

Design of Software to Support Families with Food-Allergic and Food-Intolerant Children

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ABSTRACT

Childhood food allergies and intolerances are increasing in prevalence and can impact heavily on the health-related quality of life of children, in addition to placing a significant burden on parents and other caregivers. This paper reports on a multi-part research study in which we examined current use and future opportunities for software to support families dealing with childhood food allergies and intolerances. In the first part of our study, we conducted an online parent questionnaire and interviews with clinicians, in order to understand the challenges faced by families with food-allergic and food-intolerant children, as well as the current levels of technology use by these families. Based on the outcomes, we focused our subsequent attention on the design of food diary software to support the care of children with non-IgE adverse food reactions, which are extremely challenging to diagnose and monitor. We conducted a week-long food diary study and follow-up design workshop, in order to evaluate food diary compliance and to elicit design inspiration for a new food diary application.

Author Keywords

Mobile health (mHealth), food allergy, food intolerance, child health.

ACM Classification Keywords

J.3. Computer Applications: Life and Medical Sciences (Health). H.5.2. Information Interfaces and Presentation: User Interfaces (User-Centered Design).

INTRODUCTION

The prevalence of allergic diseases, including anaphylaxis, food allergy, asthma and eczema, is increasing worldwide. Globally, 200-250 million people are estimated to suffer from food allergies (Pawankar et al., 2012), and children are affected disproportionately in terms of both the growing prevalence and severity of food allergy. Australia has one of the highest rates of childhood food allergy in the world, with a recent Melbourne study finding that 10% of one year olds “had

challenge-proven IgE-mediated food allergy to one of the common allergenic foods of infancy” (Osborne et al., 2011). In general, it is thought that food allergies affect approximately 5-8% of toddlers, and 1-2% of adults (Fiocchi et al., 2011).

The growing rates of food allergy impart a significant burden, not only on those affected, but also on their families and the broader community.

In young children, allergies can disrupt sleep, learning, memory and behaviour (Access Economics, 2007). Severe cases (anaphylaxis) can be fatal. The impact of a diagnosis of food allergy on the quality of life of children and their parents is substantial: for example, multiple studies have found that food allergy has a greater impact on health-related quality of life (HRQL) than insulin-dependent diabetes (Flokstra-de Blok et al., 2010; Avery et al., 2003).

The impacts on parents can be wide-ranging. For instance, parents “are more likely to stop working, reduce their work hours, or incur other financial hardships and to limit overseas vacations” (compared to parents of non-allergic children) (Fiocchi et al., 2011).

The economic costs of food allergy are substantial but difficult to quantify. One study estimated that the cost of food-induced allergic reactions and anaphylaxis in the United States in 2007 was approximately half a billion U.S. dollars, of which direct medical costs amounted to \$307 million, and indirect costs, such as lost earnings, amounted to \$203 million (Patel et al., 2011).

The above discussion focuses primarily on those with IgE-mediated allergy, sometimes referred to as “true allergy”. However, there is also a sizable and growing population, including children, affected by other types of food hypersensitivity and food protein-induced gastrointestinal diseases, including food protein-induced enterocolitis syndrome (FPIES), eosinophilic gastroenteritis and related disorders (Heine, 2004). Unlike acute IgE-mediated allergic reactions (“true allergy”), gastrointestinal allergic reactions generally evolve slowly and are extremely challenging to identify. Diagnostic tools for this type of reaction include atopic patch testing (Niggemann et al., 2000) and gastrointestinal biopsies (Heine, 2004); however, definitive diagnosis commonly relies on oral food challenges consisting of “gradual feeding of the test food under close observation” (Rancé et al., 2009).

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Children with food hypersensitivity and food protein-induced gastrointestinal diseases can potentially react to many different foods, and therefore may need to undertake large numbers of oral food challenges. Furthermore, children can outgrow food allergies and intolerances, which makes regular re-evaluation of problem foods necessary. These two factors imply protracted periods of challenging foods: for some children, spanning several years. Less is known about the HRQL impacts of non-IgE gastrointestinal allergic diseases than the HRQL implications of “true allergy”; however, it is clear that restrictive diets and long periods of challenging foods can be extremely stressful for both children and their families.

Mobile, social and pervasive computing technologies all arguably carry the potential to improve healthcare outcomes, HRQL and stresses within healthcare systems, provided they are applied appropriately and with an understanding of the needs of patients and their families, caregivers and clinicians. Our research is concerned with the design of software to support families with food-allergic and food-intolerant children, with particular focus on the needs of those with slowly evolving, non-IgE food hypersensitivities, which are generally the most challenging to understand and diagnose.

In this paper, we present the results of a multi-part research study consisting of:

- an online questionnaire probing the demographics, perceived challenges, stress levels, and current levels of technology use by families with food-allergic and food-intolerant children;
- open-ended interviews with clinicians; and
- a week-long food diary study and follow-up design workshop focusing on the needs of families dealing with ongoing food challenges for non-IgE food hypersensitivities.

PARENT QUESTIONNAIRE

We conducted an online survey of Australian parents and caregivers from late December 2011 to early January 2012. The survey was open to any Australian adult regularly providing care for one or more children with any type of food hypersensitivity, including food allergy/anaphylaxis, food intolerance, coeliac disease, FPIES and eosinophilic disorders.

