

BMJ Open 'Hope you find your 'eureka' moment soon': a qualitative study of parents/carers' online discussions around allergy, allergy tests and eczema

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ABSTRACT

Objectives To explore understandings and concerns surrounding allergy, food intolerances and their potential impact on eczema among parents and carers of children with eczema who had posted messages in online forums. **Methods** We conducted a scoping review for active UK-based discussion forums that did not require password/registration to view posts and identified two parenting discussion forums with high activity and frequent use. We used their internal search functions to identify and export discussion threads relating to allergy and allergy testing for eczema from 2011 to 2016. We carried out an inductive thematic analysis of the 120 exported discussion threads. **Results** 246 pages of text were analysed. Analysis led to three main themes: (1) confusion over the language surrounding 'allergy' and 'intolerance'; (2) diverse beliefs about allergy testing in relation to eczema and (3) parents' frustrations with perceptions of health professionals as uninterested and unhelpful about allergy testing. Forum users were concerned about immediate and delayed-type allergies but showed confusion in how terms were used, as well as different approaches to testing. Parents sought experiences of others, seeking social support as well as practical guidance.

Conclusions The confusion around allergy-related terminology and its possible relationship with eczema means that it is essential healthcare professionals are able to signpost parents to accurate, accessible information. The lack of consistent information currently available means parents may use online discussion forums as an important source of information. This study suggests that the confused nature of discussions on these forums is inaccurate at best, and detrimental at worst.

BACKGROUND

Childhood eczema is very common, affecting over 20% of children aged 5 or under at some point.¹ Eczema can cause significant distress to the child and family due to sleep disturbance and itch.^{2,3} In the majority of cases, eczema starts before the age of 4 years and clears by the teenage years, although relapses may occur.⁴ The National Institute for Health and Care Excellence (NICE) Guideline on

Strengths and limitations of this study

- The use of forum posts covering a 5-year span means that current and historical posts were included in the analysis, allowing for a range, and potential change, in views to be explored. As data were collected retrospectively, our analysis is limited to the data available as it is impossible to ask parents to expand on posts.
- There is a possibility forum users had more difficult experiences than parents not accessing forums for advice, so these results cannot be generalised outside this specific environment.
- Participating in online forums may influence patients' experiences and has implications for our understanding of patients' roles in managing their health.

Atopic Eczema in Children⁵ concludes that the main cause of treatment failure is non-adherence to prescribed treatments. This may be related to a mistrust of treatments⁶ and the mismatch of views between parents/carers and health professionals causing disillusionment with treatment.⁷ A major area where views of parents/carers and health professionals are at odds is approaches to diet and allergy as a potential 'cure' for eczema.

Despite the popularity of dietary exclusion in eczema, there is little evidence to suggest that this is helpful for most people's symptoms.⁸ A review of dietary exclusions for the treatment of eczema found little evidence that 'few food diets', 'removal of milk/eggs' and 'elemental diets' are of benefit to individuals who have not had testing.⁸ Furthermore, NICE guidance on eczema in children states that food allergy is unlikely in eczema unless the child has reacted to a food with immediate symptoms, or where moderate or severe atopic eczema has not been controlled by optimum management, particularly if associated with

gastrointestinal symptoms.⁵ However, people may initiate dietary exclusions for a range of perceived problems, including intolerance as well as allergy.⁹

In 2017, 80% of adults used the internet daily or almost daily¹⁰; the internet is changing how patients access health information and support.¹¹ Online forums are discussion sites for people to interact through asynchronous written communication¹²; they contain naturalistic data¹³ and have been used widely in qualitative research.^{14–16} Participating in online forums may influence patients' experiences and has implications for our understanding of patients' roles in managing their health.¹⁷

The permanence of written exchanges in online forums ensures that future users have access to both current and historical posts. Many users may turn to online forums for support,^{17 18} especially if they did not understand information provided by their healthcare professional.¹⁹ Concerns have been raised regarding the accuracy of information found online,²⁰ but many people, particularly those with long-term health conditions, are using online forums due to an unmet need for information and support.²¹

