Perceptions of expertise in food hypersensitivity on social media: An email interview study

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Abstract

Background: Seeking and sharing information are primary uses of the internet and social media. It is therefore vital to understand the processes individuals go through when engaging with information on these diverse platforms; especially in areas such as health and risk-related information. One important element of such engagement is evaluating and attributing expertise to others.

Objective: The study aimed to explore how meanings around expertise in relation to food allergy/intolerance (food hypersensitivity) were constructed by two groups of social media users; 1) those who use platforms for reasons relating to food hypersensitivity, and 2) those seen as experts by this community.

Methods: Email interviews were conducted with food hypersensitive adults (n = 4), parents of food hypersensitive children (n = 4), and perceived experts in food hypersensitivity on social media (n = 5). Data were analysed thematically using Braun and Clarke’s approach.

Results: The thematic analysis demonstrated that judging expertise on social media is a complex and multi-faceted process. Users might be judged as expert through their professional background, or their experience living with food hypersensitivities. How users behave on social media, and the traces of their online activity can influence how others will see them. Such considerations are both measured and moderated through the social media community itself. Findings highlighted how social media often acts as a supportive information tool following a diagnosis, but this also raised concerns if patients cannot access suitable vetted information.

Conclusions: This work has implications for understanding how users perceive expertise on social media in relation to a health concern, and how information assessments are made during management of risks. Findings will prove beneficial to both medical and organisational stakeholders involved in the support of those living with life-changing conditions, such as food hypersensitivities.

Keywords: social media; expertise; food allergy; food hypersensitivity; coeliac disease; email interviews; thematic analysis

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Introduction

In today’s internet age, people attend to the information they encounter on social media, and seeking and sharing health-related information is common practice [1-3]. In situations where there is the possibility of negative health consequences it is important that people are acting on truthful and reliable information. Judgements about the expertise of the source are an important part of this, and it is therefore important to know what the heuristics for judging expertise are in the context of social media. One such situation with potential negative consequences to health is that of food hypersensitivity – conditions associated with the need to avoid specific foods that cause adverse reactions [4]. By gaining an insight into perceptions of expertise in food hypersensitivity on social media, and from the perspective of both those living with hypersensitivity and those deemed to be expert in this area, we can further shed light on the dynamics of expertise on social media in relation to food, health and risk. A greater understanding of the factors that affect individual perceptions of expertise online may have implications for agencies and organisations that support people with health concerns.

Food Hypersensitivity

Food hypersensitivity occurs in people who suffer reproducible adverse symptoms when eating specific foods, and denotes both food allergy and non-allergic food hypersensitivity e.g., food intolerance and coeliac disease [5]. Living with food hypersensitivities involves constant risk assessments surrounding the foods one consumes. This is especially the case when eating outside the home [4, 6-8]. Those with food intolerance wish to avoid repeatable adverse reactions to foods such as bloating, constipation, vomiting and diarrhoea. Coeliac disease is an autoimmune disease caused by the immune system reacting to the protein gluten (found in the cereals wheat, barley and rye), which shares similar adverse reactions, but can have long-term consequences if undiagnosed, such as anaemia, fatigue and weight-loss. Food allergic individuals, in more severe cases, must avoid consuming allergens that could lead to anaphylaxis (associated with breathing difficulties, sudden drop in blood pressure, and which may be fatal). Given these characteristics of food hypersensitivity, this is an ideal domain within which to explore attributions of expertise on social media, since misinformation may have significant consequences. The aim of this email interview study was to explore how food hypersensitive (FH) social media users and perceived experts in food hypersensitivities on social media construct meanings around expertise. To this end, we will first consider how expertise can be defined and interpreted, how internet users seek information on social media, the cues they use to assess potential expertise and how they validate the information they encounter.

Defining Expertise

Experts typically have comprehensive and authoritative knowledge in a specific area [9]. They are well-regarded by their peers, relay accurate and reliable information, and have gained
extensive knowledge through their experience [10]. Being an expert is normally considered a good thing; to be respected or cited in relation to one’s area of expertise [11]. Expertise is largely an attribution; someone is usually considered an expert because others say so [11]. Expertise typically encompasses assessments of credibility, trustworthiness, believability and accuracy of information [12]. Expertise might be assessed through academic qualifications, years spent in a specific role, or experience [13]. The importance of experience, however, highlights how distinctions between experts and lay persons can be flexible and dynamic, for example if a lay person has experience in a certain area [14]. Expertise is contextually valuable; an individual may know a lot about specific contexts and situations (e.g., from their life experiences) but little outside of that environment [14]. Whether expertise on specific social media platforms holds true for expertise in other contexts (e.g., offline or via different platforms) is worth consideration; Sternberg and Frensch [11] note “experts in one place or one time are not necessarily considered to be experts in another place or another time” (p.195).