As we were interested in the demographics and habits of those currently using online resources, we recruited participants through Facebook, Twitter and a well-known Australian discussion forum for parents¹. For a broader demographic, we will recruit a second set of survey participants through paediatric allergy and gastroenterology clinics at a later stage of the research project.

¹ Essential Baby Parenting Forums:
<http://www.essentialbaby.com.au/forums/>

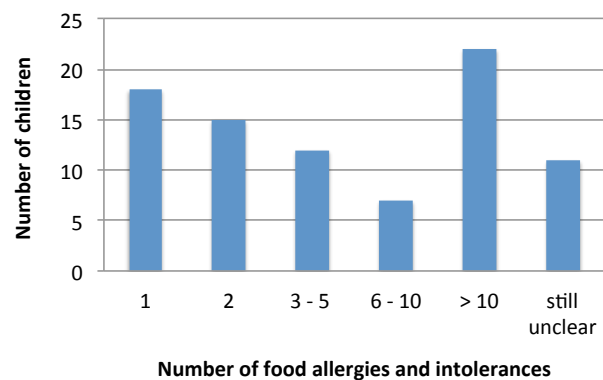


Figure 1. Number of reported food allergies and intolerances for the 85 children in the online questionnaire.

There were 56 respondents, all of whom were parents or stepparents of children with food hypersensitivities. 54 were mothers, one both a mother and stepmother, and one a father. 22 (39.3%) were caring for more than one child with food hypersensitivity. The mean length of time that the respondents had been caring for someone with food hypersensitivity, or dealing with their own food hypersensitivity, was 5.14 years.

The respondents collectively provided data about 85 children with food hypersensitivity. The majority of the children were reported to have more than one food allergy or intolerance, with 22 children (26%) reported as allergic or intolerant to more than 10 foods, as shown in Figure 1. In addition, a majority had other complicating medical conditions, the most common being eczema (64%), allergic rhinitis (44%) and asthma (34%). 28 (33%) of the children were at risk of life-threatening reactions or anaphylaxis, 11 (13%) had coeliac disease, 11 (13%) had eosinophilic disorders, and 3 (3.5%) had FPIES. The results were skewed towards particular conditions owing to the method of recruitment: for instance, we believe that the relatively large number of children in this group with eosinophilic gastroenteritis was the result of one or more respondents recruiting further survey participants through an Australian eosinophilic disorder support group.

We asked the survey respondents to rate nineteen everyday tasks on a numeric scale of difficulty, ranging from *not challenging at all* (0) to *very challenging* (5). The list of tasks was drawn from an analysis of discussion topics on online forums related to food allergies and intolerances, as well as informal discussions with a number of parents of children with food hypersensitivities. Recognising that the list was not exhaustive, we also included open-ended questions inviting survey respondents to share other pertinent information about everyday challenges.

The highest-rated challenges within the list of nineteen (i.e., the most problematic) are shown in Figure 2. The tasks with the highest mean ratings were dining out and travelling, followed by the need to educate others about food allergy or intolerance. The survey respondents also noted difficulties with gaining timely access to helpful medical specialists, which is consistent with an ongoing

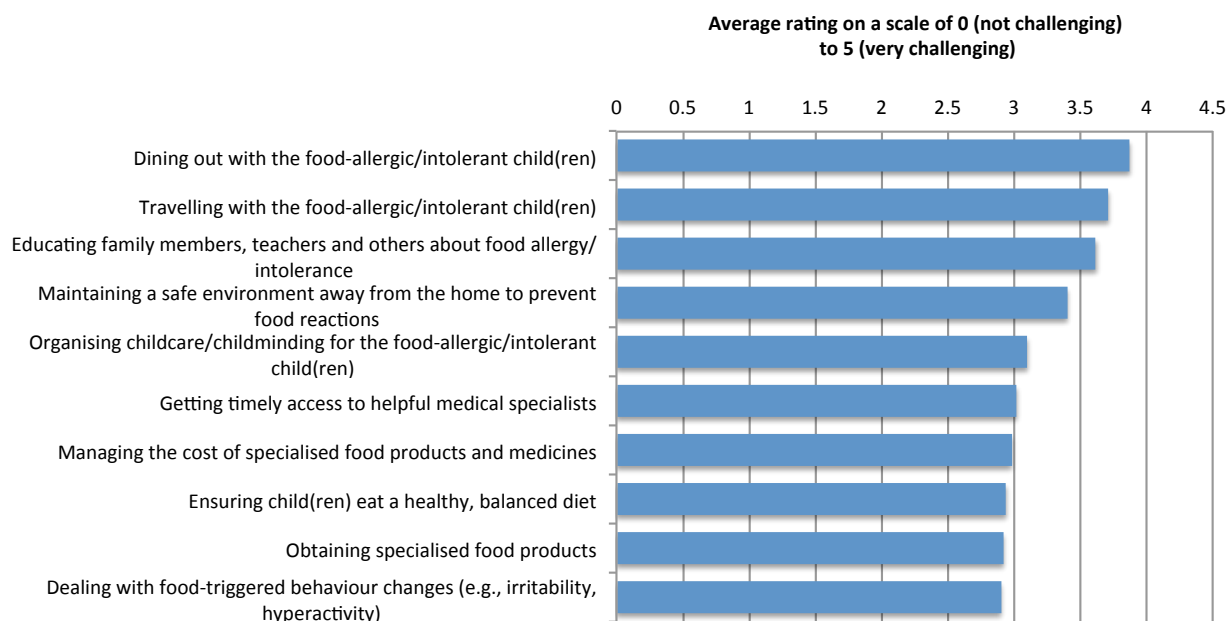


Figure 2. Top ten challenges (from a list of 19), as rated by parents in the online questionnaire.

shortage of paediatric specialists in Australia, unanticipated growth in the number of children with various types of food hypersensitivity, and increasing awareness of food allergy and intolerance.

