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Avoiding Reactions Outside the Home: Challenges, Strategies, and Opportunities to Enhance Dining Out Experiences of People with Food Hypersensitivities

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ABSTRACT

People with food hypersensitivities experience adverse reactions when eating certain foods and thus need to adapt their diet. When dining out, the challenge is greater as people entrust the care of their allergy, intolerance, or celiac disease, in the hands of staff who might not have enough knowledge to appropriately care for them. This interview study explored how people with food hypersensitivities avoid reactions while eating out, to inspire future digital technology design. Our findings show the social and emotional impact of food hypersensitivities and how people practically cope by investigating restaurants' safety precautions, correcting orders, or even educating restaurants' staff. We discuss our findings against the experiences of other people living with chronic conditions and offer design opportunities for digital technologies to enhance dining out experiences of people with food hypersensitivities.

CCS CONCEPTS

• Human-centered computing → Empirical studies in HCI.

KEYWORDS

Food hypersensitivities, food allergies, food intolerance, dining out, avoiding reactions, qualitative research, self-care, health

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1 INTRODUCTION

Food hypersensitivities such as food intolerance, food allergy, and celiac disease are characterised by adverse health responses to specific foods [16, 47, 101]. In mild cases, food hypersensitivity reactions result in eczema, diarrhoea, and stomach ache. In severe cases though, people can experience anaphylaxis, which consists of difficulties breathing caused by constriction in the airways and swollen tongue or throat [40]. Having an anaphylactic reaction can be fatal if people do not have access to medication and appropriate medical care, thus it is very important to avoid reactions. Around 200–250 million people are estimated to live with food allergies worldwide [78] and a 2018 survey estimated 1% of the worldwide population lives with celiac disease [91]. Having food hypersensitivities not only negatively influences individuals' decisions around eating and meal preparation, but it also disrupts social activities and creates emotional and psychological distress [32]. As a result, people with food hypersensitivities often report decreased quality of life for them and their families [12–15, 23, 27, 53, 64].

Food reactions often occur within and beyond the home including social settings such as a friend's house, work, school, restaurants as well as while attending social events and travelling [27, 63, 64]. Dining out is one of the most problematic activities for people with food hypersensitivities because they do not control food preparation and transport [42]. When dining out, people with food hypersensitivities need to search for or ask about ingredients and preparation processes of meals to avoid reactions [79], but the lack of knowledge or experience from restaurant staff puts them at risk [2, 84]. As a consequence, many people report experiencing reactions when eating out that impact their quality of life. A recent survey across eight European countries on the impact of peanut allergy reported that 89% of the participants (of a total of 1846 respondents) felt very restricted when selecting where to eat out, 90% felt stressed, and 65% felt isolated [29]. However, there is limited research describing the everyday needs and dining experiences of people with food hypersensitivities, and how they practically cope with the social consequences of these conditions.

This study explored how people with food hypersensitivities avoid reactions while eating out to inspire future digital technology design. We were inspired by the abundance of literature on the challenges of eating out and the absence of detailed descriptions of how people avoided reactions. Our research was guided by two main research questions: 1) How do people with food hypersensitivities avoid reactions while eating out? and 2) How do people use technology to support them to manage food hypersensitivities while eating out? Drawing on 25 interviews with people with food hypersensitivities, we uncovered the social and emotional impact of these conditions, as well as the practices that participants used to safely eat out. Our findings show that participants investigated restaurants' safety precautions, corrected orders, and educated restaurant staff to avoid future reactions. The participants in this study used apps, websites, and restaurant recommendation systems to inform their restaurant choices, but they found the existing technology support to be insufficient to keep them safe while dining out. We discuss our findings against prior work on living with food hypersensitivities and other chronic conditions, highlighting the parallels with and differences from prior research. We also offer design opportunities to inspire the development of future digital technologies to enhance the dining out experiences of people with food hypersensitivities.

Our study contributes to Human-Computer Interaction (HCI) and health communities by providing empirical understandings and design opportunities based on the dining out experiences and practices of people with food hypersensitivities.

2 BACKGROUND

This section introduces the context of our research. We start by presenting food hypersensitivities and then describe prior work on the experiences of living with food hypersensitivities. Finally, we review existing technologies aiming to support the management of food hypersensitivities.

2.1 Food hypersensitivities

Food hypersensitivities are medical conditions that trigger adverse reactions when people eat certain foods. Food intolerance, food allergies, and celiac disease, all fall under the umbrella of food hypersensitivities as they consistently produce “*reproducible symptoms or signs, initiated by exposure to a defined stimulus*” in quantities that do not affect people without the condition [47]. Food intolerance is present when people have difficulties to digest certain food ingredients causing abnormal and unpleasant reactions on their bodies [20, 56, 59, 103]. Food allergies are caused by an immune response to certain proteins in the food, confusing them with real threats [20, 59, 103]. Celiac disease is a food allergy in which the small intestine produces an immune response when gluten is present [65].

The foods that trigger people to have a reaction are very varied. The most common types of food intolerance are to lactose and to gluten [67]. Other common types of food intolerance include fructose, fructans, and FODMAPs (fermentable oligosaccharide, disaccharide, monosaccharide, and polyol) especially in people with gastrointestinal disorders [31, 94]. Furthermore, the most common food allergens, or ingredients that cause allergic reactions, vary

from place to place. In Portugal, the three most common allergens are shellfish, peanut, and nuts [57], while in the US they are milk, eggs, peanuts [21], and in Australia seafood, tree nuts, and mango [30]. These variations are due to differences in diet, accessibility to food, eating habits, and genetic differences [35].

The reactions triggered by food hypersensitivities are distinct depending on the condition that originates them. People with food allergies can experience itchy sensations, urticaria, swelling (in the face, tongue, mouth), vomiting, and in the worst case an inability to breathe because of anaphylaxis [66]. People with food intolerance can experience bloating, abdominal pain, gas, or diarrhoea, as a consequence of difficulties digesting certain foods [67]. People with celiac disease experience diarrhoea, abdominal pain, bloating, constipation, and can face difficulties absorbing nutrients due to the damage in the intestine caused by the immune response [65]. Food intolerance and celiac disease often occur with Irritable Bowel Syndrome (IBS), a gastrointestinal condition which can be triggered by food in addition to stress, infections, or gut changes [20, 26, 62]. Since there is currently no cure or prevention for food hypersensitivities, the most common treatments are to avoid eating unsafe foods and use medication to address reactions.

When someone with food allergies accidentally digests an allergen, they should take immediately antihistamines or adrenaline to address the symptoms [66]. Antihistamines help reduce or block histamine, the chemical produced as part of an immune response, and hence alleviate allergy symptoms. When severe allergic reactions occur, such as anaphylaxis, adrenaline helps reduce swelling and thus improve breathing. For a small set of food intolerance, individuals can use supplements to prevent potential reactions. For example, people with lactose intolerance can take Lactase enzyme before eating dairy products to help digest lactose [97]. There is still limited guidance and evidence on the efficacy of some dietary interventions such as the low FODMAP diet [31, 94], which should be followed by a gradual food reintroduction plan to help people build up tolerance to certain foods, increase dietary variety, and minimise the impact on human gut microbiota [56].

People with food hypersensitivities could be allergic or intolerant to a wide variety of foods at the same time. Since these reactions can vary from person to person, or even from episode to episode, people with food hypersensitivity have to learn how to manage their symptoms, constantly monitor their eating situations, and make decisions to avoid potentially negative reactions.

