

**The food allergy journey: understanding the lived experiences of food-allergic consumers as a pathway towards improving their wellbeing**

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**ABSTRACT:**

While consumer vulnerability can affect anyone, it is recognized that some groups are at a higher risk. To ensure market and policy responses aimed at at-risk groups facilitate control it is important to understand their experiences and behaviour. In this article, we explore the experiences of food-allergic adults and the implications of their experiences with food allergies in terms of consumer vulnerability. We held four focus groups with food-allergic adults where they could openly discuss their lives with food allergies. The food-allergic adults in this study experienced consumer vulnerability at different stages of their lives (e.g., during their journey to diagnosis, the post-diagnosis adaptation period, and their ongoing lives with food allergies). We identified food allergy specific factors that influenced their experience of vulnerability in different contexts. These included individual characteristics (e.g., food allergy type, and symptom severity), individual states (e.g., stage of adaptation to food allergy, and level of knowledge acquired), and external conditions (e.g., discrimination/stigmatization, cost and availability of allergen-free food, labelling of food, and the knowledge level of café and restaurant staff). Understanding of these factors presents an opportunity for policy development and market changes that facilitate reestablishment of control to food-allergic consumers and improve their wellbeing.

**KEYWORDS:**

Food allergy, lived experiences, consumer vulnerability

Transformative consumer research recognizes that the wellbeing of consumers is important and can only be improved by studying problems that are meaningful to consumers and translating the findings for their benefit (Ozanne et al. 2011). In this research, we used a transformative approach to understand life with food allergies. Our aim was to explore the experiences of food-allergic adults and understand the implications of life with food allergies in terms of consumer vulnerability. Our overall goal was to improve the wellbeing of food-allergic consumers.

Consumer vulnerability is a term used to describe the experience of a loss of control and dependence on external factors to create a fair marketplace (Baker et al. 2005). For example, if an individual is unable to achieve their consumption goals due to circumstances that are beyond their control. The model of consumer vulnerability developed by Baker et al. (2005) shows how individual characteristics, individual states, and external conditions each contribute to the experience of consumer vulnerability. Food-allergic consumers are likely to experience consumer vulnerability because of their food allergy and society's response to their food allergy. By understanding the experiences of food-allergic adults, it will be possible to learn if consumer vulnerability is in fact experienced and how this can be addressed to improve wellbeing among food-allergic consumers.

Our approach was to facilitate an open discussion within a diverse group of food-allergic adults (e.g., range of food allergies, symptoms, ages, socio-economic, and cultural backgrounds). We employed a qualitative method (focus groups) to enable the discussion of a range of contrasting ideas and perspectives. This approach enabled us to understand the problems that are relevant to food-allergic consumers. The results of this research can be used by food-allergic consumers, support groups, policy makers, food businesses (e.g., food

manufacturers, cafés and restaurants), and other interested parties to improve the wellbeing of food-allergic consumers.

### **Background to food allergies**

Food allergies affect 2-10% of the general population and appear to be increasing in prevalence (Sicherer 2011). Variation in inclusion criteria, methods used to confirm food allergy, and study population characteristics contribute to the differences in published prevalence data (Sicherer 2011). Symptoms of food allergy usually affect the skin, respiratory tract, gastrointestinal tract, or can be systemic (i.e., affect multiple organ systems). The most severe form of food allergy results in anaphylaxis. Anaphylaxis is defined as “a severe, potentially fatal, systemic-allergic reaction that occurs suddenly after contact with an allergy-causing substance” (Metcalf et al. 2008). Anaphylaxis due to food allergy generally involves multiple organ systems, often including severe respiratory and cardiovascular symptoms. Food-induced anaphylaxis accounts for approximately 30% of anaphylaxis cases presenting to hospital emergency departments (Liew et al. 2009; Sicherer 2011).

Food allergy is a chronic health condition that is managed by dietary avoidance of the allergen/s and treatment with an injection of adrenaline in the event of exposure to the allergen (for those with anaphylaxis). Quality of life research is particularly important in the case of chronic conditions where treatments do not provide a cure for the problem, but rather provide alleviation of symptoms to make the condition easier to cope with. If a treatment has a high impact on a patient’s quality of life, it can have a number of

implications for their long-term health, for example, by reducing treatment adherence and by increasing the risk of stress-related health problems (Sapolsky 2004; Martin et al. 2010). Treatment adherence is important because good management of illness is linked with fewer symptoms and better functioning, resulting in lower use of health-care services (Lyons and Chamberlain 2006).

Management of food allergies is challenging and has been shown to significantly impair the health-related quality of life of food-allergic consumers (Sicherer et al. 2001; Marklund et al. 2006; Östblom et al. 2008; Flokstra-De Blok et al. 2010). Research comparing food-allergic individuals to those with other chronic health conditions found the health-related quality of life of food-allergic individuals to be poorer than the health-related quality of life of diabetics (Flokstra-De Blok, Dubois et al. 2010). This indicates that dealing with the avoidance of allergenic foods from the diet may be more problematic than the medical, dietary and lifestyle changes involved in the treatment of diabetes.