Seeking Information from Experts on Social Media

Seeking and sharing information are primary uses of the internet and social media [15-18]. In comparison to more traditional media, social media allows users to communicate in a reciprocal way, exchanging knowledge, sharing opinions or challenging information from others [19]. Health information-seekers can readily connect with those who share similar health concerns [20, 21]. In fact, information circulated among peers, especially those perceived to be similar, may be more influential than formal expertise [21, 22]. Social media can offer access to other people living in similar circumstances, and as a result those managing health conditions often turn to their social media peers for help, perhaps for emotional peer support e.g., from other parents of allergic children [7, 23]. This instant and supplementary access to other perspectives contrasts with information provision practices within a more formal medical setting.

Information seeking practices online can be dependent on individual characteristics or motivations of the user. Metzger and Flanagin [12] highlight how the level of accuracy an information-seeker is aiming for, their “accuracy goal” [24], will vary when using the internet. When using social media, for example, information seeking might be quite casual – where accuracy in the information is less crucial (e.g., searching for ideas on Pinterest), or purposeful – where getting the correct information in important (e.g., around a medical concern). Information in line with current beliefs tends to be noticed and valued more, with discrepant information more likely to be disregarded – even when opposing arguments are well argued and evidenced [25].

Thriving groups of specific health-concerned users exist on social media, for example diabetic users on Facebook [1], and food allergic/intolerant individuals on Twitter [26]. Those with health-concerns are sharing experiences as well as gaining independence and self-sufficiency online [3]. For people caring for loved ones, social networking platforms and forums comprising people in similar circumstances can be a source of reassurance and support [20]. However, having many “authors” of
relevant information on social media can pose difficulties for credibility assessments since the origin and development of a source can become difficult to authenticate [12]. A lack of verification systems or formal gatekeepers, and the fact that in the majority of cases any user can publish or post information online, mean that it is important to understand how people assess the credibility of the information they encounter [2, 12, 16, 27]. In light of this, we now turn to consider the cues used to assess information online. Metzger and Flanagin [12] provide a useful framework for considering the kinds of cues that could affect perceptions of expertise in terms of source, author and message assessments.

Source Assessments

In internet research to date, source has often referred to the websites that present information; ‘source’ and ‘site’ are often used interchangeably. Cues to credibility provided by the source of the information have included – design, navigability, absence of errors, links to other reputable sources (or academic citations), evidence of sponsors, or whether the site makes money from advertising or product promotion [12, 28-30]. In a review of several studies about online health information seeking, Cheever and Rokkum [31] highlight how testimonials or comments from other users upon web content are increasingly being employed to assess the credibility and veracity of online content. However, in the realm of social media, a ‘source’ is more challenging to define. It might refer to the platform user profiles are held upon (e.g., Facebook, Twitter or Instagram) – but user profiles themselves might be seen as separate sources, as they hold much of the information to be considered a site in their own right (e.g., their own web-address, content and layout). Research around website assessments of credibility are likely to relate to certain sources such as blogs, but the multi-dimensional nature of social media does not translate so easily: a platform that might be considered credible by users may not necessarily always contain credible sources of information although familiarity with a specific platform may give a user better tools to make assessments about the information or users within [32, 33].

Author Assessments

Certain characteristics of the authors of online material can help other users assess the expertise of the published information. Metzger and Flanagin [12] highlight factors such as the author’s qualifications, reputation or professional association, available contact information, and lack of commercial motives. Social media allows us to make quite detailed judgements about individuals we encounter as users leave traces of their online activity. For example, having many followers on one’s social media accounts, or having forum answers ranked highly by other members could be potential signals of expertise [34]. Similarly, the reactions of others may have some bearing on how individuals judge the expertise and reputation of social media accounts; shares, retweets, comments, and likes can be used as indicators to affirm how others see sources of information online [34, 35].
Often in the absence of an official or qualified source, users with experiential knowledge or “situated understandings” may be mobilised to offer additional insights on an issue [36]. People with long term illnesses may become expert in their particular condition based on experience and specific contexts that relate to their health concern [14]. Cues relating to shared and lived experience can lead to a sense of collective trust. For example, parents of newly diagnosed food allergic children were seen drawing on the expertise of other parents they knew had gone through the same sorts of issues [23]. In another example, users of a multiple sclerosis (MS) support forum were seen to share experiences and treatments in addition to (what was considered) static online advice monitored by the professional MS bodies [37].

Message Assessments

There are a range of cues that may be utilised to infer the credibility of the online content: clarity of writing, accuracy, presence of bias, recency of information, and supporting evidence [12, 28-30]. In the realm of health information online, the use of medical discourse holds high social status and legitimacy [see 38], increases a user’s social credibility and is often a cue to expertise [38]. Furthermore, employing community terminology (such as abbreviations and acronyms), as well as presenting information as factual are also ways of performing expertise [39-41]. Cues of a social nature that are attached to social media posts, such as comments, likes and shares are likely to play a significant role in how users make message assessments, for example whether they accept or trust the information provided, or wish to participate in the discussion themselves [31, 35, 42].