2.2 Living with food hypersensitivities

Learning and managing to live with food hypersensitivities can be stressful due to the constant threats of having a negative reaction [51]. Individuals with food hypersensitivities often have to make everyday decisions based on these potentially life-threatening scenarios [42]. Complete avoidance of potential food ingredients is often the most recommended treatment but is difficult to achieve. For example, allergen-free food may be difficult to find or too expensive [79], the labelling on food products can be misleading or confusing [11] and even the food preparation process may introduce hidden ingredients when eating out [58, 79]. As a result, individuals with food hypersensitivities often have to adopt risk-averse behaviours, such as changing their diets, avoiding foreign food

products, restaurants, and travelling, as well as making or eating new food [12, 27, 79]. The constant fear of adverse reactions and the stress about finding safe food often negatively influence the quality of life of individuals with food hypersensitivity and their family members, causing depression, anxiety, and other mental health problems [27, 32, 53, 61, 79].

In particular, social activities outside the home, such as family meals or school activities, can become very unpleasant and dangerous if negative reactions are triggered [58]. Eating in places where individuals with food hypersensitivities have little control of the content of the food, such as a restaurant or a catering event, can increase emotional and physical burden in deciding what is safe to eat or not [10]. In many studies [11, 52, 79], participants reported spending a considerable amount of time and financial resources to figure out where and what to eat. Findings from these studies also showed that people with food hypersensitivities constantly worried about embarrassment or rejection resulting from disclosing their conditions and needs, and that many participants considered completely avoiding social gathering or dining out for safety and convenience.

When dining out in an unfamiliar environment, people with food hypersensitivities often have to rely on others to manage potential reactions. However, lack of training and transparency in food preparation can be life-threatening. For instance, in a study performed in Brazil (São Paulo) with 12 restaurants, all managers reported that their staff lacked the training to deal with people with food allergies [2]. In a study conducted in the United States, restaurant managers and staff believed that people with food allergies could eat small portions of allergens without having a reaction [84], which reveals misinformation. Meals made solely with safe ingredients can still cause reactions if they were prepared with utensils that were in contact with allergens [10, 45]. Additional dressing or other food prepared in the same space could contaminate the dish – what is usually referred to as cross-contamination [33].

To promote food safety, the European Union introduced the allergen information legislation from 2011 [10, 13]. Many states in the United States also mandate restaurants to provide written or verbal allergen information and proper training to staff [93]. However, in practice, written information is limited and often only specifies the most common unsafe ingredients (e.g., gluten and nuts). Many people, especially the ones with allergy or intolerance to less common foods, still have to inquire staff to find out about the content of foods and alternative options [10]. These conversations can be time-consuming and be perceived as nuisance [11, 52, 79]. Experiencing significant burden when navigating safe options, people with food hypersensitivity often opt to visit the same dining venues to avoid unpleasant surprises [5].

Prior literature on food hypersensitivities examined people's negative experiences when dining out and the consequences on their quality of life. Nevertheless, limited attention has been given to the everyday practices and strategies people employ to avoid reactions, which will be the focus of this work.

2.3 Technologies to support the management of food hypersensitivities

There are some technologies to support people with food hypersensitivities, including systems for supporting food shopping, tracking symptoms and food intake, detecting allergens, providing restaurant recommendations, and supporting emergency response to allergic reactions.

The first group of technologies consists of assistants to support food shopping. Included in this group are mobile apps that scan barcodes of packaged foods to assess their safety (e.g., *ipit*¹, *Spoon Guru*², *The Gluten Free Scanner*³, or *Food Code Breaker* [1]). By comparing barcodes against a pre-curated database, these systems provide point-of-purchase alerts to inform individuals whether the food package they are looking at contains specific food allergens [36]. Also included in this group are technologies that suggest safe food products for their users to try. *ipit*, mentioned above, suggests alternative food products when users scan a product that is unsafe [36]. *FODMAP Grocery Guide*⁴ displays a list of products that are safe for people adopting a low FODMAP diet, and the prototype from Altamirano et al. [3] includes a list of safe products for people with celiac disease to try. Finally, we can also refer to systems that suggest safe recipes based on the users' specific food hypersensitivities. *Receitas sem Alergias*⁵ provides safe recipes for people with hypersensitivity to milk, eggs, wheat, dried fruits, and/or soy, while *Monash FODMAP App*⁶ provides recipes for people adopting a low FODMAP diet.

There are also some apps for tracking symptoms and food intake. The *Monash FODMAP App* (mentioned before), *mySymptoms*⁷, and *MyHealthyGut*⁸ enable users to log their symptoms and food on a diary, to enable diet change or investigate food hypersensitivities. A recent diary study with *mySymptoms* involving 163 users showed that this app can help to identify dietary triggers and potential food intolerances [22]. In addition, a recent study of *MyHealthyGut* with people with celiac disease or gluten intolerance reported that some participants had fewer gastrointestinal symptoms after using the app and found the app to be best suited for newly diagnosed individuals [28].

Some devices enable users to test hidden allergens before they eat. For example, a personalised testing platform, named *iTube*, combines a portable device (test tubes) with the smartphone camera to optically detect and quantify allergen concentration in food samples of approximately 40 grams taking up to 20 minutes per analysis [24, 36]. The *TellSpec* smartphone-based food scanner combines near-infrared spectrometers with machine learning and bioinformatics techniques [36] to test for food ingredients and contaminants [34, 36, 102]. *Nima*⁹ enables users to test food samples

¹*ipit* is described at: <https://www.ipit.com/>.

²*Spoon Guru* is described at: <https://www.spoon.guru/the-app/>.

³*The Gluten Free Scanner* is described at: <https://play.google.com/store/apps/details?id=com.theglutenfreescan>.

⁴*FODMAP Grocery Guide* is described at: <https://apps.apple.com/us/app/fodmap-grocery-guide/id1220227921>.

⁵*Receitas sem Alergias* is described at <https://elearning.up.pt/repositorio/alergia-alimentar/>.

⁶*Monash FODMAP App* is described at: <https://www.monashfodmap.com/ibs-central/i-have-ibs/get-the-app/>.

⁷*mySymptoms* is described at: <https://www.mysymptoms.net/>.

⁸*myHealthyGut* is described at: <http://www.myhealthygut.com/>.

⁹*Nima* is described at: <https://nimasensor.com/>.

for gluten and peanut by placing a small portion of food in the test capsule and examining the protein compositions using antibody technologies [36]. Allergy Amulet¹⁰ similarly detects eight common allergens in foods using molecular polymer technology and electrochemical systems. While these portable devices have shown the potential to help identify the content of the food, they are costly and have low to moderate accuracy [36]. Also, since these devices are designed to detect one allergen at a time, the time and financial costs escalate if individuals have multiple food hypersensitivities [36].

Some restaurant recommendation systems exist to help individuals with food allergies and celiac disease to share information about food and restaurants to support making dining out decisions [3]. For example, AllergyEats¹¹ and Biteappy¹² provide restaurant recommendations based on user-specified diet restrictions. A recent analysis of user-generated reviews from the restaurants listed on AllergyEats highlighted how the efforts of the restaurant staff have a positive influence on the ratings of the restaurants as well as how the lack of communication of the staff and cross-contamination negatively influence the ratings [98]. In addition, Find me Gluten Free¹³ helps individuals find restaurants serving gluten-free meals in their region. However, many of these platforms do not maintain up-to-date information and only target the most common food allergies. As a result, even with recommendations, individuals with food allergies often still have to explicitly inquire and confirm allergic recommendations to ensure food safety. To address these burdens, Hsu et al. designed AllergyBot [44], a chatbot that supports young adults to explore dining options with customized interactions. Preliminary studies also show that users consider using AllergyBot feasible, but the long-term use results remain unknown [4].