Food allergy can also be considered a form of disability as food-allergic individuals are faced with social barriers to participating fully in society (Pitchforth et al. 2011). However, it is a hidden or 'invisible' disability, which makes it more difficult for those affected to gain the cooperation of others. Insight into the perspectives and experiences of food-allergic consumers will foster a better understanding and a greater ability to empathize among non-food-allergic individuals (including health professionals, food service providers, and the general population). In addition, other food-allergic consumers can benefit from this insight through the knowledge that they are not alone in these experiences and by learning about the coping strategies that others have found helpful.

## Methods

Focus groups lasting 90-150 minutes were held with four different groups of food-allergic adults (3-11 participants per group, total n=29). Participants were recruited by advertising the study in the community and through allergy support organisations in New Zealand. The focus group participants were involved in an in-depth discussion about their food allergy-related experiences. A non-directive approach was taken by the focus group facilitator to allow the participants' views to emerge spontaneously. Initial instructions were given to explain the purpose of the focus group and examples of core topic areas of interest were presented but it was emphasized that the participants were free to discuss any issues related to their food allergies, even if they did not fit any of the core topic areas. The role of the facilitator, to keep the discussion going and to keep it focused rather than acting as an active participant, was explained.

A descriptive summary of the participants is given in Table 1. All participants self-reported they had a medically diagnosed food allergy to one or more foods. For the purpose of this study, food allergy was defined as a reproducible adverse reaction resulting from an immune-mediated response to a food or food component. Our definition was based on the World Health Organisation revised nomenclature for adverse reactions to food (World Health Organisation International Food Safety Authorities Network (INFOSAN) 2006).

**Table 1. Characteristics of focus group participants**

Pseudonym	Male/Female	Age	Food Allergies	Symptoms	'Something positive' quote
Valerie	Female	43	Seafood, tree nuts, bananas (plus milder reactions to other fruit)	Anaphylaxis	"Going to friends' houses who know about your allergies . . . you don't have to worry at all . . . that's always a positive experience."
Caroline	Female	49	Legumes (incl. peanuts, soy beans), cow's milk, goat's milk, sheep milk	Anaphylaxis	"I have wonderful cholesterol."
Angela	Female	39	Cow's milk, shellfish	Gastrointestinal	"With the high prices in dairy it's getting easier to find dairy free food."
Mary	Female	55	Eggs, mustard	Anaphylaxis	"My kids haven't got any allergies."
Graham	Male	48	Tree nuts	Anaphylaxis	"Hard to think of positives. I guess . . . emergency departments have always impressed."
Theresa	Female	41	Gluten (biopsy-confirmed coeliac)	Chronic tiredness	"I quite like cooking and I buy a lot of cook books so it's an excuse to buy more cook books."
Doreen	Female	60	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, skin reaction	"I think the most positive thing for me . . . is that we've been acknowledged and that restaurants etcetera are catering for us."
Keith	Male	72	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, skin reaction	"Instead of being 45 kgs I'm now back to 60. And I think that was a second go at life."
Patrick	Male	48	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, skin reaction, mouth ulcers, irritability	"In Canada two months ago all three of us got well over 3 weeks. They had all this good food in restaurants and it was great."
Claudia	Female	20	Peanuts, tree nuts, seafood, shellfish, eggs, chicken	Anaphylaxis (egg/fish/shellfish)	"As an overall theme I suppose I find my food allergies have actually made me who I am . . . I've had them since I was a child"
Patricia	Female	25	Cow's milk	Gastrointestinal, skin reaction, itchy eyes, nasal congestion	"A positive is that I'm allergic to chardonnay which means I don't have to drink it."
Carmen	Female	50	Gluten (biopsy-confirmed coeliac)	Gastrointestinal	"My mother had serious osteoporosis but was never diagnosed . . . with coeliac disease and because I've got the advantage of having been diagnosed, hopefully that will be something that won't happen to me."
Deirdre	Female	48	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, respiratory	"My daughter that isn't [coeliac] and my partner are like the food police. Whenever we go out . . . they double check and triple check."
John	Male	43	Cow's milk, eggs, soy beans	Anaphylaxis (egg), gastrointestinal (soy), respiratory (hay fever-like) (cow's milk)	"Dairy and egg contribute to most of the chocolate cakes and biscuits . . . I'm a lot thinner than I used to be"
Sophie	Female	23	Gluten (biopsy-confirmed coeliac)	Gastrointestinal	"Went to a café had the most delicious chocolate blondie and a chocolate brownie"
Jia-Li	Female	32	Peanuts	Respiratory, skin reaction, itchy throat, eyes (red, watery & itchy)	"Probably the most positive thing out of this is that I'm more aware of what I eat and I think I eat more healthy as a result."