Research Objective

In this study, we investigate how users construct meanings around expertise on social media in the area of food hypersensitivity. We explore the construction of expertise from two user-perspectives; 1) social media users who are FH or parents of FH children, and 2) perceived experts in food hypersensitivities within the FH social media community.

Method

Design

In total, 13 email interviews were conducted with 8 FH adults/parents of FH children who use social media (hereafter referred to as FH participants), and 5 perceived experts in food hypersensitivity on social media. Given the focus of the study, we knew participants were confident to engage online; social media users are likely to be technologically able, and access to the internet was not an issue. Email interview techniques were chosen here as they are particularly appropriate when participants are asked about something that they are unlikely to have explicitly considered before, or that may require conveying pasts experiences or memories [43, 44]. The approach gives participants time to contemplate questions; we were able to explicitly ask participants to consider their responses before replying, as well as provide examples from their own social media activities if it helped them get their point across or jog their memory. The ability to review responses sets this approach apart
from many other forms of qualitative data collection, and can provide more articulate responses and richer, more focussed data [44].

Participants

Two groups of interview participants were recruited. One consisted of FH social media users who identified potential experts in food hypersensitivity within their social media networks. This sample of users had taken part in a previous survey and had given permission to be re-contacted for this follow-up study [4]. 14 FH social media users were invited to participate in the study; 8 took part. Demographic characteristics can be seen for the FH participants in Table 1. Another sample comprised of users identified by the FH participants as experts in relation to food hypersensitivity. From respondents on the previous FH survey, 98 potential experts were identified; this list contained multiple duplicates, and following inclusion criteria for accounts managed by individuals (as opposed to larger organisations), and those contactable through social media or public email addresses, a list of 30 potential experts was created. 16 users from this list were randomly selected and invited to participate; 5 took part. The professions and backgrounds of experts varied, comprising a health journalist and writer, food policy official, FH travel writer, social media discussion group moderator, and FH recipe blogger. There were four female experts and one male expert.

Table 1. Demographic characteristics for FH participants

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<td>FH Adults</td>
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<td>Parents of FH children</td>
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<td>Diagnosis</td>
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<td>Allergy</td>
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<td>Coeliac Disease</td>
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<td>Speed of reaction</td>
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<td>Immediate</td>
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<td>24 hours +</td>
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<td>Reaction causing allergen*</td>
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<td>Cow’s milk</td>
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<td>Nuts</td>
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<td>Eggs</td>
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<td>Gluten</td>
<td>3</td>
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<td>Peanuts</td>
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* FH adult or child may experience reactions from more than 1 allergen.
Materials

Email interview schedules covered questions relating to typical use of social media, and aspects of accounts that may be considered as cues to expertise (or lack of expertise). Questions were informed by the literature and were checked and clarified with the research team and other colleagues in order to minimise the possibility that participants would require clarification or explanation for participants, which would have unnecessarily increased the number of email exchanges. FH participants were asked questions around their reasons for highlighting specific users as expert. Questions to experts asked participants to reflect on their own expertise and their thoughts on being perceived as expert by others users. The schedules were intended as guides to the interview structure with a degree of question flexibility for follow-ups on relevant information. Separate email invitations and consent forms were developed for each group.

Procedure

After participants agreed to take part in the study and provided informed consent, participants were emailed the first set of questions. Like face-to-face interviews, subsequent questions followed-up aspects of previous responses and asked for elaboration or further explanation, as well as providing the next schedule questions. On completion, a final debriefing email was sent to thank participants for taking part, and to give further information about the study. Due to the longer duration of email interviews, and time taken by participants to type responses, a £20 Amazon voucher was given to interviewees as compensation for their time and to thank them for participating. On average, there were five email exchanges (i.e., email sent and responded to) with each participant; a minimum of three and maximum of seven. Typically, each interview email included two or three questions (with probes) for participants to respond to. Email interactions were anonymised and saved as Microsoft Word documents to facilitate analysis. Pseudonyms replaced names of individuals referred to in the interviews. Names of organisations were retained. Participants were able to use their preferred internet-enabled device to respond, and at a time and place that suited them.