Emergency response is critical when allergic reactions occur. Individuals with severe food allergies and their caregivers are often prescribed with preloaded adrenaline autoinjector (i.e., EpiPen¹⁴) and instructed how to administer the injection. However, managing the medication can be burdensome, and people often do not have experiences with injections. To support better training with adrenaline injection in an emergency, Hernandez-Munoz and colleagues designed AllergieSense that provides step-by-step training with sensors detecting injection procedures [43]. In a two-week deployment, they found that training with sensing support improved injection training skills and individual self-efficacy. Another example is EpiClub¹⁵, which educates individuals with food allergies, caregivers, and medical professionals to properly use and manage an EpiPen.

While a number of devices and mobile applications are emerging to support people with food hypersensitivities, many of the existing technologies have not been validated to be effective, usable, or used in real-world scenarios. The lack of studies documenting the use of digital technologies by people with food hypersensitivities motivates this study to investigate people's challenges and how

they use technologies to help them avoid reactions to inform future digital technology design.

3 METHODS

To understand the challenges and practices of people with food hypersensitivities, we conducted qualitative semi-structured interviews with people with these conditions [55]. We purposefully selected [77] people with different hypersensitivities to enable us to learn about different experiences across these conditions and to support constant comparison [19].

3.1 Study design and data analysis

The Interview guide was created based on a literature review and it inquired about (1) how people with food hypersensitivities learn to live with their condition, (2) what are the everyday challenges they face when eating out, and (3) how they practically cope with these challenges to avoid reactions and cross-contamination in restaurants. We also inquired participants about whether and how they used technology to: (1) avoid reactions when dining out, (2) search for information and advice about restaurants and meals, and (3) manage reactions (e.g. EpiPen). Additionally, we asked participants questions about demographics, their medical diagnosis, and current treatments for context.

To recruit participants, we emailed students from the University of Porto, attended an event organised by Associação Portuguesa de Celiacos (Portuguese association of celiac patients), invited contacts of the research team, and used snowball sampling [77]. In total, 19 participants (8 females, 11 males) were interviewed between February and April 2018. Participants age varied from 20 to 69 years old ($M=27.1$; $SD=10.9$). Most participants were students affiliated with the university, which may have limited our findings to describe perspectives from people with other occupations. However, we believe the variety of experience our participants have still provided insights into how to better support individuals with food hypersensitivities. Our participants had a variety of food hypersensitivities including food allergies (11), food intolerance (11), and celiac disease (2) as described in Table 1. Six of these participants have co-existing conditions, i.e., food allergies and intolerance.

We invited all participants to a second interview, after analysing the first interviews, in order to re-examine themes raised by other participants and to discuss potential technology design opportunities. Nevertheless, only six participants attended the second interview. Interviews continued until reaching meaning saturation [41]. All participants provided written informed consent. Participants were not compensated for their participation.

Our study included 25 interviews that were audio-recorded (15 hours), transcribed, and anonymised. The analysis of the interview transcripts followed Thematic Analysis [17] and remained as close to the data as possible. We used Scrivener software¹⁶ to facilitate the creation and iteration of codes and themes. The interviews and analysis were conducted in Portuguese to avoid losing meaning in the translation [96]. Two members of the research team reviewed the transcripts and created the initial codes. Codes were then grouped and organised into themes that were continuously checked and adapted as the analysis continued. The themes were then discussed

¹⁰ Allergy Amulet is described at: <http://www.allergyamulet.com/>.

¹¹ AllergyEats is described at: <https://www.allergyeats.com/>.

¹² Biteappy is described at: <https://biteappy.com/>.

¹³ Find me Gluten Free is described at: <https://apps.apple.com/us/app/find-me-gluten-free/id431006818>.

¹⁴ The EpiPen is briefly described at: <https://www.epipen.com/>.

¹⁵ EpiClub is described at: <https://www.epiclub.com.au/>.

¹⁶ Scrivener software is described at www.literatureandlatte.com/scrivener/overview.

with the remaining two members of the team who do not speak Portuguese. The analysis was iterated regularly, double-checking the new interpretations with the initial codes and interview data in the original language [96]. The final themes and quotes were translated into English for reporting the findings. The main themes are presented in the section below using pseudonyms and complemented with previous research findings when applicable.

3.2 Study context

The findings from this study are tightly connected with the eating practices of our participants, who were all living in Portugal. Even though food hypersensitivities are a global challenge that affects people everywhere, the consequences of food hypersensitivities are specific to where people live and eat, as people face reactions or restrictions within specific traditions and socio-cultural practices. To introduce the context of our participants to the reader, we provide some notes on eating in Portugal as well as on the local regulations related to food hypersensitivities.

People in Portugal traditionally have 4 main meals a day: breakfast, lunch, afternoon snack, and dinner. Lunch and dinner are the main meals and are likely to include a soup, a main course, and a fruit or dessert [100]. Meals in Portugal have a tendency to be long and it is very common for families or groups of friends to eat together in restaurants for lunch or dinner [95]. The work law guarantees that workers have one to two hours break for lunch [75], in recognition of the importance of this meal, but meals accompanying celebrations can take up to three hours. The food in Portugal is influenced by the Mediterranean diet, with a strong presence of bread, olive oil, wine, fish, and vegetables [95].

Dining out is seen both as an opportunity for satisfying food needs and a deeply social activity. In a country where meals are long, where coffee shops are used for hanging out with friends, and where most celebrations happen around the table, being unable to fully participate in meals can have a considerable social impact. For example, one participant from this study was extremely frustrated to be intolerant to coffee as he could neither drink an alcoholic beverage nor have a coffee when he drove to the Café to hang out with friends in the evening. Another participant talked about the inability to go to a specific restaurant restricted him from hanging out with friends every week. Other participants also talked about how being unable to eat at certain restaurants often left them struggling between going and starving or forcing everyone to go to a different restaurant.

In terms of regulations, Portugal has specific laws for supporting people with food hypersensitivities. The European law 1169/2011 [25] on food information display has been transposed with Decreto-Lei 26/2016 [76], making it mandatory for all food items sold to the public to display a list of ingredients that can trigger allergies or food intolerance, be they packaged foods or meals served on restaurants. Cooks and chefs need to abide by the hygiene and safety regulations of the sector but can avoid going through formal cooking training. Restaurants are required to train employees on a regular basis, including on the topics of food hypersensitivities, but there is no close oversight of such training sessions. Moreover, the country has a national authority for inspecting the safety and hygiene of restaurants, with powers to fine and close establishments.

Unfortunately, having negative reactions at a restaurant is not totally unexpected, considering the lack of formal training of staff in the restaurants in Portugal. Even with the strict national safety and hygiene regulations, these do not work in practice and there are often violations to these rules due to lack of knowledge or organisation. Since the restaurants are seldom prepared to deal with people with food hypersensitivities, people need to be extremely vigilant if they want to avoid a reaction.

4 FINDINGS: PRACTICES FOR AVOIDING REACTIONS WHEN DINING OUT

Dealing with food hypersensitivities was very complex for our participants, especially when dining out as they did not completely control their food. As a result, participants engaged in monitoring and seeking practices and developed different strategies to help them dining out without reactions. In particular, our participants: i) avoided eating in unsafe restaurants, ii) learned about a restaurant before going there, iii) investigated if a restaurant is safe after arriving, iv) ordered one of few safe meals, v) corrected orders and educated staff, and vi) used medication to soften reactions. Before presenting each of these practices, we provide some overview of the context of participants.