**Table 1. Characteristics of focus group participants, continued**

Colette	Female	22	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, skin reaction, anaemia	"The way I found out I was gluten intolerant was I could go on like fainting when I was attempting to do sport and I don't do that anymore so that's good."
Tom	Male	46	Legumes (beans, peas, peanuts), eggs, shellfish, seafood	Gastrointestinal, respiratory, skin reaction	"Now the eczema's . . . basically gone."
Lin	Female	58	Tree nuts, soy beans, cow's milk, gluten	Anaphylaxis (tree nuts, soy beans, cow's milk), gastrointestinal (gluten)	"I learnt a hell of a lot more about food than I knew."
Sandra	Female	28	Wheat	Gastrointestinal, disorientation & anxiety	"It's put me into my career path."
Oscar	Male	77	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, respiratory	"I've managed to help a lot of other people who've had similar troubles with eating disorders, and then diagnosed with coeliac disease."
Charlene	Female	55	Gluten (biopsy-confirmed coeliac)	Skin reaction (swelling), anaemia	"All my friends are aware of it now."
Lisa	Female	39	Gluten (biopsy-confirmed coeliac)	Gastrointestinal	"Last Easter we went to Christchurch . . . I thought I won't be able to have a hot cross bun. And I got there, and my mother-in-law had bought a hot-cross bun."
Sally	Female	36	Peanuts, tree nuts, tomato, pineapple, kiwifruit, spirulina, gluten	Anaphylaxis, gastrointestinal (gluten)	"I've got very good at talking to strangers in cafes and restaurants and explaining that if you just take the tomato off the salad, I'm still gonna swell up and die on the ground."
Phyllis	Female	31	Gluten (biopsy-confirmed coeliac)	Gastrointestinal	"I play hockey. And I've just noticed such a difference. I used to just feel like I was dragging myself around the field . . . now I'm starting to get a bit more energy."
Kim	Female	44	Gluten, shellfish, seafood	Gastrointestinal, skin reaction	"Indian food's almost always gluten free."
Simone	Female	45	Gluten (biopsy-confirmed coeliac)	Anaemia	"I was sitting at the gastroenterologist. And I said to him, so is it hereditary? He said yes . . . I said, so my daughter who has slightly low iron levels . . . So she's been diagnosed as well, at thirteen, instead of waiting until forty-five like I did."
Hannah	Female	54	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, tiredness	"I can still eat chocolate."
Amy	Female	33	Gluten (biopsy-confirmed coeliac)	Gastrointestinal, skin reaction, mouth ulcers	"Shortly after I was diagnosed, I went out for dinner with my husband . . . we went out to a restaurant and it was so fantastic . . . it kind of gave me confidence."

Many of the participants so enjoyed the opportunity to talk with people who had similar experiences that it was difficult to stop the focus group at the planned two-hour limit. In fact, one focus group continued a further 30 minutes because the whole group was in consensus about wanting to continue the discussion. After the focus groups, several participants exchanged contact details and/or continued to talk among themselves before leaving.

Audio and video recordings were used to prepare verbatim transcripts of the focus group sessions. Thematic analysis of the focus group transcripts was completed using the NVivo 9 software package (QSR International 2010). The main aim of the thematic analysis was to provide a rich description of the entire data set. An inductive approach was taken, identifying themes and coding the data while reading through the transcripts (Braun and Clarke 2006). As the coding progressed, themes were refined and grouped into main themes and sub-themes.

This study was approved by departmental ethics committees (Department of Food Science, and Department of Psychology) at the University of Otago. Written informed consent was obtained from the participants prior to their participation in the research.

### **Findings**

These findings tell the stories of the 29 food-allergic adults who participated in the focus groups. The participants shared their experiences with food allergies during the focus



groups, including their journey to diagnosis, their reaction to the diagnosis, post-diagnosis adaptation, ongoing life with food allergies, and their experience of symptoms.

*The journey to diagnosis*

Discussion about when their food allergies began revealed differences in the experiences of those with severe immediate reactions (e.g., anaphylaxis) and those with mild to moderate reactions. For participants with anaphylaxis, the identification of the culprit food was relatively straightforward, as Graham explained:

“I was 3 years old. Went to the supermarket, touched the walnuts in the supermarket got big puffy eyes. And anaphylactic shock when I was 11 at a party . . . teenage years, experimenting with cashews, ‘Oh I’m not allergic to them’, ‘Oh yes I am’ [laughs].”

