken the problem seriously. Parents suggested that the GP did not understand the dangers of nut allergies, saw the dangers as exaggerated, or believed the children in question did not have allergy.

General delays between referral by the GP and the appointment at the hospital were another hindrance to rapid diagnosis. There were four clear examples of this in the interviews. In two cases there were significant delays in the hospital issuing the first appointment, possibly reflecting shortages of allergy specialists in secondary care. In five cases, the diagnostic process was more complicated or delayed than usual because the child had a co-existing medical condition, including eczema, asthma, hayfever and chickenpox. In four examples, parents themselves contributed to delay in getting a diagnosis, usually because they were uncertain of what was causing the reactions or feared being seen as neurotic.

Four parents described their shock and anxiety at receiving the diagnosis of nut allergy.

Then we went to see the dietician which was quite a scary bit really [...] and of course it was then like a major shock thinking on life style change and it ... I think that's when the panic set in.
(Interview 20)

All parents appeared to have received similar professional advice on how to manage the child's allergy: to ensure that the child did not consume or have any contact with nuts (including surfaces contaminated by handling nuts, such as other people's hands or food preparation areas), and to carry an adrenaline autoinjector (a device for administering a dose of adrenaline) at all times to be used in the event of exposure to nuts.

Mike Bury²⁵ distinguished between two types of "meaning" in chronic illness. Chronic illness may mean practical *consequences* for the individual patient – managing disruptive symptoms and treatment regimens, finding ways of dealing with an altered daily life, and so on. A second form of meaning, however, lies in what Bury calls *significance* - the different connotations and imagery that medical conditions carry with them. Bury notes that these may have profound impacts on how individuals see themselves and how they think others regard them. For parents in our study, it was clear that they had to confront both the *consequences* and the *significance* of having a child with a nut allergy, and that these two were intimately linked.

Nut allergy as stigma

For all families in our study, the diagnosis of nut allergy was experienced as a form of biographical disruption²⁶ involving a transition to a new, and often unwelcome, identity and set of responsibilities and roles for both parents and children. Parents reported that, in attempting to fulfil their role as the child's protector, they frequently experienced having a child with a nut allergy as stigmatising. Stigma reduces a 'whole and usual person to a tainted, discounted one'.²⁷ A distinction can be made between 'felt' and 'enacted' stigma.²⁸ 'Felt' stigma refers to feelings of shame or fear of rejection. In one account, this 'felt' stigma was implicated in delayed diagnosis of the child's condition:

Mother: and, 'cos all the while I felt like a bit of a fraud...

I: DID YOU FEEL AS THOUGH YOU WERE MAKING A FUSS OUT OF NOTHING?

Mother: That maybe he hadn't got a nut allergy and maybe he'd be all right. Yes, I suppose because he hadn't had the breathing difficulties. I felt that maybe he wasn't sort of proper, (embarrassed laugh), proper nut allergy. (Interview 26)

'Enacted' stigma refers to people experiencing overt discrimination or rejection. Examples of enacted stigma were common in parents' accounts. They reported that they often encountered

people who did not believe that nut allergy was a serious, life-threatening condition, and instead treated the parents as neurotic, over-anxious, fussy, and ‘faddy’ when they raised concerns, asked for special arrangements, or requested information.

Insisting on the removal of nuts from environments was often deeply problematic for parents, involving a challenge to their identity as sensible, rational people. Parents described prioritising their role as the child’s protector even though it meant they lost ‘face’ as a result of enacted stigma.

...my sister in law came over to me, she said, “I don’t want to alarm you,...but [child is] sitting down there with a packet of peanuts with <name1>” <husband> went to ...my aunt who was the hosting party and said... “<child> has a nut allergy and we haven’t bought his<adrenaline auto-injector> , would you mind putting the peanuts away?” and, well she was really shirty, and she was horrible. And for the rest of the evening there were jokes ... sort of pulling faces and complaining to other people that they’d had to put the peanuts away and because we were being polite you know we didn’t react... it was really awful and we drove home and we were both quite upset about it ...(Interview 27)

In many studies of chronic illness, patients describe avoiding potential stigma by making efforts to ‘pass as normal’²⁷⁷ seeking to conceal illness from others. Passing as normal may be easier to do if the condition is more or less invisible – like diabetes. A particular challenge for parents in this study was that the child’s condition was invisible, but required parents to make the allergy public in order to secure the child’s safety. The option of trying to pass as normal was not therefore available; the problem, indeed, was that children passed too easily as normal, and it was the attempt to make claims for the special vulnerability of the child that exposed parents to risks of stigma and discomfort.