Participants in our study had a variety of food hypersensitivities, including food intolerance, food allergies, and celiac disease (see Table 1). Depending on their hypersensitivities, participants also experienced different reactions. For instance, lactose-intolerance causes vomit and stomach aches, celiac disease triggers serious diarrhoeas, and allergic reactions result in difficulties in breathing and the possibility of anaphylactic shocks. The duration of the reaction and its consequences were also distinct, with some people feeling bad for an afternoon or day, while others had to stay home for 3-5 days in a row (with all the consequences of missing work or school). Despite the various types, levels, and reactions of their hypersensitivities, all participants reported having practical and social consequences due to their condition that added significant burden and work to their everyday life. The worst situation had to do with avoiding reactions while dining outside the home, and thus this paper focuses on these practices.

This paper focuses on the experiences of people with food hypersensitivities in restaurants as most fieldwork stories took place in these settings. Nevertheless, participants also faced reactions at cafés, bars, and other places that serve food, so some examples presented occur in those settings. Moreover, we also listened to information-seeking practices in which participants tried to learn more about their condition, identify whether certain ingredients were safe, or find replacements for unsafe products they appreciated, as described in prior work [61]. Nevertheless, these practices are out of the scope of the paper and were thus not discussed.

4.1 Avoiding to eat when dining out

All participants referred to dining out as a potentially risky situation for having a reaction. The waiter could fail to communicate to the kitchen that a customer has a food hypersensitivity, the cook or chef could forget the requests made, and the overall handling of the food by staff could lead to cross-contamination of an otherwise safe

Table 1: Study participants' characteristics.

Part.	Age	Sex	Occupation	Food hypersensitivity	Consequences
Amelia	22	F	MSc student	Intolerant to lactose	Gastrointestinal discomfort, malaise
Anna	23	F	MSc student	Allergic to dried fruits. Intolerant to lactose	Diarrhoea, stomach pains, malaise, flatulence
Arthur	27	M	PhD student	Allergic to gluten. Intolerant to milk protein	Hives, itching
Carl	20	M	BSc student	Allergic to some types of fish, eggs. Intolerant to lactose	Swollen eyes, lips and throat, stomach pain
Clara	33	F	Teacher	Allergic to chocolate, strawberry, beans, peas, canned food	Swollen eyes, hives.
Ethan	22	M	MSc student	Intolerant to lactose, caffeine	Diarrhoea, vomit, malaise
Felix	22	M	MSc student	Fat fish (e.g., salmon)	Chills, dizziness, vomit
Hugh	35	M	Researcher	Intolerant to lactose, gluten	Stomach pain, skin irritations
James	27	M	PhD student	Allergic to seafood, except fish	Swollen throat, anaphylaxis
Jessica	22	F	MSc student	Celiac disease	Stomach pain, anemia
John	69	M	Retired	Celiac disease	Diarrhoea
Jonas	22	M	MSc student	Allergic to shellfish. Intolerant to lactose	Vomit, headaches
Lucas	23	M	MSc student	Intolerant to lactose, chocolate	Vomit
Mark	23	M	MSc student	Allergic to nuts	Trouble breathing, swollen throat, anaphylaxis
Mia	26	F	PhD student	Allergic to conservatives and seafood. Intolerant to lactose	Diarrhoea, headaches
Nathan	22	M	MSc student	Allergic to eggs	Malaise, vomit, skin reactions
Rita	25	F	Researcher	Allergic to nuts, stone fruits. Intolerant to flour, lactose	Anaphylaxis
Rose	21	F	BA student	Intolerant to lactose	Diarrhoea, swollen throat, lips
Sarah	31	F	PhD student	Allergic to lettuce, cabbage, wheat flour	Headaches, vomit, malaise, hives

meal. All of these risks were real possibilities that our participants considered when deciding whether to eat out.

One common strategy used by our participants to avoid reactions was to refrain from dining out. Many participants confessed that their food hypersensitivity diagnosis led to a reduction in the number of times they dined out. Restaurants that were formerly appropriate choices now were avoided as they could trigger them to have reactions.

John: “I used to eat fish every Wednesday at lunch with friends in Matosinhos [city close to the sea in the north of Portugal] and I had to stop because of the problem of contamination. No matter how much I asked... I told people [staff] that I am allergic to gluten. I said: Look, I am celiac patient. And they [staff] asked me if it was the name of a religion (...) They do not know how to deal with my meal, because a small bread crumb falling on my plate is enough for getting me into problems.” – 69, celiac disease.

Being diagnosed with celiac disease had a strong impact on John's quality of life. On the positive side, John stopped having diarrhoea episodes that confined him to the home for several days. On the negative side, John stopped being able to socialise with his friends every week, as he could no longer eat in the places they attended. Being unable to eat everywhere was a tough change for John, as he lived without food restrictions for almost 65 years of his life, however, what John missed the most was the opportunity for eating weekly with his friends. Being confronted with loneliness and social isolation is likely to impact John's wellness [68], which is extremely concerning as loneliness in older adults is a strong predictor for functional decline and death [80].

Occasionally, participants went to unsafe places, prepared for not being able to eat there. Examples of these events include birthday parties, weddings, and other special occasions. John described how

he coped with these situations by eating beforehand or packing his own meal.

John: “The greater difficulty is the social part... socializing. For example, going with my kids out for lunch or dinner... I cannot eat lunch or dinner. I have to eat at home or take a packed lunch with me. I have been to weddings and baptisms [banquets] with my packed lunch. I sit in the corner of the table and eat first. Then I can hang with the people at the table, but only after (...). This is my biggest issue at the moment.” – 69, celiac disease.

Dining out presented many dangers to people like John who often avoid eating at unsafe or potentially unsafe restaurants. Besides food avoidance, which is often reported in the literature (e.g., [32]), our participants developed other coping strategies. For example, some participants commented that they would eat before going to the restaurant, to make sure that they would not starve at the restaurant or feel tempted to eat unsafe food. Other participants commented that they would prepare a safe meal and bring it with them to the restaurant. If the conditions were appropriate, participants would eat the meal of the restaurant, however, they prepared for the worst-case scenario. In any case, having to eat beforehand or to pack food takes time, effort, and planning, to the point that John considered it to be his “biggest issue at the moment”.

While avoiding food prevents reactions and protects the health of people with food hypersensitivities, it may leave them feeling upset that they were not able to enjoy foods that they appreciate.

Mia: “For example, in Brazil people do birthday parties with many sweets. Here, on a wedding, there is a table with sweets and I cannot eat. That really bothers me!” – 26, allergic to conservatives and seafood; intolerant to lactose.

Being unable to eat the food they love often made participants feel down and upset that they might not be able to eat the food they

loved ever again. This meant that participants had to change their previous habits, adapt to new taste preferences, and deal with the emotional impacts of losing some experiences. Prior work [32, 81] asserts food hypersensitivities can also bring emotional distress to family members, as they may also need to adapt their practices and lives. Nevertheless, our participants did not mention distressing experiences of their family members or friends.

Some participants also felt embarrassed when friends and peers noticed they were not eating and brought it up in the conversation. For example, Jessica explained that her friends were sometimes sadder than her because she could not eat with them at a restaurant. Although these situations made Jessica feel uncomfortable because she did not want her condition to affect other people, once discovered, her food hypersensitivity became the central focus of the conversation over the meal. Jessica would rather avoid these conversations and others' feeling sorry for her, but it was not an option for her to eat unsafe food and face a reaction.