Not all of the participants with anaphylaxis developed food allergies as a child, although some started with milder food allergies in childhood. Valerie, who was diagnosed with anaphylaxis in early adulthood, shared her thoughts about what, in hindsight, were possibly milder reactions to the same foods as a child:

“I started having allergic reactions when I was about 21 . . . Banana was first and I had a number following that . . . But interestingly in my baby book it said that I didn’t like banana when I was given it once as a baby and, and I had never eaten it until I was 21 again so maybe I had a minor allergy to it then or something. And the same with nuts. I remember as a child eating a

piece of fruit cake with nuts in it and having a horrendous feeling in my mouth and having to clean my teeth. When I was about seven. And my mum saying ‘Oh don’t be so stupid’ . . . I was probably having a reaction then but, nothing else again. I avoided nuts with nothing else till I was 21.”

Mary described an increase in the severity of her reactions over time:

“I’m allergic to eggs and mustard. Have been all my life. I get anaphylactic shock now but it sort of started off as just severe vomiting and diarrhoea and I still get that plus it goes on to anaphylactic shock. It just seems to be getting worse every time I get caught out.”

In contrast to the participants with anaphylaxis, those with other forms of food allergy described indistinct symptoms that were often more difficult to diagnose. In some cases, an alert general practitioner sent away for the right tests resulting in a quick diagnosis, as Theresa described:

“I just didn’t really have any of the extreme symptoms that people have but I’d just been feeling tired for a long time and I thought ‘Oh my iron levels are low.’ So I went to the doctor, had some tests . . . I think my particular GP had had a few people with coeliac unexpectedly so she ticked the box.”

Simone was diagnosed solely because of the proactive approach of a gastroenterologist she saw for a different problem:

“Entirely coincidentally I went to a gastroenterologist for diverticulitis, so that’s lower bowel. And he automatically tests all his patients for coeliac disease when he does post-op blood tests, which is I think very proactive.”

In many cases, however, the road from start of symptoms to diagnosis was long and difficult. Participants described feeling unwell for a long period of time and attending numerous appointments with their doctor before learning the cause of their symptoms. For example, Sandra described her experience during the 18 months of trying to find the cause of her symptoms:

“I just started feeling really sick every day and went to the doctor on a regular basis and she couldn’t find anything wrong with me . . . After a lot of to-ing and fro-ing and I just stopped eating coz every time I ate I got sick so I stopped eating and lost 12 kgs in about 3 months. Didn’t feel sick anymore [laughs]. And eventually went had blood tests and skin prick tests and determined that I had an allergy to wheat.”

Oscar described struggling with symptoms from childhood right through to age 53 before finally being diagnosed with coeliac disease:

“I’ve experienced a lengthy period of illness. And when I say a lengthy period of illness, from the age of seven to the age of fifty-three.”

He went on to describe multiple doctors’ appointments during childhood:

“I was seven years of age and it started. I lost weight and a lot of weight. And mother took me to various doctors. And ‘Oh, he’s got a nervous stomach.’ ‘He’s got irritable bowel syndrome.’ And so the story went on.”

Oscar’s struggle for answers continued through adulthood:

“We lived in different parts of the country. And so I was with different doctors each time. And all the doctors came up with the same diagnoses – irritable bowel syndrome, you know. And it wasn’t until I attended a local doctor who said, ‘There’s no such thing as trouble with . . . eating disorders.’ ‘Eat what you like’, he says. ‘It’s all up here, all up here’ [pointing to his head]. So he sent me to a psychologist [laughter]. I attended the psychologist in [place omitted] in 93 and uh. He said after an hour interview, ‘There’s nothing wrong with you.’ He said, ‘I’d like you to see a, get an alternative medical opinion’, which I did.”

At this point Oscar finally saw a doctor who was able to identify the problem:

“And he put his finger on it right away. And he sent blood tests. And then I went to [name of gastroenterologist] . . . and had a biopsy.”

This struggle with symptoms without diagnosis took a psychological toll as well as a physical one, as participants described starting to doubt themselves. For example, Lin described:

“You begin to wonder whether it’s all in your head.”

### *Reaction to diagnosis*

Most participants felt a sense of relief when diagnosed, particularly those who struggled with symptoms for a long time. For example, Phyllis described:

“I got diagnosed, yeah, in March, which is quite a relief really. Coz I think, you know. You start to sort of, all these symptoms. You start to think something seriously is wrong. Doctors are saying, ‘Oh it’s just IBS [irritable bowel syndrome]’ or something like that. But, it’s just great to get a diagnosis.”

Those who did not have significant symptoms did not share this feeling and reacted to their diagnosis in a very different way. For example, Charlene described stages similar to those of grief/loss in their reaction to the diagnosis (e.g., denial, bargaining). She described rebelling against the diagnosis and justified not following the diet based on the doctor having said she is not that bad:

“The doctor rang me up and said, ‘You’ve got coeliac’. So I rebelled! I really rebelled. Because, um, you know, it was just, I’m just new . . . So, um, it was kind of like ‘Well, he told me that I’ve still got villi. It’s not that bad.’ ‘You’re on the lower end of the spectrum, and if you don’t do anything, you’ll probably be okay. But, now that you know that you’ve got it, you should probably do the diet’, you know.”