Additional challenges cited by respondents in the open-ended questions included difficulties with: birthday parties; food labelling legislation; social isolation; explaining food restrictions to young children; food policies in schools and kindergartens; challenges in identifying and diagnosing allergies and intolerances; and challenges when children react to airborne substances or trace amounts of allergens.

We asked how often parents used a variety of online and traditional (e.g., print) resources. The most frequently used resources were: online discussion forums (used *sometimes*, *often* or *very often* by 77% of the respondents); books, such as reference books and cookbooks (75%); and allergy websites, such as the Anaphylaxis Australia² and Australasian Society of Clinical Immunology and Allergy (ASCIA)³ websites (73%). Many parents also reported sourcing recipes online, with 70% using cooking websites, at least *sometimes*, and 58% visiting recipe blogs, at least *sometimes*. 59% of parents reported using Facebook at least *sometimes* for allergy-related purposes, such as obtaining information or sharing their child's status. 6 out of 56 parents (11%) reported using allergy-related mobile apps either *sometimes*, *often*, or *very often*.

² Anaphylaxis Australia website: <http://www.allergyfacts.org.au/>

³ Australasian Society of Clinical Immunology and Allergy (ASCIA) website: <http://www.allergy.org.au/>

24 of the 64 respondents identified additional resources they would like to use, if available. These included: tools to find rural hospitals while travelling in case of life-threatening allergic reaction (n=1); online access to medical specialists (n=2); an eating out guide for those with allergies (n=4); tools to assist with identification of problem ingredients while shopping (n=3); a meal planner and recipe database (n=2); an online community based on experience and recipe sharing (n=1); and a mobile/online food and symptom diary (n=4).

When analysing the questionnaire responses, it is important to note the presence of subgroups within the respondents. The concerns of those respondents dealing only with IgE reactions ("true allergy" and anaphylaxis) are quite different from those dealing only with non-IgE food hypersensitivity; however, there is also a small group of respondents dealing with both. For the first (IgE only) group, there are fewer concerns with accurately identifying the cause of food reactions, but substantial concerns around safety for children who are at risk of anaphylaxis; having access to acute care (e.g., hospitals in remote and rural areas); and protecting children from reactions whilst in the care of others, such as relatives and school teachers. Participants in the second (non-IgE) group are more concerned with identifying elusive food reactions and maintaining accurate food and symptom diaries. However, a number of challenges, such as those concerned with eating out and travelling (the top two challenges listed in Figure 2) are common to almost all families dealing with food hypersensitivity.

INTERVIEWS WITH CLINICIANS

As well as gathering demographic and other background information from parents and caregivers, we conducted open-ended interviews with three clinicians: a paediatric

gastroenterologist at a children's hospital and two dietitians with specialties in food hypersensitivity. We focused predominantly, but not exclusively, on slowly evolving, non IgE-mediated food hypersensitivity. We were interested in gauging clinician support for mobile and web-based software designed with the combined goals of:

- recording food intake and symptoms, particularly in relation to medically-indicated oral food challenges; and
- providing sharing mechanisms for social support and exchange of information such as restaurant and recipe reviews.

Of the three clinicians we interviewed, the gastroenterologist was the most receptive. Prior to our contact with her, she had already been interested in the development of this type of software for technology-literate parents of children with food allergy and multiple food protein intolerance. She described how some parents already use camera-equipped mobile devices to diarise adverse food reactions, without a purpose-built app. Following on from our initial interview, we have developed a fruitful collaborative relationship and elicited some important clinical requirements for the software.

In the interviews with the two dietitians, we probed the current use of (paper-based) food diaries for patients with suspected food allergy or intolerance, and asked the dietitians to comment on potential benefits and problems of mobile food diary software versus paper-based diaries.

The first dietitian focused on the potential for food diary software to provide interactive content, such as access to public databases of nutritional, allergen and food chemical⁴ information for common foods. She viewed the food diary as an important tool for verifying patient compliance with a prescribed diet or assessing nutritional adequacy. She was receptive to the idea of visual content generated by users taking photographs using their mobile phones, but was concerned about assessing portion size and nutritional content via a photograph. She responded negatively to the idea of mechanisms for sharing user-generated content, such as ingredient lists or recipes, citing research showing that many people are unable to reliably read and interpret food labels.