4.2 Learning about a restaurant before going there

4.2.1 Searching for a safe restaurant online. Finding a safe place for dining out was a process that usually started before entering the restaurant. Having heard about a restaurant, our participants would search for its name online to understand if it was safe for eating. If they needed to eat in some part of the city, participants would search that area for a restaurant that would fit their needs. Participants visited restaurant review websites such as Zomato¹⁷ or Tripadvisor¹⁸ as well as the website of the particular restaurant they were searching for. Motivated by the desire to avoid reactions, participants used these websites to read the menu, view pictures of meals, and read reviews and opinions from other customers. This information helped participants understand and confirm the available safe meal options, the hygiene of the place, or even the knowledge of staff regarding food allergies. Participants also commented that the pictures of the meals gave an idea of the sauces used, which is hard to understand from the menu but very useful to help verify if a meal is safe. Most participants would make a decision based on the information available online. However, to avoid surprises at the restaurant, some participants developed the habit of calling the restaurant to ask for further clarifications and make prior arrangements.

James: *"If there is no menu [online] and if there are not many restaurants in the area I will always call the restaurant to talk... to ask if they can serve something [safe to me]."* – 27, allergic to seafood except fish.

James often called restaurants to know about the meals and whether they could cater to his needs. As he could have an anaphylactic reaction from being in contact with seafood, he wanted to verify whether restaurants had non-seafood options and whether these options were not cooked or seasoned with seafood. If James found out that meals could have unsafe ingredients, he would ask about the possibility to change them, which was usually conceded by the restaurant staff. The decision to call the restaurants was based on the number of potentially safe restaurants available in the

area. Many options meant that James could go to one restaurant and switch to another if the conditions were not appropriate, but if options were scarce, James would always call to pre-assess the restaurant's safety.

4.2.2 Seeking advice from others on safe restaurants. Our participants actively sought advice from friends and family on safe places to eat out. People without food hypersensitivities offered important insights about a restaurant's hygiene and flexibility to accommodate special requests. The level of hygiene of a restaurant gave an idea of whether food could become contaminated during preparation or transportation, which helped the decision-making process. The restaurant's ability and willingness to deal with special requests (i.e., remove or replace food) also influenced the decision of our participants to go to the restaurant. Contrary to what one could expect, healthcare professionals were not mentioned as sources of safe restaurant recommendations. While healthcare professionals often provide important information about unsafe foods [89], they do not seem to play an important role in understanding which restaurants are safe for eating.

Moreover, the advice from others with food hypersensitivities was even more appreciated. Most participants referred that the advice from others with similar experiences would save them from some of the work trying to understand whether a restaurant is safe for them.

Carl: *"I think I would give more importance to the review of someone with [food] allergies, as people without allergies do not have sensitivity... they are not in the mindset to understand that something wrong happened. (...) If a person who has a different allergy than mine... if they went to a restaurant and had a reaction without expecting, then I would be more careful to go there, because if they [restaurant staff] were not careful enough in that situation, maybe they would not be careful with my allergy either."* – 20, allergic to some types of fish and eggs; intolerant to lactose.

While most participants only knew few (if any) people with similar issues, they believed advice from other people with food hypersensitivities would provide them with important information. As Carl explains, knowing that a restaurant has a negative track record of triggering reactions is important, as it is a sign that established practices may be inappropriate. In addition, drawing on experiences from others could save people with food hypersensitivities from asking so many questions, reading the menu so carefully, or actively monitoring the environment. Positive and informative reviews would help them gain trust in the restaurant sooner and thus lower their level of vigilance.

Although most participants valued the experiences from others, they also expressed concerns in taking other's advice to heart as the type of hypersensitivity, reaction, and intensity strongly vary. For example, Anna, who is allergic to dried fruits and is lactose intolerant, explained that her intolerance affects people with different levels or intensities. While some people can eat traces of milk without strong consequences, others can have severe reactions. Anna thus argued that it is important to understand the level of intolerance of the person doing the recommendation as the advice

¹⁷Zomato is available at: www.zomato.com.

¹⁸Tripadvisor is available at: www.tripadvisor.com.

receiver might not be exposed to the same level of danger. Nevertheless, advice from others with the same food hypersensitivities would always be useful to help them manage the condition and its potential consequences.

4.3 Investigating if a restaurant is safe

4.3.1 Observing the restaurant's conditions. Upon arrival at a restaurant, participants started observing the environment thoroughly. They paid attention to the kitchen, eating rooms, and the dynamic of staff to understand and verify if they were at high risk of having an allergic reaction.

Sarah: *"I need to see the kitchen and the places where food stays before going to the table or to wash. If I cannot see these, I will not stay there. I have to understand the hygiene, if the dish is clean, if the staff has clean hands (...) when [staff] brings the things to know how they picked up the cutlery with the hands... if they touched the food on the plate."* – 31, allergic to lettuce, cabbage, and wheat flour.

Besides asking questions to verify whether a dish is safe to eat, our participants carefully observed the internal operation of restaurants to get insights and prevent potential reactions. For example, Sarah identified clean facilities as a sign that a restaurant respects safety and hygiene standards and indicates that they will be careful with people with food hypersensitivities. Clean plates and careful waiters who do not touch the food suggest a lower level of risk that one's meal can be contaminated due to staff touching it with their hands after they touch unsafe ingredients (cross-contamination). In contrast, a negative appreciation could result in the decision of leaving the restaurant or not ordering food.

4.3.2 Scrutinising the menu and guessing what is missing. When participants with food hypersensitivities observe the environment, they also start carefully reading the restaurant's menu. Our participants focused on the ingredients, preparation methods, and sauces, because all these elements can trigger an allergic reaction. In rare occasions, restaurants provided the list of allergens for each meal on the menu (see Figure 1), which helped them make a faster decision about what to eat and instil a feeling of trust in the restaurant's ability and willingness to deal with food hypersensitivities. However, many participants felt they were dealing with many unknown meals as detailed menus were rare and they had to start guessing the possible ingredients. For example, Jessica, who is celiac (cannot eat gluten), is always vigilant for the cooking methods of rice. As she explained, rice cooked with onions and garlic is perfectly safe for a person with celiac disease. However, if the restaurant uses chicken stock cubes, which can contain flour (and thus gluten), she can have a reaction. This means that when seeing rice on the menu, Jessica needs to remember to ask staff whether stock cubes were used and whether they can cook the rice without stock cubes for her meal.

Avoiding a reaction at a restaurant requires not only awareness of the unsafe ingredients, but also about the preparation methods and recipes. Had Jessica had less knowledge about how rice is prepared in some restaurants, she would have had a reaction that would confine her to the home for several days. While learning about their food hypersensitivities, our participants referred that

they engaged in significant trial-and-error, trying different foods and eventually having reactions. This process helped them know what they could or not eat, and also what to look for in restaurants. Participants also benefited from the cooking knowledge from their family and friends.

Mark: *"Basically it was my mother [who taught me]. She would let me know if there were some recipes or meals more likely to have nuts."* – 23, allergic to nuts.

Mark learned many tips from his mother when he was a child, like many others with similar issues [38, 48], but he had to continue learning about the foods he reacts to and how food is prepared, in both traditional and modern restaurants. Otherwise, he could become vulnerable to potential reactions because the staff might not be as knowledgeable about all possible ways that unsafe foods can make it to his meals.