... birthday parties are the nightmare because obviously now he’s at school he’s started to get invited and trying to explain to people’s parents that he’s got an allergy and people don’t understand it...some people might think it’s a bit faddy you know saying you’ve got it just ‘cos you think it’s trendy. But I don’t think people can realise the full implications and that it can be life threatening and ... that’s the element that scares me. (Interview 1)

Parents were thus put in a position of tension between ensuring the child’s well-being and exposing themselves to stigma. They typically resorted to the use of techniques of ‘impression management’²⁹ to resolve the identity-threatening predicament and gain the cooperation of others in ensuring the child’s safety. These techniques included underlining the medical risks of the condition, and warning people not to call their bluff.

We just went to our... local coffee bar and ...we got a little snack and I just said "Oh does it contain peanuts at all?", and I think the guy ... probably didn't understand the full implications but he thought it was ... a kind of a, a jokey...kind of thing to say ... "There are repercussions if you give my son peanuts you'll have an ambulance at, at the door ...in five minutes". (Interview 1)

Children also reported experiencing stigma, for example describing feeling excluded when treats – such as chocolates – were handed out at school. Some schools had a policy of not allowing nuts in school, but the policy was not always fully enforced and children reporting having to take action that marked them out from others. Where nuts were not banned from packed lunches, children had to decide where to sit, and this led to enacted stigma, including being teased and taunted.

It's been hard for her at school sometimes as well because it's difficult for lunchtime, she has packed lunches, any food that goes into school as in hot dinners is guaranteed to be nut free but obviously they've got no control on what other children take in...quite a long time she was being moved every single day, "You can't sit there, somebody's got nuts" and not, you know peanut butter or a packet of nuts or whatever, and she was teased and things like that, people saying, "I've got nuts and I'm gonna come and touch you" and things like that. (Interview 20)

The protector role and its problems

Parents created 'safe places' for the child by excluding nuts completely from environments that they could control, including their own home. When in environments they could not control, parents adopted a number of strategies, including direct supervision of the child, exercising vigilance over the content of food and presence of nuts near the child, and seeking to educate others about the risks posed.

Creating 'safe places'

Keeping the child's home free of nuts was seen as the most obvious way of constructing a safe zone for the child, and was mentioned in 13 interviews.

... even my other little boy's now he's adapting to the fact that his older brother's got this issue and he even checks if it's okay because we've now said he can't have peanuts, as simple as that, peanuts are not allowed in this house, any kind of form of peanuts, just we don't do. No chocolate, nothing, it's just not in this house. (Interview 19)

In ten interviews, parents described keeping the child's diet focused on what they knew to be safe to eat. In nine cases, the parents described preparing their own food from scratch in order to ensure that the child had a nut-free diet.

Yeah, I find that you know sometimes you have to go back to home cooking on certain, even just a cottage pie, you can't go out and just get one. You know and it's, you gotta make it from scratch and things like that. (Interview 24)

Parents had to impose rules of restriction to manage the child's eagerness to consume 'forbidden' food. This was a source of potential tension in the relationship with the child. In four interviews, parents described strategies for overcoming this including convincing the child not to eat the food, finding alternatives for the child to eat, and allowing a child to try small amounts of low risk food to see if it was safe.

... Crunchies, fat lollies, he likes those but they do say may contain traces of nuts and if he's adamant that he wants it we tend to say to him, "Okay then <name>, if you want it you may have a reaction, you may have to have your <adrenaline auto-injector> and go to hospital, do you still want it?" and then he'll say, "No, no I won't". (Interview 4)

Trying to control risks outside the home

Risks outside the home arose in all kinds of environments, including school, transport, and other people's houses, but were extremely difficult for parents to control fully. In 17 interviews, parents and children described actively monitoring the environment when outside of the home by asking about nuts and reading the labels of products. This was sometimes combined with strategies such as small 'challenge' tastes of food.

