

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

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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). These findings suggest a need for policy development and market changes that facilitate reestablishment of control to food-allergic consumers and improve their wellbeing.

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. Food-allergic consumers are likely to experience consumer vulnerability as a result 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 focus groups allowing an open discussion of a range of ideas and perspectives within a diverse group of food-allergic adults (e.g., range of food allergies, symptoms, ages, socio-economic, and cultural backgrounds). This approach enabled us to understand the problems that are relevant to food-allergic consumers. 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.

Journey to diagnosis

For participants with anaphylaxis, the identification of the culprit food was relatively straightforward while those with other forms of food allergy described indistinct symptoms that were often more difficult to diagnose. In many cases, 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. This struggle with symptoms without diagnosis took a psychological toll as well as a physical one, as participants described starting to doubt themselves.

Reaction to diagnosis

Most participants felt a sense of relief when diagnosed, particularly those who struggled with symptoms for a long time. Those who did not have significant symptoms did not share this feeling and reacted to their diagnosis in a very different way, describing stages similar to those of grief/loss in their reaction to the diagnosis (e.g., denial, bargaining) and rebelling against the allergen exclusion diet.

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 (a drastic improvement in their health). 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, difficulties did arise in adjusting to the dietary changes. 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 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. However, some felt they were left with little or no support during this transitional period.

On-going life with food allergies

Participants described positive aspects of how their lives had been shaped by their food allergies (e.g. career choices, becoming more health conscious) as well as negative experiences (restrictions). Negative experiences included difficulties finding suitable

foods to purchase (e.g. because of 'may contain labelling', widespread use of some common allergens in processed foods, and cost), 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. Worry about accidental exposure (e.g., due to cross-contamination) also led to restrictions in social activities. In addition, they expressed concern about the effects on the lifestyle of immediate family (e.g., their partner and/or children).

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. Gastrointestinal symptoms were often extreme and debilitating. Allergic reactions in public places were associated with feelings of anxiety and embarrassment.

Implications

Our 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. 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.

Implementation of a policy mandating the use of the VITAL 2.0 risk assessment tool (Allergen Bureau, 2012) 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.

References

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