4.3.3 Questioning staff about the meals. The next coping strategy shown by our participants with food hypersensitivities was to call the waiter and start a series of questions to better understand the meals they are interested in.

Rose: *"I have to ask if things have milk and tell 30 times – look, its without cheese. It is really complicated... And then I say: Is there anything [in the meal] that has milk, cream, or butter? And they say: No, this only contains condensed milk. Condensed milk is milk... So this is how things happen."* – 21, intolerant to lactose.

Asking questions about meals and their ingredients is extremely important. The problem is that people with food hypersensitivities need to ask the right questions to be able to identify unsafe ingredients. Rose could have asked if the meal had Lactose, but since the waiter might not know which foods include Lactose, she asked about several ingredients that can contain it (i.e., milk, butter, cream). Despite her efforts, Rose was almost given unsafe food in this particular situation that she told us about.

When questioning waiters, participants also asked about sauces, unmentioned ingredients, and methods used to prepare the meals they were interested in having. Participants then asked if it was possible to remove or replace unsafe ingredients used (e.g., stock cubes). Moreover, asking about cooking practices revealed a lack of knowledge of the restaurant's staff about food hypersensitivities.

Mia: *"I think sometimes the waiters do not know what to answer regarding what is in the meal and they have to get that information from the chef. We stay more vulnerable. Many times in those cases I will change my order."* – 26, intolerant to lactose and allergic to seafood.

Eating at a restaurant required participants to have a significant level of trust in the staff. If waiters did not know important information about the meals, people like Mia worried that their questions could be disregarded by the waiter. In fact, when people suspected that they could be deceived or be the target of retribution, they would change their order to a safer one, or even refrain from eating at a restaurant.

One major challenge was that the questions from people with food hypersensitivities were often misinterpreted by staff. Rita summarises this experience.



EMENTA Refeitório I3's

Semana de 20/07/2020 a 24/07/2020

SEGUNDA	SOPA	Creme de cenoura (30% batata, 40% cenoura, 10% cebola, 10% abóbora, 10% couve-flor)	Sobremesa: Fruta da época
	CARNE	Lombinhos de porco grelhado com molho demi-glace e arroz de tomate	
	PEIXE	Atum à Brás com cogumelos e cenoura	
TERÇA	SOPA	Creme de feijão-branco com espinafres (30% batata, 10% cenoura, 10% cebola, 20% feijão-branco, 30% espinafres)	Sobremesa: Fruta laminada
	CARNE	Empadão de alheira e grelos	
	PEIXE	Red-fish escalado com arroz de legumes	
QUARTA	SOPA	Creme de brócolos (30% batata, 20% cenoura, 10% cebola, 10% couve-flor, 30% brócolos)	Sobremesa: Fruta da Época
	CARNE	Panadinhos de frango com arroz branco e batata rustica	
	PEIXE	Pescada no forno com batatinha e brócolos	
QUINTA	SOPA	Sopa de alho-francês (30% batata, 20% cenoura, 10% cebola, 40% alho-francês)	Sobremesa: Fruta da Época
	CARNE	Canelones de salsicha e espinafres	
	PEIXE	Peixe-espada grelhado com batata cozida e legumes	
SEXTA	SOPA	Caldo-verde (60% batata, 10% cebola, 30% couve-portuguesa)	Sobremesa: Gelatina
	CARNE	Carne de porco à Portuguesa	
	PEIXE	Pataniscas de pota com arroz de feijão	



Figure 1: Menu displaying food allergens from a restaurant where Rita used to eat. One of the reasons why Rita went there was related with the convenience of immediately seeing the allergens of each meal.

Rita: “When you go somewhere you have to be that annoying person that is always asking things. And if you have more than one allergy it is very annoying because they think you are being picky. This part is very annoying.” – 25, allergic to nuts, stone fruits; intolerant to flour and lactose.

These experiences described by Rita highlight the emotional demands of the condition. Rita knew that staff might have considered her questions as a sign of being a picky or an inconvenient customer, so she tried to be efficient and explain why she wanted to know about meals. Rita also felt uncomfortable for having to ask many questions, but they were necessary to avoid a reaction.

To make matters even worse, our participants often felt pressured to order fast. As they were the only ones that needed to scrutinize



Figure 2: Arthur went to lunch with two friends and the only safe option for him was a fruit salad (see top right of the bottom tray).

the menu and ask questions, people with food hypersensitivities were likely to be the last ones to order, leaving all others waiting for their food. Delaying the service for everyone can be stressful but a necessary strategy to find safe options.

4.4 Ordering available meals and playing safe

Having read the menu and clarified doubts about the meals, participants were ready to place their order. However, they may be left with a food option they do not appreciate that much. One of the problems is that safe food options on the menu can be very restricted, especially in low budget restaurants. For example, Arthur, who is allergic to gluten and intolerant to milk protein, went once with friends to have lunch in a place he had not visited before. His friends ordered pizza slices and chocolate cake, which were unsafe for Arthur to eat. After thoroughly checking all meals, Arthur concluded that the only safe option for him was a fruit salad (see Figure 2). Even though he was as hungry as his friends, he had to settle for a small dessert that he did not appreciate that much.

When confronted with different menu options, participants often chose the safer one. For some participants this meant ordering a salad; for others, a steak seasoned only with salt. Options like these were chosen because they had fewer ingredients and thus it was harder for restaurant staff to add unsafe ingredients to them.

Moreover, the unsafe ingredients people asked to remove from their meal were not always replaced, which meant that their meals lost some flavour. Eating food without any sauces or seasoning meant that participants often ended, as Anna puts it, with “uninteresting or tasteless meals” impacting their dining out experience.

4.5 Correcting meals and educating staff

The challenges of our participants did not end when they ordered. Very often people with food hypersensitivities were provided with meals that contained unsafe ingredients, so they needed to scrutinise the meal they were served.

Jessica: “I really ordered: Look, I would like the scrambled eggs, but I cannot eat anything with flour, etc. He said: Don’t worry. Then he brings me the eggs with bread. I had to send it back and then he became very upset. He said: But you only need to remove the bread from the top. I replied: No, this is not a whim, it is my disease. I cannot!” – 22, celiac disease.

When a meal includes unsafe ingredients, people with food hypersensitivities need to reorder as it is very likely that they will experience a negative reaction. Participants in our study often tried to carefully explain the reasons why the food was unsafe so the waiters and the chefs could better understand their hypersensitivities and how to care for them. Nevertheless, people with food hypersensitivities were often treated with hostility as if they wanted staff to indulge their whims, or as if they wanted to be troublemakers. The possibility of having to reorder and face the rage or retribution from the staff was yet another reason that made people reconsider eating out as the obstacles are too high for enjoying a calm meal out.

Aligned with previous research [2], participants also experienced reactions due to the lack of knowledge, training, or care from restaurant staff. This became an opportunity to use these episodes to educate staff about the importance of learning more about the products they use and the procedures they follow to prepare safe meals for people with food hypersensitivities.

Rita: “Once they had codfish cakes in the university cafeteria and I ate them. I asked [before] what they were made of, and they said only potatoes and cod. I had a terrible lactose intolerance crisis, one of the worst. Then I went there and asked again what the codfish cakes had and they said they had milk...” – 25, allergic to nuts, stone fruits; intolerant to flour and lactose.

After the allergic reaction, Rita returned to the cafeteria not only to confirm that her meal was not allergen-free but also to tell the staff about her reaction and the terrible days she had because of it. Rita recalled that the staff did not even ask her how she was feeling. However, by admitting to Rita that they were wrong and that the codfish cakes contained milk, they were open to improving their food practices to help avoid reactions. Similar to Rita, James also returned to places that caused him to have reactions so that staff could learn from these instances and better support his needs in the future.

