

Article

Understanding the Needs of Food-Allergic Adults

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Abstract

Food allergies are a growing issue, yet society's understanding of how individuals' lives are affected is limited. We conducted four focus groups with food-allergic adults in New Zealand to gain an in-depth understanding of the issues that impacted their quality of life. Key themes identified included allergen-free eating issues, health care system issues, costs of having a food allergy, effects on well-being, external influences (e.g., others' lack of awareness), and internal influences (personal growth and adaptation). The unmet needs of food-allergic adults led to risk taking, increased stress, and social isolation. A lack of awareness in others (including medical professionals, food service providers, and the general public) had a negative impact, suggesting that an intervention targeting awareness would be beneficial. Adaptation, particularly in terms of assertiveness and organizational skills, was important for coping, so we suggest training in these skills be made available for food-allergic patients.

Keywords

coping and adaptation; focus groups; illness and disease, chronic; lived experience; quality of life; risk, behaviors

Food allergy is an important health problem that can significantly impair quality of life (Flokstra-De Blok et al., 2010). Food-allergic patients require long-term (often lifelong) treatment to prevent reactions and to treat symptoms when they occur. Symptoms of food allergy usually affect the skin, respiratory tract, or gastrointestinal tract, or they can be systemic (i.e., affect multiple organ systems). The most severe form of food allergy results in anaphylaxis, "a severe, potentially fatal, systemic-allergic reaction that occurs suddenly after contact with an allergycausing substance" (Metcalfe, Sampson, & Simon, 2008, p. 103). Anaphylaxis from a 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, Williamson, & Tang, 2009; Sicherer, 2011).

Food-allergy treatment involves complete avoidance of the food allergen and, as a result, individuals with food allergies face very different issues compared to those with other chronic health conditions. Eliminating one or more foods from one's diet is not a simple task because processed foods are commonly used and contain "hidden" ingredients. In addition, food-allergic patients engage more health care services than non-food-allergic individuals, resulting in an increased cost to the health

care system (Patel, Holdford, Edwards, & Carroll, 2011). Thus, the development of interventions to improve quality of life will not only benefit food-allergic individuals and their families, but will also reduce the economic burden on society as a whole. However, it is important to address the need for a better understanding of food-allergy quality-of-life issues first, to ensure that meaningful interventions are developed.

An important development in recent years is the availability of validated, health-related quality-of-life instruments to measure the impact of food allergies on patients' lives (Flokstra-de Blok & Dubois, 2012). Such tools provide information about the impact of food allergies on different parameters (e.g., dietary restriction, emotional impact, risk of accidental exposure, and food-allergy-related health), which makes them useful for monitoring or comparing the effectiveness of interventions. However, because of the closed nature of the questions used, these instruments might not reveal all there is to know about living with a food allergy. For example, questionnaires

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Miranda Mirosa, Department of Food Science, University of Otago, PO Box 56, Dunedin 9054, New Zealand. Email: miranda.mirosa@otago.ac.nz cannot provide an explanation for why certain issues have a high impact on quality of life.

Only qualitative methods can provide in-depth information about how and why different issues affect quality of life. Most published qualitative studies have focused on the experiences of food-allergic children (DunnGalvin, Gaffney, & Hourihane, 2009; Fenton et al., 2011; Pitchforth et al., 2011) and adolescents (Akeson, Worth, & Sheikh, 2007; MacKenzie, Roberts, Laar, & Dean, 2010; Marklund, Wilde-Larsson, Ahlstedt, & Nordstrom, 2007; Olsson, Lyon, Hornell, Ivarsson, & Sydner, 2009), or explored the perspectives of their parents (Gillespie, Woodgate, Chalmers, & Watson, 2007; Mandell, Curtis, Gold, & Hardie, 2005; McBride, McBride-Henry, & van Wissen, 2010). Qualitative research looking at quality-oflife issues in food-allergic adults is limited to a few studies, which have focused on adults with a particular type of food allergy and/or a selected issue affecting quality of life (Leftwich et al., 2011; Nettleton, Woods, Burrows, & Kerr, 2010; Sverker, Hensing, & Hallert, 2005; Voordouw et al., 2009).

Focusing on a selected issue affecting quality of life can result in gaps in the understanding of life with food allergies because some issues might not fit in a specific category, and it is not possible to explore the interaction between different issue types in detail. In addition, research including adults with only a specific type of food allergy can contribute to segmentation, possibly decreasing the impact of the data by reducing the population to which it applies. Investigating the issues in a holistic fashion by allowing an open discussion of all issues and using a heterogeneous group of food-allergic adults will allow us to gain a better understanding of what life with food allergies is like. Such information will facilitate the development of clinically significant interventions. Our study therefore involved the use of focus groups to identify and better understand the issues that affect the quality of life of food-allergic adults and to identify strategies to improve their quality of life.

Methods

We used focus groups to generate data in this qualitative study to allow us to capture a range of perspectives from the target group of consumers (food-allergic adults). In addition, focus group participants were able to discuss and provide reasoning for contrasting ideas and perspectives, adding to the understanding of why certain issues affect some and not others (Liamputtong, 2011). The relatively open structure of this type of research also allows for the identification of issues that previous research might not have examined.