The second dietitian provided us with richly detailed information about how she approaches a consultation with a child with suspected food allergy or intolerance. She described how she carefully evaluates both the family situation and information about the child's diet and symptoms, tailoring her recommendations accordingly. She told us that she does not use a standard food diary template for her patients, as she asks each family for different types of information and different levels of detail. She believed that some of her patient families would enthusiastically adopt food diary software, but at

the same time was concerned that it would add to the stress levels of other families. In particular, she was wary of a tool that encouraged unnecessary long-term monitoring of food and symptoms, telling us that she generally asks families to complete food and symptom diaries for only two to three days at a time.

Based on our discussions with the three clinicians, we see a role for food and symptom diary software for a particular subgroup of families, especially those dealing with conditions that require regular oral challenges over extended periods, and who are already enthusiastic technology adopters. We see the clinician playing a role in guiding families in relation to the amount of data they should collect with the tool, such that families maintain sufficient records to support high quality medical care, but are not unnecessarily burdened or stressed.

FOOD DIARY STUDY

The remainder of the research that we present in this paper (and our ongoing work) is concerned with the design, development and evaluation of software tools to support families dealing with food allergies and intolerances. As discussed in the previous section, we are predominantly interested in software that can assist with monitoring oral food challenges and enabling families to share information and provide mutual social support. Though there are a variety of mobile and web applications already available for this domain, the results of our parent questionnaire suggest that they are not yet in widespread use in Australia. Further, there is no published research on the design considerations that are specific to this area, nor on the degree of fit between what is currently available and the needs of the family and clinician.

As discussed in the previous section, paper-based food diaries are a common tool that clinicians use to investigate patients' non-IgE food hypersensitivities. We conducted a food diary study to investigate the differences in patterns of use and food diary compliance with a simple iPhone food diary application as compared to a paper-based diary. The study employed a general-purpose, off-the-shelf app in a similar vein to a technology probe (Hutchinson et al., 2003). That is, we used the app as a means to collect data about food diary compliance in real world settings; to field test an appealing app design; and to generate design inspiration for a new purpose-built food diary application for those with non-IgE food hypersensitivities (both adults and children).

Previous studies have found that compliance with food diaries and other health-related diaries is low (Mamykina et al., 2006; Stone et al., 2003). In our study we aimed to compare compliance levels with the mobile app and paper-based diaries, and to identify factors positively or negatively affecting compliance.

Study design

We recruited 22 participants who were split between two groups. Participants in the first group were asked to record all food and non-water beverages they consumed

⁴ For example, salicylate, amine and glutamate levels for those following the Royal Prince Alfred Hospital elimination diet (Swain et al., 2004).

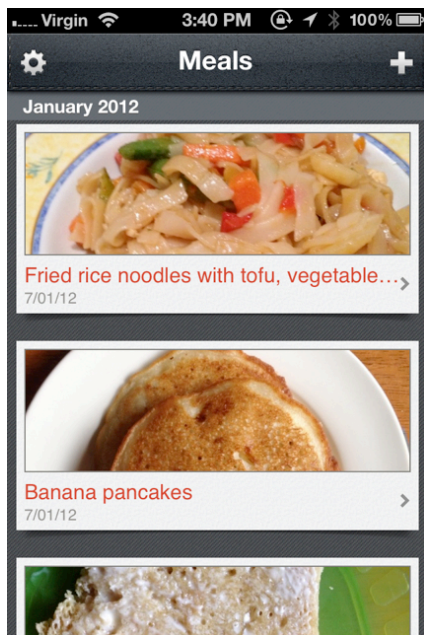


Figure 3. Meal timeline view in Evernote Food.

over a period of seven days using an iPhone app. The second group was asked to complete the same task with pen and paper, using a food diary template that we obtained from a dietitian.

Four of the 22 participants were parents who responded to our online questionnaire, lived locally, and indicated a willingness to be involved further in our research study. The remaining participants were recruited through our personal and professional networks. Not all of the participants were parents. The food diary study focused on compliance rates of adults recording their own food intake, and it is anticipated that adults with food hypersensitivity will be one target group for the software that we develop. The follow-up design workshop, which we will describe later in the paper, was used in part to explore additional issues that arise within the family context and in connection with maintaining food and symptom diaries for children. We also intend to probe the issues surrounding family use of food diary software more deeply when we trial our first software prototype (developed based on the research outcomes presented in this paper) with a group of paediatric gastroenterology patients.

The iPhone application we employed in the study was Evernote Food⁵, chosen as the closest match to the software we envisaged developing later in the project. Specifically, we selected this app on the basis of its simple design, its visual approach using food photographs captured with the iPhone's camera, and its integration with popular social networking tools (Facebook and Twitter).

⁵ <http://evernote.com/food/>

Meal entries in Evernote Food consist of zero or more photographs accompanied by a title, meal notes, tags, and an optional location. Meal entries are organized into a simple scrollable timeline based on time of entry. Figure 3 shows the timeline view. The app contains no special features for those attempting to maintain a comprehensive food diary, nor for describing allergens and adverse food reactions. It is designed for a general audience: broadly, anyone who wishes to record and share memorable food experiences.

At the end of the seven days, we collected information from the participants via an online questionnaire. We also invited participants to take part in the follow-up design workshop, described later in the paper.