*Adjustment to a new life*

For those who had suffered extreme symptoms and/or for long periods of time, the biggest initial post-diagnosis change was a positive one. Participants described a drastic improvement in their health. For example, Oscar described feeling better within weeks of changing to a gluten free diet:

“Within two weeks, two weeks [said with emphasis] of coming off gluten . . .

I was a different person. A totally different person. Two weeks.”

In some cases it seemed like the participants felt they should not complain about difficulties they had adjusting to a new diet and lifestyle as it was so much better than having to continue to feel unwell. However, it was evident from the discussion that difficulties did arise in adjusting to the dietary changes. For example, Sandra explained having to change eating habits and sometimes reverting to old habits without thinking:

“I had to reprogram the, the clock. And I remember after I’d had my diagnosis for about 6 months, we had a shared morning tea at school and there were bread buns and a packet of chippies. And I went to make myself a chippie sandwich and went like this [indicates taking a bite from the sandwich]. And then actually had to spit it out again because my natural reaction, for whatever reason, had lapsed for a second. And I went to go and eat it and then I went ‘That was dumb!’”

The availability of information about allergen-free eating (e.g., recipes, what foods are safe/not safe) and access to support from patient organisations (e.g., ability to discuss issues with others who understand) were found to be helpful in the adaptation process. For example, Amy explained:

“The thing that made such a difference for me when I was first diagnosed . . . Things like . . . the magazine from the coeliac society. But, also, just the wealth of resources that are available on the web. And even at times it can feel overwhelming. There’s such good information. People write lots of good recipes and all that sort of stuff. It was really about being proactive and finding the resources that I needed to find information. But also, sort of support and camaraderie and all that sort of thing.”

Some felt they were left with little or no support during this transitional period, for example Tom explained:

“Once you’ve got some sort of diagnosis . . . what is there for you? I mean, as adults. I think as children it’s probably better. As parents of children it’s probably better. But it’s adults.”

A number of participants revealed that in the early stages after diagnosis they were tempted to eat some of the foods they missed, while for others the fear of worsening symptoms kept them from taking risks. The following quotes illustrate this:

Charlene: “My doctor said to me that I’m on the lower end of the spectrum, and if I didn’t do anything, I’d, probably nothing would happen. So I keep thinking to myself, ‘Will I have this piece of cake?’”

Sally: “I did that once . . . French pie, which I missed. And I was sick for about four days, like really sick.”

Kim: “As you get older you’re at such an increased risk of all sorts of... all those abdominal cancers. That would be my criteria for not eating a gluten diet. Is because I don’t wish to increase my . . . chances of any of those kinds of . . . cancer and stuff.”

Sally: “If you have what you can now and if you can manage the symptoms then I guess that’s your option. But you might just be really sick later on.”

### *On-going life with food allergies*

Participants described positive aspects of how their lives had been shaped by their food allergies as well as negative experiences (restrictions). In general, life with food allergies can be difficult and the participants felt it restricted their lifestyle in many ways. In addition, they expressed concern about the effects on the lifestyle of immediate family (e.g., their partner and/or children).



*Having food allergies has shaped my life path*

One positive result of having food allergies for some was how it had influenced their choices in life. For example, Claudia explained that having food allergies has shaped who she is as a person and what career path she decided to follow:

“I find my food allergies have actually made me who I am . . . I wouldn’t be the same person or studying the same thing without them.”

Sandra believed that having an undiagnosed food allergy as a teenager kept her from following her peers down the path of going out and drinking (alcohol):

“When I was first diagnosed I was a teenager. And because I was feeling nauseous all the time I never got into the drinking stuff because I saw absolutely no benefit in going and drinking and making myself feel sick when I already felt sick thank you very much. . . . so I actually had a completely different teenage experience from everybody else.”

Several participants believed that having food allergies made them more health conscious and saw this as a benefit of their condition. For example, John described having to do without cakes and biscuits as beneficial for his weight:

“I guess the biggest benefit is um dairy and egg contribute to most of the chocolate cakes and biscuits and things that I shouldn’t eat [laughter] so I’m a lot thinner than I used to be.”

Jia-Li described an increased awareness of what she was eating:

“Probably the most positive thing out of this is that I’m more aware of what I eat and I think I eat more healthy as a result.”

*Having food allergies restricts my life*

Negative experiences included difficulties finding suitable foods to eat when out (e.g., at restaurants, cafés, when travelling), extra time spent sourcing and preparing food, and a lack of understanding from others, which for some led to a restricted social life. These and other issues related to living with food allergies have been discussed in more detail in another publication (Peniamina et al. 2014). In addition to discussing the issues they faced in everyday life, the participants also shared how they dealt with these issues to find a balance between keeping safe and minimising the restriction on their lives. This is illustrated by the following conversation about the issue of ‘may contain’ labelling which revealed how the participants felt about ‘may contain’ labelling, how they dealt with it, and the level of risk faced by those with anaphylaxis:

Angela: “It is getting better but a lot of the places still cover themselves by saying ‘Also manufactured in a . . . .’”