We obtained ethical approval from the Department of Food Science and Department of Psychology ethics committees (University of Otago) prior to commencement of the study. Participant recruitment involved advertising on community notice boards and through allergy support organizations. All participants self-reported a medically diagnosed allergy to one or more foods. For the purpose of this study, we defined food allergy as a reproducible adverse reaction caused by an immune-mediated response to a food or food component, which is in line with the World Health Organization's definition of food allergy (World Health Organization International Food Safety Authorities Network [INFOSAN], 2006). This definition includes both immunoglobulin E (IgE)-mediated reactions (reactions involving immunoglobulin E antibodies, e.g., peanut allergy, cow's milk allergy) and non-IgE-mediated immune responses to foods (e.g., celiac disease). We provided the participants with detailed information about what would be involved and gave them the opportunity to ask questions before obtaining their written consent. Participants each received a \$20 fuel voucher to compensate them for travel costs.

The participants each completed a short online survey (collecting basic demographic and food allergy information) prior to attending a focus group. The online survey also asked participants to list up to three food-allergy-related issues that had the most impact on their quality of life. We used these issues to develop a list of 10 statements about living with food allergies (see Figure 1). This list of statements formed the basis of the introductory exercise that participants completed prior to the group discussion. To complete the introductory exercise, we asked participants to rate each of the statements in terms of their importance/level of impact on their life. The purpose of the introductory exercise was to provide a starting point for the discussion that followed.

We conducted focus groups lasting 90 to 150 minutes with four different groups of food-allergic adults (3–11 participants per group, N=29). Theoretical saturation usually occurs after three or four focus groups with one target group (Krueger & Casey, 2001). The fourth focus group elicited no new information (i.e., theoretical saturation was reached), and we therefore did not conduct any further group discussions. The 29 participants (6 men, 23 women) were aged 20 to 77 years (mean = 43.6 years). The sample included participants with a range of food allergies and symptoms (see Table 1); 9 of the participants reported two or more food allergies.

Although most participants identified themselves as New Zealand European, the sample also included participants who identified themselves as Māori (n = 2), Chinese (n = 2), Canadian (n = 2), and Australian (n = 1). In terms of socioeconomic background, the sample included participants who were married/living together, with children (n = 10); married/living together, with children no longer living at home (n = 4); married/living together, with no children (n = 7); single, with no children (n = 6); and

Introductory Exercise

Rate each of the statements in terms of their importance/impact on your experience of living with a food allergy.

Allocate a number (0 to 5) to each statement based on the guide below:

- 0 = not at all important/no impact on my life
- 1 = very slightly important/very slight impact
- 2 = somewhat important/some impact
- 3 = moderately important/moderate impact
- 4 = highly important/high impact
- 5 = extremely important/extreme impact

Statements:

- ☐ I am regularly troubled by symptoms due to inadvertently eating food containing an allergen.
- ☐ Having a food allergy makes it difficult for me to find suitable foods to eat.
- ☐ It is difficult to find safe foods that are quick/easy but also healthy when away from home.
- ☐ I feel sad about missing out on certain foods.
- ☐ It is more expensive to buy safe (allergen-free) foods.
- ☐ Having a food allergy means I have to spend a lot more time on shopping for and preparing foods.
- ☐ Other people don't understand about my food allergy and are uncooperative or unkind toward me.
- ☐ I avoid or experience stress about social occasions involving food (e.g., eating at restaurants or at a friend's house).
- ☐ I experienced difficulties getting a diagnosis or accessing a suitable doctor with regard to my food allergy.
- ☐ I regularly feel anxious or stressed about my food allergy.

Figure 1. Introductory exercise with ten statements about living with food allergies.

Table 1. Summary of Study Participants' Food Allergy Details.

Food Allergy	Type of Symptoms	Diagnostic Method/s	Diagnosed By
Peanuts/treenuts (n = 7) Seafood/shellfish (n = 5) Cow's milk (n = 5) Eggs (n = 4) Soy (n = 3) Gluten (n = 18) Wheat (not gluten; n = 1) Other foods ^a (n = 6)	Anaphylaxis $(n = 8)$ Gastrointestinal $(n = 25)$ Respiratory $(n = 12)$ Skin $(n = 18)$ Other ^b $(n = 9)$	Skin-prick testing $(n = 11)$ Blood tests $(n = 18)$ Elimination diet/food challenge $(n = 9)$ Other ^c $(n = 20)$	General practitioner (n = 7) Allergy specialist (n = 9) Gastroenterologist (n = 15)

^aOther foods: tomato, pineapple, kiwifruit, spirulina, legumes, chicken, banana, goat and sheep's milk.

single (divorced or widowed), with children no longer living at home (n = 2).

Reported household incomes (or individual income if single) ranged from less than NZ\$25,000 to more than NZ\$150,000 per annum (median values: single NZ\$32,500; couple with no children at home NZ\$90,000; couple with children at home NZ\$90,000). Six participants were classified as low income (below national median), 11 as medium income (at or near national

median), and 12 as high income (above national median) based on household income information from Statistics New Zealand (2012). Most of the participants were well educated, with at least a university degree (n = 20); the remainder indicated that their highest level of education was a tertiary-level diploma or certificate (n = 5), professional membership (n = 1), or high school diploma (n = 3).