Ethics

To give consent, participants were asked to type their name and date in the final section of the email information sheet to confirm they understood the study information. An email interview approach itself can resolve some ethical considerations associated with typical face-to-face interviews; participants must actively click to send responses, and this arguably acts as a second phase of consent – the risk of participants inadvertently sharing something is much lower. Data security and confidentiality remained paramount. Data was stored on secure password-protected university servers, and names or associations linked to participants were removed from transcripts. Approval to contact participants from a previous study was granted approval by the University of Bath ethics committee (reference: 16-146), approval for this project was also granted by the same committee (reference: 17-004).
Analysis

An in-depth qualitative thematic analysis was conducted, following the guidelines set out by Braun and Clarke [45, 46]. Early stages of analysis featured thorough familiarisation with dataset content and development of initial codes (e.g. through annotation of interesting elements relevant to the research questions). Following initial descriptive first-order coding, codes were grouped into more specific/related second-order codes, which were used to develop overall themes. Final themes were reviewed and refined to ensure that they appropriately explained their content, and considered as much of the data as possible. The number of interviews analysed would be considered appropriate in line with typical email interview samples [see 47]. Guest et al [48] note when coding for overarching themes, a sample of six interviews can be sufficient to enable development of meaningful themes and beneficial interpretations. The homogeneity of our sample (the FH-concerned) and clear aims surrounding perceptions (of expertise) further support the suitability of our sample size [48].

Findings

In outlining findings, we discuss observations across and within groups in order to develop a clear narrative that highlights associations and overarching concepts relating to perceptions of expertise in food hypersensitivity on social media. In quoting from FH participants (P1-8), FH demographic information is highlighted: FH ‘Adult’ or ‘Parent’ of a FH child; sensitivity as ‘Allergy’ or ‘Coeliac’. Perceived expert participants are denoted by E1-5. Five main themes were identified in the data: 1) advice surrounding diagnosis, 2) expertise acquired through lived experience, 3) discerning traditional expertise online, 4) social validation of FH information, and 5) cues to expertise in social media content.

1. Advice Surrounding Diagnosis

One prominent theme related to the way in which social media played a role in providing information surrounding FH diagnosis, primarily following diagnosis. Here the locales of expertise begin to be defined in the data, such as traditional medical expertise required before and at diagnosis, and expertise in living with food hypersensitivity thereafter. The recently diagnosed were seen as having a strong desire to learn as much as possible at a time of perceived vulnerability; when it was important to find information that could be trusted:

*I think people new to the world of allergy struggle to see what is correct and what isn't*  
(P8-Adult-Allergy)

Participants spoke about personal experience as well as the experiences of others. Information that related to the everyday experience of living with food hypersensitivity was needed and valued at the time of diagnosis. Social media was a place the newly diagnosed could find those with plenty of experience living with their condition:

*I’ve recently met some mums who have just started out on their CMPA1 journey and I’ve recommended these groups to them. They’ve found them so useful … such a shame dieticians

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1 CMPA is an abbreviation for cow’s milk protein allergy
aren't signposting people to these useful groups or NHS trusts setting up their own! (P1-Parent-Allergy)

Individuals were drawn to forums and discussions related to their particular allergen concern, and spoke about using information gathered online to supplement the information formally conveyed to them at diagnosis. Participants gave examples of the information they sought, such as appropriate food product choices, recipes and advice on eating-out, travelling, or caring for children with allergies when at school/nursery. Traditional expertise appeared to be relevant and primarily located at the time of diagnosis, and seen to provide initial guidance only:

However, my personal experience … is you get your diagnosis, you go away with your list of foods and your left to it. Yes you have a follow up appointment with the dietician 6 months after and can call for advice. But I feel you are just left to work the rest out (P1-P-Al-CM,E)

One participant was keen to highlight how the National Health Service (NHS) support after diagnosis was more child/parent-focussed, and that additional support on social media was useful for adult patients:

[The Facebook group] provides … support to those newly diagnosed especially adults. As children have more support than adults with these allergies it’s hard to get the adult point of view (P8-Adult-Allergy)

These issues were also picked up by the perceived expert sample, who also highlighted the issue of limited support post-diagnosis as well as further emphasising the vulnerability of newly diagnosed individuals when seeking FH information:

Those coming fresh to social media looking for answers after getting short shrift from their GP etc. are more likely to fall into the trap laid by self-styled experts (E2)

Perceived experts expressed a broader concern that those newly diagnosed and new to the FH information exchanged on social media were at risk of misplacing trust, particularly when it concerned medical information relating to diagnosis:

I fear that some ‘allergy mums’ look to other ‘allergy mums’ for expert advice – instead of just restricting themselves to seeking emotional support/food product advice e.g. when such allergy mums have used an unorthodox allergy test (e.g. IgG testing) and then promote it to other mums on an ‘it worked for us’ basis – alarm bells ring (E1)

Overall, participants highlighted how traditional expertise from the medical profession was associated (and best placed) at diagnosis, but information about living with food hypersensitivity was often needed to supplement this. Expertise from those with experience was required and available through social media.