Qualitative research among parents of children with allergy has explored concerns, particularly around meeting nutritional needs, development of 'picky' eating²² and exploring coping among families of children with allergy.^{23 24} Qualitative research among families of children with eczema has explored the impact of the condition,^{25 26} information needs,^{27 28} concerns about topical steroid use⁶ and frustrations with seeking information about eczema online.²⁹ One study explored parents' frustrations with health professionals who did not appear to 'take seriously' their child's eczema; while parents saw dietary exclusions as a potential cure, they perceived healthcare professionals as uninterested in this.⁷ However, to date, there has been no qualitative research aimed specifically at exploring concerns around diet and allergy among parents/carers of children with eczema.

We chose to carry out a qualitative study of discussions focused on eczema, diet and allergy in online discussions as these provide a forum where users' experiences and perspectives are discussed openly in a naturalistic way without researcher influence.³⁰ This study aims to explore the understandings and concerns surrounding allergy and food intolerances and their potential impact on eczema among parents and carers of children with eczema who have posted messages on online forums.

PATIENTS AND METHODS

Data retrieval

In October 2016, a scoping review was conducted (by DN, a medical student, supervised by MS, an academic general practitioner (GP), and AH, a research fellow, both with qualitative expertise) to identify relevant forums. The terms 'eczema +exclusion' and 'eczema +elimination' were entered into two search engines (Google and Bing). For every search conducted, 15 forums were identified or three pages of results (10 per page) were evaluated. This

process identified 40 different forums, which were evaluated against chosen criteria (format, registration requirements, internal search functions, activity (how frequent posts were, such as daily, weekly, monthly), commercial interests, site moderation and the exclusion of non-UK based forums). Two parenting websites were selected for inclusion in this study as they met our selection criteria as well as showing frequent use (daily–weekly posts). Registration was required to post messages, but not to view threads. Both websites had site moderation (an employee who removed spam and occasionally responded to comments).

DN familiarised herself with these forums, enabling a search strategy to be devised. 'Eczema exclusion' and 'eczema elimination' were searched for using the internal search function. The first three pages of results (10 per page) from January 2011 to October 2016 were reviewed. One hundred and twenty discussion threads were copied into Microsoft Word and then exported into qualitative data management software NVivo V.10.

Ethical considerations

This study adopted British Psychological Society Guidelines³¹ which consider online forum messages to be within the public domain, provided the researcher did not need to register in order to view them, an approach used in other studies.^{15 32–34} To preserve anonymity, forums are not identified and data excerpts have been paraphrased. Paraphrasing has been checked for maintaining original meaning by all authors.

Patient and public involvement

The following research questions arose from the James Lind Alliance Priority Setting Partnership for eczema: (1) 'What role might food allergy tests play in treating eczema?' (2) 'How much does avoidance of irritants and allergens help people with eczema?' (3) What is the role of diet in treatment eczema: exclusion diets and nutritional supplements?³⁵

This study was early scoping work, initially carried out by a medical student, in order to understand public perceptions of allergy and eczema in this under-researched area. No patient advisers were involved in the conduct of this study. Patients and the public are involved in other work on allergy and eczema being carried out by the authors.

Data analysis

Inductive thematic analysis³⁶ was conducted. One author (DN) read each discussion several times and coded relevant posts line by line. Codes were derived inductively from the data and grouped to produce an initial coding frame. Codes and theme/subtheme definitions were iteratively developed by DN, AH and MS through multiple team discussions. The coding manual was iteratively developed and fitted and explained all of the data, having searched for disconfirming cases. Data saturation was achieved. During the analysis, original posts were considered within the discussion thread they were originally posted in order

Table 1 Forum information

| Forum | F1 (general parenting) | F2 (baby care) |
|--|------------------------|----------------|
| Total users | 159 | 96 |
| Number of pages of text | 113 | 126 |
| Total included threads | 31 | 51 |
| Median posts per thread (range) | 12 (2–31) | 4 (1–26) |
| Median users per thread (range) | 7 (1–15) | 3 (1–9) |
| Median posts per user over all threads (range) | 16 | 1–40 |

to retain context (for example, being able to position advice to the specific question being asked).