The focus group participants were involved in an indepth discussion about the food-allergy-related issues

^bOther symptoms: tired/lethargic, watery/itchy eyes, anxiety, swelling, itchy throat, blocked nose/sinuses

^cOther diagnostic methods: biopsy of small intestine, diagnosis based on presentation with immediate and severe reaction after consuming the allergenic food.

that affected their life. The first author facilitated all four focus groups, using a nondirective approach to allow the participants' views to emerge spontaneously. She explained the purpose of the focus group and gave examples of core topic areas of interest, but 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. Next, the first author explained what her role would be during the discussion (i.e., to keep the discussion going and to keep it focused rather than acting as an active participant). She then revealed her own food allergy and shared a personal experience related to it with the participants. This helped engender trust among the participants so they were more comfortable with idea of sharing their own experiences. The insider status of the first author also enhanced her ability to relate to and empathize with the focus group participants.

With the participants' permission, the focus group sessions were audio- and video-recorded and verbatim transcripts were prepared using the recordings. Thematic analysis (based on the six-phase method described by Braun & Clarke, 2006) of the focus group transcripts was completed by the first author using the NVivo 9 software package (QSR International, 2010).

The first author's own food allergy allowed a unique insider perspective to the data analysis. However, she was also aware that a person's culture and the society in which he or she lives, as well as age, gender, and socioeconomic status, could all strongly influence perceptions in relation to illness and related experiences. This awareness enabled her to approach the data from an outsider's perspective as well. By being aware of her insider/outsider status, the first author was able to reflect on how this might influence her approach to the research and take measures to minimize the effects of potential disadvantages of each position while attempting to maximize the strengths.

The main aim of the thematic analysis was to provide a rich description of the entire dataset. We used an inductive approach similar to grounded theory, identifying themes and coding the data while reading the transcripts. The first author's prior awareness of issues related to living with food allergies assisted the coding process, and her interpretation of the overall essence of themes guided the selection of code names. As the coding progressed, themes were refined and grouped into main themes and subthemes. We interpreted the importance of the different themes based on a combination of how much a theme was talked about (paying particular attention to whether there was consensus within and between focus groups) and how participants talked about it (e.g., emphasis/tone of talk, level of emotion).

Although the aim of this study was to improve theoretical knowledge about quality of life for food-allergic adults, the primary driver for this research was to improve

their quality of life. For this reason, collaboration and trust between researcher and participants was important. To facilitate collaboration, the first author explained the overall end goal of the research to the participants at the start of each focus group. Reciprocity was also important for this research, and we achieved this through participants sharing support and advice during the focus groups. For many participants it was the first opportunity to share their experiences openly without feeling they were being bothersome.

Findings

The key themes we identified from the focus group data were grouped into three main categories and seven subcategories: (a) issues related to living with a food allergy (allergen-free eating issues, health care system issues, costs of having a food allergy, and effects on well-being); (b) external influences (others' lack of awareness and others' attitudes); and (c) internal influences (personal growth and adaptation). We developed a theoretical model to represent the key issues and their interactions (see Figure 2). As illustrated in Figure 2, we found the issues related to having a food allergy to be complex and highly interrelated.

Issues Related to Living With a Food Allergy

Allergen-free eating issues. We identified three key themes in relation to allergen-free eating: (a) lack of availability of suitable allergen-free food products, (b) difficulties eating out, and (c) taking risks. The first two key themes (lack of availability of suitable allergen-free food products and difficulties eating out) are standalone themes. Based on the way participants discussed the third theme (taking risks), we believe it is influenced by the first two themes and therefore discuss it in combination with the other themes as well as separately.

The first key theme considered a problem for most of the participants, particularly for those with multiple food allergies, was a lack of availability of suitable allergenfree food products: "That feeling of going through a supermarket and just going aisle after aisle and there's nothing. There's nothing here." Although the participants acknowledged there were a range of specialized products available for certain food allergies, they did not always consider them suitable. They thought some were inedible because of poor taste and/or texture characteristics; for example: "They're not very nice tasting and so I just stopped buying them. I just don't eat that."

Participants eating wheat-free or gluten-free food products discussed texture characteristics: "Gluten-free bread is, you know....It's like a bath sponge rather than being like, you know, sponge cake." The participants also

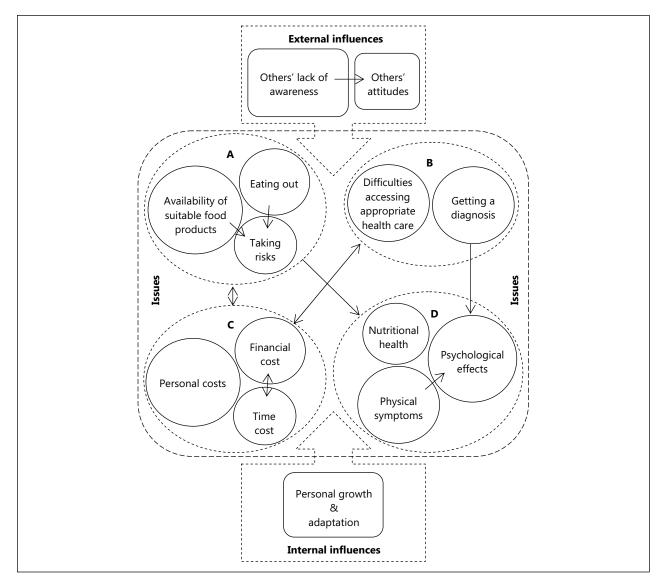


Figure 2. Overview of key themes and how they interrelate.