4.6 Using medication to soften a reaction

Another reported practical strategy was the use of medication to lessen the effect of reactions. In particular, participants with lactose intolerance have an advantage over others, as they can take a pill with Lactase, to be able to digest foods with lactose.

Anna: “For example, I asked about going on holidays outside of the country, which is something I do. When you go out of the country it is even more complicated to control what you eat or don’t eat... For example, going to a wedding, people are not going to cook food without lactose... and I asked the doctor if there was some medication to take in these situations for avoiding a reaction. He said no, but as I am persistent I went to Celeiro [store where biologic food and food supplements are sold] and asked the lady and tried to inform myself. They told me about a thing which I have taken and avoided a reaction. It is called Lactase. So you take that and supposedly that decomposes the lactose when you eat. Of course, you have to take it before eating... if you take after [eating] it does not make such a strong effect. You take it and then you do not have a reaction. At least I don’t.” – 23, allergic to dried fruits; intolerant to lactose.

This incident highlights how difficult it is to travel to another country. When one does not know well the ingredients or ways of preparing food, it is much harder to prevent reactions in restaurants. To cope with this issue, Anna took the medication before a meal she suspected or knew to contain lactose, and thus could avoid a reaction. The participants we met did not use Lactase on regular basis, but kept it for exceptional situations. Nevertheless, participants tended to carry it with them, so that they could be prepared to avoid a potential reaction if they could not avoid lactose.

Participants with food allergies or celiac disease did not have a similar medication to avoid a reaction. However, if they felt they were eating unsafe food, by perceiving the taste or gained more information from others, they would immediately take an anti-histamine pill to address the potential allergic reaction and avoid impacting their lives for several days. These participants also carried antihistamine pills (or EpiPens) with them at all times, to be able to take it when needed.

5 DISCUSSION

In this paper, we reported how people with different food hypersensitivities avoid reactions when dining out. The results showed that participants manage their safety through the careful orchestration of different coping strategies developed or adopted to be prepared and take control in potentially unsafe situations. Building on these findings, we discuss the navigation practices alongside the emotional and cognitive demands of living with food hypersensitivities. We also discuss the practices of people with food hypersensitivities in relation to those of other people living with chronic conditions. We then present three design opportunities to support the design of technologies centred on the dining out issues of people with food hypersensitivities.

5.1 Navigating dining out experiences and maintaining safety

This paper shed light on how people with food hypersensitivities manoeuvre dining out experiences before, during, and after eating out. While our participants suffered from different levels and types of food hypersensitivities, their stories and experiences were quite similar – the journey of dining out was lengthy, laborious, and had a considerable impact on their social interactions and quality of life. Extensive research on food hypersensitivities has focused on medical perspectives looking at treatment, knowledge, and potential risks of these conditions [37–39, 46, 90]. The focus on knowing unsafe foods and managing treatment is important to minimise symptoms, but there is a limited understanding of how people practically cope with them [15, 27, 32, 81, 86]. Moreover, most prior work focused on specific aspects of a particular type of food hypersensitivity, which is curious considering that many people have multiple food hypersensitivities. Our study expands on this literature, looking at the practical and social consequences of these conditions with particular focus on understanding dining out experiences and the navigation practices and multiple negotiations that take place regardless of the particular condition(s) people have.

Dining out safely required a series of coping strategies to avoid or minimise the potential negative effects of having a reaction. Unlike prior work, which argued that the most used strategy for avoiding reactions was refraining from eating out [32], we saw participants engaging in complex practices to ensure they were able to continue dining out. Our findings also point out the social values participants attached to dining out and how they tried to be as safe as possible. Key coping strategies to maintain safety include bringing their own meal, eating before social events, searching information about a restaurant online, asking others for restaurant recommendations, calling a restaurant to verify the menu, correcting orders, educating staff, and bringing medication with them all the time. These coping strategies were carefully planned and executed to help participants (re)gain some control and minimise disruptions of their dining out experiences. An important element for these strategies reported by all our participants was relying on the self and embodied knowledge they have acquired over the years. This experiential knowledge came not only from their mothers, families, and clinicians but also from trial-and-error practices conducted by themselves to learn about the potential effects of reactions and the physical limitations these conditions imposed on their bodies.

To maintain safety, participants were very vigilant at all times, they had to navigate across multiple sources of information, different types of relationships, and different environments. To choose restaurants and prevent reactions, participants relied on their self-knowledge and searched online on restaurants’ websites and reviews, scrutinising the menu and asking questions in search for reassurance. Additional information came from actively monitoring the environment as well as from social interactions that were often difficult for our participants.

Navigating multiple social interactions with others such as family, friends, and restaurant staff requires complex negotiations especially due to the socially ambivalent status of food hypersensitivities [81]. These negotiations can have negative connotations and contribute to social exclusion or stigmatisation [81]. John’s

case (Section 4.1) is one example of how the restrictions imposed by celiac disease were perceived as a form of social exclusion as the condition limits John's ability to engage in meaningful social interactions with others. Aligned with previous research [2], our study shows a lack of awareness of restaurant staff in relation to food hypersensitivities and how our participants educate them on how to prepare safe meals for people with food hypersensitivities. Participants also described frustration as staff became hostile when they asked questions or requested the correction of an order. Similar to prior studies, our participants also reported episodes of "social embarrassment" as they felt that asking extra questions about food broke social norms and brought unwanted attention while dining out [11, 79]. There were also participants (e.g., Jessica in Section 4.1) who described how others felt sad or sorry for them clearly showing how our participants were victims of enacted stigma [87] by members of staff or by friends. The desire of social experience puts participants in the midst of struggles between safety and emotional wellness.

5.2 Common experiences with other people living with chronic conditions

The practices of people with food hypersensitivities show strong resemblance with the self-care of others living chronic conditions. According to Barlow et al. [9], self-care or self-management is the "individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition". Similar to many others living with chronic conditions, people with food hypersensitivities need to manage their symptoms or reactions. They engage in treatment when they take antihistamines, when they use the EpiPen, or when they take Lactase preventively. People deal with the physical and psychosocial consequences of the condition, for example, by staying home for some days to recover from a reaction, or by dealing with the emotional burden of not being able to eat at certain places. Moreover, they need to perform lifestyle changes, for example, to stop eating in certain places that can make them have reactions.

The mundane concept of self-care put forward by Nunes and Fitzpatrick [69] also seems to apply to the practices of people with food hypersensitivities. First, avoiding reactions entails great work, for example, in searching for restaurants, scrutinising the menu, or asking questions about meals. Second, the practices of participants were heavily intertwined and ingrained in daily life, because eating is at the same time a way of satisfying food needs, a source of pleasure, and a social activity. Third, similar to people with diabetes [60, 72], people with food hypersensitivities made compromises, for example, when they brought food to a certain restaurant or when they refrained from eating. In these situations, people gave priority to being with others even if that meant they could not eat food from the restaurant. Moreover, their self-care was dynamic, as people risked having a reaction when eating out, which meant that they might need to act and address it at a later point during the day. The knowledge of people with food hypersensitivities, based on trial-and-error, clinicians feedback, and advice from others with the same condition or family, also shares resemblances with the experiential knowledge developed by people living with chronic conditions [8, 73, 74, 82].