RESULTS

A total of 100203 words were analysed, on 239 pages of text: this included 31 discussions (159 users) from a general parenting forum and 51 discussions (96 users) from a baby care forum. This is shown in [table 1](#). Overall, the discussions were similar in both forums: generally conversational in tone and supportive in nature. Both forums are based in the UK, as were most of the users (shown, for example, through references to UK hospitals). Some users explained they were based abroad, especially if this provided more context to their post (eg, by explaining that their healthcare system is different from the UK).

Analysis of parents/carers' discussions about allergy and allergy testing highlighted three main themes: (1) confusion over the language surrounding 'allergy' and 'intolerance'; (2) diverse beliefs about allergy testing in relation to eczema; and (3) perceptions that healthcare providers were uninterested and unhelpful about allergy testing in eczema. Selected quotes are used to illustrate themes and subthemes. Paraphrased quotes are shown with participant ID and forum.

Confusion surrounding 'allergy' and 'intolerance'

Throughout the discussion threads, there was confusion surrounding the terms 'allergy' and 'intolerance' and an apparent absence of shared understanding about their meaning. They were used interchangeably, both by individuals within posts and different users within threads.

F2-P24-1

So what are symptoms of allergy/intolerance? I'm going dairy free and my GP hasn't been helpful, saying I'm basically wasting my time.

F2-P29-1

I thought it had to be a problem with food and so while we were waiting for a dietician appointment (it took eightweeks) I eliminated the obvious allergens. You have to work out intolerances (so called slow

reaction allergies) by elimination diet as allergy tests won't show them.

On occasion, allergy/intolerance would be used in a post, and someone would reply but referring to the other: in these instances, forum users appeared unaware they were referring to different conditions which could impact on the relevance of advice. Other terms used included 'true allergy' and 'major allergy'; allergies were also described as 'bad', and as something changeable depending on the season.

However, some users were clear in their understanding of the different terminology and how it related to the types of testing available. Terminology was often used without explanation of what it meant (for example, 'EpiPens and quick acting antihistamines'), assuming prior and shared knowledge and understanding.

Diverse beliefs about allergy testing in relation to eczema

Parents feeling testing does not provide answers

Although some users differentiated between types of testing available, often no distinction was made between conventional tests in the form of skin prick tests and specific IgE blood tests, and 'testing' via other means such as an elimination diet or testing via 'high street' or internet providers using unregulated methods.

F1-P6-1b

You can't really do an allergy test for it because the reactions are different—they are the type of reactions that you need an epipen for. Maybe antihistamines. They show up straight away so the tests just confirm the allergy really. The slow reactions are different but they won't show up in these tests because they take a while for you to react and get things like an upset stomach, rash and so on.

While many forum users were sharing experiences of pushing for allergy testing, several users expressed concerns over this, believing that testing does not always provide answers and advising caution.

F2-23-P1

I think you'll find that allergy testing is not that accurate. All the people on allergy boards will tell you this because the tests can't diagnose all allergies. It can point you in the right direction but you can't tell for sure from the tests. The only way you can really tell how your daughter's body will react is by eliminating food. My daughter's tests came back saying that she's really allergic to eggs (which she's not!) and that she's not allergic to shellfish (which she has really bad reactions to!).

Parents feeling testing does provide answers

Several parents wrote about how useful testing had been for their children, with one believing they would not have been able to ascertain their child's triggers without 'specialist testing'.

F2-P10-3

I really needed help to figure out what set his symptoms off. He is allergic to loads of stuff, with some reactions coming on straight away and others being delayed—there is just no way I could have done it without the specialists.

F2-P2-26

My little one had eczema since she was a newborn and our GP thought it would get better in time and we just had to check she didn't get an infection when it got red. I couldn't just wait so I saw a nutritionist who asked us questions and then said it was milk. At first I wasn't convinced so we went for the blood test and that showed clearly she was allergic to milk as well as wheat and egg.