A: allergen-free eating issues; B: health care system issues; C: costs of having a food allergy; D: effects on well-being. Arrows indicate the influence of one issue area on another (bidirectional arrows indicate that both issues influence each other). Dotted lines indicate groupings of themes and subthemes within different categories. Shape size reflects relative importance of themes.

questioned the price and the nutritional quality of specialized allergen-free products: "The cost thing I found was quite prohibitive." "Why would you pay three times the price for something that doesn't have any flavor or is full of sugar and salt and fat?" Concern about cross-contamination was another factor contributing to limitations on what participants considered suitable to eat: "I've been avoiding all those things, because I just think they, the risk of cross-contamination is too high."

The participants saw the widespread use of "may contain" labeling on food products as a major obstacle to finding suitable foods to eat, and this contributed to risk taking, even among those with anaphylaxis. Participants

saw it as a choice between risking a reaction and eating nothing:

If I actually avoided everything that said "may contain traces of nuts" because it's made in a factory...I actually ignore those...I don't know if I'm, probably I'm putting myself at risk but I just, I wouldn't eat anything.

Seeing complete avoidance as being too difficult to achieve because of the limited availability of safe foods was another factor contributing to risk taking. One participant described finding it too difficult to avoid her food allergen because it was too widespread in food products:

"I mean, milk, it's just in everything." She described giving up at times, and knowingly eating allergen-containing foods because of it: "I know I can't avoid it so...." Participants with more severe symptoms (e.g., anaphylaxis) did not follow this strategy.

The second key theme, difficulties eating out, was an issue for all of the participants. Eating out at restaurants, cafés, or other social settings is a stressful event in the lives of many food-allergic adults: "You're frightened to go out to a restaurant." The participants described different strategies they used to deal with this stress and to minimize risk. Some considered eating out too risky and/or stressful, and employed a strategy of complete avoidance: "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." Another avoidance strategy discussed was to go out but not eat anything: "I just don't eat when I go out."

Even though they considered eating out risky, many of the participants employed strategies they felt would reduce the stress and risk of a reaction rather than avoiding it completely. Contacting the restaurant in advance was one of the strategies discussed: "I always look at the menu before I go if I can, online. And that's really handy, and then at least you can see that there's maybe two or three things that you might be able to have." Other common strategies involved choosing simple items on the menu ("You go to a restaurant, look for the simplest thing on the menu") or choosing the same dish each time ("I always order the same thing").

Participants also described strategies to minimize risk at shared meals. One of these strategies was to bring enough food for their entire meal: "You bring a lot of dishes but at least I know these are safe." Another common strategy was to serve their meal first, before their "safe" dishes became cross-contaminated by others:

You've gotta grab the food before anyone else. So it looks as though you're starving to death, you know. "You can now eat." Shoom! [laughs]. And you grab your stuff before anybody else has touched it because the minute they start touching and cross-contaminating, you dare not.

Finally, in addition to taking risks as a result of limitations of the food supply or to reduce the social isolation associated with avoidance strategies, some participants chose to eat foods they knew they were allergic to because at times they felt the enjoyment of eating a food they liked was worth the consequences. This was not a strategy employed by those with anaphylaxis. One participant with a moderate allergy to milk explained:

Do I really wanna have an ice cream once every six months and spend the next three days acting and feeling like I got a really bad cold, drugged up to the eyeballs? Is it worth it? And some days, yeah, it is worth it.

Health care system issues. We identified two key themes in relation to access to appropriate health care: (a) the struggle of getting a diagnosis, and (b) difficulties accessing appropriate health care. In relation to the struggle of getting a diagnosis, participants talked about the importance of getting diagnosed quickly: "Getting an early diagnosis is really important....Sometimes I get a bit grumpy and I go, 'I wouldn't have all the problems I've got today if somebody had put their finger on it right back then.""

There was a consensus among the participants that having a clear diagnosis made a big difference to their life. They felt it was a relief to know what was causing their symptoms: "It's been a big release having been diagnosed. Prior to that, food to me was a poison. I didn't like food. I knew that as soon as I consumed food I was in trouble." However, getting a diagnosis was a struggle for many: "It's been an absolute minefield, and you know, I can't believe that I could go to a doctor and say, 'If I eat this I get sick' [laughs], and it still took more than eighteen months." Participants expressed having experienced symptoms for lengthy periods and having to return to their doctor repeatedly or change doctors several times before they finally got their diagnosis: "I was extremely unwell and um, I spent two years going backwards and forwards to the doctor." Participants believed getting a diagnosis was a matter of luck: "Getting the diagnosis is, is the luck of the draw."