Mary: “Yeah, yeah.”

Caroline: “Oh this one really irritates me.”

Valerie: “Coz it means you can’t. If I actually avoided everything that said ‘may contain traces of nuts because it’s made in a factory that’ . . . I actually ignore those . . . probably I’m putting myself at risk but I just, I wouldn’t eat anything.”

Caroline: “Well exactly!”

Valerie: “Obviously they’re covering themselves, aren’t they?”

Caroline: “. . . sago the other day. May contain traces of peanuts. I mean, we can’t even buy a basic raw product. I mean we spend hours cooking from scratch, and you know, even the basic products say ‘may contain’, which is like, I’d starve.”

Valerie: “Yeah, yeah.”

Graham: “I won’t. I won’t eat ‘may contains’ if I’m, remote. If I’m in town I’ll do it. If I’m miles and miles . . . it was a bar of chocolate we were eating, tramping, we were 2 days from anywhere. We had the first half of it, but we were eating it at night. Hoh, the next day we cracked it open . . . had a big nut sitting there, it’s just phew, close! And we were two days from help. I just would’ve had to lie down . . . sleep . . . Close to home I don’t worry about it.”

The use of ‘may contain’ labelling as well as the widespread use of some common allergens in processed food products has restricted the participants’ ability to make food choices based on their preferences. This is illustrated by the following conversation where participants discussed the increasing restrictions on what foods they can safely choose to eat.

Caroline: “I remember you know, having lists of all the things I couldn’t eat but also all the lists of things I could eat, which is how I know that,

you know, dairy's crept into our, you know, processed foods so much coz it used to be a list about that long of bought biscuits, sweet biscuits I could eat now there's not a single one I can eat."

Mary: "Isn't that frustrating! You know, they start cutting down what you could eat."

Caroline: "Yeah. And you know, okay bought biscuits isn't a big deal, except for when you're travelling, then it's really good to be able to have something that gives you a bit of energy."

A limited supply of suitable allergen-free foods was a problem for many participants, particularly those with multiple food allergies. This is illustrated by the following quotes:

"That feeling of going through a supermarket and just going aisle after aisle and there's nothing ..." (Tom)

"Like you said, you go down the, go down the aisles and you, you basically come back out with an empty basket." (Lin)

Participants also discussed restrictions on food choice because of the price of allergen-free food products, for example, Keith expressed:

"Everything costs extra you know plus you miss out on certain things because of the cost."

Theresa described the restriction on choice when eating at restaurants:

“It’s almost a case of what can I eat? This or that? Okay well I’ll have that then.”

Valerie, who has anaphylaxis, described having the choice taken away from her at some restaurants where they refused to serve her because of her food allergy:

“I’ve had the experience where people have said that ‘Oh well I’m not prepared to give you anything to eat.’ Anything! You know. Like dessert, ‘I’m not prepared to give you dessert just in case.’ It was like well, ‘Can I not just have an ice-cream please?’ [Laughter]. Ice-cream, you know? Coz I’m pretty sure that’s gonna be okay, you know, with nuts, you know. I, I would eat vanilla ice-cream. But they’re like ‘Well no I think you should just not have a dessert.’ So they’re kinda making the decision for you coz they’re scared, you know that you might sue them or something.”

The conversation continued with a discussion of restrictions, which included eating out, drinking wine, and travel:

Graham: “The only thing I feel really restricts things is eating out . . . Can’t just walk into a restaurant and order anything on the menu. It would be nice.”

Mary: “Or even actually being able to go and have a drink because they’ve slipped egg into just about every wine imaginable . . . I can’t even opt for a wine now.”

Valerie: “I think it’s affected my choice of where I travel a bit as well. Coz there’s ... I’ve had reactions on a Fijian Island, having a romantic beachside meal and had a reaction from it and then ... a mountain village in Cyprus, you know, so I, you know, I actually think now if I go to Fiji I’m gonna go somewhere that I know will have more of an English kind of um sort of menu options ... and now obviously with my daughter as well I’ve gotta think about that and it sorta makes you think well actually maybe we won’t go there, you know ...”

Graham: “I wouldn’t go to China or something like that”

Valerie: “It’s a real shame though coz it feels like you kind of restrict where you ...”

Gerry [overlapping]: “Yeah, definitely.”

Mary: “I’ve never even considered travelling, because of it. Um, Ozzie’s [Australia] about as far as I’ll go. I wouldn’t even think about travelling any further.”

The impact on ability to travel and/or risk involved in travelling was discussed in other groups also. For example, Doreen revealed that she experienced difficulties with keeping a gluten free diet while travelling: “I travel a lot ... and there are times where I had to eat food with gluten in and suffer the consequences.”