In 14 interviews, parents described using active surveillance and supervision of external environments to ensure that their child did not eat nuts. They often stayed with the child during events away from home or became involved to a greater extent than would be normal in planning and managing events.

...they had a Christmas party and ... all the parents was to just do a bit of food and bring it all in for the kids to have a party and they did say to me on that day can I actually come in and stay just in case obviously there is something here that will have nuts in or anything and they ... said ...at least I'm here to give her you know the <adrenaline auto-injector> if she needs it. (Interview 11)

The vigilance and level of restriction exercised by parents varied. In five interviews, parents described avoiding all possible contact with nuts and consequently severely limiting what the child

and family could do, including social interaction. Children themselves were engaged as co-agents in vigilance and surveillance of the environment, and had been trained to scan for risk.

Interviewer: AND IF YOU WERE AT A PARTY AND SOMEBODY OFFERS YOU SOME FOOD WHAT DO YOU DO?

Child: I say, "Has it got any nuts in?" And then I ask, one of the adults who own the party and they tell and if it has got nuts in I don't have it but if, if it hasn't then I do have it.

Interviewer: WHAT IF THEY DON'T KNOW?

Child: I won't have it. (Interview 16)

Having been enlisted as co-agents by their parents, children exercised responsibility by checking for risks across a range of environments and by mobilising support from their parents.

And he will ask as well... he'll say is, you know if, particularly at school the kids are giving out sweeties and that he'll come home and he'll say, "Can I have this, has it got nuts in it?" ...he won't eat anything straight away, he'll just ask. (Interview 1)

Family and friends

One interview shows how other family members may extend the safe zone by also stopping nuts from entering their homes.

Mum and Dad have ... they try not to buy anything with nuts anymore because she stays over at night and everything. And even my brother's children, they live together, so you know... they try not to have nuts when <name>'s around. (Interview 3)

In 14 of 26 interviews, however, parents reported family members or friends giving the child nuts or having nuts in the house. The interviews include 11 examples of family members and four examples of friends causing incidents or worry. Parents described lack of awareness, sensitivity, or vigilance, which may be described as acts of omission. Less frequently, they described acts of commission, where people appeared to have deliberately given the child nuts in defiance of parents' instructions and explicit requests. Parents often described family members as exposing children to the risk of nuts, either during routine visits or at times of gathering and celebration, such as Christmas or birthdays.

Mother: We're ... worried about parents and family, they're the ones that concern us the most.

Father: Even though they've been told they still bring out peanuts and that when.

Mother: I mean we, we were so annoyed we went up to me in-law's over the weekend and they'd, you know they've got Bombay mixes there, it's got nuts in, I mean "Try some of this, try some of this", "Sorry but we're not allowed to have it." I mean I just couldn't get it through to [husband's] Mum that we can't, eat it, you know and you shouldn't be eating it as well you know because it, as soon as you then hold her, touch her, that's it... (Interview 21)

Often friends and families reacted and responded well to parents' requests for a nut-free environment. But there were also many accounts of unsympathetic responses, particularly from those who felt that the parents' behaviour was excessive and unnecessary. Again, parents found these responses hurtful and upsetting.

I don't think people do [understand it] because I think unless you actually live with it you don't. Well I've got one friend who before he actually had his peanut prick test she said, "Well why don't you just give him a <chocolate and peanut bar> and see?" (makes disapproving noise) and you just, people just don't understand, all the implications of it. (Interviewer: RIGHT. OKAY. DOES THAT FRUSTRATE YOU?) Mother: Yes sometimes 'cos I think yeah these are supposed to be people that are your friends and, and I suppose you know you're looking out for ... your children. (Interview 23)

These incidents highlighted the emotional demands imposed by having a child with a nut allergy, where attempts to protect the child could involve the parents in angry or upsetting confrontations. It also highlighted how stigma could be enacted by those closest to the parents and child, which was often very hurtful.

Two years ago now we got invited up for a party ...gave them a list of what he could eat, thought everything was gonna be fine, walked in there and I couldn't believe my eyes, big bowls of peanuts in between all the food, we basically left, well to be honest we were both panicked and we were in shock...obviously you know I wasn't best pleased so got a bit heated and we left... I don't really have much ... support really from... (Interviewer: DID THEY GET UPSET WHEN YOU LEFT THEN DID THEY?). They thought I was over dramatising. (Interview 25)

Three parents described incidents where they suspected that people had deliberately given the child nuts, perhaps to test if the child's allergy was authentic.