Analysis

The food diary study yielded useful results in three respects. First, it uncovered a broad set of challenges in everyday use, such as forgetting, incompatibilities with existing work and family routines, and social issues around the use of the app in public settings. Second, it yielded comparative data on compliance rates with the two types of food diary; hints as to why the compliance rates differed; and a corresponding set of design considerations that will inform our future work. Finally, the act of completing the food diary gave the participants a common first-hand understanding of the challenges in food diary compliance, a useful starting point for inspiring collaboration on new designs in the design workshop.

Compliance

We collected data from the study participants on how many food diary entries they made on each of the seven days. Figure 4 shows the average number of entries for each participant group on each day. There were two participants, one in each group, who gave us no data. We excluded them from the calculation of mean daily entries.

The paper diary group averaged 4.4 diary entries per day, while the Evernote Food group averaged 2.7 entries. There was a gradual decline in the number of daily entries over the course of the week, as shown in Figure 4, especially for the paper diary group. Looking at the individuals' patterns of recording over the week, we noted that 2-3 individuals in each group stopped the diary study early. In the paper diary group, one participant ceased recording on day 4, another on day 5, and a third on day 6. In the Evernote Food group, one person ceased recording on day 2, and a second on day 5. These results are consistent with published findings about low rates of compliance with food diaries (discussed earlier), and with the experiences shared by the dietitians we interviewed.

Based on an analysis of the questionnaire comments, and on remarks made during the design workshop, we believe that the lower numbers of daily entries made by the Evernote Food group can be attributed in part to the method of data input (photograph-based) and the inflexibility of the app's timeline. These factors are discussed below.

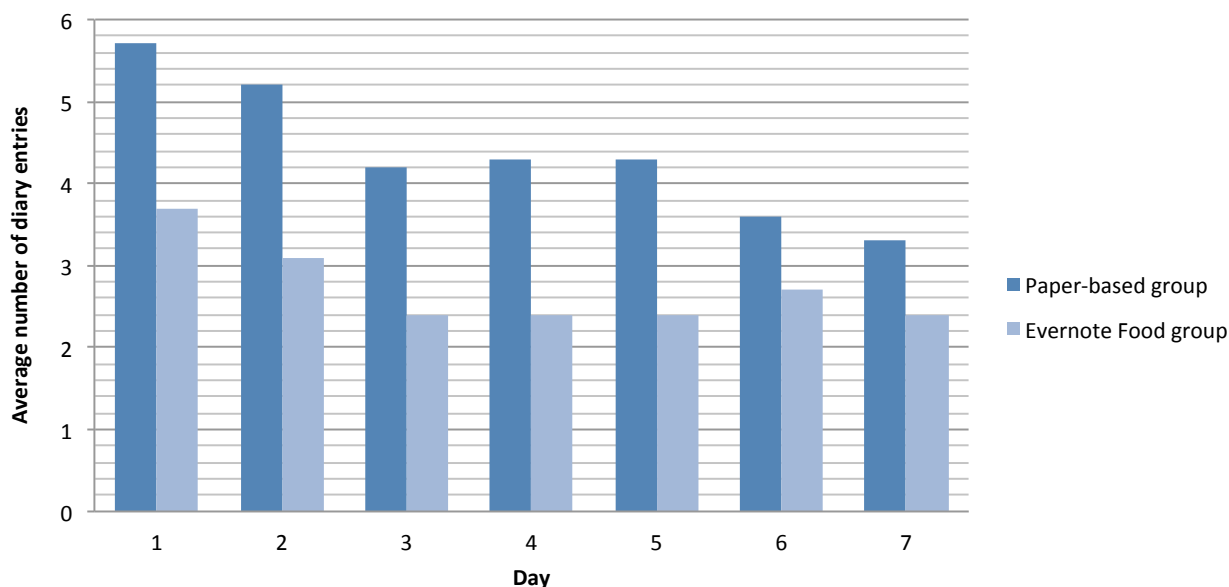


Figure 4. Average (mean) food diary entries on each day of the seven day diary study.

Missed entries

We asked the participants to estimate how many meals, snacks or drinks per day they forgot to record, why they thought they forgot, and which types of entry they most often missed. The Evernote Food group on average thought they missed recording just two food diary entries per day, as compared to 1.3 entries per day for the paper-based group.

The Evernote Food group cited the following reasons for missing or forgetting entries: not carrying their phone / phone on the charger (n=7); too busy or preoccupied (n=4); socialising at the time (n=2); and low motivation (n=1). The paper-based group gave similar reasons for forgetting: not carrying the food diary at the time (n=4); too busy or preoccupied (n=2); and low motivation (n=2).

Different types of entries were missed by the two groups. The Evernote Food group particularly reported problems with recording dinner (n=5) and breakfast (n=4). In contrast, the paper diary group experienced the most difficulty with snacks (n=4); coffee and other beverages (n=2); and meals consumed out of the house (n=2). These differences can be explained by the different patterns of use seen with the two types of diary. Just half of the paper-based diary group reported recording meals at the time they were consumed. The remaining participants completed their diary at the end of the day or sporadically as they remembered to do so. For this model of recording, the main meals are generally the easiest to remember, and small snacks and drinks the easiest to overlook. For the Evernote Food group, it was more difficult to retrospectively make food diary entries for two reasons:

- The main component of an entry is a photograph, which ideally must be taken prior to consuming food or drink. Although it is possible to insert a placeholder image from the iPhone's Camera Roll or other albums, and some participants reported doing so, this is a somewhat unnatural way to use the app. Evernote Food

entries *can* be created without any attached photograph, however some of the participants did not realise this was possible, while others were reluctant to do so because the photographs seemed such an integral part of the application. One participant commented:

"I wanted to be able to photo every meal, and if I forgot then didn't feel the record would be complete."