Worry about accidental exposure (e.g., due to cross-contamination) also led to restrictions in social activities. Participants described avoiding certain social situations or

reduced enjoyment of social events due to stress/anxiety about the consequences of accidental exposure. For example, Graham described a reduced involvement in some social occasions:

“Anything to do with food, you don’t join in as much. That’s just life. It’s just too stressful [laughs]. [Expressions of agreement from other participants]. So it’s mildly socially limiting but not . . . not drastically. And I guess, for me, now I’m not that interested when people are going, talking about wonderful food and wonderful food [laughs]. Go for a bike ride instead or something, do something else. I think I replace those activities with something else so it doesn’t worry me all that much.”

John felt limited in terms of being able to spontaneously go out to eat:

“I can’t just go out and eat at lunchtime.”

Simone and her family avoided eating out because of the stress:

“And we don’t go out for dinner . . . The enjoyment of going out for dinner is outweighed by the stress of what it’s gonna be like so we just don’t go out. I mean, in some ways maybe we’re restricting our life . . .”

### *Understanding the experience of symptoms*

The participants in this study described a variety of different symptoms including skin reactions, respiratory symptoms, and gastrointestinal symptoms, as well as some with anaphylaxis. Quotes describing food allergy symptoms have been included to improve

understanding of what it feels like to live with recurring food allergy symptoms and/or the fear of a severe reaction. For example, Caroline explained her experience of allergic eczema:

“My worst problem is really absolutely appalling eczema that people really don’t have an understanding of. They have an understanding of really bad asthma but they think eczema’s just a little bit of itchy you know on your elbows and behind your knees. But actually . . . you’re totally um swollen . . . not able to walk . . . I don’t actually tell people I have that because people don’t understand it.”

Patricia described a combination of symptoms after eating foods containing cow’s milk:

“Not being able to breathe because my sinuses are so blocked. My, I can’t see anything because my eyes are so watery and I need to go to the toilet every hour on the hour.”

Gastrointestinal symptoms were often extreme and debilitating. Several coeliac participants shared their experiences of gastrointestinal symptoms after eating something containing gluten. For example, Amy found it difficult to function when she experienced symptoms:

“I was sooo sick I couldn’t even function!”

Kim described symptoms similar to food poisoning as a result of her food allergy:

“Throwing up into a bucket, with the other end going.”



Deirdre explained how her symptoms would be particularly bad for the first day but that it would take a long time for her body to get back to normal after an accidental exposure to gluten:

“I’m sick within two hours. And I’m sick, vomiting . . . like really bad for about 8 hours and then I’m unwell for at least a month.”

Claudia, who has anaphylaxis, also described gastrointestinal symptoms as part of her reaction:

“I get crippling, crippling stomach pain as well with my allergies . . . like to the point where it’s like ‘Oh I wanna die!’”

Lin, who has anaphylaxis, described feeling scared and embarrassed when she experienced a reaction while out in a public place. Based on the description she gave of that reaction it was a severe allergic reaction, yet she described it as being much less serious than an anaphylactic reaction, which she described as terrifying:

“I can remember having an absolutely big um big splat at a posh restaurant and being too scared to tell anybody about it but literally saw stars and was hanging onto the towel rail trying not to pass out. Um the anaphylaxis one was quite a bit more serious, everything shut down and I actually, by the time I got to hospital I couldn’t speak. . . . Anaphylaxis is um is terrifying . . . and um happens so quick. You know how all that mumbo jumbo about your life flashes past you? You don’t even have a chance.”

### Discussion/Implications

From our findings, it is evident that consumer vulnerability is likely to be experienced by food-allergic consumers, particularly in situations outside of the home. Prior to diagnosis, some participants were unable to exercise control over their state of health in the conventional way (i.e., treatment from a doctor) because their access to allergy specialists was hindered by location and price (i.e., specialist doctors only available in some parts of the country, private specialists are expensive). Their response or adaptation to this differed between individuals. For example, Sandra attempted to gain control over her symptoms by choosing not to eat so she would not feel sick all the time. These results indicate that current health policies do not cater sufficiently for the needs of food-allergic consumers. We suggest that a review of current healthcare provision is necessary to determine if and where more specialists should be made available or if the healthcare needs of food-allergic consumers can be met by providing allergy training to general practitioners.

After being diagnosed, many of the participants saw their diagnosis as a way of being able to regain control over their health. However, some participants did not have extreme symptoms prior to diagnosis and therefore experienced their diagnosis as a loss of control over their food choices. For example, Charlene initially rebelled against her diagnosis because she did not believe eating gluten would do much harm. This belief was based on her doctor having said there was not much damage to her villi. However, after some time and self-education about coeliac disease, she was able to come to terms with the diagnosis and the need to follow a gluten free diet. Consumer vulnerability was also experienced at

various times after the participants had adjusted to the dietary changes required as a result of their food allergy (e.g., at restaurants, grocery shopping, when visiting friends/relatives, or travelling). In agreement with the consumer vulnerability model developed by Baker et al. (2005), individual characteristics, individual states, and external conditions contributed to the experience of food-allergic adults' vulnerability in these contexts. These factors will be discussed in more detail in the following paragraphs.