Participants believed the main reason for the difficulties they experienced accessing appropriate health care was a lack of trained specialists available: "There aren't enough specialists where we are." "I have to afford a trip to [location] with the whole family to get the whole family in front of them [allergy specialists]." This resulted in an increased dependence on general practitioners or doctors specialized in other fields to diagnose food allergies and provide information and/or treatment. In many instances, participants felt that these doctors were not adequately equipped to meet this need effectively: "They don't know as much and so their, their...way of helping you, the things they have to recognize is, is much slower. We have to do all the research ourselves. Do all the testing ourselves." "We've noticed that we've had to train every single doctor we've met, with one exception."

Some participants expressed a loss of belief in the health care system: "I don't have a lot of faith in allopathic medicine any more, really." Participants discussed having to turn to alternative medical practitioners: "I then thought, 'Okay, I can't cope with this incredible pain.' So I then went to, I should have just switched doctors but by then I had gone backwards and forwards so many times. Um, so then I went to a naturopath."

Costs of having a food allergy. We identified three key themes in relation to costs of having a food allergy: (a) limitations on lifestyle (personal costs), (b) everything

costs more (financial cost), and (c) a loss of time (time cost). Some participants found their food allergy had a profound effect on their daily life:

Just trying to get through the day and you know, sort of um, mustering the concentration you need to get the task done that you need to do. Just to get through the day. You can't sorta get ahead at anything.

Participants described being limited in terms of social activities: "Anything to do with food you don't join in as much. That's just life. It's just too stressful." Another major limitation was the ability to travel: "That really restricts, you know, where you can go." One participant described avoiding international travel completely: "I've never even considered traveling because of it." Participants also worried about or felt guilty about passing on their food allergies to their children: "I feel quite guilty about [name], and you would have the same thing. You do feel guilty but you can't change it." One participant with multiple food allergies said, "It's just as well I haven't had kids, because I need to stop these genes right here."

"Everything costs more" included a discussion of medical costs and the cost of allergen-free foods. Increased medical costs were particularly a problem when trying to get a diagnosis: "She sent me to an allergy specialist. I did all the pricks, the whole test. I went to him about four or five times. It cost me a fortune." The cost of epipens (epinephrine auto-injectors) was an issue for those with anaphylaxis:

You can't just say you can't carry it because you can't afford it. You have to have, you've got no option, you have to have adrenaline. You have to have it. There's just no, no if, buts. And as far as I'm concerned um, oh, oh God, that the whole thing of, about nonfunding is, is just extra stress again.

In general, the participants agreed that allergen-free foods were more expensive, particularly specialized allergen-free products: "Everything costs extra, you know." However, this did not necessarily translate to increased food bills. Participants described making changes to their eating habits to reduce overall cost: "You miss out on certain things because of the, of the cost." The participants also described a lack of availability of suitable food products and difficulties eating out as reasons for an overall reduction in food costs: "Cheaper for me [laughs]. Eat less!" "We eat so much less in the way of fast foods. And we don't go out for dinner."

For the participants it was also about a tradeoff between financial cost and time cost. Those who could not afford the extra cost of processed allergen-free foods had to spend a lot more time sourcing and preparing foods:

That's where my time comes in, is that there. If I don't, if I don't wish to keep to a budget, then I have to buy expensive things where I can get them all at once at the supermarket. Or I can spend a bit of extra time going to the extra shops.

Participants felt they spent a significant amount of time on having to source ingredients, plan, and prepare food. Sourcing food and ingredients often involved going to several different shops: "So it's a lotta preparation of getting the right materials from the right place at the right time and buying bulk." Having to read food labels also contributed to the time spent sourcing foods: "It's definitely a cost in terms of time!...Going around the supermarket and reading all the labels." Not being able to make use of preprepared food products contributed to the extra time needed for food preparation: "I have to cook from scratch, and it can be quite hard and a lot more time consuming."

Effects on well-being. We identified key themes in relation to the effects on well-being and grouped them into three main themes: (a) recurring physical symptoms, (b) nutritional health concerns, and (c) psychological effects. Several participants felt that despite their best efforts to avoid eating foods containing allergens, they were regularly plagued by recurring symptoms: "I've lost count of the times that I've thrown up." Eating out was a common cause of symptoms: "I ended up in hospital four weeks ago eating at [restaurant]." One participant described experiencing escalating symptoms because of repeated accidental exposures: "It just seems to be getting worse every time I get caught out."

In relation to the second theme, nutritional health concerns, participants felt they were eating healthier overall because their food allergy made them more aware of what they were eating. However, they also expressed concern about nutritional deficiencies because of dietary restrictions: "I really worry about fiber. I'm not sure if I get enough." Participants wondered if their restricted diets could be to blame for other health issues: "I don't know whether there's something that I'm not eating that...." Participants also described situations in which they did not eat anything because there was no safe food available: "I'll just eat nothing and I'll just suffer." Other participants described eating unhealthy foods on the go because there were no healthy alternatives available:

I'm sure the packets of McDonald's chips and sundaes I've had as meals have a lot to do with my size [laughter]. It's really hard. I mean you can, I go for sushi. A lot of sushi is, is quite good. But, if it's after hours or it's late or you're driving somewhere, it's really hard to find stuff.