- Second, Evernote Food utilises a simple and restrictive timeline, which offers no control over chronology: that is, entries cannot be retrospectively inserted back into the timeline. This led to comments like the following:

"Sometimes I wouldn't remember until after another meal, then it felt too late to record."

To address the issue of forgetting to use the app at the time of the meal, two participants set alarms on their iPhones for their usual meal times, while a further two expressed a desire for this type of reminder in their responses to the questionnaire.

The problems of low compliance and high rates of missed entries seen with the Evernote Food group arose in part because we asked the study participants to complete a comprehensive food diary using a tool designed for occasional recording of meals. It is clear that an image-based food diary tool does introduce new challenges for retrospective recording, completely separate to the Evernote Food-specific issues with the timeline. However, with an appropriate design that facilitates retrospective recording and flexible types of data entry, we believe that we it will be possible to achieve compliance rates closer to (or even exceeding) those seen in the paper-based diary group. We will test this hypothesis in our future work, using the data collected in this study as a baseline for future benchmarking.

Family, work and social context

The explanations that participants gave in relation to when they missed entries and why revealed a range of tensions between the requirement to complete the diary

and other family, work and social demands. One busy parent in the Evernote Food group offered this explanation for why she forgot to record her dinners:

“So many things happening at once, cooking dinner, washing, children who need help with home work, packing school bags for next day, work issues in my head, co-ordinating the family’s training and driving.”

It is difficult to generalize about which environments were most challenging for the use of a food diary: some participants reported that the work environment was the most problematic for them, while others, such as the participant quoted above, experienced the greatest difficulty at home while attending to family needs. The challenge reported most consistently was that of recording meals when out and about. Several participants reported forgetting to make entries while they were eating out or socializing, and one noted that making an Evernote Food entry – in particular, photographing somebody else’s cooking – was socially awkward. Only one participant told us that she found it easier to remember to use her food diary while eating out. The explanation she offered was that these meals were the most memorable ones, and the ones that she would be inclined to share with others, as per the natural and intended usage model of Evernote Food. If designed appropriately, we believe that sharing mechanisms can be a useful feature to help motivate users to enter data.

This study involved recording food intake for adults. In the case of children, “eating out” would commonly occur at childcare, kindergarten or school – and, for older children especially, at the homes of friends. Where the child is physically separate from a parent or caregiver who is maintaining the food diary, there is a significant extra layer of challenge. Evernote Food’s image-centric model of data entry and inflexible timeline, which broke down in our relatively simple diary study, would almost certainly be inadequate for more complex patterns of family use.

Sharing

As discussed earlier, we selected Evernote Food for our study in part because of its support for sharing entries to Facebook and Twitter. In our initial instructions to participants, we flagged the sharing features, but made it clear that their use was optional.

Only one person in the Evernote Food group used the sharing functionality – and even then, only on one occasion: for a special meal. Several participants commented that they didn’t think that their regular friends would be interested in their meals, but that they would willingly share with a special group where sharing was reciprocal, or for a special purpose, such as reviewing a fine dining experience or telling others about an especially delicious meal.

Despite low uptake of the sharing functionality in this study, we intend to further investigate more purposeful and directed types of sharing: for instance, sharing of allergy-friendly dining experiences and recipes with families who have similar allergens or food restrictions.

Discussion

We have couched much of this analysis in terms of *compliance*, a concept that is useful when evaluating food diary software and the extent to which it can successfully be used in everyday life to capture high quality information about food intake. At the same time, we note that this concept is somewhat simplistic, and not necessarily relevant to all families and clinicians for whom we intend to design food diary software.

A comprehensive food diary may be the target for a patient who is undergoing a short-term dietary evaluation in conjunction with a clinician. However, a family conducting a food challenge may not need to capture all meals, but only certain foods that are of interest. For instance, the family may simply record daily amounts of milk consumed during a dairy challenge, as well as any observed symptoms potentially related to the challenge.

When evaluating our future food diary prototypes, we believe it will be important to examine both whether the diary software supports full compliance, as a gold standard of sorts, as well as whether it adapts well to other patterns of use. The latter type of evaluation will arguably best be achieved by studying the use of the software by real families and for real purposes, which we plan to do in conjunction with a small group of paediatric gastroenterology patients.

DESIGN WORKSHOP

Following the food diary study, we ran a three-hour design workshop. Six of the study participants attended. Two of the participants were parents of food-allergic and food-intolerant children, and contributed valuable insights both from the perspective of having recently completed the food diary study and having previously monitored their children’s food intake and symptoms. The remaining four participants were all experienced users of health and lifestyle monitoring applications, as well as being experienced software designers and/or developers (two PhD students and two academics within our school).

The workshop consisted of a general discussion session, in which participants shared their experiences of the diary study and brainstormed ideas for a new food diary design, followed by a paper prototyping exercise carried out in two groups.