2. Expertise Acquired through Lived Experience

The concept of expertise developing through experience featured strongly for both FH participants and perceived experts. Their view was that if you have lived with (or cared for someone with) food hypersensitivity for a long time then you are likely to have become expert in managing the condition, and therefore are more likely to be considered expert by others if they are aware of this:

Having easy access to people who have already been through it who share this knowledge may mean people are seen to be ‘expert’ sources of information (P5-Adult-Coeliac)
Both FH participants and perceived experts commented on how advice and support from the patient or parent perspective is a different kind of expertise, associated with day-to-day living with food hypersensitivity and not readily available from one’s physician. This might include advice around managing a child’s allergy at school, appropriate places to eat out, or guidance on eating-out in other countries. Users mentioned how social media can fill a gap in support provided by health professionals and highlighted how certain types of expertise require specific kinds of credentials. In terms of diagnosis and medical concerns – health professionals serve as the best sources of expertise, but when it comes to managing the everyday challenges of food hypersensitivity those who have been through it hold additional and valuable expertise. Two quotes illustrate this concept:

You can't get more expert than someone who appreciates and lives with the strains, stresses, worries of an allergy; and I feel that Facebook support groups provide this. Medical professionals know the "medical" bit but they don't deal with the day to day living (P1-Parent-Allergy)

I don't claim to be an expert on allergy but after almost ten years I'm pretty expert on parenting a child with allergies! (E4)

Although the perceived benefits of information from those with experience was clear, there was also an appreciation that the information they provided was a function of differences in the ways that FH individuals approach their condition, or differences in their conditions (e.g., reaction severity, or types of allergy/intolerance). For example, those who have lived with a food hypersensitivity for several years and feel confident in their lack of reaction to certain food products may be less concerned about 'may contain' labelling or cross-contamination, compared to an adult or parent just starting out on managing their sensitivity:

That there is a spectrum of people with different risk appetites. From those who like me eat may contain to those who are much more cautious (P8-Adult-Allergy)

Variations in the way some people may take 'risks' could create some confusion particularly to those who have just been diagnosed (P5-Adult-Coeliac)

Similarly there was some acknowledgement that the experience of different reactions to the same allergen could be associated with information that was possibly inappropriate. One perceived expert – an experienced FH mother and not a medical professional – demarcated the boundaries of her expertise explaining that she would avoid handing-out health advice and rather point people in the direction of medical professionals:

I share my own experiences but never give medical advice - I always refer to a doctor or official resource … I would say I am an 'expert' parent in the sense that I have experience managing allergies day-to-day, and can advise on issues such as handling school and nursery (E2)

Another expert praised FH parents on social media for recognising that their knowledge and experience may not always represent all FH cases:

Some allergy mums/mum bloggers are absolutely fantastic – and understand science, and that their personal experience and case scenario cannot and does not represent the wider picture (E1)
3. Discerning Traditional Expertise Online

Although FH experience expertise was highly valued, there was a simultaneous recognition that one marker of expertise online was being a professional (often a medical professional). Some referred to experts they had met in an offline capacity (e.g., at conferences or events) or to the expert being their own or their child’s doctor or nurse. Even the perceived experts considered this traditional expertise as the gold standard in food hypersensitivity online. In this context, there was a range of indications of professional expertise:

*Qualifications are important. I also look for those who are sceptical/avoid promoting unproven or discredited theories, tests or ideas (E1)*

Participants highlighted how using an official title or job description online increased the likelihood of attributions of expertise. Claims of qualifications were also unproblematically equated with having expertise. Those who working or associated with experts within the field were also considered more credible:

*To consider them an expert they would either be working within the field of allergy or involved in research (P4-Parent-Allergy)*

Thus, traditional sources of expertise formed a benchmark against which users sought to discern the credibility of social media information:

*When I look for advice I tend to compare it to other sources especially if it concerns a topic I am unfamiliar with. I use the NHS and Coeliac UK websites and printed materials as a basis to assess the information (P6-Adult-Coeliac)*

Benchmarking against traditional expertise was also evident in relation to social media information. This was seen to require greater scrutiny that could be done in relation to traditional materials which were more likely to have been checked and evidenced with scientific backing and/or recommended by qualified health professionals:

*Social media gives a platform to people who can say almost anything they like. When I was first diagnosed … I noticed there were a lot of contradictory information. As I was given an information pack by the NHS I used this as level 1 point of reference and compared what I found on the internet to this so I could sort the facts from the hearsay (P6-Adult-Coeliac)*

*In a hospital setting you are less on guard for erroneous information. Social media you take more time on trusting people’s opinions. That you have your guard up for bad advice. I think it’s to do with the dodgy advice you sometimes see. That you have to have more of a filter on what you take and what you leave (P8-Adult-Allergy)*

Thus there were two pillars that buttressed those seeking credible information on social media: 1) information about the experience of living with food hypersensitivity, and 2) medical information. Social media support post-diagnosis was viewed as legitimately sought and provided in relation to experience of living with food hypersensitivity; though it was recognised by some at least that this may be inappropriate since experiences of food hypersensitivity varied greatly. The interviews showed reticence both to seek and give FH medical information on social media alongside concern about implications of not being reticent.
4. Social Validation of FH Information

Both FH and expert participants saw social media as containing and facilitating a supportive FH community; where users and the information they shared would be subject to a process of social validation that led to confidence in expertise and credibility.