According to Baker et al. (2005), individual characteristics that may influence how a consumption context is experienced include biophysical characteristics (e.g., age, gender, and ethnicity) and psychosocial characteristics (e.g., cognitive ability, education, self-concept, and socioeconomic status). For the food-allergic consumers in our study, food allergy specific characteristics such as type of food allergy and severity of reaction also influenced how a consumption context was experienced. For example, restaurants refusing to serve anaphylactic participants and participants with dairy allergy finding it difficult to access dairy free processed foods. In addition, self-confidence was an important individual characteristic for food-allergic consumers to ensure fair treatment in the marketplace.

Individual states (e.g., level of acceptance of food allergy diagnosis, stage of adaptation to food allergy, level of knowledge acquired) also contributed to whether vulnerability was experienced in a consumption context. We found that some food-allergic consumers went through a period of disorientation due to their loss of ability to eat the foods they were accustomed to. During this period they were more vulnerable. Reprogramming of food-related habits was an important part of adaptation in response to

this vulnerability. Those who were well-informed about their food allergy were more likely to have accepted their diagnosis and the need to follow the diet required to manage their condition. This also meant they were able to take a more positive view of the necessary dietary restrictions to some extent. Provision of clear information about their food allergy and the importance of following the diet at the time of diagnosis will allow for quicker adaptation and more effective self-management among food-allergic consumers. Access to ongoing support and dietary advice would further facilitate this.

Our findings indicate that food-allergic consumers are more likely to experience consumer vulnerability in situations outside of their own home (e.g., when visiting friends/family, eating out, or travelling) because they must rely on others to provide safe food and/or accurate information about the food that is available. This is relevant to the 'external conditions' portion of the consumer vulnerability model (Baker et al. 2005). External conditions that were important for the food-allergic adults in this study and how they experienced a consumption context included discrimination/stigmatization, cost and availability of allergen-free food, labelling of foods, and the knowledge level of café or restaurant staff. These factors are beyond the immediate control of food-allergic consumers and therefore present an opportunity for policy development and market changes that facilitate reestablishment of control to food-allergic consumers.

The widespread use of 'may contain' labels on food products, including basic raw ingredients is an example of a market response that impedes control for food-allergic consumers and thus increases their likelihood of experiencing vulnerability. An alternative

response that would facilitate control could be the use of risk assessment methods such the VITAL 2.0 tool developed by the Allergen Bureau (2012). Implementation of a policy mandating the use of the VITAL 2.0 risk assessment tool will ensure the food industry takes responsibility for ensuring good manufacturing practices are followed to reduce the risk of cross-contamination of allergens into other food products. It will also allow manufacturers to label their products appropriately and with confidence, reducing the number of products with unnecessary 'may contain' labels. Food-allergic consumers will benefit because more food products will be available to them. In addition, the level of risk associated with a 'may contain' label will be clearer.

Other policies that are likely to facilitate control include funding for public education about food allergies and compulsory food allergy training for café, restaurant, and food industry workers (particularly relating to the control of cross-contamination). A good public education campaign would reduce the occurrence of discrimination/stigmatization and improve awareness with a possible flow-on effect of better allergen-free food availability and labelling. Compulsory food allergy training for café, restaurant, and food industry workers will enable food-allergic consumers to eat out with more confidence and without fear of stigma or discrimination.

The current study has provided an insight into the experiences, views, and behaviours of food-allergic adults; however, the generalizability of these findings needs to be assessed using quantitative methods. Future research should quantitatively assess the frequency and impact of the issues identified in this qualitative study. Such quantitative

data will substantiate the need for the policy changes we have suggested based on our findings. In addition, there is a need for better prevalence data to allow policymakers to understand the proportion of the population affected by food allergies.

### **Conclusions**

Consumer vulnerability is experienced by food-allergic consumers at different stages of their lives both prior to and after diagnosis. Food allergy specific factors that influence whether they experience vulnerability in different contexts include food allergy type and symptom severity (individual characteristics); level of acceptance of food allergy diagnosis, stage of adaptation to food allergy, and level of knowledge acquired (individual states); and discrimination/stigmatization, cost and availability of allergen-free food, labelling of foods, and the knowledge level of café or restaurant staff (external conditions). This article contributes to a better public understanding of what it is like to live with a food allergy and therefore has the potential to reduce discrimination/stigmatization and improve access to allergen free foods. Government policies are needed to improve access to food allergy diagnosis and follow-up advice, reduce discrimination/stigmatization experienced in social settings, and regulate the use of 'may contain' labelling. In addition, food-allergic consumers can gain strength from knowing that they are not alone in their experiences and insight as to how others adapt and cope.

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