In the third theme, psychological effects, participants described the strain of having to be constantly alert for fear of making a mistake, feeling anxious or scared, and concern over the effects on self-image. One participant described constantly having to be alert as exhausting:

It's an exhaustion thing sometimes that I think, "Oh God, I'm just really tired about thinking about this." The idea that you have to think about how everything is prepared and everything that I put into my mouth. Sometimes I think, "Oh I just wanna have a day where I don't have to worry about it. I don't have to think about it."

Another participant described trying to remain in control (constantly being alert) as a source of stress: "The stress thing, uuh. I think it comes down to the sense of you feel you have to be in control, but at some level that's impossible." Participants expressed anxiety or fear as a lack of ability to trust that foods are safe: "You just can't trust anything."

The participants discussed the effects of having a food allergy on self-image in terms of feeling isolated, embarrassed, or defective. One participant felt isolated and stigmatized: "You become a little bit of a joke....It's, it is isolating." Social embarrassment was discussed in terms of standing out as being different, and concern about being perceived as a nuisance: "You feel kind of precious and like you're a bit annoying and a burden on people." Some participants expressed feeling defective indirectly: "You think, 'Why can't I just be normal?" Others directly stated feeling defective because of their food allergies: "Particularly with more and more allergies coming up with food, I just feel a bit defective. And it's just like, God, what else is going wrong?"

Factors That Influence the Perceived Impact of Food Allergy and the Ability to Cope

Both external influences (how others affect the food allergy experience) and internal influences (how the food-allergic individual could influence his or her own experience) had an impact on quality of life. The external and internal influences discussed by participants could make it either easier or more difficult to cope with the issues related to living with a food allergy.

External influences. We found that two main external influences—others' lack of awareness and others' attitudes—had an impact on the issues related to living with a food allergy. The participants experienced a lack of food allergy knowledge among medical professionals, food service staff, and the general public, which made it more difficult to cope with having the allergy. Low awareness among medical professionals such as general practitioners and dietitians contributed to extended delays in getting a diagnosis and receiving poor dietary advice. Participants discussed feeling that medical professionals

did not take their symptoms seriously prior to their diagnosis: "There's still a lot of medical people who, who don't take it seriously." This made it difficult to find a suitable doctor: "It's very hard to find a doctor who will actually listen and work with you."

One celiac patient was referred to a dietitian following her diagnosis by biopsy, only to be told she could still eat gluten: "She just honestly didn't know. She is, 'Oh no. You could probably have gluten." Another participant with celiac disease shared her experience of going to see a dietitian as disheartening because the dietitian did not appear to understand her needs:

I was referred to a dietitian, and it was a terrible experience. And we just didn't, she didn't get the whole thing at all. And it was awful. And I'd been feeling relatively positive about the whole thing. I can make these changes and it's gonna be okay, and I've got friends and family support, and all that. And I went to a dietitian, and I was crushed afterwards.... She said, you know, "If you want a treat, you can have diet jam on a rice cake with banana." And I was thinking, "Ooooh, lucky me!" [said with sarcasm]. You know, so just not getting what the reality of life was gonna be like afterwards. And it was horrible.

Participants reported that a lack of awareness among restaurant and café staff was a major concern, contributing to stress when eating out and resulting at times in accidentally eating allergen-containing foods: "They didn't know couscous had gluten in it. Made me wonder what else they didn't know." "Oh no, it's got no nuts in it, but we're just gonna use a peanut oil over the top.' That could kill someone."

According to the experiences of the participants, there is an overall lack of awareness of food allergies among those who do not have food allergies, which made it more difficult to cope with allergen-free eating and food-related social occasions, and could impact on physical and psychological well-being:

Then there's the one that think a little bit won't hurt you. They have absolutely no understanding that we're not putting this on. Yeah, and um that it is...totally serious.

They know I've got a peanut allergy but it's like they can never remember. And they'll bring stuff with peanuts in it and then they'll tell me, "Just pick it out or just eat around it." And I'm thinking, "If something's poison would you tell someone, 'Just eat around the poison? Just take it out of the poison?" You know? And that just gets me.

Participants found that the lack of knowledge about food allergies among the general population sometimes resulted in people being judgmental and unkind toward them: "I've had some really horrendous experiences where people have

been downright rude." They believed the popularity of fad diets, where people choose to avoid eating certain food types (e.g., dairy, gluten) further exacerbated this problem. Participants felt that people perceived their food allergy as a fad rather than a genuine health problem, which negatively impacted people's attitudes: "A lot of people say they're allergic to milk when they're not. I say I'm allergic to milk and people just think I'm being precious."

Internal influences. Internal influences (personal growth and adaptation) affected the food-allergic individuals' ability to cope with the issues and therefore affected the level of perceived impact of having a food allergy on quality of life. Participants described educating themselves about their food allergy: "I've just read so much. There's just so much out there to read." They actively sought information: "Being proactive and finding the resources that I needed to um, find information." This was evident in the wealth of knowledge they were able to share during the focus groups. Participants described attaining a good general knowledge of their food allergies and learning how to source and prepare allergen-free foods as important steps toward being able to cope with the condition.