The biggest difference to the experiences of other people living with chronic conditions has to do with how people with food hypersensitivities rely on external actors and environment to maintain their health and safety. Even though people with food hypersensitivities might be taking extreme care with their health and avoid all possible unsafe foods, it is possible for an external actor to cause them a reaction and force them to take a prolonged period of time to recover. This reliance on external actors or environment is similar to some of the other food-related conditions, such as diabetes and irritable bowel syndrome (IBS), especially when others cook for them or when they eat out. However, people living with diabetes can exercise, eat more, or use insulin, to help them address the effects of an unorthodox meal; while people with food hypersensitivities might not even realise the food they were served is unsafe before eating it. Moreover, the variety of food hypersensitivities and the potential coexistence of multiple hypersensitivities often leave these individuals with even less control than people living with diabetes or IBS.

The multiple similarities of the practices of people living with food hypersensitivities and other people living with chronic conditions, leads us to think that existing self-care technologies [70] might prove appropriate for these users as well. The next section describes specific opportunities for technology stemming from our fieldwork, nevertheless, we encourage the community to study and assess whether people with food hypersensitivities can also benefit from self-care technologies.

5.3 Opportunities for technology design

Digital technology design has the potential to support people with food hypersensitivities in dining out. Although policy and social-system changes are necessary to enhance dining out experiences, these changes may not cover all instances and challenges people with food hypersensitivities encounter. Complex restaurant workflows can prevent staff from closely complying with regulations, which may increase the health risks for people with food hypersensitivities. In fact, our participants felt that they had to actively minimise their risk of having a reaction, even in restaurants recommended by others – participants had to be sure they were safe. To better support people with food hypersensitivities in dining out, in settings with strict or loose regulations, e.g., when travelling, we offer design opportunities drawing on our findings and prior literature.

5.3.1 Supporting the practical knowledge development of people with food hypersensitivities. Our participants had in-depth knowledge about how to dine out safely. As described in Section 4.3, after years of trial-and-error, participants achieved a state in which they know what they can eat, where they can eat, how to assess if an unknown place is safe for eating, and how to deal with reactions. However, developing this practical knowledge took years of experimentation and reactions. To improve the quality of life of people with food hypersensitivities, technology could support the development of practical knowledge sooner. For example, technology could support more rigorous self-experimentation [50], by enabling people to systematically track what they ate, what eating contexts they were situated, and when they had reactions. Expanding on prior work focusing on tracking different aspects of eating decisions or

routine behaviours (e.g., diabetes [92], Irritable Bowel Syndrome [49], or migraine [88]), technologies supporting individuals with food hypersensitivities could focus on the variety of aspects about eating (e.g., meal preparation, serving process, or hygiene practices) that potentially contribute to their reaction.

Another opportunity would be to create technologies that help instil best practices for avoiding reactions when dining out. As described in Section 4.2.2, participants often knew very few others with food hypersensitivities, from whom they could seek advice. As a result, participants often had to learn and develop coping strategies on their own, such as how to observe a restaurant, how to interact with restaurant staff and ask questions, how to manage and respond to feelings of embarrassment and enacted stigma by others, as well as other strategies described in the paper. Web forums [83], PatientsLikeMe [99], and health video blogs [54], have been successful in providing information and emotional support between people with similar conditions, and systems supporting people with food hypersensitivities could build on these successful designs to share experiences and provide practical steps and exercises to help improve one's skills.

5.3.2 Including food hypersensitivity information in online restaurant reviews. People with food hypersensitivities valued the advice from others with similar conditions, but since they knew few others in those situations, they rarely received or shared advice. As a consequence, participants needed to do in-depth assessments of the safety of all new restaurants they planned to visit, from thoroughly reading online reviews (Section 4.2.1) to physically assessing the environment (Section 4.3.1). To better support the needs of people with food hypersensitivities, one could leverage and adapt existing restaurant review systems to include information about food hypersensitivities. Similar user-driven review systems have been proposed in prior research, such as friendly locations to support breastfeeding [7] or to accommodate people with hearing loss [71]. Similar to HearAdvisor [71], review systems for food hypersensitivities should include needs and challenges specific to individual conditions. For example, the profile of the reviewer could include information on their hypersensitivities, reactions, and levels of reaction, so that other users could filter relevant advice and know the characteristics of those writing the reviews. As suggested by users of Feedfinder [7], such systems could start by populating information from existing systems, such as AllergyEats and Biteappy, but allow users to create reviews relevant to their individual experiences. For example, in the platforms that display menus, users with food hypersensitivities should be able to mark the meals with unsafe ingredients, drawing either on their reactions or on the discussions they had with the staff at the restaurant. Moreover, one could imagine adding review fields for rating the staff knowledge or willingness to adapt meals to people with food hypersensitivities. Besides serving as support for people with food hypersensitivities, prior success in systems like Feedfinder also showed that these systems could also support public awareness and constructive conversations in the society[7]. In that sense, by including additional data about food hypersensitivities, restaurants would have additional motivation to improve their service and the training for staff.

5.3.3 Increase information and support about food hypersensitivities for restaurant staff. As described in Sections 4.3.3 and 4.5, many

participants mentioned the lack of knowledge of staff about food hypersensitivities, and how that impacted their dining out experiences, influencing their safety, or even the decisions to dine out. The literature presents some resources supporting sporadic staff education (e.g., training event [6], posters [85], and pamphlet [18]), but there is a need to provide more effective and efficient training. For example, promoting simple practices, such as personal and environmental hygiene, unsafe food ingredients identification, and menu designs that highlight unsafe ingredients can significantly improve safety and the eating experience of individuals with food hypersensitivities. Since there is a wide variety of food hypersensitivities, technologies could also support checklists and summaries for different types of food hypersensitivities. For example, when learning about a customer's hypersensitivities, staff could quickly check which food may include specific ingredients, what precautions should be made in the kitchen, and potential adaptations in preparing and serving the meal. More research is needed to understand restaurant workflow, staff existing experiences, and their challenges dealing with food hypersensitivities. However, these ideas could potentially improve the safety and dining experience of individuals, while supporting restaurant staff.

6 CONCLUSIONS AND FUTURE WORK

This paper reported an in-depth interview study investigating the dining out practices and experiences of 19 participants who live with food hypersensitivities. We described participants' challenges, constraints, and the impacts of living with food hypersensitivities, as well as the way participants coped with these issues. While some participants decided to play safe and select one of the few safe meals available on the menu, other participants invested a lot of time and effort investigating restaurant menus, seeking advice from others, correcting meals and even educating staff. All these preparatory and precautionary strategies and on-the-fly vigilant practices in restaurant's environments helped participants to get reassurance and enjoy safer dining out experiences. By discussing their everyday navigation practices across different people and environments, we provide in-depth understandings of the practical, social, and emotional impact of food hypersensitivities on our participants. We also present opportunities for design at the individual and restaurant level to enhance the dining out experiences of people with food hypersensitivities.

While our findings present several coping strategies that can inform the design of technologies to support the learning of food hypersensitivities and enhance dining out experiences, these are far from complete. Future research should continue investigating the needs, practices, concerns, and coping strategies of people with food hypersensitivities and how technology could be designed to better support them to improve dining out experiences. In addition, future work should investigate the perspectives, practices, and challenges faced by restaurant staff and how technology can support them to improve their knowledge to help them cater for the food needs and dining experiences of people with food hypersensitivity. Last but not least, field studies are needed around the deployment and use of novel systems to evaluate the impact of technology and design choices in minimising disruptions in social activities and positively impacting the quality of life of people with food hypersensitivities.

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