I mean my father-in-law gave him a sweet with a nut in, (sighs) he's a funny guy, ... now whether it was deliberate or not I don't know but I blew a fuse, and I made a huge fuss and gave <name> <antihistamine>straight away...Yeah I suppose in my heart of hearts I felt that he'd given it deliberately, my husband doesn't want to believe that his father would do that...Yeah I don't

trust his father. Although I think my reaction will have made him think and at one point he did say, "You must keep reminding me". (Interview 7)

Pubs, restaurants and cafés

In ten interviews, parents commented on issues they experienced when eating out. Parents believed that staff were not usually aware that they should wash their hands after handling nuts, and that people do not seem to have been trained or given information on nut allergies. For some parents, the restrictions on eating out amounted to a form of social exclusion.

Some restaurants are very good, others don't want to know and they can't possibly do anything about it and every dish could contain ... nut traces as far as they're concerned. So I don't know. I feel quite cross actually and quite upset really, because it is, it's socially excluding people. (Interview 12)

People who handle the nuts ... in these kind of places ...when we've been to the ... pub and we've had meals, they don't know why people are saying they don't want nuts ... or they're not aware... (Interview 2)

Trips to restaurants could also present dangers from other diners. Interview 14 explained how a child is chased around by another child in a play area. The other child only wanted to play but had been eating nuts which makes the situation dangerous. The mother explained how the other mother got 'a bit huffy' when told about the problem. This made the meal an unpleasant experience for the family.

Supermarkets and shops

Comments on negotiating safe products while shopping appeared in ten interviews. Parents resented the label 'may contain nuts'. Some parents did avoid any food labelled 'may contain nuts' in case it has been on the same handling line, but were concerned that food producers overuse the warnings. Parents perceived that supermarkets were protecting themselves against liability rather than providing useful information.

Well it's reliable because they disclaim everything. I mean <supermarket> is hopeless, you couldn't shop in <supermarket> if you wanted to know whether it had peanuts, you couldn't buy a thing in <supermarket> that guarantees it's nut free that's <supermarket>'s own brand, because they say, (sighs) recipe: no nuts, factory: no nuts, and then they say ingredients cannot

guarantee nut free, because they're shipping the ingredients in and they won't vouch for them...(Interview 15)

Some parents described a sense of injustice. They pointed out that the help available to a child with allergy is far less than that available to vegetarians or others with dietary restrictions, and suggested that this was a form of discrimination.

Oh that gets me angry because ... I feel that, you know ...there's so much help out there for people with diabetes...that are vegetarian but there just is not, there's hardly anything really out there for, people with peanut allergies...where you know you can go one hundred per cent and your child's gonna be safe so every time I give him something that may contain traces it's a gamble, I'm gambling ... that's the battle really and I don't think... there was enough... information out there for us. (Interview 19)

Discussion

This study provides important evidence about the challenges faced by children and parents in relation to nut allergy. The advice given by the allergy clinic to avoid nuts had a huge impact on families' lives. The diagnosis had both practical consequences and social consequences, including the experience of biographical disruption on the part of parents. Our data suggest that the living with a child with nut allergy required parents to assume the role of an 'alert assistant', who seeks to create safe places for the child and guards against exposure to risk through exercising vigilance and acting as the child's advocate, and the child enrolled as a co-agent. The child's condition was invisible, but parents had no option of 'passing as normal' since the only way of protecting the child was to make known the child's vulnerability.