F2-P30-2

Our son's a year old and had allergies since introducing solids at 6 months. I knew he had cow's milk protein allergy but it was the eczema which got us referred to the paediatrician. We had allergy tests done, the usual dairy, nuts, fish etc. Best of luck, hope you find that 'eureka' moment soon.

Users who had positive experiences of allergy testing often expressed incredulity that other families were unaware of such services, or unable to access them.

F2-P12-4

I just can't believe how few people on here have had allergy testing! My son's skin was horrific but when he was 12 weeks old he was diagnosed with a dairy allergy so I cut dairy from my diet at that stage. The results were brilliant—within a week his eczema cleared up and now he only gets the occasional patch of dry skin.

Alternatives

Other users talked positively about alternatives to allergy testing that lack support from scientific evidence. People seemed particularly drawn to these where they were dissatisfied with their clinical care.

F2-P17-1

He is due to have allergy testing but I feel like stopping this and maybe trying Chinese medicine

F2-P22-1

We went to a naturopath who used [electrodermal non-evidence-based test] to test for different allergies. It showed my daughter is allergic to dust mites and tomatoes. Since we have removed these, her eczema has nearly gone in a few days. I would recommend this test, it's non-invasive and works!

In a more worrying account, one user offered advice for how to test an allergen at home, which would clearly be dangerous for some children and is never an appropriate action.

F1-P6-1a

I would test the egg at home. Get [brand of liquid antihistamine] ready just in case. Find a patch of skin on his arm free from eczema, draw a small circle and dip your finger into egg white before touching the inside of the circle. Don't rub it. Wait for an itch. An anaphylactic reaction would have happened by now and [brand of liquid antihistamine] has been effective in the past, you can't avoid eggs and the allergist isn't concerned enough to test, so you're not putting your son at risk. Leave for 24 hours, if there isn't a reaction then the allergy is not there, or very mild. Give [brand of liquid antihistamine] when the itch becomes painful and red, and spreads beyond the circle or when hives appear. If his breathing becomes difficult or if he vomits then dial 999.

Perceptions that health professionals are uninterested and unhelpful about allergy testing

Many users shared negative experiences of their GP not referring them for allergy testing, with some being told that allergy testing would have no benefit and to trial food elimination instead.

F1-P3-1

We did a food exclusion last summer and we gave up everything for two weeks (both of us as I was still breastfeeding) and then reintroduced each thing two weeks apart with a diary of symptoms. Nothing appeared to make a difference. I did ask the dermatologist about allergy testing but he seemed to think it wasn't worth it. What tests did you get?

F2-P9-3

My little boy has had eczema nearly since he was born and we had the same issues with our GP. When he finally got referred to the allergy clinic (aged four months and we had to wait three months for the appointment) it showed he was allergic to dairy and egg. I am still angry about this—I sat in my doctor's office and refused to leave until I got a referral. Doctor kept telling me the eczema would be 'non-specific' and so there was no point looking for triggers. Well, they showed up clearly on the prick test!

Some parents encouraged others to 'insist on' a referral, even where they appeared unaware of the symptoms that other users' children were experiencing, and seemed to assume they were similar to their own.

F2-P10-1

The GP's fobbed me off by prescribing antihistamines for a while. I think if your child is that bad (and I understand as DD was the same) then you need a referral to a dermatologist/for allergy testing and probably steroids. Allergy diagnosis and correct treatment transformed my daughter within weeks!

F2-P18-2

I would insist on blood tests, DS (nearly two) was diagnosed with CMP allergy at 9 months. I'd been

completely ignored previously as I suspected it was something to do with formula. A sympathetic consultant did blood tests after taking one look at him.

F2-P4-1

I think my son is slightly intolerant to milk, he has many bouts of diarrhoea and can only eat a little bit of dairy. But my GP said he's clearly not allergic because the symptoms would be worse and he does have a bottle of formula which he seems to tolerate. Can you force a GP for allergy/intolerance testing? How?

DISCUSSION

Main findings

Analysis of online discussions about allergy and intolerances in relation to eczema identified three themes: (1) confusion over the language surrounding 'allergy' and 'intolerance'; (2) diverse beliefs about allergy testing in relation to eczema and (3) parents/carers perceiving health professionals as uninterested and unhelpful around allergy testing, which many parents perceive as having great potential benefit for eczema.