The participants also felt they had to be more organized: "Everyone thinks I'm so organized 'cause, you know, my, you know, fast-food company is my deep freeze [freezer]. You know? Portions of meals that I can use if I can't be bothered cooking." Participants often prepared for situations in advance: "Has everybody else learnt to carry enough food in their handbag to keep them going?" This helped them to gain some control over the food-allergy-related issues affecting their life.

The participants discussed the importance of being assertive: "I've got very good at talking to strangers in cafés and restaurants and explaining." Participants agreed that assertiveness was a necessary quality to keep them safe and to ensure that others took their food allergies seriously: "It's really important that you say, 'I'm highly allergic." However, the participants recognized that being assertive could be very difficult for those for whom it did not come naturally:

If I went to a restaurant I wouldn't actually say, often, I was allergic to something because I felt like I was, you know, putting the spotlight on me a bit kinda thing....And now I actually do say, now, but you know you do have to be quite assertive. And I'm sure there's a lot of people who would find, who just wouldn't go to restaurants or who would limit their food so much because you know they, they weren't able to do that.

Discussion

To our knowledge, this is the first comprehensive qualitative study investigating the range of issues impacting on quality of life of food-allergic adults. Although some of the issues discussed by the participants in this study have been noted in earlier research articles (e.g., precautionary labeling restricting food choice [Voordouw et al., 2009], difficulties with eating out [Leftwich et al., 2011], risk taking [Sverker et al., 2005], and concern about accidental exposure [Flokstra-de Blok et al., 2009; Sverker et al.]), our article adds further insight, allowing a deeper understanding of these issues. For example, Sverker et al. reported disclosure avoidance and risk taking among adults with celiac disease but did not explore their participants' reasoning for this in detail. Moreover, in our article we explore the complex interrelationships between issues (see Figure 2).

Our findings add to the health-related quality of life data published by Goossens et al. (2011), which was generated using the validated health-related quality-of-life measure for food-allergic adults developed by Flokstra-de Blok et al. (2009). In agreement with our model, total scores for availability of suitable food-product items and psychological-effects items published by Goossens et al. are large and similar to each other (indicating a similar high level of importance), and items related to eating out give a smaller total. The validated measure did not address loss of time because of food preparation and/or sourcing foods; risk-taking behavior; lack of access to appropriate health care; the frequency and magnitude of symptoms experienced because of accidental exposure; concerns about cross-contamination; or the influence of uninformed or misinformed people on the way food allergy is experienced.

An additional strength of our study is the inclusion of adult participants from different age groups, ethnicities, and socioeconomic backgrounds, who had a range of food allergies and symptoms. This heterogeneity allowed for the collection of information about a wide range of issues, and the identification of both common and different perspectives on these issues. For example, some participants with milder symptoms chose to eat allergen-containing foods on occasion; celiac participants discussed problems with food texture; and participants on a budget avoided extra financial cost by spending more time sourcing and preparing foods.

We have found that the health care and food supply needs of food-allergic patients are currently not met effectively. For the participants in this study, allergen-free eating issues (e.g., lack of suitable food products available, difficulties eating out) and health care system issues (e.g., difficulties accessing appropriate health care and getting a diagnosis) influenced the costs of having a food allergy and effects on well-being. Addressing the key allergen-free eating issues and health care system issues will therefore have the added benefit of reducing costs and improving overall well-being.

Getting a timely and clear food allergy diagnosis was a problem for many of the study participants, with a negative impact on their physical and psychological wellbeing. Based on the results of this research, there is a need for more trained allergy specialists. However, even where allergy specialists are available, general practitioners are generally the first point of call for patients with symptoms of food allergy. In agreement with the experiences of the participants in this study, research with primary care physicians has shown their knowledge and confidence in the area of food allergy diagnosis is insufficient (Gupta et al., 2010). An improved awareness of food allergies and training in diagnostic methods among general practitioners would be highly beneficial to promote timely diagnosis and minimize patients' suffering.

Limitations of the available diagnostic methods can make food allergy difficult to diagnose, particularly in the case of non-IgE-mediated food allergies (Sicherer, 2011; Skypala & Venter, 2009). Development of better foodallergy diagnostic methods such as those discussed by Caubet and Sampson (2012) would be beneficial. In the experience of the participants in this study, the advice of dietitians was not always helpful, and on one occasion, misinformed. It would be helpful if dietitians involved in caring for food-allergic patients received specialized training to have a thorough understanding of realistic and appetizing alternatives to allergen-containing foods. Advice from a dietitian who is experienced and knowledgeable in the area of food allergies would be highly beneficial to newly diagnosed food-allergic patients.

Our findings highlight the importance of patient-centered care. Patient-centered care means the experiences and preferences of the patient, scientific evidence, and practitioner knowledge all shape the provision of health care (Thille & Russell, 2010). Food-allergic patients will benefit from an improved understanding among medical professionals of the difficulties they face because of dietary and lifestyle changes imposed on them. This will allow medical professionals to better empathize with food-allergic patients and to provide relevant and appropriate advice regarding management of their condition.