The practical *consequences* of the diagnosis of nut allergy were, in many ways, quite unlike those of many chronic illnesses described in the literature. The child did not have to deal with daily symptoms, and did not experience deterioration in physical function, pain or physical restrictions or disability. On the contrary, children were generally healthy (though some had problems such as eczema or asthma). It was the attempt to exclude the child from all contact with nuts that constituted the major practical consequence of the nut allergy. Implementing this objective was often highly challenging, and fraught with significance (to use Bury's term), requiring parents and children to take multiple precautions. Parents had to engage in multiple negotiations of relationships both with the children themselves and with others outside the immediate family in order to ensure the child's safety. These negotiations were made especially difficult by the socially

ambivalent status of nut allergy as a diagnosis: parents vividly described how not everyone accepted it as an authentic condition with potentially deadly implications, instead seeing it as a frivolous and self-indulgent fad invented and maintained by neurotic, attention-seeking people. This meant that parents struggled to preserve their own identity as sensible, credible people who deserved to be taken seriously. Even when others did accept the reality of the allergy and potential outcomes, they were not always as vigilant or competent as parents felt was required to secure the child's well-being.

Nettleton et al³⁰ argue that on the whole allergy and intolerance sufferers are treated differently, and that food allergy sufferers are seen as less problematic or morally troublesome than those with intolerances. These authors also outline how there is some conflation of the terms 'allergy' and 'intolerance' in lay discourse. Our data suggest that this conflation has important practical and social consequences, but our study also strongly suggests that even having a 'proper allergy' does not shield families from the risk of stigma and negative responses, both within and outside the family.

Our data indicate that the social consequences of nut allergy were amplified by poor labelling and control of foods and products containing nuts, which causes considerable difficulties for families. In contrast to Japan, where it is illegal to use the 'may contain' label,¹⁶ the UK and EU both allow use of the label 'may contain nuts'. This and similar labels were perceived as unhelpful and as serving the interests of manufacturers and retailers rather than families. Research in three other European countries has similarly highlighted the problems of precautionary labelling for food consumers.³¹ In our study, families suggested that the failure to address the needs of people with nut allergy amounted to a form of social exclusion or discrimination, particularly when their needs are compared with those of vegetarians or others with food restrictions.

In many ways, then, nut allergy is more properly considered a form of disability rather than a chronic illness, though parents and children do report some of the features of a chronic illness as aspects of their experience. A social model of disability understands disability not in terms of the individual, but in terms of the social barriers that people face in participating fully in society. Nut allergy not only alters the families' relationships with 'normal' people (and thus has social consequences), but it is itself in many ways a consequence of social arrangements. It is the design of regulatory systems, the characteristics of physical and social environments, and the attitudes of others that intensify the problems of having a child with a nut allergy.

A number of practical steps could help families in the short term. One is better GP awareness of the condition, which is likely to be encouraged by the recent publication of NICE guidance.³² Second, it is

clear that delays in obtaining an appointment to have a suspected allergy confirmed is a source of considerable stress. Reducing delays as far as possible (which has already occurred in the clinic where the study was conducted, with first appointments now issued within one month of referral) may be important. Finally, enabling education opportunities for families to meet as groups outside the clinic may be an important way of providing support and information, sharing “tips”, bolstering confidence, promoting reflection, and enabling carers and family members to be feel included.

Table 1

Interview	Mother	Father	Child	Age at diagnosis	Male/Female	Age at interview
1	✓	✓	✓	Pre-school	Boy	4
2	✓			Pre-school	Girl	7
3	✓	✓	✓	Pre-school	Girl	9
4	✓			Pre-school	Boy	7
5	✓			Pre-school	Boy	4
6	✓			Pre-school	Girl	6
7	✓			Pre-school	Boy	4
8	✓	✓	✓	Pre-school	Boy	5
9	✓	✓	✓	School age	Boy	12
10	✓		✓	School age	Girl	8
11	✓			Pre-school	Girl	3
12	✓			School age	Girl and Boy	Girl 17, Boy 15
13	✓	✓		Pre-school	Boy	3
14	✓			Pre-school	Boy	~6
15	✓	✓	✓	School age	Boy	8
16	✓	✓	✓	School age	Girl	9
17	✓	✓	✓	School age	Boy	9
18	✓		✓	School age	Girl	7
19	✓			Pre-school	Boy	5
20	✓	✓	✓	School age	Girl	~8
21	✓	✓		Pre-school	Girl	4
22		✓		Pre-school	Boy	~7
23	✓	✓	✓	School age	Boy	8
24	✓			Pre-school	Two boys	3 years; 18 months
25	✓			School age	Boy	7
26	✓			Pre-school	Boy	4

Table 1: Characteristics of families participating in interviews

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