The discussion session yielded a number of creative suggestions aimed at improving food diary compliance, such as:

- special mechanisms for dealing with repetitive and easily forgotten entries such as drinks: for instance a running tally that could be incremented without the need for a new diary entry;
- gamification mechanisms: for example, progress indicators or visualisations of statistics and analytics as a means to encourage further data entry; and
- prompts and reminders around known meal times.

The discussion also branched off into a brainstorming session on features that would complement the basic functions of a food and symptom diary, including

shopping list and meal planning functions, as well as opportunities for sharing and crowdsourcing information.

In the prototyping exercise, the groups were given free reign to develop a use case and a corresponding design using paper prototyping materials. One group focused on prompting for forgotten meals and the other on recipes and meal planning.

The first group's solution included adding placeholders to the food diary software for the common meals, including breakfast, lunch and dinner, such that, when the user entered a new meal, the app could prompt for both the expected meal and all those that had been omitted previously.

The second group looked at extending the diary with lists of foods to be avoided and trialled (a feature also flagged as important by the paediatric gastroenterologist), and tools to assist the user with translating the two lists into menu plans. The designed solution included recipes searchable on ingredients, mechanisms for sharing and recommending recipes, and mapping of recipes and meal plans into shopping lists. In their design, the members of this group focused on the family context and on traditional parental roles in a two-parent family, drawing on the experiences of one of the group members as a father of food-allergic and food-intolerant children.

The workshop was a valuable complement to the food diary questionnaire in understanding the participants' experiences of the diary study, allowing us to probe deeper and uncover some misconceptions that were not evident in the questionnaire responses. For example, we discovered that some participants were not aware that multiple photos could be added within Evernote Food for a single diary entry, while others had not worked out that it was possible to create an entry without a photo. The preliminary design concepts and other findings from the workshop will be iterated towards a software prototype over the next phase of the project.

DESIGN THEMES

Common threads emerged through the parent questionnaire, interviews with clinicians, food diary study and design workshop that can be used to inform the design of a new food diary application. In this section, we identify some important recurring themes.

Designing to support the primary caregiver and engage additional caregivers

It is perhaps unsurprising that the majority of respondents in our initial parent questionnaire were female, as mothers are still most often the primary caregiver for young children. Although some gender bias can be attributed to the method of recruitment (for example, women make up the majority of members on the online parenting forum through which we advertised for participants), it is still telling that we had only one response from a father, with the remaining 55 (98.2%) responses being from mothers/stepmothers.

In this context, we believe that we must design to support the role of the primary caregiver (often, but not always,

the mother), and at the same time to facilitate the engagement of additional caregivers, including those in the child's extended social support network. In their responses to the open-ended survey questions, several parents told us of the difficulties of conveying information about the child's food restrictions to others, including members of the extended family, friends, teachers and health professionals. One mother described her frustration as follows:

"[I would like to have] a tool that makes it easy to create an information video clip about my own child's needs that I could easily share with kindly, grandparents, friends' parents, etc., so I don't always have to tell them over and over again what he can eat and not eat."

When describing the challenges of parenting a child with food hypersensitivities, the questionnaire respondents cited problems of isolation, restriction, lack of social life, dismissiveness of others, and fighting to make their child's needs understood. In our future work, we wish to examine whether software that facilitates sharing of information about the child's diet and adverse food reactions, and promotes the formation of social support networks using social software, can help to alleviate some of these difficulties.

We observed problems with Evernote Food's inability to support access to a single food diary across multiple devices, a consequence of which was to prevent two or more parents or caregivers from collaborating to maintain shared records. Appropriately designed software for this domain should respect existing family and caregiver roles, while at the same time helping to bridge rather than widen gaps between the respective roles.

We have not examined the issues surrounding family breakdown, and how the care of children with special dietary and medical needs is managed and negotiated within co-parenting arrangements, but this must be addressed with sensitivity.

Designing for families under stress

Consistent with the published data on HRQL for children with food allergies and on the impacts of food allergy on parents, we found that families are under considerable stress. In our questionnaire, 17% (n=11) of respondents told us they were *extremely stressed* when dealing with food allergies or intolerances in everyday life, and nearly 30% (n=19) rated dealing with food hypersensitivities and related medical conditions as *very challenging*. As discussed earlier, nearly 40% are caring for more than one child with food hypersensitivity, and the majority of children with food hypersensitivity also have other conditions such as eczema, allergic rhinitis and asthma. These conditions carry their own HRQL impacts.

These findings are consistent with the message that we received from the clinicians. The second dietitian we interviewed told us that the majority of the parents she sees have "a lot of other things going on", are extremely stressed, and require very simple and clear instructions. She thought that food diary software, while appropriate

and helpful for some families, would add to the stress levels of others. Further, she argued that long-term monitoring of a child's diet is neither normal nor necessary in most cases, and can transfer stress to the child, especially in the case of older children. These are considerations that need to be balanced against the benefits of accurate record keeping. The largest benefits would arguably be for those children with delayed food hypersensitivity who require repeated medically-indicated food challenges over extended periods, as discussed earlier in the paper.