A lack of suitable allergen-free foods was a major contributor to risk taking, and resulted in an increased likelihood of regular physical symptoms. The widespread use of "may contain" labeling was one of the main issues identified as causing a lack of availability of suitable foods. This supports previously reported findings that precautionary labeling is a burden for those with food allergies (MacKenzie et al., 2010; Monks et al., 2010; Voordouw et al., 2009). In the current study, even foodallergic adults with severe allergies (i.e., anaphylaxis) admitted ignoring "may contain" labeling, and therefore were putting themselves at risk.

It would be useful to make the use of a risk-assessment tool such as VITAL 2.0 (Allergen Bureau, 2012) compulsory to determine the use of precautionary labels. In addition, educational material should be available to food-allergic patients and their families about the risk-assessment protocols used and the level of risk associated with the resulting "may be present" label. This will enable those with food allergies to make an informed judgment (based on their own level of reactivity) about whether to eat certain foods.

Dietary restrictions and increased time and/or financial costs related to allergen-free eating were a source of stress. There is a need for prepared allergen-free food products that are affordable and of good nutritional quality, without compromising taste or texture qualities. The cost of specialized allergen-free products is a barrier to the ability of food-allergic individuals to make use of them. Because most food-allergic individuals do not have the financial capability to spend more on food, they restrict their diet (i.e., omitting certain types of foods) and their lifestyle (e.g., not eating out) to keep a manageable budget. This helps to explain why higher total cost of living was not evident in households with a food-allergic member (Voordouw et al., 2010). In addition, food-allergic individuals often prepare dishes "from scratch" (i.e., using basic ingredients rather than convenience products), resulting in an increased time burden.

The demands of modern society mean that some foodallergic adults find it difficult to fit the extra food preparation time into their already busy schedules. In addition to dietary and lifestyle restrictions, the participants' explanations of the tradeoff between financial cost and time cost also help to explain the findings of Voordouw et al. (2010). Based on our results, it is likely that both time and financial cost measures such as those used by Voordouw et al. (2010) will provide lower-than-expected overall averages. We theorize, however, that a cross-analysis of such data would show subgroups with higher time and/or personal costs (and lower financial cost) and subgroups with higher financial cost (and lower time and/or personal costs).

Finding allergen-free foods "on the go" (e.g., while out working, shopping, or traveling) was perceived as incredibly difficult without compromising nutritional health. The participants believed this was because readily available allergen-free food options (e.g., potato chips, French fries, chocolate) tend to be high in salt, sugar, or fat (or a combination thereof). It would be useful if mainstream stores that are open outside standard daytime hours stocked healthier allergen-free options that are usually available only in specialty stores.

The lack of awareness among medical professionals, food service providers, the food industry, and the general public had a negative impact on the quality-of-life issues

discussed in this article. This lack of awareness has been reported previously, both from the perspective of those affected by food allergies and via surveys assessing the food-allergy knowledge of restaurant staff (Ahuja & Sicherer, 2007; Ajala et al., 2010), the general public (Gupta et al., 2009), and primary care physicians (Gupta et al., 2010).

Published research has shown that food-allergic children/adolescents feel isolated or excluded because of the actions/comments of uninformed or misinformed people (Fenton et al., 2011; MacKenzie et al., 2010). We found that this also applies to food-allergic adults. Like with other illnesses, it is evident that the experience of having a food allergy is socially constructed. Food allergy is in many respects still a contested illness (i.e., not widely recognized or acknowledged as a distinct medical condition). As a result, many people in our society do not take food allergies seriously. This has a profound effect on how food-allergic patients experience life both prior to and after getting a diagnosis. An intervention addressing this lack of awareness is likely to improve quality-of-life issues. Any such educational intervention should focus on the perspectives of food-allergic patients in addition to a clinical description of food allergy.

The main qualities seen as important for coping with allergen-free eating were assertiveness and organizational skills. Improved assertiveness will help food-allergic individuals to be able to ask for allergen-free foods and explain their needs to others, thus reducing risk-taking behavior. Organizational skills will enable them to manage their time more effectively, reducing the time burden. Interventions focusing on strengthening these skills in food-allergic individuals would improve their chances for successful adaptation to the management of their condition.

Conclusion

Our results contribute to an improved understanding of the issues affecting the health-related quality of life of food-allergic adults. Our findings will be useful to medical professionals to inform their patient-centered care. We identified a number of potentially useful approaches to reduce the impact of food allergy on quality of life. Health professionals, policy makers, and the food industry need to work together to implement these changes. Clinicians can contribute to an improvement in quality of life by (a) providing information to improve awareness among non-food-allergic individuals (particularly general practitioners, dietitians, and food service providers); (b) assessing food-allergic patients' quality of life and providing access to training in key skills for successful adaptation (e.g., assertiveness and organization); and (c) advocating for policy change (e.g., mandatory use of risk

assessment to determine the use of precautionary labeling). Our results also indicate that in many respects different food-allergic groups (e.g., IgE-mediated food allergy, celiac) have the same needs. It would therefore be beneficial to consider them together as one group (i.e., "food allergic" as defined by the World Health Organization; World Health Organization International Food Safety Authorities Network, 2006).

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