The confusion surrounding terminology appeared to make it difficult for users to identify whether advice was applicable to their own child. Similarly, users' lack of distinction between conventional and 'alternative' allergy tests makes advice difficult to interpret for their own child's circumstances. Although guidelines suggest that allergy testing is not helpful for most children with eczema,⁵ some parents perceived allergy testing to have benefited their child's eczema and were dismayed that others had not received this, while others advised caution, citing inconclusive or inaccurate results.

Findings in context of previous research

Previous qualitative research on health-focused online forums has shown them to have an important role in learning from others' experiences¹⁷ and gaining social support, particularly for users who felt health professionals were not listening to their views. A recent meta-synthesis highlighted how users of multiple forums sought information from 'expert patients'.²¹ Forums provide a space in which information can be exchanged in 'plain English',³⁷ and often faster than through healthcare providers as users can search for relevant content. Previous research examining online forums¹⁷ has found that conflicting information from people with different experiences can cause confusion and anxiety, a finding that came through strongly in our study.

Previous research among parents/carers of children with eczema found frustration with health professionals' lack of interest in diet and allergy approaches as a potential 'cure' for eczema, as well as frustration relating to conflicting advice offered by different health professionals.⁷ Recent research showed that some parents believed eczema to have a root cause, such as allergy, which needs identifying and avoiding and this is potentially a

barrier to treatment of the child's eczema³⁸: our research echoes these findings as it shows parents/carers are often confused about treatment and are interested in allergy as a possible cause. We found similar frustrations in online discussion forums, possibly related to the widespread belief in allergy testing for eczema conflicting with guideline advice. Numerous reports have cited the need for greater education and training around allergy in both primary and secondary care^{39 40} so it is likely that parents may not receive sufficient explanation and discussion when they discuss potential allergy with health professionals, leading them to seek support elsewhere.

Strengths and limitations

This research reports a valuable method of exploring parents/carers' concerns about their child's eczema. As data were collected retrospectively, our analysis is limited to the data available as it is impossible to ask parents to expand on posts. The searches identified a large quantity of relevant information, although it is possible that using different search terms may have yielded different findings. Forum users may have had more difficult experiences than parents not accessing forums for advice, so these results cannot be generalised outside this specific environment. However, the consistency in concerns about allergy and intolerance in relation to eczema, and the range of (often inaccurate) information shared, suggest these need addressing within healthcare.

Implications for future research

We found evidence of a gap in shared understanding of the role of diet and allergy, as parents/carers' views in online discussion forums differ substantially from guidelines and usual clinical practice. It is unsurprising that this frustrates parents and further qualitative research could explore how these perceptions develop. Observation of interactions in consultations, or interviews with parents about their reactions to mainstream medical messages about allergy and eczema, could further elucidate how shared understandings can be achieved.

Implications for clinical practice

Parents/carers need greater clarity and consistency in terminology surrounding 'allergy' and 'intolerance'. Although confusion is likely to be magnified in online discussion forums, comprehensible language and clear definitions are an essential first step towards shared understandings between parents and health professionals.

It is important that healthcare professionals are prepared to discuss allergy with parents and signpost to accurate, reliable and accessible information online. Without this, parents are likely to turn to online discussion forums, which are confusing at best and detrimental at worst.

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Contributors MS and IM designed the research study and DN collected the data. All authors were involved in/commented on data analysis which was led by DN and AH and overseen by MS. AH and MS developed the manuscript, to which all authors contributed and approved the final version. KG and EA provided allergy-specific expertise in interpreting the data.

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Competing interests EA has been paid personal fees to be an advisory board member on one occasion for Stallergenes, Meda and Schering Plough. 1 honaria lecture Meda, 1 conference place SOSA meeting ALK. KG reports personal fees from Nutricia, personal fees from Abbott, personal fees from Mead Johnson, personal fees from Nestle, personal fees from Reacta Biotech, outside the submitted work.

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