The clinicians we spoke to tailored the recommendations they made to parents based on the whole family context as well as the child's medical needs; similarly, we envisage that clinicians would be able to guide families in their use of the food diary software. We favour a design that supports a variety of use cases, including short-term use by some families (for example, to support diagnosis or investigation of nutritional adequacy) and extended monitoring of food challenges for others. We hope that this type of design will also support changes in family requirements over time: for example, as the family's experience level increases and children outgrow some or all of their food hypersensitivities.

When evaluating the food diary software, we hope to probe the impacts on parent and child stress levels, and the ways in which children of different ages experience and interact with the software.

RELATED WORK

There are no published studies, to our knowledge, addressing software for individuals or families with food hypersensitivities. However, prior work has examined food diary use for other health concerns such as diabetes and obesity. Mamykina, Mynatt and Kaufman conducted a study into the role that food diaries can play within the health management practices of people with diabetes (Mamykina et al., 2006). Effective diabetes self-management requires individuals to understand how diet, exercise and medication influence blood sugar levels, which in turn requires self-monitoring. Mamykina et al. supplied study participants with a laptop-based diary application with which they could record activities, meals, medications and emotional state. They found that, while self-monitoring using this type of diary is challenging and compliance is generally low, it can support patients with forming hypotheses about relationships between their actions and their blood sugar readings. This is useful but also leads to risks such as confirmation bias, whereby an individual forms a hypothesis and then actively seeks out evidence to support it, while at the same time discarding contradictory evidence. Confirmation bias is also a strong risk for those seeking to identify slowly evolving, non-IgE food reactions, and therefore must be a design consideration for the food diary software that we develop.

Tsai et al. investigated a mobile phone application to support self-monitoring for weight loss (Tsai et al., 2007). They conducted a comparative evaluation of paper-based versus mobile phone-based diaries, similar to the

comparative evaluation that we carried out in our study. The diary considered both diet and physical activity, and focused on the calculation of real-time caloric balance. The study found that the mobile phone and paper groups used their diaries a similar number of times per day; however, the mobile phone group reported higher levels of convenience. These results encourage us to aim for a similar result when implementing diary software for those with food hypersensitivities.

The above two studies dealt exclusively with adults completing food diaries to manage their own health. Two additional studies that specifically addressed health concerns within a family context are also relevant.

Grimes, Tan and Morris investigated diary keeping as a means for families to reflect on their own health data and improve motivation and discussions around healthy living (Grimes et al., 2009). They recruited families with older children, aged 8 to 12, to carry out a week-long journaling activity, followed by a semi-structured interview and design activity. The research yielded a broad set of findings in terms of how families collaboratively gather and reflect upon data, as well as how they approach sharing, competition and comparison. The goals of this work were markedly different from those of our own research; however, the findings are somewhat applicable when considering how older children with food hypersensitivities could be engaged to collaborate with their parents in maintaining food and symptom diaries.

Kientz, Arriaga and Abowd examined a broader form of record keeping for parents of young children (Kientz et al., 2009). Their main goal was to support the capture of memories as well as developmental milestones, partially as a means to support improved communication with paediatricians and diagnosis of developmental delay. Similar to our food diary study, Kientz et al. focused on software features to help parents accurately record data, specifically looking at reminders, keepsakes, online data sharing capabilities, and an integrated way to capture photographs and videos. They conducted a comparative study with two different versions of their Baby Steps software, showing that the above four features were useful in promoting frequent and accurate record keeping. These results lend weight to our own research findings from the food diary study, particularly in relation to reminders and sharing mechanisms as effective forms of motivation for entering data.

CONCLUSIONS

In this paper, we presented a research study on the design of software to support those with food allergies and intolerances, particularly focusing on children with slowly evolving, non-IgE food hypersensitivity. This work is relevant and timely, as rates of allergic disease and food hypersensitivity are on the rise, implying a growing burden in terms of HRQL impairment, family stress levels and economic cost.

Designing software for the family context is both interesting and challenging, and, as we have seen, introduces a slew of design considerations revolving

around established family roles and routines. Further, this area is challenging from the perspective that food hypersensitivity is not a single condition, and is not experienced in the same way by all affected families. We have looked predominantly at the challenge of how to design food diary software that can be used successfully across a variety of family, work and social contexts and, where needed, can support comprehensive dietary monitoring with high levels of compliance and data quality.

Earlier work has looked at the use of food diaries in relation to diabetes, obesity and promotion of healthy living, however this is the first study to look specifically at the needs of those with food hypersensitivity.

Our future work is concerned with translating the design considerations identified in this paper into a new food diary prototype that can be evaluated for food-hypersensitive paediatric gastroenterology patients. We will consider that the software is successful if it leads to improvements in patient outcomes, HRQL and/or family stress levels.

In the longer term, we see community benefits in the use of software to collect data about the outcomes of food challenges. At the same time as overall rates of food hypersensitivity are growing, new allergens are emerging as clinically important, and some types of food hypersensitivity appear to be becoming more persistent: that is, children are outgrowing them at later ages, or not at all. Statistics about these population-level changes are expensive and time-consuming to collect. Food challenge data pooled by a community of committed families could help clinicians and researchers to identify trends earlier. The success of this type of community-led approach has already been demonstrated by social health sites such as PatientsLikeMe (Wicks et al., 2010).

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