News, research outputs or articles, as well as product recalls, recipes and advice on FH parenting was shared:

I found these Facebook groups my lifeline. I use them to ask questions/advice allergy related to other parents/carers, people (including myself) post images of “safe” food finds they/ I have found, we post petitions regarding allergies, studies regarding allergies and anything allergy related really (P1-Parent-Allergy)

#AllergyHour, a weekly hourly discussion on Twitter around allergy matters, was considered to engender a sense of trust and a location of shared knowledge and experience:

I often join in with … #allergyhour where you can ask anything allergy-related and someone will have experience to share. There is a tremendous support network on Twitter. We very much see ourselves as an allergy family. (E4)

Many of the members interacting within the community were considered as well-known to one another and this increased trust in the information being shared in that it was assumed members of the community would pick up any misinformation. If information was shared without challenge, disagreement or interrogation, this was considered as a validation and a product of vetting. A valued attribute of social media was being able to draw on a pool of advisors that could be trusted to weed-out misinformation:

People like the collectiveness. They, subconsciously perhaps, believe if lots of other people are following/believing someone there is safety in numbers and it must be true (P3-Parent-Allergy)

From the perspective of the perceived experts, the public nature of social media made them more able to respond to and correct inaccurate or misleading information:

At other times, it will be a conversation in response to an issue or an article. (E2)
I think the perception is due to the fact I respond to tweets, correct factual errors, I am quite vocal (E3)

Twitter communities and Facebook groups were seen to create a circle of trust, as well as a location of knowledge. Members of these social media communities were able to validate information or user-credibility if it had been vetted or accepted by other trusted users.

5. Cues to Expertise in Social Media Content

The content of social media also provided cues to the expertise of the information source. From the perspective of perceived experts, both the relevance and novelty of their social media communications served as cues to their expert status:

I don’t tend to share material or news which is already ‘doing the rounds’ or has been shared widely already by others – I’ll trust that my followers will already have seen it (E1)

Expert information needed to be factually correct and the source identified e.g., from research journals, official publications, or trusted sources:
I share from credible sources, but in all cases I read the article or link on the Tweet to make sure I am reposting something which is accurate, share interesting materials/facts/research (E3)

I like professionals with a passion for allergy who share evidence-based practice and keep updated on current research. (E4)

Those who did not give evidence for their claims, or were promoting information users felt had no medical/research backing, was a clear marker for lack of credibility:

[Researcher: In what way might you consider someone on social media as non-expert?]

People who claim they cured their allergy with simple lifestyle changes such as buying a salt lamp. Or people pedalling Vega tests which have no medical backing whatsoever (P4-Parent-Allergy)

People who don't know what IgE mediated allergy is or do not know the difference between lactose intolerance or CMPA. People who think someone with CMPA can have a little diary and be okay (P3-Parent-Allergy)

Whether users were seen to give appropriate and informative responses to queries was also a factor in judging expertise. However, drawing on and deferring to the expertise of other users and being open to feedback were also seen as markers of expertise:

I also look for non-qualified people who defer to qualified people – always a good sign (E1)

The two bloggers I referred to in my previous responses tend to offer advice and welcome feedback rather than making statements they believe to be fact (P6-Adult-Coeliac)

The option in many social media platforms to tag other users within posts and thus draw them into discussion, can support these practices.

Participants noted how connections with key FH stakeholders served to warrant credibility or expertise. These connections included relationships with associated charities, businesses or organisations:

[The Facebook group moderator] talks directly to companies and gains assurances that certain products are completely nut free. This has led to the Facebook group being very popular as lots of people value [their] knowledge and the contacts [they] have (P2-Adult-Allergy)

A mark of trusted expertise was brokering the content supplied by relevant external stakeholders, or to put this another way, the credibility of the content was enhanced when it was mediated by a trusted expert. However, there was also a view that people may attempt to align themselves with the official profiles of organisations in order to project a greater sense of legitimacy. The ability to include and link to others affords users who may not have expertise the possibility of enhancing their presentation of authenticity:

The individuals have yet to demonstrate themselves in the arena, the audience have yet to form a view on whether they are credible and borrowing from the reputation of others can ease this (E3)

Reputations for expertise were enhanced by virtue of the synergies between events, activities and relationships in the on and offline FH world. One expert noted how their presence as part of the organisation they worked for was likely to promote a sense of credible expertise:

My position within [the organisation], I think it makes me a credible expert (E3)
Another, alluded to how being known for their offline writing activities about food hypersensitivity was likely to be associated with perceived expertise; though the use of scare quotes for ‘expertise’ seems to indicate a recognition that this is one manifestation of expertise that may not necessarily be considered so by others:

*Obviously in researching and writing about these subjects for almost 20 years I have come to develop a particular ‘expertise’ in them (or aspects of them) (E1)*

We have seen that the affordances of social media - for example sending messages linking to other users - provided cues contributing to judgements about expertise. However as noted earlier simply sharing, liking or retweeting posts was enough to warrant claims of expertise:

*I look for accounts that interact with other people… I don’t have a lot of time for accounts that only retweet other people’s tweets (E4)*

The number of friends or followers a user has, visible to observers on Facebook and Twitter, can influence how others perceive their credibility. Linking back to the role of social validation, large numbers of following can imply that other FH users think they are worth following, thus serving as a cue to being a trusted expert:

*I think they became to be seen as an expert by blogging originally and then creating the website and Facebook group. This has then attracted a large number of followers and so then people consider it as expert/knowledgeable simply because of the number of followers and it becomes self-fulfilling (P3-Parent-Allergy)*

Others rued the possibility that people attended to others on the basis of the size of their following.

*I fear a lot of people equate lots of followers with knowledge or expertise (E4)*

*There is definitely fake authority imbued by someone who has tens of thousands of followers - for instance some celebrities or self-styled food gurus. Social media makes it easier for these people to have a voice. (E2)*

**Discussion**

In exploring how those managing food hypersensitivity and perceived experts constructed meanings around expertise, we identified five themes. The first related to seeking advice surrounding the time of diagnosis; both FH participants and experts here were aware of the risks misinformation posed to those recently diagnosed. The second and third themes were associated with the location of expertise; either acquired through managing food hypersensitivity, or being valued as an expert in a more traditional manner e.g., through qualifications and professional knowledge. Both forms of expertise were valued, traditional expertise was most often unchallenged and taken-for-granted. The fourth theme demonstrated how FH social media information typically goes through a process of social validation; information is authenticated by other users through various affordances of social media (e.g., liking, sharing, commenting, replying). Finally, the fifth theme highlighted specific cues to expertise in social media content. Users were seen to attend to various markers of expertise in the FH realm, such as evidenced posts, connections with stakeholders and examples of deferring to other FH experts.
A key finding related to the concerns felt around the time of diagnosis for FH individuals and parents. Several participants across both FH participants and experts emphasised the importance of patients being able to get access to correct information, and that this was not always guaranteed when using social media. It is a paradox that social media provides important perspectives post-diagnosis about managing the condition – perspectives that are not available through traditional medical channels often instrumental in diagnosis – and yet they cannot be unproblematically taken on-board – cues to expertise have to be found and interpreted. A medical background or qualification was a taken-for-granted factor in defining expertise in the FH area. However, in an absence of expert knowledge we see experienced FH patients/carers offering advice through social media about the day-to-day management of avoiding allergens. Research looking into internet use in patient-practitioner relationships has suggested that it would be beneficial for both parties if physicians used their knowledge to guide patients to approved sources [49], and this may help reduce anxieties surrounding users taking advice that may not correspond with medical opinion [50].

Social media was seen as providing a ‘treasure-trove’ of non-professional expertise [37], and highlighted the value placed on experiential knowledge or “situated understandings” [36]. However, participants were often clear to stress that they would frequently take information read on social media and consider it in-line with more official (e.g., NHS) materials, and their own knowledge. It is not simply the case that social media information is considered as credible as more traditional media sources [12]; social media information sometimes was used as a source on-top of, and to complement, traditional materials. This finding has also been seen in parents of children recently diagnosed with food allergy; parents wanted to quickly improve their food allergy health literacy, and utilised websites, journal articles, and online support groups to do so [23]. This time-dependent need for finer assessments of credibility and expertise is something we do not feel has been clearly demonstrated in the literature. Nonetheless, Metzger and Flanagin’s [12] observations around receiver characteristics such as past experience, reliance and prior knowledge are associated with this, but the focus here is more on experiences as a patient with food hypersensitivity as opposed to experience as a social media user per se.

Interview discussions demonstrated clearly-defined groups of FH users on various social media platforms (e.g., Twitter discussion participants, or members of Facebook support groups); supportive groups similar in nature to those seen by Broome et al [23], Greene et al [1] and Hamshaw et al [26]. Groups supported fellow users when information or advice was needed, and drawing on and deferring to the knowledge of others (even when considered an expert yourself) was considered a highly-regarded trait in someone supporting the community. A similar finding is presented by Lovatt et al [33], where use of caveats relating to one’s level of expertise was key to the development of trust in online breast cancer forums. Trusted familiar users (either traditional or experience experts) on social media were imbued with the ability to convey social validation, such that their reactions to other users acted as a benchmark of status or believability. In a similar way to Metzger et al’s [25] findings around the use of social information pooling (such as reliance on testimonials, reviews or ratings), social validation was conveyed here in FH users liking, sharing or commenting on posted
messages, which demonstrates a form of rating for the social media post itself. However, as suggested by the name, ‘social’ media perceptions of credibility can involve a much more social assessment – users can partake in two-way interactions, question authors of original content and ask advice of other trusted users. Thus, highlighting variance with typical observations relating to online credibility assessments associated with sources that are more static. The credibility of expert knowledge was also visible within social media sources such as Twitter discussion groups like #AllergyHour and Facebook support groups. Again, a factor that sets social media cues to expertise apart from those associated with typical web-sources, was the level of engagement expected to validate expertise e.g., by taking part in discussions, challenging misinformation and being available to comment – also noted as encouraging trust online by Lovatt et al [33]. This further highlights an affordance of social media, and a different way that expertise can be assessed online in a more hands-on fashion, due to communication capabilities of these platforms.

When considering research around the more static forms of online media such as websites and assessments of their credibility, findings may relate to social media, but the multi-dimensional nature of these platforms was not always seen to translate so easily here. Frameworks relevant to assessments of online information, such as those presented by Metzger and Flanagin [12] and Fogg et al [28] must now move further to account for the more complex nature of social media information. Users are assessing information that blurs the boundaries between source, message and author – does one assess the post itself or the platform it resides upon? Does the post come directly from the poster or has it been ‘shared’ or quoted from elsewhere? Although our findings highlight many credibility cues suggested by frameworks, such as information recency, accuracy, and relevance, as well as author qualifications/credentials, and absence of commercial motives – it is clear that social media does not fit these moulds well. Furthermore, platforms like Twitter offer users regular real-time updates (through hashtags) on matters of interest, but due to the limited (though recently extended) character capacity for tweets, credibility assessments are more challenging. Social media posts often do not have the space to give as much detail as a website might to suggest expertise (e.g., references, evidence, associations with reputable organisations). Recent research has shown that links to other sources of evidence in social media posts can promote a sense of credibility [18], however the extent to which this can be considered the same as references or evidence cited within online sources needs to be considered.

Limitations

The interview sample was only a small number of social media users. However, it did consist of an array of FH concerns, from FH adults, parents of FH children, allergic and coeliac, as well as those who make a living around food hypersensitivity (e.g., writing about it, or working for support organisations). Several potential experts in the healthcare sector on social media were targeted during
recruitment, and although three individuals did give informed consent, they did not respond during our interview timescale. Thus, we were not able to consider this perspective.

The email interview approach gave participants a high level of control over their data; they could consider replies, gather information, and add to previous responses. This reflection time slows down the research process, and the lack of face-to-face contact means participants can more easily ignore or forget about questions. Reminders proved useful in some cases, but it was difficult to know when to start and stop prompting. Compared to face-to-face interviews, developing rapport with participants was more challenging due to lack of social cues. Participants had their own communication styles and we needed to adapt to these. Creating an interview schedule also presented additional issues. There is little opportunity to prompt participants, and confusing questions might lead to withdrawal. It was essential that questions were clear and likely to promote rich detailed responses. We also encouraged participants to be as detailed in their responses as possible. Thus, email and face-to-face interviews need to be viewed as distinct research approaches, each requiring a slightly different set of skills.

Conclusion

This study has begun to unpick factors associated with constructions of expertise on social media, specifically in the area of food hypersensitivity. Traditional perceptions of expertise, such as formal qualifications, remain a taken-for-granted sign of expertise; however, it was acknowledged that those living with food hypersensitivity could be seen as expert through their lived-experience. There appear to be several cues to FH expertise on social media, including those typically anticipated such as factual and appropriate information, and evidence. The two-directional (‘social’) nature of social media highlighted how social validation cues, such as likes, shares, follows, comments, and communication with other reputable sources or users could aid in assessments of expertise in a different way to more static forms of online media.

Future work would benefit from exploring constructions around expertise on social media from the perspective of those considered traditional experts, and how experiential expertise is considered here. This study suggests that more support may be needed in relation to living with food hypersensitivity – especially following diagnosis. Exploring approaches that encourage the mutual support of traditional and experienced patients/carers in managing health-concerns (e.g., online) could prove valuable. Understanding the processes involved in social media information assessments could help support groups to design interventions to improve the information evaluation skills of social media users; such applications could prove vital as people increasingly turn to online sources for help and support in relation to their health.

Participants who had given informed consent and sent the first phase of interview questions were sent a reminder email if responses were not received within a reasonable timeframe (approximately one-two weeks). Further reminders were not sent to avoid harassing participants who may have decided they no longer wished to take part in the email interview.
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Conflicts of Interest

None declared.

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Abbreviations

FH: food hypersensitivity